DEVELOPING A MENTAL HEALTH RECOVERY MODULE FOR THE WHOQOL-BREF

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Abstract

The 26-item WHOQOL-BREF is the brief version of a multi-faceted, patient-reported, cross-cultural health-related quality of life (HRQoL) survey developed by the World Health Organization (WHO) that assesses generic quality of life (QoL) issues commonly impacted by health problems. This thesis outlines how a two-phased exploratory sequential mixed-methods study identified seven items for a mental health recovery module to improve the precision of the WHOQOL-BREF to measure mental-health-related QoL (MHRQoL) by adding personal recovery determinants that affect the QoL of people with mental health issues.

A qualitative phase (Phase 1) invited 88 participants to discuss how QoL is changed by mental health issues and during recovery from mental health problems. Coders identified potential MHRQoL themes from the recorded group and interview discussions with participants with lived experience (LE) of mental health issues and recovery supporters. Results were rank-ordered after summative frequency analysis and then triangulated against LE participant-rated importance data to identify 24 personal recovery determinants that more frequently affected QoL.

A question writing team evaluated these 24 determinants and wrote candidate items that reflected LE participant experiences in the WHOQOL question format. Questions were then placed at relevant points within a 55-item research survey comprising of 26 WHOQOL-BREF items, 5 New Zealand (NZ) national items, and 24 Phase 1 candidate items. Finally, a pilot group of LE volunteers reviewed the comprehensibility and relevance of the survey items, survey time and cognitive burden, prior to the survey's use in Phase 2.

A quantitative phase (Phase 2) invited participants with and without mental health or addiction issues to complete the Phase 2 research survey. The 667 surveys that met inclusion

criteria comprised of 389 surveys from LE participants and 278 surveys from comparison group participants.

An established set of classical test theory (CTT) and Rasch criteria, previously developed to identify NZ items for the WHOQOL, were used in Phase 2 to identify the final items for the MHRQoL module. CTT analysis established that, other than the spirituality item, 23 out of 24 candidate items differentiated between the comparison group and LE participants. Seventeen candidate items: (1) did not duplicate existing WHOQOL-BREF, NZ national items, or candidate MHRQoL items; and (2) correlated with specified MHRQoL construct variables. These 17 items were reduced to seven items through 12 steps of iterative partial-credit Rasch analyses. Items misfitting against established item response theory (IRT) criteria were progressively eliminated. The final seven items that met Rasch's unidimensional model fit requirements enquired about (1) believing in recovery; (2) recognising strengths; (3) self-awareness; (4) acceptance; (5) relating to others; (6) feeling understood; and (7) recovery progress. Ordinal-to-interval scale conversion tables are provided to optimise measurement precision.

Seven MHRQoL items were identified for an adjunct MHRQoL module to be used with the WHOQOL-BREF. The WHOQOL-BREF with adjunct MHRQoL module can be used in research applications as a patient-reported outcome measure (PROM) to support a service’s aim to be recovery orientated, to assess the effect of interventions on QoL, and to support people with mental health issues to improve their QoL.

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Attestation of Authorship

An article describing this research was published in *Quality-of-Life Research* by SpringerLink. The thesis author and supervisory team were the writers. Parts of this thesis will align with that article, as it summarises the current research described in this thesis.

Other than the above, I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no non-cited material previously published or written by another person, nor material to which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Publications

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Intellectual Property Rights

Ethics Approval

The proposal for this research was reviewed by the Auckland University of Technology Ethics Committee and was approved on 25th September 2014. Approval number AUTEC 14/227 (see Appendix A for a copy of the ethics approval letter).

List of Abbreviations and Key Terms

Abbreviation	Definition
ACC	Accident Compensation Commission
ADOM	Alcohol and Drug Outcome Measure
AHMAC	Australian Health Ministers Advisory Council
AoD	Alcohol and drug
CFI	Comparative fit index
CMHC	Community mental health centre
Consumer	Another term for a person who uses mental health services. Some peer support workers can be called Consumer Advisors.
Comparison group	The people without lived experience of mental health or addiction problems that completed the research survey in Phase 2. The comparison group was used to see which candidate items differentiated between those with and those without mental health or addiction problems.
COREQ	Criteria for reporting qualitative research.
CTT	Classical test theory
DALY	Disability-adjusted life years
Discussion meetings	This term refers to the semi-structured Phase 1 groups and interviews used to collect data about MHRQoL issues (see Appendix G for the discussion meeting protocol used for data collection in Phase 1).
DHB	District health board – a government run health service.
DIF	Differential item functioning
DSM	Diagnostic Statistical Manual
EFA	Exploratory factor analysis
HoNOS	Health of the Nations Outcome Survey
HRQoL	Health related quality of life

ICD	International Classification of Diseases
ICF	International Classification of Functioning
ICIDH	International Classification of Impairments, Disabilities, and Handicaps
ICIDH-2	International Classification of Impairment, Disability and Handicap – 2nd edition
IMR	Illness management and recovery
IRT	Item response theory
ISOQOL	International Society for Quality-of-Life Research
LE	Lived Experience. The term lived experience refers to participants with a current mental health diagnosis or an addiction issue, to peer support workers who were in recovery at the time of participation, or to participants with a history of those experiences.
LS	Life satisfaction
MHR	Mental health related
MHRQoL	Mental health related quality of life
MOH	Ministry of Health
NDHB	Northland District Health Board
NGO	Non-government organisations – not for profit publicly funded services that are self-governing entities.
NZ national items	Five items important to the quality of life of New Zealanders (Krägeloh et al., 2015, 2016). These five items ask about: (1) belonging, (2) control over one's life, (3) respect from others, (4) meeting the expectations of others, and (5) able to manage personal difficulties. The New Zealand national items can be added as an adjunct module to the WHOQOL-BREF when investigating, interested in assessing, or measuring the QoL of people living in New Zealand.
NZ WHOQOL-BREF	The NZ WHOQOL-BREF is the same set of 26 items contained in the international WHOQOL-BREF that

	was validated for use in New Zealand as a reliable and valid generic QoL measure (Krägeloh et al., 2013).
PCA	Principal component analysis
PGDipCBT	Postgraduate Diploma in Cognitive Behavioural Therapy
PRIMHD	Programme for the integration of mental health data
PROM	Patient-reported outcome measure
PSI	Person Separation Index
QoL	Quality of life
Recovery	In the context of this thesis, the term *recovery* refers to recovering from a diagnosed mental health condition or addiction issue. People with addiction issues only were identified in the demographic data collected yet not especially targeted nor eliminated from the recruitment or data analysis processes in the current research. The WHO recognised that the scope of what is referred to as mental disorders or illness is broad. They include neurological and substance use disorders and the specification that a diagnosis meets ICD classification criteria. The WHO highlight that mental disorders are evidenced by subjective disturbances sustained over time and significant enough to be distressing to the person or others, yet are also brought about by, or maintained by, ecological and social factors (WHO, 2015). People participating in this research from NGO and district health board secondary mental health services meet the criteria for mental disorders, either at the time of participating, or in the past. People receiving primary mental health services also participated in the current research and self-identified having a mental health diagnosis past or present when participating. Mental health is defined differently from mental illness by the WHO. Zikmund (2001) wrote that the WHO's definition of mental health is defined as: "a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to contribute to his or her community" (p. 528).

	The WHO definition of mental health is aligned to a mental health recovery direction when considered against the definition of personal recovery used within the current research discussed by Anthony (1993).
Recovery supporters	Participants who have not had their own personal lived experience of mental health or addiction issues yet have had experience of supporting people with lived experience in their recovery, as family members, support workers, clinical staff, or as members of recovery outcome analysis and research roles. Their role in Phase 1 was to speak to their observations of issues affecting the QoL of people recovering from mental health issues when providing data in Phase 1.
RMSEA	Root mean square error of approximation.
SAC	Scientific Advisory Committee
SAMHSA	Substance Abuse Mental Health Service Administration
SEM	Structural equation modelling
Service user	This term, when used in the thesis, refers to a person with lived experience of mental health or addiction issues who is in recovery and is using a mental health or social service that provides recovery orientated support.
SF	Short form
SIG	Special interest group
SRMR	Standardised root mean square residual.
Stakeholders	The primary stakeholders are defined in this study as: (1) people with mental health issues; (2) as mental health service providers or researchers interested in mental health recovery or QoL; and (3) as recovery supporters, family, or whanau members of people in recovery from mental health and or addiction issues. Phase 1 invited people from all three of these groups to share their direct experiences of the changes to QoL that mental health problems brought to service users and to discuss what determinants of mental health recovery affected QoL the most from their lived experiences.
STORI	Stages of Recovery Instrument
TLI	Tucker-Lewis’s index

UI	Uncertainty interval
WHO	World Health Organization
WHOQOL-BREF	The WHOQOL-BREF is a brief 26-item version of the original cross-culturally developed WHOQOL-100 tool. The WHOQOL-BREF was reduced from 100 items to 26 items through statistical re-analysis of the original WHOQOL-100 data (World Health Organization Division of Mental Health, 1996). The most statistically robust question was taken out of each of the 24 facet clusters of the WHOQOL-100 to ask about that QoL facet in the WHOQOL-BREF. Two general questions are also included that ask about satisfaction with overall physical health and overall QoL (World Health Organization Division of Mental Health, 1996).
YLD	Years lived with a disability.

Chapter 1

Introduction

Rationale for this Research

Increased rates of mental health problems and suicide frequently raise public concern worldwide (Pirkis et al., 2021; WHO, 2022b). The 65th World Health Assembly highlighted that the global burden of mental illness accounted for 25%–33% of all disabilities and required prioritisation for redress (World Health Organization [WHO], 2012). A suicide awareness publication from the WHO stated that one in a hundred deaths are from suicide (WHO, 2021c). The WHO (2021c) reported suicide as the fourth leading cause of death for those aged 15–29 and that 703,000 people end their lives each year through suicide.

The WHO also reported that 50% of mental health problems begin by age 14. These often remain undiagnosed and untreated (WHO, 2018). However, the *Live Life* campaign, launched by the WHO in 2021, highlighted that when countries actively target the reduction of suicide, their suicide statistics reduce. The *Live Life* report provided evidence of a 36% reduction in suicide rates between 2000 and 2019 from the efforts of 38 countries that actioned suicide prevention strategies (WHO, 2021c).

The current *WHO Comprehensive Mental Health Action Plan* (WHO, 2015) asks all countries to review their mental health policies, target the factors that lead to poor mental health and commit to reducing rates of suicide and mental health problems (WHO, 2015). An improved response to mental health problems and suicide is needed to answer this call.

People with mental health problems have significantly lower quality of life (QoL) than people with other health conditions (Bayliss et al., 2012; De Abreu et al., 2012; Mayer et al., 2021; Maris et al., 2012; Masthoff, Trompenaars, Van Heck, Hodiamont, et al., 2006; Picardi et al., 2006; Skevington & McCrate, 2011; Trompenaars et al., 2006a). Researchers have found QoL assessment to be a valid and reliable way of understanding how mental health problems are affecting people's lives (Awad, 2016; Fahy et al., 1999; Herrman et al., 2002; Mas-Expósito et al., 2011; Masthoff et al., 2005; Masthoff, Trompenaars, Van Heck,

De Vries, et al., 2006; Masthoff, Trompenaars, Van Heck, Hodiamont, et al., 2006; Medici et al., 2015; Melle et al., 2005). QoL assessments and interventions can also improve the effectiveness and relevance of services provided to people with mental health issues (Awad, 2016; Revicki et al., 2014).

Several mental health studies reviewed the QoL ratings of people who attempted suicide and noted patterns of progressive deterioration in people's QoL ratings had occurred before their suicide attempts (De Abreu et al., 2012; De Freitas Melo et al., 2022; Ponizovsky et al., 2003). Additionally, De Abreu et al. (2012) found that all of the domain scores of the WHOQOL-BREF were lower for people with bipolar affective disorder who attempted suicide than those who had not, particularly in the environmental domain. De Freitas Melo et al. (2022) noted that a progressive deterioration of QoL scores in the psychological domain of the WHOQOL-BREF was the clearest predictor of suicide risk.

Research studies have highlighted that QoL assessment is a valid and reliable way of evaluating mental health service and treatment outcomes (Atkinson & Zibin, 1996; Picardi et al., 2006; Priebe et al., 2011; Prince & Prince, 2001; Renwick et al., 2012; Trompenaars et al., 2007). Alves et al. (2016) highlighted that exploring QoL assessment results with service users during service delivery reviews can identify unmet needs. Identifying and meeting unmet mental health treatment needs can also improve people's QoL (Fleury et al., 2013).

Researchers who have highlighted the problems with using HRQoL assessments within mental health service environments have named specific problems that need to be solved (Connell et al., 2012; Katschnig, 2006; Keetharuth et al., 2018; Orley et al., 1998; Petkov, 1998). They highlight a need for reliable and valid HRQoL measurement tools sensitive to the QoL issues relevant to people recovering from mental health problems and straightforward ways to implement the information gained from QoL assessments or recommendations from QoL research in clinical practice situations.

The WHO's QoL questionnaire, the WHOQOL-100, was developed to address the need for a valid, reliable, cross-cultural HRQoL measure. An international collaborative research team developed the WHOQOL-100 in the 1990s. The project aim was to develop a cross-cultural HRQoL measure that could be used world-wide by better understanding what common facets of human experience are negatively affected by health problems, irrespective of the health condition or culture a person came from (The WHOQOL Group, 1998).

The WHOQOL-100 has 100 items. There are four general questions and four questions nested under 24 facets of QoL (WHO, 1997). The 24 facets of the WHOQOL-100 are categorised within six domains: (1) Physical health (energy and fatigue, pain and discomfort, sleep and rest); (2) Psychological health (body image and appearance, negative feelings, positive feelings, self-esteem, thinking, learning, memory and concentration); (3) Social health (personal relationships, social support, sexual activity); (4) Environmental health (financial resources, freedom, physical safety and security, health and social care, home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation or leisure, and physical environment issues such as pollution, noise, traffic, climate, and transport); (5) Spiritual health (religious and personal beliefs); and (6) Autonomy and independence (mobility, activities of daily living, dependence on medicinal substances and medical aides, and work capacity) (The WHOQOL Group, 1998).

The WHOQOL-BREF is a briefer 26-item version of the 100-item questionnaire. The data used to develop the WHOQOL-100 was used to develop the WHOQOL-BREF. The WHOQOL-BREF includes two of the four global items from the WHOQOL-100 asking about QoL and physical health and the most statistically robust question from each of the 24 facet areas within the WHOQOL-100. The items within the WHOQOL-BREF cluster around four primary domains: (1) physical health, (2) psychological health, (3) social health and (4) environmental health. Items related to the two domains of spiritual health and autonomy

within the WHOQOL-100 were added to the domains of psychological health and environmental health, respectively, to reduce the six-domain structure of the WHOQOL-100 to a four-domain structure in the WHOQOL-BREF.

The WHOQOL-BREF is a widely used, valid, reliable, cross-cultural, generic HRQoL questionnaire used as a patient-reported outcome measure (PROM) for various health conditions and treatment programmes (Skevington & McCrate, 2011). Being generic by design, the WHOQOL does not aim to identify QoL issues specific to a particular health condition (Skevington et al., 2004b). Skevington et al. (2004b) described the strength of the WHOQOL when explaining "the person-centred development process means that the WHOQOL-BREF fulfils perhaps the most important pre-requisite for a good PROM, namely the involvement of users" (Skevington et al., 2004b, p.50). Health and population-specific modules were subsequently developed for the WHOQOL, and this design principle is maintained when developing adjunct modules for the WHOQOL (WHO, 1993).

Adjunct modules for the WHOQOL identify condition-specific QoL items. Modules developed to date include: (1) the HIV module (World Health Organization Quality of Life Instrument HIV Group, 2003) and its brief version (O'Connell & Skevington, 2010); (2) PAIN (Mason et al., 2004); (3) OLD (Power et al., 2005); (4) dialysis (Yang et al., 2006); (5) disabilities (Power & Green, 2010); (6) AGE (Caballero et al., 2013); (7) spirituality, religiousness, and personal beliefs (Skevington et al., 2012); and (8) diabetes (Lin et al., 2017) modules. Before conducting the current research there was no adjunct module to identify unique HRQoL issues experienced by people diagnosed with mental health issues.

The relevance of HRQoL assessment in mental health was highlighted by Akvardar et al. (2006), who wrote that lower QoL is a common cause of, as well as a consequence of, psychiatric illnesses. People with mental health diagnoses share the generic QoL problems common to all other illnesses, making the WHOQOL a relevant generic measure for use with

this population (Oliveira et al., 2016; Skevington & McCrate, 2011). QoL monitoring has identified patterns of progressively deteriorating QoL prior to suicide attempts within the mental health population (Alves et al., 2016; De Abreu et al., 2012; De Freitas Melo et al., 2022; Ponizovsky et al., 2003). The WHOQOL is a valid, reliable HRQoL measure, sensitive to identifying changes in QoL over a two week period and validated as reliable for use within mental health populations (Berlim et al., 2005; De Vries & Van Heck, 1994; Garcia-Rea & LePage, 2010; Mas-Expósito et al., 2011; Masthoff et al., 2005; Oliveira et al., 2016; Rocha & Fleck, 2009; Rocha et al., 2011; Skevington & McCrate, 2011; Trompenaars et al., 2006b).

Researchers have highlighted, however, that specific HRQoL issues occurring when recovering from mental health problems can be missing from commonly used generic HRQoL measures (Connell et al., 2012, 2014). Authors discussing factors critical to the delivery of recovery-orientated services (Slade, 2002, 2013) and the interface between QoL and the construct of recovery itself (Chiu et al., 2010; Ho et al., 2010) name determinants of mental health recovery, that upon review, are not included in the generic WHOQOL tools. Adding recovery-sensitive QoL items could therefore improve the WHOQOL's precision when used to research or measure changes in QoL within mental health populations.

Research Aims and Purpose

The implicit research question was: Does the WHOQOL-BREF require additional items to improve its precision as a PROM for people in mental health services, and if so, what items would be best to include? This question emerged out of a practice context. A community of practice group using the WHOQOL-BREF as a PROM within the mental health service environment was interested in the answer to this question. Previous WHOQOL research methods informed the current research design: (1) WHOQOL module development methods described in the WHOQOL Study Guide (WHO, 1993); (2) Methods of statistical

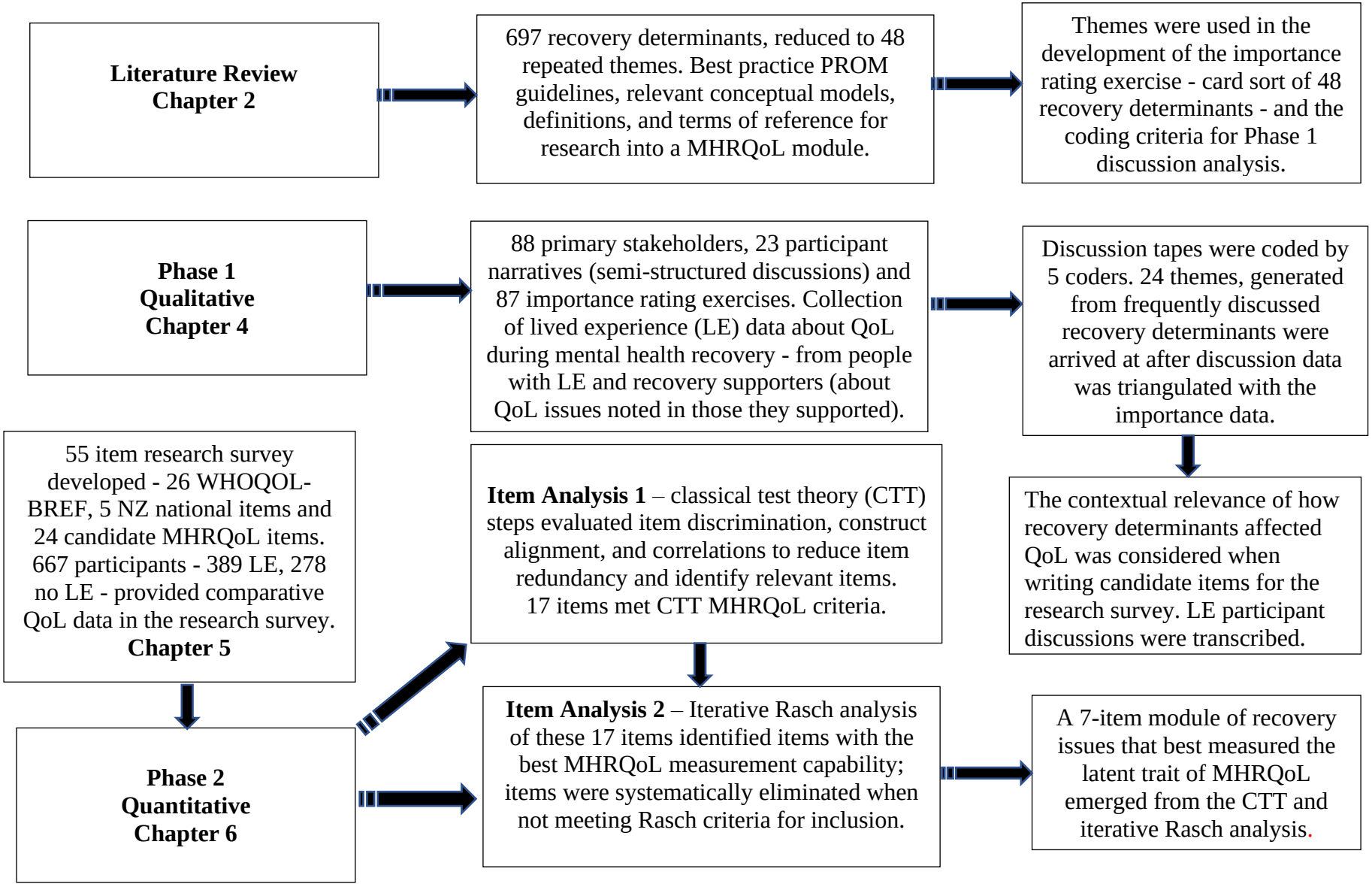
analysis used to identify New Zealand national items for the WHOQOL (Feng, 2011; Krägeloh et al., 2015, 2016) were replicated in Phase 2 to identify MHRQoL module items.

The current research used a two-phased mixed methods study to identify valid, reliable items for an adjunct mental health recovery module for the WHOQOL. Figure 1 summarises the stepwise process used to develop the module. This figure tracks the research process from the preliminary work before the research began to the final module development. This figure can be used as a guide to the chapters within this thesis and highlights central tasks involved within each step. Namely, Chapter 2: Literature review; Chapter 3: An overview of theoretical and conceptual models of QoL, personal recovery and the research methodology; Chapter 4: Phase 1; Chapter 5: Survey development; Chapter 6: Phase 2; Chapter 7: Discussion and interpretation of the final research results; Chapter 8: Overall discussion, limitations, recommendations for future research, and conclusions.

Figure 1 also displays the order in which research tasks were completed. The direction of the arrows shows the series of tasks involved with developing the module within two primary research phases. Phase 1 was a qualitative phase that gathered discussion data from primary stakeholders, the majority of whom were people with lived experience of mental health recovery, to identify candidate items for the proposed module. Phase 2 was quantitative phase that involved evaluating 24 candidate items generated from Phase 1 themes within a survey of responses to these items within a larger New Zealand (NZ) sample using item response theory (IRT) methods to find the best items for a MHRQoL module.

Figure 1

Overview of the Research Process



The following chapter discusses a narrative literature review conducted as a preliminary step to examine relevant information pertinent to measuring HRQoL, mental health recovery, and developing a QoL PROM in a mental health service environment. Recommendations from the literature inspired modifications to the current research design and identified potential recovery determinants missing from the WHOQOL. Departures from and compatible philosophies or approaches used in similar personal recovery, QoL, and recovery instrument development research were explored. Methods relevant to adapting or retaining a replication of the methods used in the aforementioned sources were identified to meet the mental health recovery and measure development context of the current research.

Chapter 2

Literature Review

Narrative Literature Review

The objective of this literature review was to investigate the need for an adjunct module to improve the WHOQOL-BREF's sensitivity and precision for use in a mental health context. The research question arose from discussions among organisations using the WHOQOL-BREF as a recovery-orientated PROM within non-government organisation (NGO) mental health services. Stakeholders were interested in improving the sensitivity and precision of the WHOQOL-BREF as a PROM and recovery planning tool.

A narrative literature review provided a foundation for the current research. The literature review was conducted with several explorative aims in mind. Literature was reviewed to clarify: (1) The research rationale and to define central terms; (2) Methodology relevant to mental health and QoL PROM development; (3) Issues related to the assessment of HRQoL within a mental health context; (4) The history of the construct of mental health and personal recovery; (5) Investigate the development of the WHOQOL tools and subsequent health modules; (6) Explore existing WHOQOL research conducted within mental health populations; (7) Examine what was considered essential to mental health recovery in the personal recovery literature to date and to consider whether the existing WHOQOL-BREF facet descriptors covered the issues raised, and (8) to ensure that relevant research design and methodological considerations had been examined and considered prior to the research methods being finalised.

A systemised review was considered too narrow for the aims of this research. No prior studies had investigated potential content for a mental health module for the WHOQOL-BREF. Existing systematic reviews within central topics relevant to the current research were sourced within the literature reviewed. A comprehensive understanding of each topic was sought before conducting more detailed literature searches within principal topic areas. Due to the broad QoL focus and the WHOQOL being a subjective self-report measure,

the literature review did not explore information discussing the biological basis for mental health problems or mental health symptom measures. The review was focused more on the effects of mental health problems on the QoL and subjective well-being of people living with, or recovering from, mental health problems.

Reviewing international personal recovery literature provided a background for comparing the local NZ data gathered in this research against international personal recovery findings. Theoretically, findings from the current research may be similar or different from those obtained in personal recovery studies internationally. Secondly, if the measure developed from the current research was used by international stakeholders in the future, the local relevance versus the broader relevance was necessary to examine and consider at the end of the study. Thirdly, the literature cited many recovery determinants; some were cited more often across studies and time. It was unknown which recovery determinants most affected QoL. A plan to assess the most commonly cited recovery determinants by using them as codes when exploring the emerging themes within discussion meetings and in importance rating exercises would enable further consideration of whether any of those determinants were more often linked to significant changes in QoL for people recovering from mental health issues.

Literature Review Methods

The best fit for WHOQOL-styled items and the conceptual boundaries of this research involved looking for recovery determinants in the personal recovery literature rather than in the clinical or mental health status literature. A detailed review of the mental health consumer and personal recovery literature was conducted within the Auckland University of Technology (AUT) library journal databases. Articles were stored and filed using EndNote. Initially, specific recovery indicators identified by people with lived experience were

searched for within systematic and narrative literature reviews and seminal articles within a 10-year limit of the research start date.

The researcher developed a record of recovery determinants cited as essential to personal recovery from the articles reviewed. The content of existing personal and process recovery instruments used in the mental health field were also reviewed. Clinical recovery literature focusing on symptom measures was not included in the review, as although symptoms can affect QoL, a QoL measure differs from a symptom tracking or health status measure. A QoL measure captures changes to subjective perceptions about objective and subjective aspects of a person's life that may or may not change as symptoms change. Many items mentioned in the personal recovery literature were cited in a review of somatic issues that affected QoL (Taminiau-Bloem et al., 2010). QoL factors related to psychosomatic illnesses were considered and ruled out from the literature search strategy as they may at times sit outside the conceptual boundaries of the research, namely, QoL issues for those with mental health diagnoses. The researcher instead investigated the determinants of mental health recovery within the findings of personal and process recovery research and within the items of mental health recovery measures.

The most frequently mentioned recovery determinants were established through summative frequency analysis and rank ordering of reported determinants of recovery within each study reviewed. The most frequently mentioned recovery determinants were compared against the existing facet descriptors of the items within the WHOQOL-BREF to identify which recovery determinants were already covered by the WHOQOL-BREF or needed to be more adequately represented. These recovery determinants were considered themes for further investigation within Phase 1 and Phase 2 of the current research.

A conservative approach was taken when eliminating any frequently mentioned recovery determinant in the literature. For instance, despite the mention of *hope* in item six of

the current WHOQOL-BREF facet descriptor asking if a person is experiencing positive emotions, primary stakeholders may also need a question asking about *hope*, specifically. This recovery determinant was retained due to its repetitive mention as being vitally important to the recovery process across studies and time.

Frequently cited recovery determinants were examined to see if they were adequately represented in the WHOQOL-BREF as part of confirming the rationale for the proposed research. Six hundred ninety-seven personal or process recovery determinants from the personal and process recovery literature and content of existing recovery measures were recorded. Removing duplicates and a thematic analysis reduced this to 48 recovery determinants that were identified as not adequately represented by WHOQOL-BREF items. These 48 recovery determinants were incorporated into the methods and design of Phase 1 by including these frequently cited recovery determinants in an importance rating exercise and in the code book used by coders and the thematic analysis of discussion themes. The 48 recovery determinants and their definitions can be reviewed in Appendix I.

The review necessitated an examination of historical literature when exploring the emergence of the construct of mental health recovery from a past era dominated by institutionalisation, the historical roots of the construct of HRQoL and its measurement, the background to the development of the cross-cultural WHOQOL measures, and when tracking the history of item response theory (IRT) to date. Literature reviews of these areas were sought initially. Additional articles were scrutinised from their mention in seminal literature or existing literature reviews to find the definitions of terms and subtopics relevant to the current research.

Best practices when developing PROMs in the mental health and QoL fields, conducting QoL research within mental health and with the WHOQOL tools, and the types of analyses to use when developing PROMs were additional pragmatic topics investigated

during the literature review. Familiarity with the personal recovery literature was already known to the researcher and literature related to IRT to the supervisory team before the research occurred. Literature was added as the study progressed and through the write-up of the thesis to address the issues arising from and within the results.

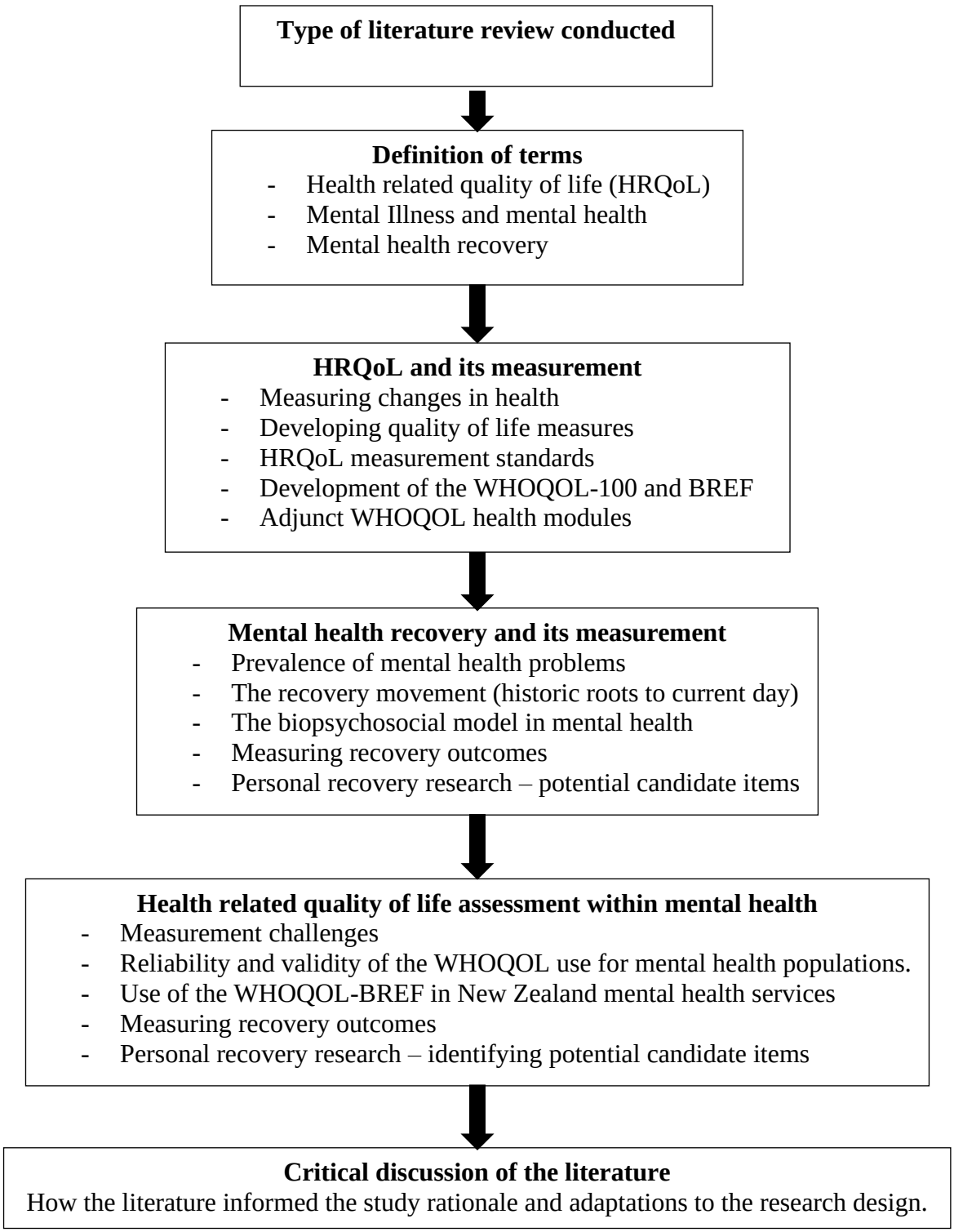
The literature review focused on five main topic areas:

1. Defining key research terms.
2. An overview of HRQoL theory, its measurement, the development of the WHOQOL measures and subsequent WHOQOL health modules.
3. Exploring the history of the mental health recovery construct and its measurement.
4. Evaluation of how HRQoL and mental health recovery are measured within mental health service settings.
5. Assessing the rationale for an adjunct mental health module for the WHOQOL-BREF.

Figure 2 outlines the topics covered in the literature review and the order of their presentation within the structure of this chapter.

Figure 2

Literature Review Roadmap



Definition of Terms

Health-Related QoL

The definitions of QoL vary. Meeberg (1993) warned that if researchers do not routinely define what they mean by QoL, the findings from QoL research can be less precise and more challenging to apply, reducing the effectiveness of QoL research overall (Meeberg, 1993). A systematic review of the literature by Haraldstad et al. (2019) reported several methodological and conceptual problems after reviewing the QoL research conducted within medical and health sciences. Haraldstad et al. (2019) stated that only 13% of studies provided definitions of HRQoL and only 6% distinguished QoL from HRQoL. The review emphasised that the field of QoL research is strengthened when researchers routinely name the type of QoL being researched and provide a QoL definition along with the underpinning QoL theory within their research write-ups. These authors advised that routine inclusion of these recommendations could improve the clarity of research findings in the QoL field.

QoL experts describe QoL as a multidimensional and multi-evaluative concept with both subjective and objective domains, both of which inter-relate and impact upon one another (Bowling, 2001, 2004; Oliver et al., 1996; Skevington et al., 2004b; The WHOQOL Group, 1998; Zikmund, 2001). Lin et al., (2013) highlighted that QoL, HRQoL, health status, and well-being are used interchangeably. They recommended a more precise delineation of the differences between these multifaceted inter-related constructs (Lin et al., 2013).

Camfield and Skevington (2008) examined the differences between subjective well-being (SWB), QoL, and life satisfaction (LS). They discussed how the recent leading panel definition of SWB (Diener, 2006) was so similar to the earlier WHO definition of QoL that making a semantic difference between SWB and QoL was not helpful to QoL research and measurement. When examining the research related to these constructs, these researchers also identified that SWB and QoL had LS as a subset of each construct, thus making LS an

adequate measure of both, more than LS being a standalone construct. Health expectations are also considered central to QoL where some vulnerable groups may not always have these expectations met, resulting in lower QoL and health outcomes (Skevington, 2011).

Ventegodt et al. (2003) have developed an integrative theory of QoL (IQOL) by bringing together several QoL theories that address factors within the broader QoL construct, such as subjective well-being, life satisfaction, happiness, meaning in life, biological functioning, actualisation of potential, need fulfilment, as well as objective factors. Their meta-theory seeks to explain a deeper existential dimension to the lived experience of QoL at the foundation of their Danish QoL Survey. They state that QoL is equal to and describes a person experiencing their life as "a good life" (Ventegodt et al., 2003, p. 1030).

Karimi and Brazier's (2016) literature review highlighted a cross-over between the constructs of health and QoL. These authors stated that using the term HRQoL adds to the confusion more than allows for clarity within the QoL research field. These authors advocate for a return to the term QoL as a solution. Other authors differentiate between QoL and HRQoL by stating that HRQoL describes how a specific illness changes QoL during its course and recovery (Carr & Higginson, 2001). These authors discussed QoL changes caused by changes to one's health status need to be differentiated from how QoL alters in response to other factors of human existence, such as political, environmental, or financial changes.

Camfield and Skevington (2008) examined how non-health-related experiences can influence QoL ratings. In poorer nations, these researchers highlighted that social capital, i.e., positive relationship experiences, helped to buffer the ways that low financial resources and adverse environmental conditions negatively affected QoL (Camfield & Skevington, 2008). Carr and Higginson (2001) explained that if researchers want to know more about how health problems affect QoL, the term HRQoL may be more relevant. HRQoL, they argue, helps to

identify that the research examines how a health condition or health-related factors affect QoL, as opposed to how non-health-related factors affect QoL (Carr & Higginson, 2001).

Those reviewing disparities between definitions of QoL within research studies agree that using a clear definition of QoL can develop more consistency within the QoL research field (Camfield & Skevington, 2008; Coons et al., 2000; Oliver et al., 1996; Zikmund, 2001). They state that the clarity of a definition also helps to determine what tools to use when researching a specific area of QoL and the relevant content for a QoL measure during its development. In the *Dictionary of QoL and health outcomes measurement,* Mayo defined HRQoL as "a measure of the value assigned to duration of life, as modified by impairments, functional states, perceptions and opportunities, influenced by disease, injury, treatment, and policy" (Mayo, 2015, p. 2642). How health system policy affects HRQoL is critical to note.

The WHO (1997) provided a holistic definition of QoL that highlights how peoples' subjective evaluations of the quality of their lives occurs within a context. The WHO (1997) definition of QoL is central to how the current research defines HRQoL, and it explains the rationale for the content of the WHOQOL tools. QoL is defined as:

> An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment. (WHO, 1997, p. 1)

The term HRQoL used in the current research refers firstly to exploring how generic QoL issues identified by the WHOQOL-BREF are affected by mental health problems. Secondly, how mental health problems and their resolution affect QoL and the exploration of mental-health-related-quality-of-life (MHRQoL). Thirdly, the existing WHOQOL-BREF

facets are recognised as potential MHRQoL items in the context of the current research. Fourthly, classical test theory (CTT) analysis in Phase 2 identified 17 candidate items as MHRQoL items and Rasch analysis identified seven of these as MHRQoL items had the best construct measurement properties.

When considering recovery from mental health problems, defining *mental health* and *mental illness* is necessary. The conceptual frameworks and most accepted ways of explaining the factors involved with recovering from mental health issues help to identify how these factors interact with the WHO's definition of QoL. The following section reviews the research related to these two terms.

Mental Illness Versus Mental Health

The WHO's *Comprehensive Mental Health Action Plan* (2013) broadly describes the scope of what is commonly identified as mental illness, including neurological and substance use disorders (WHO, 2013). The recent *WHO Mental Health Report* defined mental disorders as "a clinically significant disturbance in an individual's cognition, emotional regulation, or behaviour. It is usually associated with distress or impairment in important areas of functioning" (WHO, 2022b, p. 1).

The term mental *illness* has been challenged by members of the personal recovery movement and clinical researchers (Deegan et al., 2008; DuBrul, 2014; Farkas, 2007; Jacob, 2015; Kvalsvig, 2018; Malla et al., 2015; Mansfield et al., 2020). Kvalsvig (2018) writes that the terminology of mental *illness* has its roots in a historical asylum-based healthcare system, and as such, it is in itself a stigmatising term. Kvalsvig (2018) stated that mental *illness* reinforces a socially constructed notion of pathology. Kvalsvig (2018) described this term as associated with media-generated dehumanising stereotypes of people with psychiatric disorders. Kvalsvig (2018) warned that the term mental *illness* can contribute to sustaining these stereotypes that maintain discrimination towards people with psychiatric diagnoses.

Malla et al. (2015) made the additional point that speaking about mental *illness* likens it to being a biomedical problem, which can bring negative consequences for people whose mental health difficulties have been caused by psychosocial, experiential, or interpersonal trauma (Malla et al., 2015). They stated that the word mental *illness* can suggest that a person's psychological distress is a biochemical problem requiring a biomedical solution. Malla et al. (2015) warned that this can mask how mental health problems severely disturb a person's identity, self-concept, social experiences and relationships with others or can occur from a range of distressing life events that require healing more than medical solutions.

Personal recovery researchers can use terms such as *mental distress* or *lived experience* as preferable alternatives to combat this problem (Deegan, 1988; Jacob, 2015; Kvalsvig, 2018). Terminology such as *healing*, *transformation*, or *overcoming* are also used in the literature as alternatives to mental health recovery (Farkas, 2007). Mansfield et al. (2020) advocated moving away from mental *illness* literacy towards a language that supports mental *health* literacy to reduce stereotypes and the subsequent discrimination that people recovering from mental health problems can experience.

Payton (2009) highlighted that the terms *mental health*, *mental illness*, and *psychological distress* are not interchangeable; they refer to distinctly different experiences. Payton stated that psychological distress is a broad term for milder forms of distress. Payton acknowledges that this can reduce stigmatisation, yet it also risks minimising the experiences of those diagnosed with severe psychiatric conditions. Payton highlighted that lower levels of psychological distress are vastly different from the severe distress brought about by symptoms that people can experience when diagnosed with a psychiatric condition, such as schizophrenia or bipolar affective disorder. Payton advised that within research, it is critical to identify what is being studied, i.e., a mental disorder, determinants of mental health, or psychological distress. Payton highlighted that there is no underlying continuum or

meaningful relationship between mental health and a mental disorder; they are distinctly separate constructs.

The generic term *recovery* is also used by people recovering from mental health and addiction issues to describe the reclamation of their health and well-being (Substance Abuse Mental Health Service Administration [SAMHSA], 2014). SAMHSA are a federal agency tasked with training and policy development responsibilities within the mental health and addiction services across all states in the United States of America. SAMHSA (2012) developed a definition of recovery to apply to the process of recovering from mental health and addiction issues as: "a process of change through which individuals improve their health and wellness, live a self-directed life and strive to reach their full potential" (p. 3).

The WHO *Mental Health Action Plan* (2013) highlighted that the determinants of mental health are multidimensional and include both in-person and social factors:

> Determinants of mental health and mental disorders include not only individual attributes, such as the ability to manage one's thoughts, emotions, behaviours, and interactions with others, but also social, cultural, economic, political, and environmental factors, such as national policies, social protection, standards of living, working conditions, and community support. (p. 7)

The WHO (2013) reported that changes to peoples' subjective world are not the sole source of distress for people with mental health issues. Distress can come from their objective circumstances changing, how the social world responds to them, and whether the capacity to survive and thrive is limited, or at best enabled, by the environments surrounding them.

Zikmund (2001) wrote that the WHO's definition of mental health is defined as: "a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to contribute to his or her community" (p. 528). This definition is not dissimilar to the SAMHSA definition above.

The WHO definition of mental illness and mental health provides a foundation for understanding the mental health recovery continuum researched within this study. What is meant by *mental health recovery* also needs to be clarified. The following section reviews literature that considers different ways to define mental health recovery.

Mental Health Recovery

Malla et al. (2015) explained that many terms are used to describe mental health recovery; there is a lack of clarity in the research about the central determinants of recovery and, therefore, different ways of measuring recovery. The concept of recovery as a construct is heterogeneous and requires definition before being studied or evaluated (Deegan, 1988, 2002; Ellison et al., 2016; Farkas, 2007; Farkas et al., 2016; Gordon, 2013; Leamy et al., 2011; Ralph, 2005).

Definitions of mental health recovery vary in the literature. They range from focussing on the personal subjective dimension of recovery (Anthony, 1993; Deegan, 1988; Farkas, 2007), recovery having defined stages (Andresen et al., 2006) or being a transformational process (Deegan, 2002), and clinically defined recovery being indicated by a reduction in the intensity and duration of symptoms (Macpherson et al., 2016). Pragmatic and functional descriptions of recovery speak to people's ability to work, socialise, and maintain activities of daily living (Anthony & Farkas, 2009; Farkas, 2013; Rapp & Goscha, 2006; Sutton, 2008). Researchers have also stated that full recovery remains impeded until the broader issue of restoring an individual's autonomy and equal citizenship occurs (Fisher, 1994, 2017) and call for public health initiatives to prioritise stigma reduction (Masuda et al., 2009; Stuart, 2006, 2016).

The word *recovery* is also a term critiqued as potentially problematic if it infers a destination for those with chronic mental health problems or narrows the focus on just resolving symptoms (Davidson et al., 2005; Ralph, 2005). Ralph et al. (2000) cautioned

services against the risks of defining recovery in ways that involve meeting specific criteria. Ralph et al. (2000) noted that service provision could be withdrawn once a person meets a set criterion. They warned that the withdrawal of services can prematurely remove the psychosocial support that enabled those criteria to be met. Exiting people from services, based upon universally set criteria, such as outcome measure results, can create the conditions for risk or relapse to re-emerge for people more chronically disabled by mental health issues who relied upon those services for stability (Ralph et al., 2000).

Roberts and Wolfson (2004) highlighted that the term *recovery* has undergone a radical re-conceptualisation throughout the mental health recovery movement. It is now defined as a process of self-discovery that is empowering, focuses on living well, and offers a realistic hope for a better life despite vulnerabilities or residual symptoms remaining. They point out that this has opened recovery to everyone, as opposed to past definitions of recovery that were narrower and reserved for those who have been cured or their functioning restored.

Davidson (2016) reported that recovery can be conceptualised in two different ways: (1) the alleviation of symptoms and improved functioning or (2) in terms of a rehabilitation framework that is more "subjective and consumer-orientated" (p. 664). Davidson (2016) stated that both approaches to recovery can be beneficial. They advocated for a synthesis of the two that supports the alleviation of symptoms and helps people live recovered lives despite the ongoing challenges of mental health problems.

Clinical Recovery

Clinical recovery refers to when a person no longer presents with symptoms that meet mental health diagnostic criteria described within standardised and internationally recognised diagnostic psychiatric manuals (Macpherson et al., 2016; Trauer et al., 2004). Clinical recovery can be encouraged by relieving symptoms through medication or interventions and learning how to manage residual symptoms to restore functioning (Slade, 2002).

Trauer et al. (2004) explain that when working towards clinical recovery, people may be offered baseline symptom measures to establish the intensity and frequency of their initial symptom presentation at the start of a service. The same measure can be used during reviews and at the end of service delivery to evaluate whether treatments have resulted in a recovery outcome. Trauer et al. (2004) stated that symptom measures are limited because they do not aim to capture how people manage their lives. The underlying assumption is that alleviating problematic symptoms enables people to re-enter meaningful roles and activities previously inhibited by those symptoms (Trauer et al., 2004).

Macpherson et al. (2016) found that clinical and personal recovery are distinctly different constructs, with no evidence of a possible trade-off between them. Macpherson et al. (2016) asserted that both are part of mental health recovery. Davidson et al. (2005) identified that clinical definitions of recovery are driven more by the medical system, whereas definitions of personal recovery have been derived from the lived experience movement. Davidson and Roe (2007) further differentiated the meaning of recovery by highlighting the difference between *recovery from* mental illness versus *recovery in* severe mental illness. They explained *recovery in* is focused on peoples' human rights to live in the community in self-determined ways despite the chronic symptoms of a psychiatric diagnosis.

Stage and Process-Orientated Recovery

Stage definitions of recovery identify that recovery is a process that can move through stages, from acute symptom states with high life disruption and levels of subjective distress, to more stable and recovered states of well-being and improved life functioning, despite the ongoing presence of residual symptoms (Andresen et al., 2003). Andresen et al. (2003) described this as being able to resume life activities through a gradual process of life restoration, signposted by moving through identifiable stages until recovery has occurred. The Stages of Recovery Instrument (STORI) developed by Andresen et al. (2006) and

validated by Weeks et al. (2010) was designed as a conceptual model to guide research, training, and practice that tracks movement from specific stages that start at moratorium and move through stages of awareness to preparation ending with rebuilding and growth.

Another example of a stage model often used with people recovering from health and addiction problems is the transtheoretical change model (DiClemente et al., 2004). This model describes stages of recovery, from not considering recovery to maintaining a recovery outcome. The stages in this model are: (1) pre-contemplation (denial), (2) contemplation (thinking about change), (3) decision-making and planning (deciding to make a change and choosing a method to make that change), (4) action (trying that method to bring about change), and (5) maintenance (maintaining the change over time). Relapse and slips are identified as ongoing features throughout the recovery journey, providing opportunities for learning, insight, and further strengthening of the recovery pathway at best or loss of resolve, motivation, and reduced self-efficacy at worst (DiClemente et al., 2004).

Davidson et al. (2010) reviewed prominent stage models of recovery and their capacity to map the mental health recovery process. These authors pointed out that these models missed crucial elements, such as the motivation and decision-making of individuals necessary for their movement from one stage to another. They write that these models do not identify the person-disorder-social-environmental interactions that can shape a recovery journey through set stages. Nor do stage models identify how social disconnection can be brought about by stigma and discrimination, limiting a person's access to resources and social support. Davidson et al. (2010) critiqued stage or process models, stating they cannot address recovery's non-linear and dynamic nature. These authors argued that there is a need to identify underlying principles behind the complexity and dynamic nature of people's recovery from mental health problems, not just to mark signposts of progress. These authors asserted that models implying linearity, with a set start point for recovery, do not address the

disabling times of illness before a person's journey to recovery begins. They also do not account for a traumatic life history contributing to breakdowns of mental health and diagnosis of a psychiatric condition (Davidson et al., 2010).

Deegan (1988) described recovery as a non-linear or time-framed process marked by setbacks and acceptance of limitations that embraces moving from anguish to suffering with an attitude of suffering driving one forward; that recovery was more of a way of approaching life's challenges. Deegan (1988) explained that mental health recovery is defined differently than the ways physical health services define recovery; there is no underlying assumption about recovering a past healthy state as a goal. Deegan (1988) explained that people whose mental health problems have emerged from a difficult childhood or traumatic experiences may not have a mentally healthy state to return to nor a set of adaptive coping skills to be restored. Deegan (2002) describes recovery as a healing and transformative process where an old self is let go, and a new self emerges. Deegan writes that healing can enable a person to start to feel that they can live without a traumatic past dominating their subjective experience and social interactions. Deegan (2002) stated:

> Recovery is often defined conservatively as returning to a stable baseline or former level of functioning. However, many people, including myself, have experienced recovery as a transformative process in which the old self is gradually let go of and a new sense of self emerges. (p. 6)
>
> Recovery has been a process of healing and transformation for me. I am not the same person I was before I went crazy. My madness has been a kind of fire through which I have walked and through which I have been changed. (p. 17)

The recovery process is also the focus of Carla Green's (2004) model, where internal motivation such as hope, optimism, and meaning are prerequisites for action that involve restoring personal agency, control, and autonomy when interacting with environmental

factors that enable these to occur. Green wrote that internal capabilities, such as self-efficacy in the face of limitations and levels of dysfunction brought about by mental health symptoms, can affect a person's ability to recover. Green also pointed out that factors around the person can disrupt or support their recovery process. Green named recovery stages in their 2004 model as marked by personal development, learning, healing, and adaptation (Green, 2004).

Ecological Models of Recovery

Socio-political perspectives of recovery focus on social determinants of mental health identified by social recovery indicators. Fisher (2017) described these as the restoration of autonomy and equal citizenship marked by equal opportunity, social inclusion, and the restoration of people's potential in all social and personal life areas. Fisher wrote that this could occur despite identifying with having a mental health diagnosis and residual symptoms remaining. Socio-political descriptions of recovery highlight the need for advocacy and the importance of positive public health promotion to change society's response to people who present in atypical ways (Onken et al., 2002, 2007) rather than ascribing their social difficulties to within-person issues (Cari et al.2022). Deegan (1996) asserted this as well:

> There is more to the recovery process than simply recovering from mental illness. We must also recover from the effects of poverty and second-class citizenship. We must learn to raise our consciousness and find our collective pride in order to overcome internalised stigma. (Deegan, 1996, p. 96)

Social perspectives of recovery can highlight issues of discrimination and stigma and the need for advocacy and support to break through a socially resistant environment, particularly at times when people are trying to recover their social lives, such as when job seeking, relationship building, integrating back into the community, and finding accommodation (Anthony & Farkas, 2009; Chou & Chronister, 2011). Researchers and peer-orientated services advocating for societal change within services and in society highlight the

need for more accepting and inclusive attitudes towards people with mental health issues to reduce the barriers of stigma and discrimination that can impede people's recovery (Collins et al., 2012; Gordon et al., 2017). The consequences of prolonged social disconnection and discrimination may be subtle, integrated into services, and require addressing within service delivery (Gordon, 2013). Stigma and discrimination can present as barriers to recovering meaningful occupation, relationships, self-esteem, social belonging, increase vulnerabilities to relapse, and slow recovery timelines during people's recovery (Collins et al., 2012; Matheson et al., 2019; Pascoe & Smart Richman, 2009; Spittel et al., 2019; Stangl et al., 2019; Thornicroft et al, 2009).

The importance of multidimensional recovery models inclusive of psychosocial support is highlighted throughout the literature (Damsgaard & Angel, 2021). Onken et al. (2007) identified two change dimensions within mental health recovery, focusing on both clinical and social recovery factors. These authors write that two distinct types of changes are involved with recovering from mental health difficulties: (1) recovery of the person from the symptoms or impact of a diagnosed condition on a subjective level (*first order change*); versus (2) overcoming the social consequences of having a mental health diagnosis. Navigating the social barriers involved with recovering one's objective life, they called *second-order change*. Onken et al. (2007) highlight the need to provide social advocacy for people recovering from mental health problems due to a corresponding loss of citizenship and belonging brought about by social marginalisation after a mental health crisis or diagnosis.

Personal Recovery

Andresen et al. (2003) reported that personal recovery describes a person's psychological recovery from the consequences of mental health issues. Anthony's (1993) often-cited definition of personal recovery came from "first-person narratives and views of

members of the psychiatric survivor movement" (Farkas, 2007, p. 69). This working definition describes personal recovery as:

> A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness. (Anthony, 1993, p. 17)

Leamy et al. (2011) reported that no systematic literature reviews investigated the factors that improved the potential for a personal recovery outcome in mental health prior to their review in 2011. Ninety-seven papers met their review criteria for thematic analysis. Critical factors that drive personal recovery were identified from their analysis, from which they developed a conceptual framework for personal recovery. Chapter 3 reviews this conceptual model as an empirical base for personal recovery-orientated research and practice. The factors describe the construct of personal recovery as a dynamic relationship occurring between the following five factors: (1) connectedness, (2) hope and optimism about the future, (3) identity, (4) meaning in life, and (5) empowerment. The anachronym CHIME is used to refer to each one of these determinants.

Damsgaard and Angel (2021) discussed how the implementation of a personal recovery focus within mental health service delivery requires a paradigm shift to reduce the sense or need for professional control over and influence on people's lives. They stated that this is more prominent in decisions driven by the medical model or clinical risk management or containment policies, stating that a biopsychosocial model can improve this situation.

Deegan et al. (2008) developed training to help orientate mental health professionals to the lived experience of personal recovery. The training was intended to encourage a compassionate, insightful, and improved engagement process between service users and

providers within the mental health system in NZ. Mary O'Hagan has also developed 10 competencies for mental health staff that encourage a greater appreciation of the personal recovery perspective within mental health services in NZ (O'Hagan, 2001). Public education and health care reform have also been described by other lived experience clinicians, such as Daniel Fisher, through the National Empowerment Centre in the United States (Fisher, 1994).

Bigelow et al. (1991) stated that restoring psychological abilities through medication and rehabilitation is not sufficient alone. They advised mental health services to address service users' personal recovery needs by moderating social demands out of their control that function as barriers to their recovery. Bigelow et al. (1991) stated that advocacy and brokerage can increase people's access to social opportunities such as housing, work, and community participation. They developed the QoL questionnaire (QLQ) to evaluate the capability of mental health services to achieve these aims. The QLQ has 14 scales that are recognised as essential to QoL. The OLQ scales address psychological distress, well-being, coping with stress, basic need satisfaction, independence, interpersonal interactions, social support, adjustment, work and living skills, employability, use of leisure time, and the negative consequences of alcohol and drug use. The content of the QLQ was established as a valid measure of the QoL construct, yet some scales had less internal consistency than others.

Summary

The previous sections of this literature review explored several definitions of HRQoL, mental illness, and mental health recovery. The definitions most suited to developing items for a MHRQoL module are the WHO definitions of HRQoL and mental health, as opposed to the WHO definition of mental disorder. The WHO definition of HRQoL underpins the existing WHOQOL tools. Conceptual consistency with the WHOQOL is essential for an adjunct health module used with that core tool. The definition of HRQoL that will align well with the mental health recovery definition needs to speak to subjective and objective factors

involved with changes to subjective well-being, including the social dimensions of mental health recovery. These two WHO definitions are well suited to the ethos of the personal recovery movement as they are positively language, individualised, empowering, and emphasise social connection that encourages personal agency to develop personal potential according to individual aspirations.

The literature has identified that mental health recovery can be approached from many perspectives. Personal recovery invites a holistic approach to restoring subjective well-being, a sense of self, social connection, and QoL despite symptoms. Personal recovery was described as an existential journey of growth and transformation unique to the individual with collective social experiences that many people in recovery share.

Jacob (2015) stated that service users want a recovery-focused, holistic, personalised, and multidimensional worldview of their issues to be embraced within mental health service delivery. Gordon et al. (2004) wrote that mental health recovery tools need to reflect a broader holistic focus to serve the needs of mental health service users. The reviewed literature highlighted that QoL and recovery measures for this population need to be affirming, capture the holistic personal and social nature of the recovery process, the transformational aspect of change, and be open to being uniquely tailored to individual recovery aspirations and needs. The ways that recovery measures are used need to support people's agency to empower people within their recovery. The following section explores literature that describes some of the considerations and challenges involved with HRQoL measurement and PROM development.

HRQoL and its Measurement

Health Status Versus HRQoL

Jenkinson and McGee (1998) stated that when a person has a health problem or illness, there are two things to be considered. One is their health status. The other is the

impact of changes in their health status on their QoL. Jenkinson and McGee (1998) wrote that health status refers to changes in a person's physical health due to changes in biological markers of wellness, the emergence of comorbid complications such as symptoms of pain, circulation problems, changes to energy levels, or new observed signs of a physical ailment such as tumours, rash, or visible signs of disease. They state that health status measures are used to identify physical symptoms of illness at the start of treatment and evaluate changes in these during or after treatment. Health status measures ask about levels of functional impairment brought about by symptoms. They write that depending upon the type of health service provided, a health status measure may be the most appropriate outcome measure to use when changes in symptoms and biological markers are the focus of the intervention that the service is funded to provide. Many medical or physical health services use health status measures as part of their outcome measurement suite (Coons et al., 2000).

Some health status measures include questions about QoL, such as the SF36 (Ware & Sherbourne, 1992). The SF36 is the 36-item short form (SF) of a longer measure developed by the medical outcomes study that identified basic physical health issues that can negatively impact people's QoL. They may be referred to as QoL measures and used as such in medical trials due to some QoL questions within the measure.

Health status measures differ from HRQoL measures such as the WHOQOL-BREF (Lohr, 2002). HRQoL measures focus instead upon a person's satisfaction with various areas of their life, which can change due to presenting symptoms or from a myriad of other consequences brought about by treatment or the direct or the indirect consequences of the health condition socially and psychologically in areas of life important to them (Lohr, 2002). Two main types of instruments can measure HRQoL and are highlighted as having different strengths and limitations, these are generic or specific measures (Guyatt et al., 1993).

Coons et al. (2000) evaluated seven measures commonly cited in the literature as HRQoL measures. They found that all measures had benefits and limitations yet were also fit for purpose for specific applications. They advised not to consider a measure better or worse than another. Instead, when considering an outcome measure or studying the QoL of a specific population, the content of the measure needs to be reviewed to ensure a measure chosen will be relevant to the population studied, to the way the health condition affects a person, and to the nature of the treatment services provided.

De Silva et al. (2014) also advise that a theory of change is essential to conceptualise before measuring a health outcome. The theory of change can predict how a good or poor outcome could occur based on how the primary factors involved in the health construct were targeted for change by the introduction of a specific intervention or type of service provided (De Silva et al., 2014).

Developing QoL Measures

QoL Measurement Challenges.

Katschnig (2006) highlighted the complexities of QoL assessment and measurement within clinical settings. Katschnig outlined the challenges of choosing and using a relevant QoL measure within multi-service and intervention settings. Katschnig emphasised several problems that require solving: (1) there are many different QoL measures to choose from, (2) there are no clear guidelines for measuring QoL provided in the literature, (3) the research into QoL describes ideals that are hard to meet, and (4) it is hard to find clear answers to resolving how to interpret QoL data (Katschnig, 2006). Katschnig pointed out that the reality of the clinical setting differs from the research setting, where service population groups can have vastly different demographic and disease severity case mixes. Cross-service comparisons are complicated when working with the same diagnostic or disease groups using the same HRQoL measures. Katschnig (2006) stated that the problems of attributing HRQoL

changes to service interventions are too complex to resolve, rendering aggregated data challenging to interpret or use during service evaluation or quality improvement processes.

Measuring Subjective or Objective Factors of QoL. Different theories about HRQoL can lead to different content within QoL measures (Lin et al., 2013). Some authors have critiqued whether predetermined content and domains within HRQoL instruments can ever truly measure the construct of HRQoL, given its subjective, individually-bound, and variable nature (Carr & Higginson, 2001). Carr and Higginson (2001) suggested that identifying an individual's goals was a way of understanding where a person wanted to experience QoL improvement. Goal achievement and working alliance were found to be the best predictors of recovery outcomes by Rose and Smith (2018). Tabak et al. (2015) also found that tracking goals helped to identify essential issues for people recovering from mental health problems.

Awad (2016) described HRQoL as having a history of being an *ethereal entity* with hard-to-define existential dimensions and difficulties resolving how to weigh subjective versus objective perspectives during QoL assessment. Awad highlighted that this is particularly pertinent within subpopulations of people in the mental health population, such as people diagnosed with schizophrenia. Awad reported that this has changed more recently, where QoL has become highly relevant to an individual's recovery within service delivery. Awad suggested that changing the nomenclature to *quality of living* may better describe the focus of QoL interventions. Awad (2016) felt that this term integrated the subjective and objective elements of the QoL construct when applied to people recovering from mental health issues.

There was a debate in the literature about whether the construct of HRQoL was best measured from a subjective, objective, or combination of both perspectives (Sirgy, 2021; Sumner, 1996). Sumner (1996) outlined that objective indicators are easily identified by an

independent viewer, not only by the individual whose QoL is of interest, such as crime, education, or pollution statistics. In contrast, subjective QoL is more akin to subjective well-being. Sumner writes that subjective measures of QoL can be influenced by within-person factors, such as a person's values, beliefs, or emotions when completing a QoL measure. Sumner (1996) wrote that subjective measures of QoL can ask about factors that affect life satisfaction and psychological well-being.

Skevington (1999) wrote that a person's view of their QoL is a subjective experience; therefore, objective indicators cannot measure it. Skevington pointed out that objective indicators require interpretation; this then introduces observer bias. Skevington explained that this is why clinician ratings of people's QoL differ from a person's self-reported QoL ratings. Skevington (1999) advised that the best way to assess a person's QoL is to ask the person directly, reinforcing the utility of subjective self-report measures such as the WHOQOL.

HRQoL Measurement Standards. Aaronson et al. (2002) discussed that QoL measurement, as a formal discipline, has been systematically refined over the last 48 years. The Medical Outcomes Trust was established to standardise the research into medical outcome measures and guide the practical use of medical outcome measures (Aaronson et al., 2002). The trust had a particular interest in self-rated and interviewer-administered measures that captured the subjective perspective of a person receiving a health service.

Aaronson et al. (2002) explained that the Scientific Advisory Committee (SAC) of the Medical Outcomes Trust attempted to resolve some of the historic problems with HRQoL measurement. These authors stated that the SAC worked to identify measurement attributes that can evaluate health status and QoL as two separate yet interrelated phenomena. The SAC collated measures of HRQoL and reviewed them to identify the measures with the best utility to end users (Aaronson et al., 2002).

The SAC developed eight criteria to evaluate measurement tools from this process. These eight criteria highlighted the features of an outcome measure for it to perform well for use in research and field practice situations (Aaronson et al., 2002). The SAC recommended these criteria as research standards for measurement developers (Aaronson et al., 2002). The eight criteria below exemplify what to address during HRQoL measure development.

1. The conceptual and measurement model is clearly articulated in ways that identify the rationale for the measure and population it is intended for; it also includes a clear identification of how the measure could be used, and can measure the scope, variability, and level of measurement of the identified health concept.
2. Reliability: To what extent the measure is free of measurement error. Evidence of internal consistency, reliability, and reproducibility of results over time is demonstrated.
3. Validity: The degree to which the measure shows its content is relevant to its intended purpose, how the content is related to the construct theoretically being measured and can be seen to measure the criterion under study.
4. Responsiveness: The ability of the measure to show change over time between people with and without the health condition and how this is ascertained.
5. Interpretability: How easy it is to use the measure, the scoring protocols, and for users to report and display scores to identify changes occurring over time.
6. Burden: The response and administrative burden for users of the measure, such as time, comprehension, training, or specific instructions required to use the measure.
7. Alternative administration methods are possible: For example, whether the measure is self-report, interviewer administrated, observer rating, computer-assisted, or performance-based and can be administered in more than one way if required.

8. Cultural and language adaptations or translations: If occurring, articulate how measurement properties and the ways any different linguistic versions developed ensure the conceptual and linguistic equivalence to the original measure and how any irreconcilable differences between the original and adapted measure were managed (Aaronson et al., 2002, pp. 196–197).

A more recent gold standard for the development of HRQoL measures was created by the International Society of Quality-of-Life Research (ISOQOL). ISOQOL identified that mixed-methods research is the preferred methodology for developing patient-reported outcome measures (PROMs), stressing the involvement of end users to ensure the development of relevant content (Reeve et al., 2013). The ISOQOL group outlined 12 criteria for PROM development to improve the validity and reliability of an HRQoL measure. The ISOQOL standards aim to improve the problem of methodological inconsistency with measuring HRQoL and provide guidance and standards for developing HRQoL measures within the field.

The criteria established by SAC and ISOQOL discussed above were referred to when designing and conducting this research. Appendix C reviews the MHRQoL module developed within the current research against the ISOQOL guidelines for HRQoL PROMs. Only the criteria for developing the measure could be evaluated at this point. The WHOQOL-BREF meets ISOQOL and SAC criteria as a QoL PROM.

The Development of the WHOQOL and Subsequent Modules

WHOQOL-100 and WHOQOL-BREF. Before the 1990s, QoL measures were considered culturally bound; their value was questioned for use with cultures outside their developed contexts (WHO, 1997). The WHOQOL Group explained that a lack of cross-culturally developed measures of QoL limited the broader understanding of QoL, and the

ability to research QoL across cultures, as well as the development of interventions to improve QoL across cultures (WHO, 1997).

In the early 1990s, the WHO sought to resolve this by initiating a multi-nation collaborative project to develop a cross-cultural QoL measure. The content of this measure was derived from cross-cultural consensus on the core elements within the multifaceted construct of QoL (The WHOQOL Group, 1998). The project involved researchers from 16 member-state countries investigating the determinants of HRQoL through focus groups with people in their local communities. The common denominators identified across countries were compiled and underwent psychometric analysis to ensure they represented independent facets of HRQoL. The result was a 24-facet measure of HRQoL that represented the multidimensional construct of QoL (The WHOQOL Group, 1998).

The measure was named the WHOQOL-100 as it contains 100 items. The WHOQOL-100 contains four questions about the 24 HRQoL facets and four general items about overall QoL and physical health within six core domain areas. The six domains are: (1) physical health, (2) psychological health, (3) environmental health, (4) social and relational health, (5) spirituality, and (6) autonomy and independence (The WHOQOL Group, 1998).

Skevington et al. (2004b) explained that the questions were formulated to assess well-being across a continuum from low to high satisfaction within each facet to avoid an overly problem-focused approach to assessing QoL. Skevington et al. (2004b) explained that *perceived objective items* (such as "how well can you …") compared to *self-report subjective items (*such as "how satisfied are you with your ability to …") were considered. Some facets could only be written as subjective self-report items (such as self-esteem, positive and negative moods, body image, or work satisfaction). It was decided that all questions would be framed as subjective self-report items (Skevington et al., 2004b).

The WHO (1997) reported that very few QoL instruments assess QoL this way. They explained that the person-environment fit model explains that individual differences in QoL ratings are due to the ratings being made in a context. Each person is rating their QoL in response to the unique features of their environment. Cognitive research identified two weeks as feasible for referencing life experiences that influence QoL, so this was chosen as the time for assessing QoL within the WHOQOL (Skevington, 1999; WHO, 1997). That the WHOQOL is sensitive to assessing changes occurring within two weeks, makes it responsive to registering the impact of brief interventions on QoL (Skevington & McCrate, 2011).

The WHO recognised that a 100-item measure may be too long for all research and clinical applications. A briefer version of the WHOQOL, the WHOQOL-BREF, was therefore developed. The 26-item WHOQOL-BREF was compiled by identifying the most statistically robust item from each of the WHOQOL-100's 24 facets, then adding two of the WHOQOL-100's generic questions about overall QoL and physical health (World Health Organization Division of Mental Health, 1996).

After their initial development, the tools were reviewed and validated in countries not originally part of the WHOQOL development collaboration, including NZ (Krägeloh et al., 2013). Since 1996, the WHOQOL-BREF has been used in over 40 countries (Skevington et al., 2004b). The WHO currently lists 76 language versions on its website (WHO, 2022a).

Skevington et al. (2004b) reported that the WHOQOL-BREF is a psychometrically sound, reliable, and valid HRQoL measure, sensitive to measuring change over 2 weeks. The items are focused on generic HRQoL facets typically affected by the consequences of ill health or disability (Skevington et al., 2004b). The WHOQOL tools have been used in research with different health populations and established as reliable and valid measures of generic HRQoL for various health conditions (Skevington & McCrate, 2011).

The generic nature of the WHOQOL's content is due to it not being designed to include idiosyncratic items particular to set populations, cultures, or recovering from specific health issues (Skevington & McCrate, 2011). This limitation initially reduced the WHOQOL's capacity to identify unique QoL issues that emerge when recovering from a particular health condition (Skevington et al., 2004b). Skevington and McCrate (2011) report that developing adjunct health and population models resolves this over time.

Table 1 displays the four domains and 24 facet areas within WHO's generic HRQoL survey, the WHOQOL-BREF. The measure's content as a PROM can be considered against: (1) the restoration of QoL that people are undertaking during mental health recovery and (2) the services provided to them within the community as they recover their lives.

Table 1

WHOQOL-BREF Domain Structure and Content

Physical QoL domain	Environmental QoL domain
1. Pain and discomfort	1. Safety and security
2. Dependence on medical treatment	2. Physical environment
3. Energy and fatigue	3. Financial resources
4. Mobility	4. Opportunities for information, skill development
5. Sleep and rest	5. Recreation and leisure areas
6. Activities of daily living	6. Satisfaction with one's home environment
7. Work capability	7. Access to health and social care services
	8. Transport needs
Psychological QoL domain	**Social QoL domain**
1. Presence of positive affect	1. Personal relationships
2. Life's meaning or purpose	2. Sexual intimacy
3. Thinking and concentration	3. Social support
4. Body image	
5. Self esteem	
6. Presence of negative affect	
G1: How satisfied are you with your overall quality of life?	**G2**: How satisfied are you with your overall physical health?

The NZ WHOQOL-BREF. The NZ WHOQOL-BREF is the Australian version of the WHOQOL-BREF validated as valid and reliable for use in NZ in research completed by members of the NZ WHOQOL Group (Billington et al., 2010; Krägeloh et al., 2013). A review of the WHOQOL-BREF content within an NZ sample found that no core facets in the WHOQOL-BREF required changing, and all WHOQOL-BREF facets were relevant to New Zealanders (Krägeloh et al., 2013). This measure was used in the current research.

NZ-specific national items have been developed for use with the NZ WHOOQL-BREF when studying or assessing QoL within NZ (Krägeloh et al., 2016). A random sample of NZ adults (18–65), with and without health conditions, of mixed cultures and genders were invited into discussion groups. Participants discussed what was important to their QoL. Their answers were analysed using classical test theory (CTT) and Rasch analysis methods. Discussion themes not covered by the WHOQOL-BREF content were identified for candidate item development and testing within a larger sample (Krägeloh et al., 2016).

Five national items were identified for the NZ WHOQOL-BREF that can be used by researchers or services interested in examining the generic and socio-cultural QoL issues important to New Zealanders (Krägeloh et al., 2016). Factor analysis of these five items resulted in allocating four items to the psychological domain and one to the social domain. The psychological domain items were: (1) meeting the expectations of others (Q27), (2) being treated with respect by others (Q28), (3) being able to manage personal difficulties (Q29), (4) having a sense of control over one's life (Q31) (Krägeloh et al., 2016), and (5) a sense of belonging (Q30) that was allocated to the social domain. The current research replicated the procedures for generating items through identifying common discussion meeting themes and analysing candidate items with the same pre-established CTT criteria and Rasch analysis methods used in the national items research.

Adjunct WHOQOL Modules. The WHO study protocol (WHO/MNH/PSF/93.9 Rev.1, 1993) guides the development of adjunct modules to support the consistency of research into identifying HRQoL issues specific to particular health conditions or populations. The study protocol ensures that adjunct modules fit the ethos and ways the WHOQOL asks about QoL. Relevant aspects of the study protocol were incorporated into the research design and were familiar to the principal supervisor of Phase 1 from their previous role in the WHO as the mental health director. The tables in Appendix B: Tables B1, B2, and B3, summarise how the current research aimed to replicate the process and methods described in the WHOQOL Study Guide.

Modules have been developed for use with people in specific populations such as those with: (1) intellectual disabilities (Power & Green, 2010); (2) the ageing population (Caballero et al., 2013) and older people (Power et al., 2005); and (3) to assess the impact of spirituality on QoL (Skevington et al., 2012). Population modules show unique QoL issues emerging for people belonging to specific populations (Bryner & Skevington, 1999).

Examples of adjunct health modules developed for the WHOQOL-BREF include: (1) people living with HIV or AIDS (World Health Organization Quality of Life Instrument HIV Group, 2003), including a brief version developed by O'Connell and Skevington (2010); (2) people living with chronic pain (Mason et al., 2004); (3) people recovering from kidney failure (Yang et al., 2006); (4) people diagnosed with diabetes (Lin et al., 2017); and (5) investigated for cancer (Byrner & Skevington, 1999). Each adjunct health module identifies unique QoL items emerging from living with the specific health condition. Table 2 displays the unique QoL items within adjunct modules developed for use with the WHOQOL for different health and social service populations. The MHRQoL module items from the current research are added for comparison purposes.

Table 2

Adjunct Health Modules Developed for the WHOQOL-BREF

Chronic pain module (Mason et al., 2004)	Dialysis module (Yang et al., 2006)	HIV AIDS module (World Health Organisation Quality of Life Instrument HIV Group, 2003)
1. Pain relief	1. Family support	1. HIV infection issues
2. Anger or frustration	2. Dialysis information	2. Accepted by people one knows
3. Vulnerability, fear or worry	3. Dialysis quality	3. HIV status blame
4. Uncertainty	4. Social care services	4. Fear of the future
		5. Worries about death
Disability module (Power & Green, 2010)	**Diabetes module (Lin et al., 2017)**	**WHOQOL OLD module (Power et al., 2005)**
1. Impact of disability	1. Diabetes-related time spent	1. Intimacy
2. Discrimination	2. Expenses involved	2. Sensory abilities
3. Advocacy	3. Glycaemic control	3. Autonomy
4. Future prospects	4. Diabetes complications	4. Past, present, future activities
5. Control	5. Diet control	5. Social participation
6. Choice	6. Physical activities	6. Death and dying
7. Autonomy	7. Weight control	
8. Communication ability	8. Diabetes treatment	
9. Social acceptance	9. Adaption to diabetes	
10. Respect	10. Family relationships	
11. Social network interaction		
12. Social inclusion, contribution		
13. Personal potential		
WHOQOL AGE module (Caballero et al., 2013)	**MHRQoL module (Rowthorn et al., 2019)**	
1. Intimacy	1. Acceptance and adjustment	
2. Sensory abilities	2. Understanding and empathy	
3. Control	3. Self-awareness and insight	
4. Use of time	4. Recognition of strengths	
5. Opportunities to achieve	5. Belief in recovery	
	6. Relationship skills	
	7. Recognising recovery progress	

Mental Health Recovery and its Measurement

Prevalence of Mental Health Problems Internationally

The WHO (2012), at the 65th Health Assembly, conveyed the outcome of their analysis of health statistics across international population studies and highlighted that mental health problems contributed significantly to disease burden and loss of QoL. The WHO identified mental disorders cause substantial economic and social costs worldwide so are a priority issue for all countries to address. They further pointed out that mental health problems can lead to states of disability. Disability increases the likelihood that people with mental health problems will experience additional environmental and social attitude barriers to recovery, such as stigma and discrimination. The WHO promoted the need for a coordinated response from all countries' health and social sectors to reduce the prevalence of mental health problems to reduce the worldwide disease burden statistic (WHO, 2012).

The WHO stated that in 2004, mental disorders accounted for 13% of the global disease burden (i.e., premature death combined with years lived with a disability). The global disease burden from mental disorders rose to 25.1% (in low) and 33.5% (in middle-income countries by their 2012 report. The WHO reported that 76%–85% of people with severe mental health conditions in low and middle-income countries received no mental health treatment, with this figure being 35%–50% in higher-income countries (WHO, 2012). The WHO (2012) pointed out that mental health issues are preventable and that there are effective treatments available and cost-effective ways of promoting good mental health. The WHO urged all member states to prioritise doing all they can through health policy to reduce mental health problems and set recommended targets and strategies to help reduce the worldwide mental health statistic within the *World Mental Health Action Plan 2013–2020* (WHO, 2013).

The WHO (2018) reviewed mental health studies within European Union countries. Their finding was that 27% of the population aged 18–65 (83 million people) experienced at

least one diagnosed mental health problem over the last year; 32% also had a coexisting mental health condition; 18% had two coexisting mental health conditions; and 14% had three or more coexisting conditions. There was a higher prevalence of mental illness in women than in men (5.6% versus 1.3%). The WHO highlighted that not all mental health problems are reported, so these results likely underestimate the extent of mental health problems in the general population (WHO, 2018).

The WHO (2019a) reported that mental health conditions contributed to a more significant proportion of the overall chronic disability statistics than other health conditions. The WHO found mental health disorders to be the leading cause of years lived with a disability (YLD) and the third leading cause of disability-adjusted life years (DALYs) in a study across European countries (WHO, 2019a). A recent analysis of DALYs from 1990–2019 was completed by the *Global Burden of Disease Mental Disorder Collaborators* (GBD 2019 Mental Disorders Collaborators, 2022). Twelve types of mental health issues included in the study had increased in prevalence between 1990 and 2019, from 80.8 million in 2009 (with a 95% uncertainty interval (UI) giving a range of 59.5–105.9 million), to 125.3 million (with a range from 93–163.2 million UI) in 2019. The proportion of all DALYs globally attributed to mental disorders increased from 3.1%–4.9% (3.9%–6.1% UI). YLD contributed to most of the DALY burden, with 125.3 million YLD (93–163.2 UI), resulting in 12.2%–16% of global YLDs in 2019 being attributed to mental disorders.

The GBD 2019 study highlighted that mental health issues remain within the top 10 causes of disease burden since 1990 (WHO, 2019a). People with prolonged disability contributed the most to the disease burden statistics (WHO, 2019a). The WHO's call for a greater focus on supporting people to recover from mental health problems strives to make a difference in these statistics (WHO, 2021a).

The WHO's (2018) Mental Health Day promotion reviewed the worldwide prevalence of mental health diagnoses. Bipolar affective disorder affects approximately 45 million people worldwide. Schizophrenia is typically diagnosed in late adolescence and early adulthood and affects 20 million people worldwide. Commonly reported mental health issues were depression (44.3 million, 5.1%) and anxiety (37.3 million, 4.3%). Depression and anxiety are 50% higher in women compared to men. Depression often presents alongside coexisting alcohol use disorders. Drug use has also been associated with increased mental health problems and is a significant risk factor for suicide (WHO, 2018). The WHO encouraged all countries to commit to developing specific mental health policies and improving people's access to treatment within the *Mental Health Action Plan* to reduce these statistics globally by 2030 (WHO, 2021a).

At the 74th World Health Assembly, The WHO extended the *2013–2020 Mental Health Action Plan* (WHO, 2013) as the targets were not achieved (WHO, 2021a). The WHO stated within the revised action plan that the HRQoL of people with mental health issues is compromised not only by symptoms of illness but also by their increased vulnerability to several social issues, which makes social policy change also important. These include unemployment, poverty, poor living and working conditions, discrimination, human rights abuses, and being more often the recipients of domestic violence, victimisation, and social exclusion (WHO, 2021a). The WHO highlighted an increased likelihood of disability and premature death among those with mental health conditions, stating that people with depression and schizophrenia have a 40%–60% higher chance of dying prematurely than people in the general population. Higher death rates result from not treating coexisting physical health issues and suicide, with suicide being the second highest cause of death among young people globally (WHO, 2021a). The WHO stated that depression alone accounted for 4.3% of the global burden of all diseases and is the most significant single

cause of disability globally (11% of all YLD worldwide), with the incidence being highest for women (WHO, 2021a).

The economic costs of mental health conditions to society are high (WHO, 2017). Mental health problems reduce a person's capacity to work and create more treatment and social care expenses (WHO, 2018). The WHO pointed out that given the early age of onset for many mental health problems, the lost life potential of young people is great; education, career paths, and life trajectories are all negatively impacted by the course of mental illness, particularly if poorly identified and treated. They highlighted the projected impact on societies and future generations' economies (WHO, 2018).

A WHO review of mental health expenditure within countries noted that only 1% of the government spending was on healthcare (WHO, 2018). The WHO's updated *2013–2030 Mental Health Action Plan* estimated the global cost of mental health services to the world economy as 16.3 trillion American dollars between 2011 and 2030 (WHO, 2021a). However, the average country expenditure on preventing and attending to mental health problems was low; less than two American dollars per person globally and less than 25 American cents in low-income countries, with 67% of the expenditure going only to crisis and hospital facilities, rather than to prevention and early intervention services (WHO, 2021a). The WHO analysed the global return on investment for expenditure if countries worked towards reducing their mental health statistics. They reported that for every dollar spent on treating depression and anxiety disorders, a benefit of four dollars comes back into the economy from the restored health and productivity of affected individuals (WHO, 2018).

According to a World Health Organization report, *Preventing Suicide – A Global Imperative* (WHO, 2017), there were 804,000 deaths by suicide in 2012, resulting in an average of 11.4 suicides per 100,000 people in the population worldwide. In high-income European countries, 3.5 males commit suicide for every female, and in low-middle-income

European countries, the suicide rate is reported as 4.1 males for every female. Suicide accounted for 17.6% of all deaths for young adults aged 15–29 in high-income European countries (WHO, 2021d). In several countries, suicide is the number one cause of death in adolescents, and overall, suicide was the second leading cause of death, following road accidents for this age group (WHO, 2019b). The WHO reported that 90% of suicides are attributed to mental health problems in high-income countries and 22% to alcohol use (WHO, 2018). The WHO (2018) also stated that males are almost five times more likely to commit suicide than women, and 11 countries with the highest suicide rates are in the European region. Recent reports stated that more than twice the number of males die to suicide than females and that this increases in higher-income countries, whereas higher female deaths to suicide occur in lower-income countries (WHO, 2021d).

In a recent WHO campaign, *Live Life*, the worldwide suicide statistic was reported to have decreased slightly since 2010 from targeted campaigns in some countries (WHO, 2021c). However, the WHO reported that many countries were not allocating resources to reduce suicide and had not developed clear suicide prevention policies. The WHO reported that suicide is still the leading cause of death in those aged between 15 and 29 years and was the third cause of death in girls between the ages of 15 and 19 (WHO, 2021c). The WHO *Comprehensive Mental Health Action Plan 2013–2030* and the *United Nations Sustainable Development Goals* have set a target to reduce suicide by one-third by 2030 (WHO, 2021a). The WHO is calling for improved international commitment to this goal through participation in the *Live Life* campaign (WHO, 2021c).

The 2018 WHO *World Mental Health Survey* found that people from high-income countries can also experience prolonged treatment delays due to poor service availability or access (WHO, 2018). Only one in five people from high-income countries and one in 27 people in low-lower-middle countries received minimally adequate treatment for major

depressive disorder (WHO, 2018). NZ researchers also raised the need for a greater focus on prevention when there are known ways to intervene earlier (Sartorius & Henderson, 1992). The WHO reported that based on the observed degree of worldwide commitment to preventing and treating mental health problems, it is unlikely that the targets set to reduce world suicide rates will be met. Sadly, they report, this will result in the preventable loss of many people's lives, increased health costs, and economic burdens (WHO, 2018; 2021c).

Prevalence of Mental Health Problems in New Zealand

NZ's suicide statistics have been rising. A UNICEF report of suicides within OECD or EU countries revealed that NZ had the second worst youth mental health statistics in the developed world, ranking 35 out of 38 countries. The suicide rate was 14.9 suicides per 100,000 teenagers, twice the average of 41 other OECD countries (UNICEF, 2020). Provisional suicide statistics for 2020 show 13.01 suicides per 100,000 NZ citizens between 2019 and 2020, falling slightly from the previous 13.93 statistics before the pandemic (Pirkis et al., 2021). It was unknown to what extent the increased amount of time people spent in lockdown during the COVID-19 pandemic altered this statistic uniquely rather than it being evidence of a fundamental change (Pirkis et al., 2021).

The New Zealand Mental Health Commission reviewed mental health service goals and objectives and developed *Blueprint II* in 2012 when goals from the previous Blueprint were not sufficiently achieved (New Zealand Mental Health Commission, 2012). Five years later, *The People's Mental Health Report* (Elliott & Cloet, 2017), a crowdfunded research project, asked for people's direct experiences receiving mental health services. Five hundred people shared their experiences, which were thematically analysed. The emergent themes from people's experiences included difficulty accessing services, long wait times, the need for more treatment options, compulsory treatment issues, staff being under strain, people not being given appropriate levels of oversight, and experiencing high levels of social and

economic stress (Elliott & Cloet, 2017). The Mental Health Foundation (2018) identified that 50% of New Zealanders live with poor mental health and a need to move away from focusing on mental illness to one of well-being and recovery. The Elliott and Cloet (2017) report highlighted the need for a formal enquiry into mental health service provision in NZ. Increased public pressure led to *The New Zealand Mental Health Enquiry* (Patterson et al., 2018).

The New Zealand Mental Health Enquiry (Patterson et al., 2018) identified that 50%–80% of New Zealanders experience mental health issues each year, with 20,000 people attempting suicide each year. The disease burden of mental health problems was cited as 5% of the gross domestic product, which amounts to 12 billion dollars annually. Patterson et al. (2018) reported that over 70% of people accessing addiction services have a coexisting mental health condition, and over 50% of people accessing mental health services have a coexisting substance abuse problem. The report stated that a mental health issue was the main reason that 60,000 people in New Zealand could not work, with a corresponding loss of nationwide income from their inability to contribute to the economy.

Patterson et al. (2018) highlighted the need to address improving people's mental health in NZ, as people's inability to work also increased the cost of health and social service expenditure. The report identified people with mental health difficulties as having a reduced life expectancy of 25 years compared to those without these problems. The report highlighted that the demand for mental health services has grown by 73% over the past 10 years in NZ. People accessing mental health services were categorised as having mild, moderate, and severe health and social service needs. The mild to moderate group comprised 16%–17% of the population, with 5% having severe needs. The current Ministry of Health funding to provide for severe mental health needs was budgeted for meeting the needs of 3% of those people each year (Patterson et al., 2018). The report highlighted that this funding gap and an

increased number of people accessing mental health services have placed a significant burden and overwhelm upon the mental health system.

Elliott and Cloet (2017) also reported that more people need mental health services, yet the criterion for access is rising. The inevitable outcome is services unable to provide for people's mental health support needs and higher levels of dissatisfaction in the general public with access to mental health services (Elliott & Cloet, 2017). The report stated that the main themes of dissatisfaction involved people wanted more well-being and community-based solutions and "help through the storms of life, to be seen as a whole person, not a diagnosis, to be encouraged and supported to heal and restore their sense of self" (Elliott & Cloet, 2017, p. 9). They recommended a change from a crisis management approach to an early intervention approach (Elliott & Cloet, 2017).

The construct of recovery within the mental health field emerged from historical roots that required a paradigm shift from illness treated in institutions to recovery in the community to resolve. The historical context of the mental health recovery movement shows why issues such as empowerment and person-centred practices are so vital for people in recovery. The next section provides the background to the recovery movement.

The Mental Health Recovery Movement: Historical Roots to Current Day

Institutionalisation and Fear of Mental Illness. Parry (2006) wrote that recovery has emerged from a historical context where fear and a lack of understanding about mental illness resulted in the complete disempowerment of, institutionalisation of, and barbaric treatment of people with mental health symptoms (Parry, 2006). The complex socio-political context of the mental health recovery movement can be understood when considering it as a curative, corrective, or healing response to these historical roots.

Reviews of the literature highlight that the assessment and treatment of people with mental illness occurred in a context of ignorance, superstition, religious belief, and

hypothesised opinion prior to the development of internationally accepted diagnostic systems or research into evidence-based guidelines to treat mental illness (Keene, 2013; Rabkin, 1972, 1974). Before de-institutionalisation in the 1970s, historians highlighted that there were very few mental health records to examine (Clark et al., 2018; Keene, 2013). The publication of institutional cases and care experiences in asylums was prohibited (Stuhler, n.d.). The earliest descriptions that can be found describe institutions for the mentally distressed as places that were constructed like jails, where once admitted, people could not leave, and where some people were chained to the walls due to public fears that disorganised ways of thinking or behaving meant people could become violent (Clark et al., 2018; Keene, 2013; Willard, 1865). The earliest records show that institutionalised care was routinely prescribed as a life sentence (Collier & Grant, 2018; Keene, 2013; Parry, 2006; Tasca et al., 2012).

Several writers reporting on first-person accounts of mental health care in asylums, such as Bedlam, state that the people admitted and their families were not offered a hopeful view of recovery (Keene, 2013; Mizock & Carr, 2021; Parry, 2006). They were advised to give up on ideas of living a typical everyday life or on goals such as marriage, work, or community living and were subjected to treatments that would be recognised as traumatic and inhumane by today's standards (Keene, 2013; Mizock & Carr, 2021; Parry, 2006).

These writers cite treatments such as rotational therapy to induce cure by vertigo, being dunked in ice cold baths, tortured, beaten, starved, chained to the walls, given purgatives, being straight-coated in seclusion, and subjected to bloodletting by leeches, with many not surviving treatment. People were described as being subjected to punitive, cruel, and inhumane asylum rules and relational processes and buried in unmarked graves without informing their families of their deaths (Keene, 2013; Parry, 2006).

Some diagnoses were gendered; women were cited as particularly vulnerable to diagnoses such as hysteria or melancholia (Tasca et al., 2012). Behaviour not defined as a

mental health problem in this era, such as a departure from gender norms, resulted in institutionalisation (Mizock & Carr, 2021; Parry, 2006; Tasca et al., 2012). Tasca et al. (2012) wrote that in the early Middle Ages, hysteria was a woman's diagnosis, with its problematic source being the uterus and an increased vulnerability to emotion, which increased their susceptibility to being possessed by the devil with exorcism as the prevailing cure. In the Victorian era, smelling salts were carried by women to reduce the impact of their emotions. The rationale for their use was the wandering womb disliked their odour, so it returned to its place (Tasca et al., 2012).

The social consequences of institutionalisation also came with a hierarchical view of who determined who was mad and what to do with people when this was determined (Rössler, 2016; Tasca et al., 2012). Researchers examining historical records stated that experts were seen to be the most relevant people to make determinations and often delivered explanations and prognoses that dehumanised the person and used labels that created negative social perceptions (Mizock & Carr, 2021; Parry, 2006). Rössler (2016) explained that this resulted in the social stigmatisation of people with psychiatric diagnoses. The person and their view of their situation were not seen as a credible source of information, nor did they need to be incorporated into the formulation process to explain what was happening for the person. Instead, the views of family, society, and doctors determined the reasons for the person's presenting issues (Mizock & Carr, 2021; Parry, 2006).

Some writers highlighted that remnants of these attitudes and practices remain within the current mental health system (Gordon, 2013; Gordon et al., 2017). The socio-political basis for diagnosing someone as having pathology when behaving inconsistently with convention remains a concern for people diagnosed with mental health problems (Moncrieff, 2010). Pascoe and Smart Richman (2009) write that mental health problems are health issues that still have a social dimension, which can negatively impact health outcomes.

Departure from social norms has been noted as a legitimate consideration within the diagnostic process when behaviour driven by distress is not typical for a person or causes social problems (Alarcón, 2009). Public health policies that determine how to respond to people who are acting out their mental distress can still involve legally enforced containment, forced treatment, or isolation orders in routine health service procedures (Wright et al., 2008).

The consequences of institutionalisation, social stigma, and discrimination throughout history have resulted in people with a mental health diagnosis still reporting difficulties adjusting to a society that views them through a fear-based lens after inpatient treatment (Stuart, 2006). People can use terms like being perceived as abnormal or a danger to others, as the media still reinforces ideas that link mental illness to violence (Stuart, 2006).

Medicalisation and Chemical Control. In the 1940s, the rise of chemical treatment approaches to treat mental illness was seen as a humane approach to treatment compared to past practices within institutions (Yohanna, 2013). Yohanna (2013) discussed that medication-based treatments meant people could be treated in the community. The move into community-based treatment addressed people's legal and human rights to live an everyday life outside of institutions. Medication offered symptom relief and a cost-effective solution for people with mental health issues compared to institutional care (Yohanna, 2013).

The medicalisation of mental health treatment has been critiqued when it is perceived as the primary, universal, or sole offered treatment approach (Double, 2002; DuBrul, 2014; Whitaker, 2010a, 2010b). Some people with lived experience of mental health problems state that medication has been crucial to their recovery, particularly for diagnoses like schizophrenia or bipolar disorder (Lehman et al., 2004). Authors sceptical of the financial benefits for pharmaceutical companies and a society that supports policies that see medication as a solution to address human distress raise concerns that medications are a

modern way of silencing, suppressing or sedating people who exhibit non-traditional views or behaviour (DuBrul, 2014; Read et al., 2008; Whitaker, 2010a).

Critics of the biological explanation of mental health problems highlight that weighting treatment too heavily upon medication-based solutions prevents investigating the non-biological reasons underlying a person's mental health problems, such as childhood trauma (Read et al., 2008). Others state that the origins of mental health problems do not reside within the individual; they are created by a dysfunctional society with distorted values that struggle to accept some forms of individuality and deviation from social norms (Moncrieff, 2010; Tudor Hart, 2010). Compton and Shim (2015) highlighted the need to change legal and social policy to improve social equity and opportunities for socially marginalised people, as this marginalisation is a significant source of stress, increasing people's vulnerability to developing mental health problems.

Laws in NZ that facilitate enforced medical treatment and the use of seclusion with mental health services include the *Compulsory Mental Health Treatment Act* and the *Alcohol and Other Drugs Treatment Act* (Te Pou, 2021). These approaches to mental health care are critiqued as unacceptable ways to resolve human crisis states, as they can exacerbate the distress of people affected at these times (Brosnan, 2018; O'Hagan et al., 2008). Modern approaches seek to balance historical ways of managing safety and risk reduction needs when people are acutely unwell by offering people more choice and control over their lives and advocating for the reduction of seclusion where possible (Gordon et al., 2017; Te Pou, 2021).

De-institutionalisation and Community-Based Treatment. Gordon et al. (2017) wrote that the worldwide deinstitutionalisation movement, emerging from the 1960s through to the 1980s, offered people the opportunity to reclaim their lives from institutional living. However, it also brought many new challenges for people recovering in the community. People researching de-institutionalisation highlight mixed opinions on the benefits and

problems of de-institutionalisation (Bredewold et al., 2018; Mueser et al., 1998; Shen et al., 2017). Some call for a broader range of evidence-based psychiatric rehabilitation techniques beyond common sense approaches (Silverstein & Bellack, 2008; Vita & Barlati, 2019).

Although the policy to deinstitutionalise care for those diagnosed with mental illness was a humane treatment approach, the lack of prepared infrastructure in place when implementing the de-institutionalisation policy resulted in creating a situation of unmet needs for the people released into the community that still required higher levels of support and social care services (Brunton, 2003). People who had lived for decades within institutions experienced difficulties adjusting to the level of independence required for successful community living. They also had to manage encounters with people in society who did not know how to respond to signs of mental distress (Rössler, 2016). Lamb and Bachrach (2001) report that these problems led to challenges such as homelessness, the criminalisation of people with mental health problems, enforced treatment policies, and more widespread encounters of stigma and discrimination towards people released from hospital facilities. Stigma and discrimination further exacerbated challenges to felt citizenship, social belonging, and transitioning back to community living (Lamb & Bachrach, 2001).

Stuart (2016) writes that although the historical roots of how people with mental illness were treated laid the foundations for stigma and discrimination, the poorly managed de-institutionalisation process further reinforced the general public's fear of people with mental health issues (Stuart, 2016). Stuart (2016) noted that stigmatised views, discrimination, and social exclusion have been sustained rather than the initial humane intent of de-institutionalisation socially realised.

Despite deinstitutionalisation occurring 40–50 years ago, researchers have highlighted that similar problems remain for people recovering from mental illness (Kleinman, 2009; Yohanna, 2013). Social awareness and anti-stigma health promotion activities are still

required to actively target marginalisation, incarceration, stigma, restriction of life opportunities, and discrimination for people with mental health issues (Collins et al., 2012; O'Hagan et al., 2008; Onken et al., 2002; Parcesepe & Cabassa, 2012; Stuart, 2016).

Davidson et al. (2001) recommend a broad conceptual framework emphasising social inclusion, like those used with people with disabilities. One that neither alienates nor requires people to succeed in resolving these issues. The deinstitutionalisation movement and the chemical treatment of mental illness eventually led to broader assessment and treatment models within mental health services (Davidson et al., 2001).

Recovery Expectations Change. Cross-sectional research reports that some people recover from mental health problems completely, some partially, and some never (Bleuler, 1968; Tsuang et al., 1979). Longitudinal studies tracking people diagnosed with severe mental illness throughout their treatment provided evidence that people initially treated within institutions can continue to recover from mental health problems after leaving and living in the community (Harding et al., 1987).

Harding et al.'s (1987) landmark longitudinal research added evidence for a recovery outcome for people not previously seen as having a hopeful prognosis. Harding et al.'s (1987) research involved following patients with severe enduring mental illness for 35 years in two cohorts across two locations in the United States (Vermont and Maine). Patients within the cohorts met the DSM-III criteria for schizophrenia at the point of their hospitalisation in the mid-1950s. At the 10-year follow-up point, the research identified that 70% of these participants had remained out of hospital. Another 25 years later, 50%–70% of these people had improved or wholly recovered and no longer met the diagnostic criteria for schizophrenia. The longitudinal research results contradicted the prognostic opinion outlined in the DSM-III for people diagnosed with schizophrenia (Harding et al., 1987). This study

highlighted that a recovery outcome was more probable than previously believed for people diagnosed with severe mental illnesses.

Further examination of Harding et al.'s (1987) data revealed that the Vermont participants had better outcomes than those in Maine (De Sisto et al., 1995). This re-analysis identified that service decisions were different between the two cohorts. Service delivery differences between the cohorts may have contributed to the cohort outcome differences. The Vermont service offered an earlier release from the hospital, and at follow-up, this cohort had adjusted better to community life.

The Vermont group had a different recovery programme from the Maine group (De Sisto et al., 1995). This finding led to considering whether the different interventions offered to each group led to the different outcomes between these two cohorts. Interest in how community-based services can optimise mental health recovery outcomes and research into the diverse and multiple factors that can contribute to diverse outcomes for people recovering from mental health problems was stimulated by the debate about the differences between cohorts (Farkas, 2007).

Critique of the limitations of these longitudinal mental health outcome studies has highlighted that these findings related to people with schizophrenia only, not to people with other mental health issues (Dorrer, 2006). Harding et al.'s (1987) initial cohort of 118 people does not match the diverse population currently receiving community-based mental health services. The evidence for a hopeful prognosis becoming popularised into a belief that most people with serious mental illness can recover as an assumed meaning from these studies can raise recovery expectations for service users, families, and staff (Dorrer, 2006).

Harrison and Mason (1993) highlighted that the participants in Harding et al.'s (1987) study were already rehabilitating in the community at the start of the study. The members of the cohorts were already showing signs of having recovery potential compared to those who

remained in institutionalised care facilities (Harrison & Mason, 1993). The varying definitions of schizophrenia and what is meant by a recovery outcome were also raised as debatable, reducing the generalizability of Harding et al.'s (1987) findings being transferable to all people with mental health problems (Harrison & Mason, 1993).

Warner reviewed 85 outcome studies to investigate the recovery rates for people with schizophrenia. Their observation was that upon review, despite the improved range of new treatment options, rates of recovery from schizophrenia have been stable from the nineteenth to the twentieth century (Warner, 2004). Green's review of outcome studies identified that typically around 20%–25% of people recover completely, 40%–45% achieve social recovery (independence in earning and housing with low social functioning problems), and 30%–40% remain with poorer outcomes (Green, 2004).

Green (2004) stated that the value of longitudinal studies was that they offered hope for a favourable prognosis among clinicians, greater interest within the research community to discover what treatments can improve the potential for recovery, and a greater interest in the drivers and determinants of recovery. These activities have led to a better understanding of what a recovery-orientated service needs to offer, compared to how the treatment of psychiatric diagnoses was approached pre-de-institutionalisation (Green, 2004; Slade, 2013; Vita & Barlati, 2019).

Dorrer (2006) highlighted that ongoing problems remain regarding the ability to generalise findings from one study to another in the mental health research field. Dorrer stated that differences between study methods, treatments offered, contextual differences among treatment sites, length of follow-up periods, and diversity of diagnostic samples could complicate the generalisability of any research findings about mental health outcomes. Establishing the ratio of people who recover from mental health problems is difficult to ascertain confidently (Dorrer, 2006). Despite this, authors strongly advocate for making

recovery the focus of mental health practice (Allot & Loganathan, 2002; Chiu et al., 2010; Copeland, 2002; Gordon, 2013; Randal et al., 2009; Shepherd et al., 2008).

The Biopsychosocial Model in Mental Health. The biopsychosocial model has replaced the biomedical model as the primary theoretical model for assessing, formulating, and treating mental health issues (Engel, 1980; Papadimitriou, 2017; Tripathi et al., 2019). Engel (1980) wrote that a biopsychosocial model calls for an integrated approach to understanding mental health problems by attempting to explain the complex interaction of coexisting factors, such as the role of biological changes, psychological predetermining and coping factors, and social determinants involved with the emergence of mental health problems and their resolution.

Papadimitriou (2017) discussed that the biopsychosocial model has gradually changed how services are delivered and has broadened the nature of interventions offered. Services can include multi-disciplinary approaches and interactions across and between services, as people can now receive multi-service interventions (Papadimitriou, 2017). Mental health treatment has gradually shifted from emphasising symptom alleviation, medication-based solutions, and managing risk issues to a growing awareness of people's subjective, personal, and social recovery needs (Donnelly et al., 2011). Donnelly et al. (2011) wrote that a significant proportion of people are treated in the community with a holistic, person-centred, and recovery-focused service provision model.

Tripathi et al. (2019) reviewed the scientific basis for mental illness and recommended that arguments to establish a cause for either biological, psychological, or social reasons end. They stated that insufficient scientific evidence supports the idea that any of these factors are the sole causal factor for people's mental health problems. These authors assert the biopsychosocial model's value in encouraging a holistic and multifaceted view during psychiatric assessment, treatment, and intervention.

The Rise of Peer Support Roles. Peer support workers are people with lived experience of mental health issues who are role models living in recovery and tasked with supporting service users in achieving their recovery goals (Shalaby & Agyapong, 2020). Positive role models were recognised as ways to offer people receiving mental health services an example of someone who can have a mental health issue and still go on to recover their lives (St George et al., 2017). Peer support has been coined as a missing piece in a clinically focused service environment (Shalaby & Agyapong, 2020).

Peer support roles within the mental health service environments provide a valuable visible reminder of a positive and hopeful recovery outcome for people diagnosed with mental health issues, service staff, and providers (Shalaby & Agyapong, 2020). Monk and Hancock (2015) discussed ways that clinicians and peer support workers can co-design interventions to combine the strengths of clinical knowledge and lived experience within mental health service provision to strengthen engagement and recovery outcomes. Critiques of the decision to professionalise peer support roles argue that peer support has lost its authentic quality when co-opted by the system; they recommend looking for ways to develop more naturally derived peer support relationships during a person's recovery (Fisher, 1994).

People with lived experience of recovery have provided continued case-based evidence for recovery outcomes in social media and the literature when sharing first-person accounts in research, as clinicians, and as advocates (Deegan, 1988, 2002; Frese et al., 2009; Longden, 2013; O'Hagan, 2002; Sutton, 2008). A broader scope of solutions is now available to help services encourage personalised recovery outcomes (Anthony & Farkas, 2009; Copeland, 2002; Farkas, 2007; Slade, 2013). Peer support initiatives to develop content within outcome measures that service users recognise as valid and reliable (Crawford et al., 2011; Rose et al., 2011) and are derived from their lived experience (Gordon & Ellis, 2013)

have also emerged to orientate mental health service delivery towards service user determined outcomes to increase the service user voice within outcome measurement suites.

Mental health issues and their recovery are affected by the socio-political context within which mental health problems emerge (Michaels et al., 2022). The University of Minnesota's School of Public Health provided a model (Cari et al., 2022) to show how an ecological perspective of mental health changes the convenient social narrative that places the origin of mental health problems and the responsibility for their resolution solely upon the individual (see Appendix D). An ecological perspective, however, increases the complexity of evaluating how outcomes occur, what affects them for better or worse, and how to measure them (Trauer, 2010).

Measuring Recovery Outcomes

Investigation into what works to improve recovery outcomes, explorations of how to measure recovery, how to identify that a recovery outcome has occurred, and the complexities involved with measuring outcomes within mental health populations have been researched for many years (Donnelly et al., 2011; Slade, 2002, 2010, 2013; Stedman et al., 1997a, 1997b; Trauer, 2010; Trauer et al., 2004; Waks et al., 2017; Williams et al., 2016). How recovery is defined can also direct what is considered an outcome, by whom, and how to measure recovery (Slade, 2002; Trauer, 2010; Trauer et al., 2004).

Trauer et al. (2004) reported that the Australian Health Ministers Advisory Council (AHMAC) have outlined the definition of an outcome and that the Ministry of Health in NZ use this definition to define an outcome. The AHMAC defined an outcome as "a change in the health of an individual or group of individuals, which is attributable to an intervention or a series of interventions" (Trauer et al., 2004, p. 2). Trauer et al. (2004) discussed this as problematic as it attributes outcomes as causally linked to interventions. Trauer (2010) explained that treatment options have broadened over time, and multiple interventions,

providers, and services are now involved in a person's recovery. Trauer et al. (2004) discuss that it is difficult to attribute an outcome solely to a health service intervention when there are no matched controls and many influencing factors outside of a health service's control that can improve or negatively affect a person's mental health. It is, therefore, difficult to work out how to establish causal links between a service provided, the service user's goals, and the outcome that occurred. They highlight that a diverse case mix, with a service delivery policy to deliver individually determined services, where multiple interventions are accessed, and service user self-directed self-help is encouraged, can provide multiple influences affecting one service's reported outcomes (Trauer, 2010).

Other challenges with outcome measurement involve the collection of outcome data. Typically, service staff and the people using services are reluctant to fill in too many forms, only sometimes cope well with lengthy assessments, and can be fatigued by multiple assessment measures or review processes (Trauer, 2010). Outcome measures need to be comprehensive yet straightforward, not too long, and have content that has practical value to service users and all relevant stakeholders (Siggins Miller Consultants, 2003). Collecting the content for PROMs from people with lived experience can also optimise the measure's relevance to service users (Crawford et al., 2011; Gordon & Ellis, 2013; Rose et al., 2011).

Reviews of recovery instruments show that they can have a diverse and heterogeneous set of items and can use different approaches for establishing how a recovery outcome has occurred (Ralph et al., 2000). Selecting an outcome measure involves carefully considering which measure will fit a service's purpose and the services provided (Burgess et al., 2011; Donnelly et al., 2011; Williams et al., 2016). Authors have explained that knowing what to measure has become increasingly important to clarify now that mental health services are required to report upon service user outcomes to funders (Burgess et al., 2011, 2012; Donnelly et al., 2011; Jacobson & Curtis, 2000; Trauer, 2010). Sederer and Dickey (1996)

highlighted that a recovery outcome is not a single event but a multidimensional construct (as cited in Waller & Thyer, 1997).

Mental health recovery measures and different ways to measure recovery are being conceptualised to meet the aims of recovery-orientated service evaluation and continuous quality improvement objectives. International recovery measures reviewed to identify any common factors in content across measures included The Crisis Hostel Healing Scale (New York Crisis Hostel Project, 1988, as cited in Burgess et al., 2011); the Agreement with Recovery Attitudes Scale (Jeong-gyu et al., 2009); The Rochester Recovery Inventory (n.d.); The Recovery Interview (Heil et al.,1998, as cited in Burgess et al., 2011); The Personal Vision of Recovery Questionnaire (Ensfield, 1998); The Recovery Assessment Scale (Corrigan et al., 1999; Giffort et al., 1995); Recovery Attitudes Questionnaire (Borkin et al., 2000); The Illness Management and Recovery Scales (Mueser et al., 2005); the Stages of Recovery Measure (Andresen et al., 2006); The Recovery Process Inventory (Jerrell et al., 2006); Mental Health Recovery Star (MacKeith et al., 2008); and Recovering Quality of Life (ReQoL) measure (Keetharuth et al., 2018).

A review of local recovery measures developed for the NZ context included the Alcohol and Drug Outcome Measure (Deering et al., 2009; Te Pou, 2015); Tāku Reo, Tāku Mauri Ora (Gordon et al., 2004), a service user developed mental health outcome measure; and Hua Oranga (Kingi & Durie, 2000; McClintock et al., 2011), a holistic 360-degree feedback measure based on the Te Whare Tapa Whā model used with clinicians, families, and people in recovery within Māori Mental Health services. The addition of family and service user versions of the Health of the Nations Outcome Survey (HoNOS) (Wing et al., 1998) was developed to better enable collaborative discussion of changes and outcomes within clinical services during HoNOS reviews (Stewart, 2009).

Trauer (2010) advised that services need to choose a relevant measure for the type of service provided if that measure is to perform well as an outcome measure. Trauer (2010) wrote that there are many ways to measure outcomes. Trauer explained there are advantages and disadvantages of choosing a suite of measures compared to using one measure across services and populations; these issues need to be considered before choosing a measure.

Interpreting the results of outcome measures can be challenging. Jencks (1987) stated that considering what measure to use and how to measure recovery is complex; the measure needs to work across different clinical practice settings for diverse case mix variations and treatment approaches within community-based mental health services. Tran et al. (2019) pointed out that services have different resource allocations; a variable affecting recovery outcomes not often considered when comparing the outcomes of different cohorts within different service settings.

Some researchers have looked into potential solutions to these issues. The barrier of case mix diversity complicating the interpretation of outcome data was resolved through a statistical method of case mix adjustment within an adolescent mental health research study to compare outcomes across service providers (Phillips et al., 2003). Deb et al. (2004) found statistical solutions to the mediating impact of demographic differences affecting treatment outcomes among people receiving different services within clinical settings. Slade et al. (2011) used statistical power adjustments to reduce the impact of sample diversity when exploring differences between mental health recovery outcomes across services and subpopulations.

Outcomes can also be influenced by service and community environments (Wu et al., 2006; Picardi et al., 2006). Historical attitudes that introduce barriers to recovery, such as stigma and discrimination towards people with mental health problems, need to be addressed, and some of these exist within service systems (Cook & Jonikas, 2002; Gordon & Ellis,

2013). Critics of the mental health system highlight that recovery outcomes and interventions are introduced within systems yet to be fully recovery-orientated (Slade, 2002). They highlight that parts of the mental health system are still affected by institutionalised, paternalistic caregiving models, policies, or procedures that limit and restrict people in service systems (Damsgaard & Angel, 2021; Oades, 2012; Slade, 2002). Gordon (2013) highlighted that service models can stem from institutionalisation and disempower service users. O'Hagan (2001) and Osborn et al. (2010) provide examples of how using clinician-rated outcome measures can foster disempowerment when the views and opinions of service users are not included when their outcomes on these measures are evaluated. Environments that foster well-being are reported as ones with a more nurturing culture (Biglan et al., 2012).

Researchers have advocated involving service users and their families in reviewing mental health recovery outcomes to counter the problems with clinician rating tools used to determine outcomes within mental health (Kingi & Durie, 2000; Stedman, 1996; Stewart, 2009). Consultative participatory processes involving all stakeholders do not discount the widely held agreement that the needs of non-service user stakeholders and service delivery agendas should not be prioritised over the needs of the people receiving those services (Bowling, 2001; Coons et al., 2000). Some researchers advise that a recovery outcome needs to be self-determined rather than service or other-determined (Gordon, 2013; Brosnan, 2018).

Some authors have recommended that establishing whether a recovery outcome has occurred or not needs to be discussed with the person in recovery; any outcome noted needs to be established as having value and meaning to the service user in the context of their life and what progress looks like to them (Deegan et al., 2008; Farkas et al., 2016; Slade, 2002). Other writers suggest that the routine involvement of service users in the process of broader service or outcome evaluation policy and procedures strengthens a service's recovery orientation, service user engagement, and the working alliance (Gordon & Ellis, 2013;

Jenkinson & McGee, 1998; O'Hagan, 2001; Stedman, 1996). Rose and Smith (2018) found that the working alliance between the service provider and service user mediated the relationship between goals and recovery outcomes; the better the working alliance on service user determined goals, the greater the recovery outcomes were for service users.

Mental health outcome experts highlight that a more complex formulation of recovery and the emergence of many different services, ways to measure and encourage recovery, and the requirement by funders to report on recovery outcomes have increased the challenges of recovery measurement for mental health services (Trauer, 2010). Deegan (2002) stated that it is impossible to measure recovery as it is such a dynamic personal and individual experience. Gordon (2013) discussed that a one size fits all approach, or establishing a set recovery destination or ideal, is problematic. Gordon and Ellis (2013) advise that a recovery measure needs to be able to track a process, not be orientated only towards a specifically defined recovery definition or destination. Using a suite of measures was advised when multiple stakeholders and outcome targets have been identified; the results of service user measures to balance the understandings gained from clinical or service-wide measures (Trauer, 2010).

Open doors in society, rather than closed doors, are required for people to participate in the social world meaningfully (Onken et al., 2002). Social barriers to recovery, such as stigma, discrimination, and prejudice, are still present within the communities in which people are trying to recover their lives (Collins et al., 2012; Gordon et al., 2017; Lourenco, 2007; Parcesepe & Cabassa, 2012; Stuart, 2016). These realities can create frustration for all concerned when outcomes sought and presented as achievable have little avenue for resourcing, support, and achievement due to systemic limitations and lack of broader community support and opportunities for people recovering from mental health issues (Onken et al., 2007).

Authors discussing these issues point out that recovery from mental health problems cannot be seen as solely the individual's burden or responsibility to attain (Onken et al., 2007). Chou and Chronister (2011) highlight that the very nature of recovery involves recovering both personal and social parts of life. They write that social advocacy requires continued attention within service provision alongside the delivery of specific mental health interventions to offset the barriers faced by people re-entering community life with severe mental health problems that cannot always be resolved (Chou & Chronister, 2011)

The following section highlights recovery determinants identified in the personal recovery literature. These were considered against the definitions of the WHOQOL-BREF domains and facets to examine whether this generic QoL measure was missing QoL issues for people recovering from mental health difficulties.

Mental Health Recovery Research – Determinants of Recovery

International Research into Recovery. Systematic literature reviews have evidenced repeated mention of recovery determinants noted to improve the potential for a mental health recovery outcome (Ballesteros-Urpi et al., 2019; Bredewold et al., 2018; Ellison et al., 2016; Haraldstad et al., 2019; Parcesepe & Cabassa, 2012; Slade, 2002; Spittel et al., 2019). Narrative literature reviews have also highlighted many factors that improve personal recovery outcomes (Allot & Loganathan, 2002; Andresen et al., 2003, 2006; Bonney & Stickley, 2008; Collier & Grant, 2018; Leamy et al., 2011; New South Wales Community Advisory Group, 2009; Onken et al., 2002, 2007; Ralph & Muskie, 2000). These reviews highlight the variety and breadth of relevant issues to consider when identifying the content for a prospective recovery measure.

A landmark co-designed service user study in California by Campbell (1989) listed meeting basic human needs as one end of the recovery continuum. They summarised the most important to recovery: overall health, nutritious food, satisfying accommodation,

enjoyable work and an income, access to necessary resources, and satisfying social lives. These authors stated that well-being flourished when people could be creative, felt their spiritual and sexual lives were satisfying, and felt happy overall.

Ralph and Muskie (2000) compiled a synthesis of recovery literature that summarised many different determinants of recovery identified within the literature they reviewed. Ralph and colleagues highlighted the following four themes within personal accounts: (1) factors within the individual (illness toll, insight, the determination to recover); (2) self-management factors (how people cope and manage their mental health; (3) external factors (the social support people have, the presence of people who believe in them and their felt sense of belonging and connection to others); and (4) empowerment (the individual's resilience or felt sense of inner strength that enables self-help, advocacy and care for oneself and others).

Ralph and Muskie (2000) discussed a project where a county mental health service asked a service-user-run business to design a way of evaluating their mental health services. Participants highlighted a need for services to be recovery focused. The participants developed recovery determinants that service users rated in psychiatric services across two pilot locations in the United States – Ohio (71) and Maine (180). Participants ranked the indicators in terms of their importance. The first four indicators were ranked as the most important to recovery by both groups: (1) the ability to have hope, (2) trusting my own thoughts, (3) enjoyment of the environment, and (4) feeling alert and alive.

Ralph and Muskie (2000) reported that the following were identified as particularly important to the process of recovering from mental health problems: (1) increased self-esteem, (2) knowing I have a tomorrow, (3) working with and relating to others, (4) increased spirituality, (5) having a job, and (6) the ability to work. The Ohio group stated that service providers had a positive impact on people's recovery when they: (1) provided encouragement, (2) believed in the abilities of the service user, (3) used empowerment, (4)

listened to and believed what service users were saying in validating and affirming ways, and (5) provided choices (Ralph & Muskie, 2000).

Ridgway (2001) highlighted the following experiences as integral to the process of recovery: (1) reawakening hope after despair, (2) breaking through denial and achieving understanding, (3) moving from social withdrawal to engagement to active participation, (4) active coping rather than passive, (5) reclamation of a sense of self, and (6) a journey from alienation to purpose. Ridgway (2001) described the recovery process as a complex journey that required support and involved partnership with service providers or natural supports.

Andresen et al. (2003) reviewed the personal recovery literature and found that people with lived experience defined recovery as a process of psychological recovery driven by four critical processes: (1) finding hope, (2) re-establishing identity, (3) finding meaning in life, and (4) taking responsibility for their recovery. Resnick et al. (2005) reviewed the recovery literature and identified themes that reflected a personal recovery experience. Their research offered a conceptualised model of personal recovery for services to use to become more recovery-orientated. These researchers discovered four main domains that encourage recovery: (1) Hope and optimism; (2) Empowerment; (3) Knowledge of mental illness, what is involved with recovery, and how services can help; and (4) Life satisfaction.

A thematic analysis and review of 170 papers on mental health recovery in Britain conducted by Bonney and Stickley (2008) identified inconsistent definitions of recovery between different stakeholder groups. However, they also recognised agreement in six clear areas that affected recovery outcomes for people receiving mental health services. These were: (1) personal identity, (2) service provision agenda, (3) social life, (4) power and control, (5) hope and optimism, (6) risk and responsibility.

Social connection and networks have been linked to health outcomes, where social isolation poses risks to many groups in society (Hawkley & Cacioppo, 2010; Ortis-Ospina,

2019; Saeri et al., 2018; Yanguas et al., 2018). Chou and Chronister (2011) researched indicators of social recovery within the mental health population. These researchers highlighted the importance of social tie characteristics when assessing recovery progress. Chou and Chronister describe social tie characteristics as equivalent to a social domain where social inclusion is integral to community living after leaving institutional or supported living environments. Social tie characteristics were essential to recovering one's social life in the community. Social tie characteristics were described as: (1) social networks, (2) tangible support, (3) emotional support, and (4) negative social exchange.

SAMHSA is a federal authority in the USA responsible for mental health research, auditing, training, and developing resources for service use. SAMHSA identified 10 guiding principles of recovery: (1) hope, (2) person driven, (3) many pathways, (4) holistic, (5) peer support, (6) relational, (7) culture, (8) addresses trauma, (9) strengths and responsibilities, and (10) respect. Ellison et al. (2016) systematically reviewed the mental health recovery literature to identify research aligned with SAMHSA's 10 recovery principles. The service delivery factors most aligned with the SAMHSA's recovery principles were: (1) Individualised, person-centred; (2) Focused on empowerment; (3) Encouraged a sense of purpose; and (4) Facilitated hope among people.

Daniel Fisher is a psychiatrist and researcher on both sides of the mental health system, as a clinician and a person diagnosed with schizophrenia. Fisher conducted an extensive number of focus groups over 10 years with people recovering from mental health problems (Fisher, 1994, 2017). Fisher noted seven characteristics evident in a person who had recovered from mental illness compared to a person who was still in the process of recovery (Fisher, 2017). These seven defining characteristics of a recovered person were within domains of: (1) decision-making, (2) social supports, (3) social roles, (4) medication use, (5) emotional intelligence, (6) overall functioning, and (7) one's sense of self.

Fisher (2017) stated that people who recovered from mental health problems showed a progressive transition from initial dependence on the mental health system to a state of independence more typical of a person living in the community, with little to occasional or no reliance upon the health system. Rothman et al. (1996) advised a balance between supporting self-reliance and providing professional services to manage risk as a way to support this gradual transition. Fisher stated that the recovery process is, in effect, a progressive movement of regaining both health and independence, where a person's life becomes less and less dominated by mental health symptoms, a diagnosis, or its limiting social consequences. Non-health-related roles and interests naturally become more prioritised as recovery occurs. Fisher reported that as people restore their role functioning, their range of life activities, social networks, and interests grow. Fisher's seven characteristics of a recovered person show this progressive shift. Fisher stated that these seven characteristics can guide the direction of recovery goals and service provision to encourage this gradual progressive transition and final recovery outcome for people (Fisher, 2017).

In conclusion, a review of the international recovery research highlighted that important indicators, determinants, and components of personal recovery are repeatedly mentioned across studies. Although many different recovery determinants were cited within each review or research study, some recovery indicators or determinants were recurrently found across different studies. The frequent mention of some recovery determinants could indicate evidence of some global or fundamental factors central to the mental health recovery process that may be of more importance to include in a recovery measure. It was unknown to what degree the different unique terms attached to the themes gave the appearance of more determinants than there are. Literature reviews that synthesised the literature to identify principles through thematic analysis and provided conceptual models of personal recovery identified common recovery determinants across personal recovery research. Conversely,

higher-order themes may miss aspects of a multifactorial existential experience when clustering diverse experiences and giving them broad new labels.

The literature often included the importance of hope, coping, self-determination, autonomy, empowerment, stigma's impact, social connection, and support. Some recovery determinants were shown to influence QoL more directly than others, several of which are included in the existing WHOQOL-BREF, such as positive emotions, negative emotions, social support, everyday life functioning, and the ability to work. Other recovery determinants needed further exploration as they may be indirectly measured within the existing WHOQOL-BREF facet items. Some process measurements could occur by assessing QoL rating patterns over time instead of requiring a specific item to measure a process indicator, such as named recovery stages.

Social recovery was a recurrent theme that identified it as a significant component of mental health recovery within the literature. The social domain in the WHOQOL-BREF contains only three questions and is reported to have lower levels of internal reliability (IIic et al., 2019; Skevington et al., 2004a) than the other WHOQOL domains. It does not necessarily cover societal stigma, the importance of community engagement, and broader social networks than family and personal relationships, or measure the effect of marginalisation and social exclusion. The social domain of the WHOQOL-BREF may require further items to cover the range of issues people with mental health issues encounter during social recovery.

Many of the determinants of a personal recovery process were ones aligned with subjective well-being. They would fall within the WHOQOL's psychological domain, such as self-esteem, finding meaning and purpose in life, positive and negative emotions, and cognitive changes. Studies discussed environmental and mobility factors within the existing WHOQOL-BREF, such as access to services, financial resources, accommodation, and opportunities for skill development. Studies also mentioned physical domain items such as

energy and fatigue, activities of daily living, capacity to work, dependence on medical treatment, and the impact of symptoms, which can affect sleep.

From reviewing the literature, the question of what is being recovered within mental health recovery can differ for different people. It can include recovery from symptoms of a diagnosis, a troubled childhood or traumatic experiences, society's response to oneself as a minority, stigma from a diagnosis, or the existential disruption to life and subjective well-being resulting from the symptoms and personal life consequences of a mental health crisis.

Keetharuth et al. (2018) posited that personal recovery can be defined as synonymous with recovering one's QoL. The use of the WHOQOL-BREF, with the adjunct MHRQoL module, could address the disruption to subjective well-being and the disruptions to objective life circumstances brought about by consequences of the mental health diagnosis. The following section explores local research completed in NZ or Australia to examine whether determinants of recovery highlighted in the international research have also emerged as necessary for people recovering from mental health issues across Australasia.

Australasian Research into Recovery. Siggins Miller Consultants (2003) analysed service-user-rated outcome measures. They held discussions with people receiving mental health services and clinicians providing services to these people in Australia. The bolded areas show concordance between the clinician discussions and those with lived experience receiving mental health services. Those not in bold type show the areas of divergence between the results of these two groups. Three domains highlighted by service users were sub-domain factors described by clinicians are represented in bolded italics.

Mental health service users felt the following domains were essential to include within the content of outcome measures: (1) ***coping and resilience***; (2) ***hopefulness***; (3) empowerment; (4) **personal relationships** described as encompassing intimate, family, and societal relationships and inclusive of pets; (5) **functioning and well-being concerning**

significant roles and activities; (6) extra-treatment factors that influence outcome such as **other things happening in life**; (7) ***symptoms of illness and early warning signs of relapse***; (8) **physical health**: including the impact of medication as well as physical symptoms and (9) health and health system literacy (Siggins Miller Consultants, 2003, pp. 37–39).

Clinicians acknowledged that certain information could only be given by service users, such as information about their subjective state, symptoms, levels of functioning, and goals. Clinicians within the discussion meeting rated the following domains as essential to include within mental health measures: (1) **life circumstances**, (2) **roles and activities**, (3) behaviour, (4) use of services, (5) mental health events that include missed appointments or admissions, (6) ***mental state***, (7) **expectations of others**, (8) **medical issues** and **physical health**, and (9) cognitive functioning (Siggins Miller Consultants, 2003, pp. 47–49).

Although this research showed that there could be differences of opinion between stakeholders about what is essential to include in a recovery measure, there were also recovery determinants that both service providers and service users agreed were important. Given the plethora of recovery research, whether we have reached data saturation on all the things that affect personal recovery is possible. Inventing new words for common themes may not be beneficial to the field. This study highlighted that common factors identified by different stakeholders could provide a method of identifying central recovery determinants to include in an outcome measure.

The Tāku Reo, Tāku Mauri Ora measure (Gordon et al., 2004) is an outcome measure developed in NZ by people with lived experience of mental health problems and mental health service use. The research team conducted focus groups to discover what mental health service users identified as priority areas to include in a recovery-focused outcome measure. The person-rated self-report measure developed from their research contains 65 issues that mental health service users identified as necessary for recovery within 11 primary domains.

There were 14 additional Māori questions to cover cultural factors relevant to recovering from mental health issues from a Māori perspective.

The areas bolded are where the previous Australian research (Siggins Miller Consultants, 2003) and NZ mental health service users named similar domains. The 11 Tāku Reo, Tāku Mauri Ora measure domains are: (1) **Relationships**; (2) **Day-to-day living**; (3) Culture; (4) **Physical health**; (5) QoL (questions in this domain ask about fun, leisure, laughter, life contentment, relaxation, doing things I like, feeling safe); (6) **Mental health**; (7) Recovery; (8) **Hope and empowerment**; (9) Spirituality; (10) Access to resources; and (11) Satisfaction with services (Gordon et al., 2012, p. 207).

Some items on this list are not explicitly covered by domains or sub-domain facet areas within the current WHOQOL-BREF or WHOQOL-BREF with national items. Items such as recovery and culture are examples of these. The QoL domain within this measure emphasises well-being facets such as states of happiness and peace of mind. This area is covered by the facet within the WHOQOL-BREF that focuses on a person's satisfaction with positive experiences and feelings of well-being, which also describes optimism and hope in its facet descriptor. Service satisfaction, access to resources, spirituality, QoL, physical health, activities of daily living and satisfaction with relationships are all covered by WHOQOL-BREF facets. The WHOQOL facet assessing negative feelings, blue mood, despair, anxiety, and depression can partially cover some mental health problems.

Daniel Sutton (2008) conducted research with people recovering from mental health problems and highlighted that the process of recovery was marked by stages of functioning that he described as: (1) "undoing" (pp. 73–74); (2) "non-doing" (p. 96); (3) "partial-doing" (pp. 118–119); and (4) "doing" (p. 147). These process indicators highlight how people's disengagement, withdrawal from, and process of re-engaging with life activities and the social world are markers of mental health problems getting better or worse. Increased

functioning and social engagement were evidence of recovery progress similar to the process described by Fisher (2017). These process indicators of recovery could be researched further to see whether the gradual reclamation of satisfaction in facet areas of the WHOQOL-BREF over time during recovery equates with stages of "partial doing" and "doing" or the gradual decline of satisfaction with more facets over time is associated with a decline in functional changes and stages of "undoing" and "non-doing" in Sutton's (2008) model of recovery.

Stewart (2009) added robustness to the HoNOS clinician-rated measure, developed by the Royal College of Psychiatrists Research Unit in 1993 (Wing et al., 1998). Stewart developed a client and family version to enable a review and 360-degree feedback process to be incorporated into this clinician-rated outcome assessment that can determine a service user's exit from secondary mental health services. The HoNOS measure assesses the following domains recognised as significant markers of mental health recovery when the observations of each are marked as not present or very low: (1) Overactive, aggressive, disruptive behaviour; (2) Non-accidental self-injury; (3) Problem drinking or drug taking; (4) **Cognitive problems**; (5) **Physical illness** or disability problems; (6) Problems associated with hallucinations or delusions; (7) Problems with a **depressed mood**; (8) Other mental or behavioural problems; (9) Problems with **relationships**; (10) Problems with **activities of daily living**; (11) Problems with **living conditions**; (12) Problems with **occupation** and activities (Luo et al., 2016). Seven of these bolded are covered by existing WHOQOL facets.

Kingi and Durie (2000) developed a mental health outcome measure from the domains of the Te Whare Tapa Whā model. Te Whare Tapa Whā describes the four cornerstones of Māori health and well-being – taha tinana (physical health), taha wairua (spiritual health), taha whānau (family health), and taha hinengaro (mental health) (Kingi & Durie, 2000). The Te Whare Tapa Whā model highlights the importance of holding a holistic view of a person that recognises how physical, relational, and spiritual health is affected

when mental health deteriorates (Kingi & Durie, 2000). The model explores how each domain can positively restore and improve a person's mental health and well-being or can negatively affect a person's mental health when domains are underdeveloped or are a source of distress. These researchers explored whether the outcome measure could be used in a 360-degree collaborative way with service users, their families, and clinicians. Their measure can be used at service entry, as a baseline measure, for recovery planning, during reviews, and as an outcome measurement tool within mental health services (Kingi & Durie, 2000).

Lapsley et al. (2002) gathered 40 narratives from Māori and non-Māori and analysed the similarities and differences between the recovery narratives. They found more similarities than differences between participant experiences. These researchers provided a conceptual framework from their research with the acronym HEART, which stood for: (1) Hope; (2) Esteem (self-esteem); (3) Agency (control over life); (4) Relationships; and (5) Transitions (of identity, reclaiming personal, LGBTI, Māori, or other cultural identity and leaving behind illness identities). Participants discussed cultural frames of reference and healing from mental health problems. Māori participants discussed cultural service provision more often. They were more distressed by the difficulties brought about by stigma and discrimination from family members who did not understand their mental health issues.

Lapsley et al. (2002) also noted that post-recovery growth had occurred after resolving mental health problems that brought new valued experiences into participants lives named as: (1) strength, courage, and determination; (2) confidence, feeling good about oneself, and courage to be real; (3) a sense of being in charge, responsible, being resourceful; (4) clarity, a sense of direction, an understanding of things and people, philosophy of life and values had been explored; (5) tolerance, empathy, compassion, understanding of others based on one's own experience; (6) having something to offer others; and (7) being more happy,

carefree and spontaneous. Participants also spoke, however, of mental health experiences leaving them with less confidence, losing trust in themselves, or more sensitive to shocks.

Mousa's (2011) review of international and local recovery literature discovered that the following four domains were thematically involved in the reviewed mental health recovery research and recovery measures. These were: (1) **general beliefs about recovery** such as how people view themselves and their potential for recovery; (2) **social connectedness and closeness** such as belonging, cultural involvement, social support, activity in the community, and spirituality. Support from people who believe in the person needing recovery, formation of trust contributing to self-belief in recovery, natural support systems, and organisations outside of the mental health system such as churches, clubs, community centres, and sporting teams; (3) **feelings within oneself** such as contentment, security, self-control, confidence, self-esteem, personal development, growth, and change; (4) **socio-political issues being managed** such as stigma, discrimination and hope, independence, freedom, personal expectations, inclusive of self-stigma and struggles with the mental health system (Mousa, 2011, pp. 7-9).

In summary, the Australasian and NZ research reviewed identified some of the same recovery determinants cited in the international recovery literature. Some universal determinants may influence mental health recovery and have cross-cultural relevance or are inherent to how mental health problems affect people in Western societies. The existing content of the WHOQOL-BREF covers some of the common determinants identified across studies, yet not all of them. The current WHOQOL-BREF contains relevant facets important to mental health recovery. The recovery determinants discussed in the literature not covered by the content of the WHOQOL-BREF reinforced the potential benefit of a mental health module to capture additional important personal and social recovery factors relevant to

mental health recovery. The following section explores the relevance of QoL assessment and intervention for people in recovery.

HRQoL and Mental Health Recovery

The QoL ratings of people diagnosed with psychiatric conditions, compared to those with other chronic health conditions, have shown that QoL is significantly lower for people diagnosed with psychiatric conditions (Böckerman et al., 2011; Bonicatto et al., 2001; Masthoff, Trompenaars, Van Heck, Hodiamont, et al., 2006; Mayer et al., 2021; Skevington & McCrate, 2011). People diagnosed with mental health problems have the lowest self-reported QoL ratings compared to people with good health, cancer, or somatic illnesses (Butorin et al., 1997; Evans et al., 2007). Low QoL, therefore, makes QoL improvement a relevant target for intervention to resolve this problem (Awad, 2016; Stedman, 1996).

Over the last few decades, the factors influencing HRQoL for people recovering from mental health problems have become more evident. Research has investigated the reasons for lower HRQoL ratings among people recovering from mental health problems. QoL research was conducted with mixed samples of psychiatric patients (Atkinson & Zibin, 1996; Connell et al., 2012, 2014, 2018; Fahy et al., 1999; Fleury et al., 2013; Masthoff, Trompenaars, Van Heck, De Vries, et al., 2006; Mayer et al., 2021; Picardi et al., 2006; Trompenaars et al. 2006b, 2007); people diagnosed with schizophrenia (Guo et al., 2018; Ho et al., 2010; Priebe et al., 2010, 2011; Rocca et al., 2009, 2010); bipolar (Saarni et al., 2010); symptoms of psychosis (Hansson & Björkman, 2006); people on the sociotype spectrum (Cohen & Davis, 2009); and personality disorder (Masthoff, Trompenaars, Van Heck, Hodiamont, et al., 2006). Studies have explored the QoL of people suffering from depression (Renwick et al., 2012; Rocha et al., 2011); and trauma as refugees (De Vries & Van Heck, 1994); as well as people with addiction and substance use problems (Garcia-Rea & LePage, 2010). Researchers found that specific mental health symptoms, the severity of symptoms, particular diagnoses, the

presence of stress, depression or a mood disorder, the person's level of functioning or disability, and the impact of coexisting problems can all contribute to the lower HRQoL ratings found in the mental health population compared to other health populations.

Lowered QoL was linked to extended periods of impaired functioning among a subpopulation of people with psychosis (Melle et al., 2005), generally (Defar et al., 2023) and for those in assisted living (Mayer et al., 2021). Lower QoL was also linked to negative symptoms more than positive symptoms of psychosis (Cohen & Davis, 2009; Narvaez et al., 2008), and to the paranoid type of schizophrenia more than to other types (Maris et al., 2012). Low social functioning also correlated with low QoL (Trompenaars et al., 2007). Low ratings in the social domain also correlated with the experience of social stigma (Lourenco, 2007).

Deterioration of HRQoL has been noted as a marker for risk issues and unmet rehabilitation needs (Alves et al., 2016; De Abreu et al., 2012; De Freitas Melo et al., 2022; Fahy et al., 1999; Ponizovsky et al., 2003). Low self-reported QoL was associated with repeated suicide attempts in people who had attempted suicide multiple times, compared to people with schizophrenia who had not committed suicide or had attempted suicide only once (Ponizovsky et al., 2003). Suicide was also linked to low QoL scores across all four WHOQOL-BREF domains in people with bipolar disorder (De Abreu et al., 2012).

Alves et al. (2016) identified those at most risk of suicide with the WHOQOL-BREF and concluded that changes in QoL scores help to identify whom to assist to reduce this risk. De Freitas Melo et al. (2022) found that QoL domains influenced 47% of the variation in risk indices, with the psychological domain being the most relevant. These researchers recommended routine QoL assessment and intervention to identify and mitigate risk within mental health services. Fahy et al. (1999) found that low self-reported QoL ratings were linked to unmet rehabilitation needs and more clinical symptoms. Hansson and Björkman

(2006) also found the same two factors, along with an additional factor, low social networks, predicted lower HRQoL ratings.

Mental health service delivery can also influence lower HRQoL ratings for people receiving mental health services. Experiences linked to lower HRQoL scores were found by Wu et al. (2006) to be service interruption, higher levels of service coercion, and service discontinuation. Differing levels of engagement and variability in the quality and extent of support planning also affected differences in QoL ratings among service users within residential settings (Picardi et al., 2006).

Researchers and authors have articulated the relevance of health-related QoL (HRQoL) assessment to improve mental health service provision for many years (Alves et al., 2016; Atkinson & Zibin, 1996; Barry & Zissi, 1997; Connell et al., 2014; Fahy et al., 1999; Frisch et al., 1992; Herrman et al., 2002; Keetharuth et al., 2018; Melle et al., 2005; Orley et al., 1998; Picardi et al., 2006; Prince & Prince, 2001; Renwick et al., 2012; Revicki et al., 2014; Spilker & Revicki, 1996; Stedman, 1996). Connell et al.'s (2012) literature review explored the QoL issues experienced by people recovering from mental health problems. The review highlighted the following recurrent themes important to the QoL of people during their recovery from mental health problems: (1) well-being and ill-being; (2) control, autonomy, and choice; (3) self-perception; (4) belonging; (5) activity; and (6) hope and hopelessness. The authors recognised that the construct of QoL and personal recovery were interrelated for people in recovery.

HRQoL Assessment Within Mental Health Service Provision. Slade (2010) discussed the value of using multifaceted subjective HRQoL tools are they can measure and offer intervention opportunities to support recovery from mental health problems without reference to stigmatising labels. Awad (2016) recommended routinely using HRQoL assessment within mental health service provision. Award suggested they can be used during

routine reviews with mental health service users to set QoL life goals, address ways to improve well-being, assess a treatment's impact, and to set intervention targets (Awad, 2016).

The diverse range of factors negatively impacting QoL are inherent to the presenting problems of people receiving mental health services. Multiple factors influencing QoL can increase the complexity of HRQoL assessment and the use of QoL PROMs with this population (Oliver et al., 1996). Acute symptoms of psychosis predicted lower subjective HRQoL ratings in a sample of people with schizophrenia (Rocca et al., 2009); however, this disappeared once the mediating effect of insight was controlled for (Rocca et al., 2010). Prince and Prince (2001) discussed ways of using HRQoL measures to improve their reliability as PROMs. Prince and Prince recommended that service users choose the domains of relevance to be tracked within a PROM, as opposed to these being determined by service providers. Tracking changes to QoL ratings in domains of interest to service users can identify how mental health issues affect QoL more effectively (Prince and Prince, 2001).

Connell et al. (2014) challenged the artificial separation of health status from HRQoL. These researchers stated that mental health symptoms and illness states, by default, negatively impact QoL. They pointed out that symptoms of mental distress, low self-esteem and confidence, being marginalised, low activity levels, hopelessness, and demoralisation is often the consequence of being diagnosed with a severe mental health problem, all of which impact QoL. Making QoL assessment and intervention vital to the restoration of well-being.

Böckerman et al. (2011) found that brief forms of generic HRQoL measures fail to capture the subjective ***well-being*** issues experienced by people with chronic health problems. ***They warned that i***nadequate coverage of HRQoL issues can lead to underfunding and inadequate resourcing when funders use the results from these measures to understand service needs or the impact of a health condition on people's lives (Böckerman et al., 2011). Connell et al. (2014) ***also*** critiqued generic ***brief*** QoL measures often used in mental health outcome

studies or evaluation research, such as the EQ-5D and SF-6D, stating they do not address the broad range of QoL issues faced by people recovering from mental illness. These authors highlighted that QoL measures that only ask about QoL in positive ways, without covering the negative experiences encountered by people with mental health diagnoses, can miss important aspects of QoL assessment for people recovering from mental health problems. These researchers stressed the importance of gathering content for PROMs from service users. They concluded that "ill-being" and "well-being" items should be included in HRQoL PROMs for people recovering from mental health problems. Recent research in the United Kingdom leading from these studies developed a recovery measure called the ReQoL that contains mental health questions such as "I thought my life was not worth living", "I felt anxious", "I felt able to trust others", "I felt unable to cope" within their MHRQoL measure to address these issues (Connell et al., 2018, pp. 1989–1900).

The Impact of Mental Health Problems on QoL Measurement. Research into the HRQoL of people with mental health problems shows that various mood and mental states can affect people's perceptions of themselves and their lives, which can be reflected in their QoL ratings (De Abreu et al., 2012; Masthoff, Trompenaars, Van Heck, De Vries, et al., 2006; Masthoff, Trompenaars, Van Heck, Hodiamont, et al., 2006; Ponizovsky et al., 2003; Trompenaars et al., 2006a). Revicki et al. (2014) reported that historically, this was thought to lower the reliability of self-report measures of QoL in mental health populations. Researchers argued for objective measurement as a better measure of HRQoL for people with mental health issues, stating that they were freer from the perceptual biases created by any presenting symptoms of mental health problems (Atkinson & Zibin, 1996; Atkinson et al., 1997; Cohen & Davis, 2009; Petkov, 1998; Priebe et al., 2011).

Later research established subjective QoL measures as valid and reliable ways to assess the QoL of people with mental health problems (Hansson & Björkman, 2006; Revicki

et al., 2014). Subjective measures can identify changes in people's mental health, as well as their response to other life factors affecting their QoL (Franz et al., 2012; Padilla et al., 1992; Panesar & Valachova, 2011; Prince & Prince, 2001). Changes in subjectively rated HRQoL scores can be used at times of review to explore potential responses to intervention, recovery progress, barriers to recovery, or relapse (De Abreu et al., 2012; Masthoff, Trompenaars, Van Heck, De Vries et al., 2006, Masthoff, Trompenaars, Van Heck, Hodiamont et al., 2006; Ponizovsky et al., 2003).

Michalos (2008) argued that both subjective and objective measures of QoL are necessary to address the multifaceted targets required for redress to improve the lives of people recovering from mental health issues. Michalos discussed that people's QoL ratings occur within a psychological context; people can accept poor living standards due to poverty and marginalisation or be grateful for any accommodation if they have little opportunity to change their circumstances. When the severity of mental health problems prevents independent living, this can result in people being forced to live in residential facilities or environments not naturally chosen when well (Michalos, 2008; Osborn et al., 2010).

Research into whether subjective or objective measures are more reliable measures of change during mental health recovery has shown subjective measures to be more respectful, reliable, and empowering. They validate the perspective of the person and their perception of their life according to their values and priorities (Stedman, 1996; Stedman et al., 1997a, 1997b). Basu (2004) highlighted that subjective HRQoL assessment gives people recovering from mental health problems the opportunity to have a voice and the ability to offer feedback about the effect of interventions on their lives during service and treatment evaluation processes. Llewellyn and Skevington (2015) found that providing individualised feedback to service users after completing a QoL measure increased psychological QoL and can improve self-monitoring, self-management, and clinical decision-making during service delivery.

The Overlap Between QoL and Mental Health Recovery. Researchers who have explored the constructs of personal recovery and subjective well-being measured by QoL instruments have identified a relationship between factors that restore or affect QoL and the factors that restore or affect mental health recovery (Chiu et al., 2010; Connell et al., 2012; Ho et al., 2010; Keetharuth et al., 2018; Leamy et al., 2011). Conceptual frameworks of personal recovery (Leamy et al., 2011; Connell et al., 2012, 2014) and HRQoL measures specifically developed for people with mental health issues (Bigelow, 1991; Connell et al., 2018; Keetharuth et al., 2018) have considered the relationship between QoL improvement and mental health recovery. Camfield and Skevington (2008) discussed subjective well-being as a subset of QoL, yet not separate from it, which may explain this interaction.

Chiu et al. (2010) researched the connection between QoL and mental health recovery in a study involving 201 people with schizophrenia, schizophreniform, and schizoaffective disorders. Chiu et al. (2010) used the 10 recovery components believed to foster recovery that established by SAMHSA. These researchers wanted to see which of those 10 recovery components best predicted HRQoL within this population. They assessed the correlation between the items of the WHOQOL-BREF and SAMHSA's 10 recovery components. Five of the 10 recovery components had the most significant effect on HRQoL in the following rank order: (1) psychosocial symptoms, (2) personal agency, (3) sense of optimism, (4) perceived support, and (5) internalised stigma. These researchers found that psychosocial issues and internalised stigma affected people's ability to feel optimistic about the future, their perceptions of social support, and their self-determination. They recommended building resilience and self-efficacy specifically to improve the HRQoL of people recovering from schizophrenia (Chiu et al., 2010).

Lorena Ho's (2011) doctoral research identified the importance of paying attention to demographic factors when examining the relationship between recovery progress and

HRQoL changes. Ho's (2011) research used the WHOQOL-BREF within a population of Chinese people diagnosed with schizophrenia. Ho (2011) found that 37% of the variance in recovery progress within this population was due to clinical variables and socio-demographic factors. Gender and marital status were significant predictors of recovery progress in Ho's (2011) sample. Ho (2011) named the following factors as predictors of a recovery outcome in this group: (1) Meaningful roles (such as worker, homemaker, student); (2) Shorter duration of illness; (3) Having confidants; (4) Being an older age; and (5) Residential service use.

In conclusion, the findings in the literature showed that despite identified challenges requiring remediation strategies, QoL assessment offers a relevant orientation for recovery intervention within mental health services that can benefit service users. The authors reviewed reported that HRQoL assessment can help to investigate how specific symptoms or diagnoses are impacting a person's life and subjective well-being. Exploration of HRQoL assessment results with service users can identify how current emotional problems, stress levels, illness course or duration, experiences of social disconnection, stigma and discrimination, service delivery environments or impacts, and the presence of coexisting problems are presenting as barriers to the restoration of QoL and well-being.

The routine inclusion of HRQoL assessment within services can provide a way to identify early signs of suicide risk, help to identify unmet rehabilitation and clinical treatment needs, and address issues like stigma or insight that can affect people's ability to move forward in their recovery. Evaluation of HRQoL scores can identify the types of service environments and service delivery issues affecting people's QoL. QoL measures with relevant content to stimulate the restoration of community living, meaningful roles, subjective well-being, and improved social connection can be used for assessment and intervention planning. Targeting the barriers affecting people's QoL for remediation can help

to address the lower QoL statistic reported for people recovering from mental health problems.

WHOQOL Use in New Zealand Mental Health Services. As previously reviewed, the WHOQOL tool has been reported to be a reliable, valid generic HRQoL measure for use within various general mixed populations common to primary and secondary community mental health service populations, as well as in specific diagnostic groups seen in tertiary level services. Strengths of the WHOQOL as a PROM include: (1) it is a self-report measure developed by end users; (2) it is sensitive to change; it can be used to assess the responsiveness of brief and long-term interventions; and (3) the content of the WHOQOL is relevant to the multifaceted objective and subjective targets for intervention during mental health recovery (Skevington et al., 2004a; Skevington & McCrate, 2011).

NGOs within NZ provide recovery services primarily to people receiving secondary mental health services and occasionally to people referred by primary mental health services, self-referred, or referred by family (Ministry of Health New Zealand, 2016a). NGO services are primarily involved with supporting the recovery of people after acute mental health episodes when they are ready to return to community-based living and increase day-to-day functioning. The intervention focus of the NGO sector is on the personal recovery and QoL goals of people wanting to restore more independent functioning from the disabling consequences of severe mental health problems (Andrews & Rowthorn, 2013). Since 2007, several NZ NGOs have started using the WHOQOL-BREF and the NZ national items for recovery planning and to evaluate individual, service, and organisational outcomes within their organisations (Andrews & Rowthorn, 2013).

NGO services using the WHOQOL-BREF began working together as a community of practice through a community networking agency called Platform Trust (Platform Trust, n.d.) (Andrews & Rowthorn, 2013). A biannual meeting was held to discuss issues related to

integrating the use of the WHOQOL-BREF into organisational systems, service delivery processes and to problem-solve the issues related to roll out, data analysis, interpretation, feedback, and data use within organisational reporting and continuous quality improvement activities (Andrews & Rowthorn, 2013). The current research arose from this community of practice's interest in strengthening the precision of the WHOQOL as a PROM.

Conclusion

In conclusion, an examination of the literature reporting on the use of the WHOQOL-BREF with people recovering from mental health problems has evidenced that this HRQoL measure is a valid and reliable instrument for use in research and service provision for this population. It has shown reliability and validity in different diagnostic samples, with and without comorbidity, sensitivity to change in response to service delivery interventions and lifestyle stressors, with reliability and validity confirmed across cultures and settings. It is a measure used internationally and locally as a recovery-orientated PROM with people recovering from mental health problems. However, a mental health module has yet to be developed to ensure that the unique QoL issues experienced by people in recovery are assessed and tracked when the WHOQOL is used as a PROM.

The literature review identified information used to review the planned methods and inform the research process when considering the development of a mental health recovery module for the WHOQOL-BREF. The definitions of HRQoL and mental health recovery were clarified, and the best practice guidelines for developing HRQoL measures and PROMs for mental health recovery were summarised. The practical problems highlighted in the literature as inherent to developing and using outcome measures within the mental health field show that a PROM developed for mental health services needs to work for a multi-service environment and diverse case mix samples. A measure must suit the services provided and have enough flexibility and dynamic responsiveness to enable its use with

individuals in multi-stakeholder, multicultural, multi-intervention, diverse case mix settings. The measure must be suitable for individual recovery planning and where aggregated data can be gathered and used for service evaluation.

The NZ version of the WHOQOL has been validated for use within NZ, providing a relevant version of the WHOQOL-BREF for use within this research. A psychometric procedure for developing a module for the WHOQOL-BREF was published within the development of the NZ national items study (Krägeloh et al., 2016). Therefore, the psychometric procedures used in the NZ national items research are available for replication in this research.

The historical context of the mental health recovery movement reinforced the importance of using empowering processes and a strong recovery orientation when developing a PROM for use with people recovering from mental health problems. The methodology outlined in the WHOQOL Study Guide (WHO, 1993) and NZ national items study (Krägeloh et al., 2016) concord with best practice protocols for PROM development when reviewed against the SAC and ISOQOL guidelines. The principles of the recovery movement are embedded in the WHO ethos for the WHOQOL tools as being person-centred in their development (Skevington et al., 2004b). The recovery literature review identified potential content for a mental health module for the WHOQOL-BREF to increase its precision as a PROM for use in mental health research and service evaluation applications. The next chapter discusses the theoretical and methodological underpinnings of the current research.

Chapter 3

Theory and Methodology Underpinning this Research Study

Theoretical Models Underpinning this Research.

HRQoL Theory

The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) model was publicised as a manual of classification by the WHO in 1980. It initially focused on the negative impacts of disease, disorders, and injuries. This conceptual framework provided a way to describe how specific diseases, disorders, and injuries impacted people's lives. The model aimed to explain how specific impairments brought about by a health condition negatively impacted upon a person's functioning, disrupting their capacity to engage in meaningful roles, activities, and participate in the social world (WHO, 1999).

A newer model was developed in 1999, called ICIDH-2 (WHO, 1999). This model included environmental factors and changed its focus to the necessary components for creating good health. The ICDIDH-2 model is founded upon the theory that a complex interactive relationship exists between a person and their health condition. The full continuum of how a health issue affects people can be explored within ICDIDH-2. It offered the opportunity to identify factors relating to the restoration of and determinants of health, as well as those being created by disease, unlike the earlier model (WHO, 1999).

The International Classification of Functioning, Disability and Health (known commonly as the ICF model) is a further evolution of the ICDIDH-2 model. It is recognised as the WHO's conceptual framework for individual and population health. It was endorsed by all member states at the 54th World Health Assembly in 2001 (WHO, 2002). The WHO describe this model as normalising the disabling effects of changes to health in ways that universalise the impact of poor health and create equality across all health conditions by using a common continuum and metric of health and disability (WHO, 2002).

The ICF can be used with the International Classification of Diseases (ICD) system (WHO, 2021b), which classifies diseases and disorders and enables countries to contribute

health data to the WHO for health data comparisons. The ICF explains how health problems affect people and what is required to restore health for health planning and can measure health system performance (WHO, 2002).

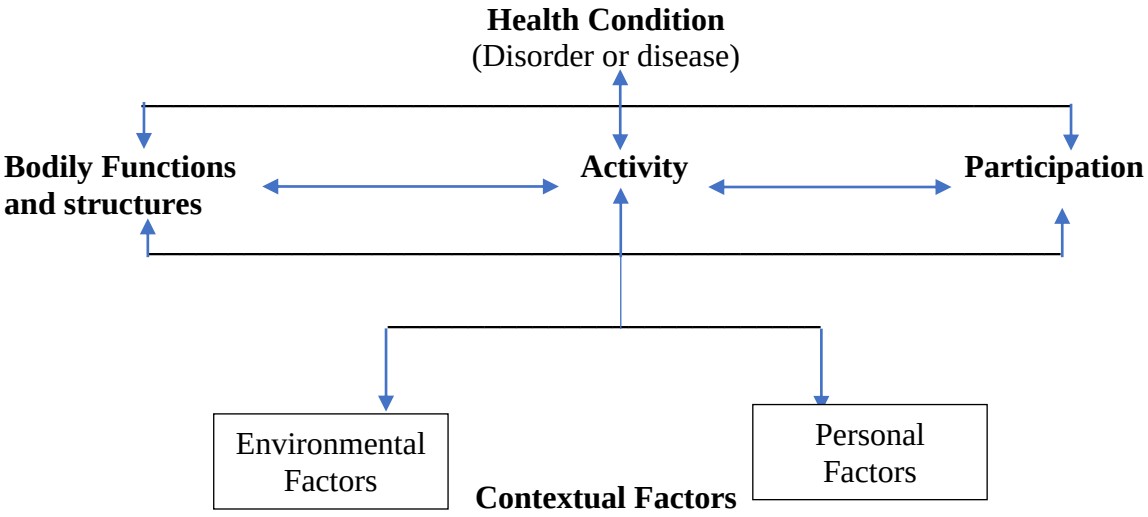
The ICD (currently in the 11th edition, WHO, 2021b) is used to diagnose mental health problems in Europe in the same ways that the Diagnostic Statistical Manual (DSM) (currently in the 5th edition, DSM-5, American Psychiatric Association, 2013) does outside of Europe. These systems determine whether a person meets the criteria for a psychiatric diagnosis and what diagnosis best describes their mental distress to others for treatment purposes. Mellsop et al. (2007) write that psychiatrists more commonly use the DSM (5th edition) (American Psychiatric Association, 2013) within NZ due to being trained in the use of this diagnostic system. NZ hospitals use the ICD system when diagnosing medical conditions (Te Whatu Ora, 2023). The Accident Compensation Commission (ACC) can accept diagnoses from either of these classification systems (ACC, 2023).

The WHO states that the ICF model can explain how having a health condition changes biological functions and structures negatively, through illness, or positively, through treatment. The WHO explain that a person's activity level and participation in essential areas of life can alter when experiencing acute phases of ill health and throughout their treatment process. They explain that the nature of these changed activity and participation levels and how a person subjectively responds to having a health problem can emerge as a personal factor. Those personal reactions can, in turn, influence a person's symptom presentation in terms of their biological health, how they are coping and the nature of their interactions with others, the ways they are interacting with their environment, how they perform their activities or can be influenced by the behaviour of others or the environmental context they are in at the time (WHO, 2002).

The ICF model presents a high-level theoretical depiction of the relationship between these main factors affecting health restoration or are affected by health consequences by the use of bidirectional arrows (WHO, 2022). The WHO (2002) explain that each factor can have a consequential and dynamic interactional relationship with each other factor. Each factor can be a point of influence for a person's disabling health outcome from a health condition or an influence for health restoration. Figure 3 shows the dynamic inter-relationship of factors in the ICF model produced by the WHO (2002, p.9).

Figure 3

WHO ICF Model



Note. Adapted from *Towards a Common Language for Functioning, Disability and Health ICF*, by the World Health Organization, 2002. https://cdn.who.int/media/docs/default-source/classification/icf/icfbeginnersguide.pdf. Copyright 2002 by the WHO under the creative commons attribution-non-commercial-share alike 3.0 intergovernmental organization license CCBY-NC-SA 3.0 IGO.

The WHO (2002) note that the general principles underlying the ICF model are closely tied to the biopsychosocial model. Tripathi et al. (2019) highlighted that the biopsychosocial model (Engel, 1980), commonly used within mental health services, provides a holistic and empathic perspective for understanding mental health problems by identifying how a person's mental health occurs in a context and is influenced by environmental and social experiences. Tripathi et al. (2019) explain that the value of the model is in its potential to explore the interaction between biology, environment, personal,

and social factors, when considering how mental health problems can develop and when treating mental health problems.

The WHO (2002) stated that the ICF model is an international tool that supports moving away from the medical model to a more integrated biopsychosocial model of the impact of health and disabling effects of health conditions. The WHO explain that it is useful for research into the impact of health conditions and what restores health after a health diagnosis that considers personal, social, and environmental contextual factors affecting a person's recovery (2002). They anticipated the "ICF will become the world standard for disability data and social policy modelling" (WHO, 2002, p. 20).

When discussing the predecessor to the ICF, the ICDIH-2 model, the WHO (1999) stated that the model is not intended to be prescriptive or closed. They acknowledged factors other than those depicted in the model can also impact people's health. They stated that the model is a way of conceptualising the interactions between biological, psychological, and social theories of health creation to provide a mechanism that can identify how the different dimensions of health: biological, social, individual, and environmental are not mutually exclusive, they are integrated and affect one another dynamically. The WHO stated that the model may help to explore the relationships between these interactions within HRQoL research (WHO, 1999).

The WHO (1999) also asserted that people themselves are not units of classification within the model, despite personal factors being acknowledged in the interactive dynamic of how a health condition affects a person. The WHO write that personal factors are of interest, as they are more amenable to intervention in a health service when supporting people to obtain improved health outcomes (WHO,1999).

Skevington et al. (2004b) reviewed the QoL literature and history of the WHOQOL's development. They explained that unidimensional models of QoL, identifying only whether

QoL has improved or deteriorated, were less useful than multidimensional models that show more specifically where that deterioration or improvement has occurred. These authors also stated that the items of the WHOQOL focus on a person's perception of the consequences of disease and its treatment to their lives and personhood (Skevington et al., 2004b). These authors discussed how QoL, despite its subjective perceptive nature, is not a mood or psychologically dependent construct. It is a construct that explains the interaction of a person with their environment or context. They explained that personal factors, such as mood or personality, are not the only determinants that affect a person's QoL judgements. These are also affected by features of the environment, social relationships, the actions of others, and other contextual factors upon them (Skevington et al., 2004b).

Strengths of the ICF Model

The WHO point out that the ICF model is simple in its design and broad in its application. This makes it useful for both individual and aggregated data set reflection, and as such, it can be applied to a wide variety of research and service evaluation purposes (WHO, 1999). The WHO stated that the model is not disability or disorder focused. Instead, it focuses more on an individual's engagement with their environment and response to the health condition. The model considers how a person is participating in activities and interacting with others and their environment functionally. It can examine how those factors in turn affect both the person's response to the health condition, as well as the way the health condition affects them. The model is not prescriptive and does not limit or direct the type of change, development, or improvement required of any factors within the model. Yet it can accurately describe the limitations brought about by changes in the condition or treatment for the person or population being studied (WHO, 2002). The WHO (1999) stated that services can explore how their interventions are linked to the dynamic interaction between factors in the model through the lens of their own change theories when evaluating outcomes.

The ICF model does not conflict with the conceptual framework of personal recovery. It includes a personal factors domain, which allows for the exploration of the subjective perceptions and responsive nature of people's unique reactions to their health circumstances. The other factors in the model influence personal recovery, such as relationships with others, functional capability, environmental influences, participation in meaningful activities and roles in life. The model does not restrict the individualised way that the interaction between these factors can occur for a person or by a service being provided (WHO, 2002). This theoretical model underpins the WHO definition of HRQoL, making it the most fitting theoretical model for WHOQOL research.

Research conducted by Cieza and Stucki (2005) explored the use of the ICF model to compare six HRQoL measures, of which the WHOQOL-BREF was included as one of these six. The model was identified as useful for comparing the value of different HRQoL measures to capture relevant content related to factors within the ICF model. Aspects of work and emotional functioning were covered by all measures. Concepts within the items of the measures reviewed were linked to 91 different ICF categories, 17 to bodily functions, 60 to activities and participation, and 14 to the environmental factor. Cieza and Stucki (2005) identified that the ICF model was better for selecting the best instrument for HRQoL research than other HRQoL models. They reported that the WHOQOL-BREF included 20 of the ICF categories.

Limitations of the ICF Model

The ICF model looks at the consequences of health problems through the lens of functional impairment and restoration of functioning (WHO, 1999). The WHO have another QoL tool that assesses the degree of functional disability occurring from a health condition, the World Health Organization Disability Assessment Schedule (WHODAS-2) (Üstün et al., 2010). The WHODAS-2 can map more directly to the aims of the ICF model as it asks people

to rate levels of functional disruption caused by a health condition in different areas of life (Üstün et al., 2010). The WHOQOL tool assesses changes in perception, subjective well-being, and satisfaction levels with aspects of life after the onset of health problems (Skevington et al., 2004b). Although this is relevant when evaluating changes to mental health, asking people about life satisfaction and functional disruptions to life are two different frames of reference.

The ICF model includes personal, social, environmental, and activity level effects involved with a specific health outcome or response to treatment. It does not detail, however, the specific subjective factors within the personal factor domain that have impacted HRQoL (Bakas et al., 2012). The WHO (2002) write that this is due to personal factors being more amenable to intervention. The WHOQOL has items that cover the broad factors in the ICF model and could be used, in principle, to assess the ICF's personal factors domain, i.e., assessing how a person evaluates aspects of the biological, social, environmental, and health condition factors by evaluating their ratings on relevant WHOQOL items.

The WHO (1999) reported that the ICF model does not explain how specific mechanisms within any factors impact health outcomes. This non-prescriptive, broad, open model can be seen as a strength, as the same model can be used by multiple services to explore the impact of their interventions through their change theory lens (WHO, 1999). Theoretically, a central conceptual framework could help to unify a complex service environment. The change formulation could include personal, social, environmental, or contextual factors related to different services provided when evaluating any differences between service outcomes using the ICF model.

Measuring Health and QoL Changes

Bigelow et al. (1991) stated that a useful HRQoL theory can conceptualise people's mental health needs, can help to describe the services that people require, and is useful for

programme evaluation purposes. They identified that two aspects of QoL, subjective well-being and objective factors such as the ability to work or live independently, can be assessed and evaluated with HRQoL measures, in relation to QoL theory. These researchers equated a mental health service outcome with positive changes in HRQoL for people and developed an HRQoL measure for use as a service evaluation measure within mental health services. The QoL theory informing their work was stated as coming from need theory (Maslow, 1954) and role theory (Sarbin & Allen, 1968).

Bigelow et al. (1991) stated that QoL emerges out of a context where a social contract is fulfilled by needs being met in response to the demands society puts upon its members. They stated that needs are met through the opportunities available within a social environment to respond to those demands. A person's psychological abilities, such as cognition, affect, perception, and physical capabilities, enable them to meet societal demands. They wrote that mental health problems compromise these abilities, which correspondingly interferes with a person's capacity to fulfil needs or use societal opportunities to meet demands. They state it is the responsibility of service providers to moderate this process to better enable people to meet the demands and fulfil their needs in order to improve their QoL.

Sprangers and Schwartz (1999) presented a theory of change model that can be used to explain response shift within HRQoL research. These authors explain that response shift can map a person's perceptions of how their life has changed after the onset of a health problem, and during its resolution. They outlined a proposed theoretical model that explained changes in HRQoL being due to an interaction between: (1) a catalyst (health condition or disease), (2) personal factors (e.g. disposition or personality, (3) mechanisms (cognitive or behavioural or emotional responses involved with adapting to or adjusting life to the consequences of the health condition), and (4) response shift (changes in the meaning of one's self-evaluation of their lives in response to changes of internal standards, values or

ways of seeing their lives). Chen et al. (2021) identified how structural equation modelling can be used to detect response shifts within HRQoL measurement.

Response shift theory could be considered in relation to Deegan's view that one's perception of self can change through the onset and resolution of mental health problems, as well as be a fluctuating phenomenon when experiencing setbacks, or facing the limitations created by mental health conditions socially, personally, and functionally (Deegan, 1988, 1996, 2002). Theories more specific to subjective well-being or personal recovery may also explain how people's QoL changes during their recovery from mental health problems.

There are several conceptual frameworks provided in the literature that necessarily involve considering different factors that operate as determinants of the recovery process or are a consequence of mental health problems that are connected to changes in QoL. The following section will focus on research that has considered conceptual frameworks that integrate determinants involved in the personal recovery process with changes in QoL.

Personal Recovery Theories

Andresen et al. (2003) reviewed experiential accounts of personal recovery from schizophrenia and other serious mental health issues. These authors considered how the concepts of recovery and personal recovery were discussed within qualitative research studies and theoretical literature. They used the common themes in the literature to present a conceptual model that identified the main psychological processes involved with personal recovery. These were: (1) finding hope, (2) re-establishing identity, (3) finding meaning in life, and (4) taking responsibility for recovery.

Andresen et al. (2006) state that these psychological processes are embedded in a larger process of recovery identified by five key stages. They went on to develop the stages of recovery measure (STORI) from their research to assess which of these stages a person

was in during their recovery. The STORI was used in Phase 1 of this research to identify the sample characteristics in relation to early, mid, or late stages of recovery.

Connell et al. (2012, 2014, 2018) conducted research into MHRQoL and developed an instrument to measure MHRQoL within the mental health population. Seven core domains of QoL were found to be relevant to mental health recovery. These were: (1) activity; (2) belonging and relationships; (3) choice, control, and autonomy; (4) hope; (5) self-perception; (6) well-being; and (7) physical health that was added later, after service user interviews were conducted to confirm the themes that had found through their analysis of the personal recovery literature (Connell et al., 2014). The ReQoL measure contains 20 items that measure negative subjective experiences that reduce QoL, as well as factors associated with improved QoL (Keetharuth et al., 2018). These researchers posited the answer to what is being recovered, within the mental health recovery process, is quite possibly, a person's QoL.

Leamy et al. (2011) conducted a systematic review of 5,208 research studies that explored the determinants of personal recovery. They found that 97 research papers met their criteria for inclusion during their analysis of factors found to be linked to the construct of personal recovery. Their findings were summarised in an acronym CHIME:

1) **C**onnectedness (involving peer support, relationships, support from others, connection to the wider community).
2) **H**ope and optimism about the future (this involves belief in recovery, motivation for change, hope inspiring relationships, positive thinking, valuing success, having dreams and aspirations).
3) **I**dentity (a positive sense of identity is redefined or rebuilt, overcoming stigma).
4) **M**eaning in Life (this can involve making meaning from mental health experiences, spirituality, QoL, attaining a meaningful life, meaningful social roles, and goals, as well as rebuilding one's life in a meaningful way after a crisis).

5) **E**mpowerment (this involves taking personal responsibility for one's health and life, having a sense of control over one's life, and focusing upon one's strengths). (Leamy et al., 2011, p. 448).

The CHIME conceptual framework posits that the interaction of these five determinants of recovery with each other describes the personal recovery process. If these five principles are focused upon during service delivery they can enhance a person's personal recovery outcomes. Leamy et al. (2011). Figure 4 presents a schematic diagram of the CHIME model developed by Ballesteros-Urpi et al. (2019, p. 2).

Figure 4

The CHIME Personal Recovery Model

Note. Adapted from "Conceptual framework for personal recovery in mental health among children and adolescents: A systematic review and narrative synthesis protocol," by A. Ballesteros-Urpi, M. Slade, D. Manley & H. Pardo-Hernandez, 2019, *British Medical Journal Open*, *9*(8). https://doi:10.1136/ bmjopen-2019-029300 Copyright 2019 by BMJ Publishing Group under the creative commons licence CC-BY-C 4.0.

A study by Ho et al. (2010) explored the connection between QoL and personal recovery to see whether 10 well-accepted recovery components developed by SAMHSA in the USA were related to the HRQoL of Chinese people diagnosed with schizophrenia. Ho et al. (2010) used the WHOQOL-BREF and structural equation modelling to consider the

interaction between HRQoL as identified with the WHOQOL-BREF against the determinants of personal recovery. They aimed to examine the correlation between HRQoL and SAMHSA's 10 recovery determinants. They developed a structural model to explain HRQoL in relation to these recovery components, and thirdly, they sought to explain the HRQoL variance by using a good-fit statistical model. The 10 recovery principles were measured on 12 separate well validated reliable mental health scales to measure each of the 10 components. Their research hypothesis was that all 12 of these variables would correlate positively with the WHOQOL-BREF domain scores. The 10 recovery components were:

1. Enhancing personal control and the self-determination of patients.
2. Implementation of person-centered treatment to enhance recovery.
3. Empowerment.
4. Enhancement of holistic well-being in mental, spiritual, and social domains.
5. Awareness of the non-linear nature of recovery and recognition that positive change is possible for patients.
6. Implementing strength-based intervention, such as building resilience.
7. Strengthening patient-peer support among individuals with mental disorders.
8. Promoting respect at a personal level and eliminating stigma from society.
9. Encouraging patients to bear responsibility in recovery and personal health care.
10. Instillation of hope for recovery. (Ho et al., 2010, p. 72)

These researchers used a range of statistical analyses to arrive at their results. Their method involved item analysis with item-total correlations of <3.0 being excluded from analysis. Principal component analysis assessed items with residual correlation to identify unique components. Transformations were performed on variables showing extreme skewness or kurtosis to improve linearity before conducting a multivariate analysis. Canonical correlational analysis was used to identify the relationship between any specific

recovery components as predictors with domains of the WHOQOL-BREF as criterion variables. The authors wrote that they used within-set, variable-variate correlations of >.30 as evidence of recovery components correlating with HRQoL. The recovery components meeting this criterion were then subjected to a second analysis using hypothesised structural models to assess their overall model fitness with structural equation modelling (SEM) estimated by the maximum likelihood method in AMOS 6.0 (SPSS). In SEM, the fit between data and model was evaluated using comparative fit index (CFI), Tucker-Lewis's index (TLI), standardised root mean square residual (SRMR), root mean square error of approximation (RMSEA). Models were considered as having adequate fit if CFI and TLI $\geq$ 0.90, SRMR<0.80, RMSEA < 0.10 and 1$\leq$ chi-square /*df* $\leq$ 5 drawing upon previous power analysis research (MacCallum et al., 1996).

Their statistical model found that five of the 10 recovery components had the most significant effect on HRQoL in the following rank order: (1) psychosocial symptoms, (2) personal agency, (3) sense of optimism, (4) perceived support, and (5) internalised stigma. The effect of psychosocial symptoms had the highest effect on HRQoL, followed by personal agency, sense of optimism, perceived support, and internal stigma. These researchers recommended resiliency and skills-building interventions to improve the QoL of people diagnosed with schizophrenia.

Methodology

The methodology guiding this research is founded upon the theoretical foundation of critical realism (Scott, 2007). This theory focuses on the interaction between qualitative and quantitative information to inform the research results. Critical realism acknowledges the limitations of both the qualitative and quantitative approaches. Critical realism aims to balance and reduce these limitations through drawing upon the strengths of both methods within the design and methods used in a research study.

The critical realist position acknowledges that sources of data collection are limited by the subjectivity of the participating researchers and participants and by the social context by which all parties have historically and currently existed at the time of data collection and interpretation (Scott, 2007). In alignment with qualitative research principles, a reflection on the subjective biases of the researchers and potential background influences affecting the current research are summarised below.

The socio-political and historical context for mental health recovery and QoL research, both past to current day, were outlined in the literature review. The mental health population can be socially marginalised and experience stigma and discrimination because of their health problems. Speaking about their experiences in a formal research circumstance could heighten feelings of vulnerability. Research recommendations involve being aware of the potential for perceived power dynamics; researchers may represent authorities or systems that have contributed to that marginalisation or may have internalised attitudes from the society around them that can be a barrier to open disclosure from participants about sensitive issues (Danaher et al., 2013; Millum et al., 2019). Considerations of power inequities occurred throughout the research process, with efforts to minimise structural power relationships between researchers and participants within discussions, consultation, and recruitment processes.

The researcher's position within this research naturally involved bringing experiences into the research circumstance that can colour perception and affect decision-making. Namely, experience working within the NGO mental health sector, prior experience with using the WHOQOL-BREF as a PROM within mental health services, the lens of their scope of practice, counselling psychology and lived experience of mental health and addiction issues within their family and personal life experiences. Several research design measures were put in place to reduce potential biases when interpreting qualitative data that could have

occurred from these experiences – the use of multiple coders, data analysis methods, such as summative frequency analysis and triangulation to determine results, quantitative and statistical methods to identify findings, and providing first-person accounts from participants with lived experience to elucidate the meaning of the final results in their own words, as authors of their own experience.

The counselling psychology scope of practice is a therapeutic scope of practice that formulates people's mental health problems within a person-environment and ecological context in light of their personal history, current values, life aspirations, and everyday life and concerns. An ecological formulation of how mental health problems can be affected by multiple social factors, based on Bronfenbrenner's (2009) ecological model, was developed by Michaels et al. (2022). The ecological framework recognises the influence of individual factors, relationships, organisations, communities, policy, and society upon a person's development of mental health problems, as well as their recovery from these issues. This model can be reviewed in full within Appendix D to understand the perspective of mental health problems being caused by broader social factors than just a within-person or within-their-life issue. The counselling psychology perspective will have influenced how the research study was approached and the literature and results were considered in this thesis. For transparency, the counselling psychology scope of practice and an example of how the ecological formulation can be applied to mental health problems is provided (Appendix D).

The research orientation of the supervisory team have also influenced the ways this study was conducted. The methodology used in the current research was replicated from their prior WHOQOL research, experiences using Rasch analysis to improve the measurement properties of various health assessments, as well as their collective experience of mental health, QoL, and addiction research.

The WHOQOL ethos of person-centred development (Skevington et al., 2004b) has also influenced the approach to the current research along with honouring the principles of the consumer movement to be seen, heard, and empowered within processes that affect them (Brosnan, 2018). The research design was influenced by the procedures outlined in the study guidelines for WHOQOL-BREF module development. These recommended first gathering qualitative data from key stakeholders prior to engaging in quantitative analysis of the data to arrive at the final result (WHO, 1993). Skevington et al. (2004b) described that the development of the WHOQOL instruments involved mixed methods, with the content of the measure being derived from the lived experiences of end users and robust statistical analyses to arrive at the final items for the measure. The critical realist position acknowledges the ways that the strengths and limitations of qualitative and quantitative data can be balanced, when aiming to answer research questions and enhanced by a mixed-methods design.

Research Design

Mixed Methods Research

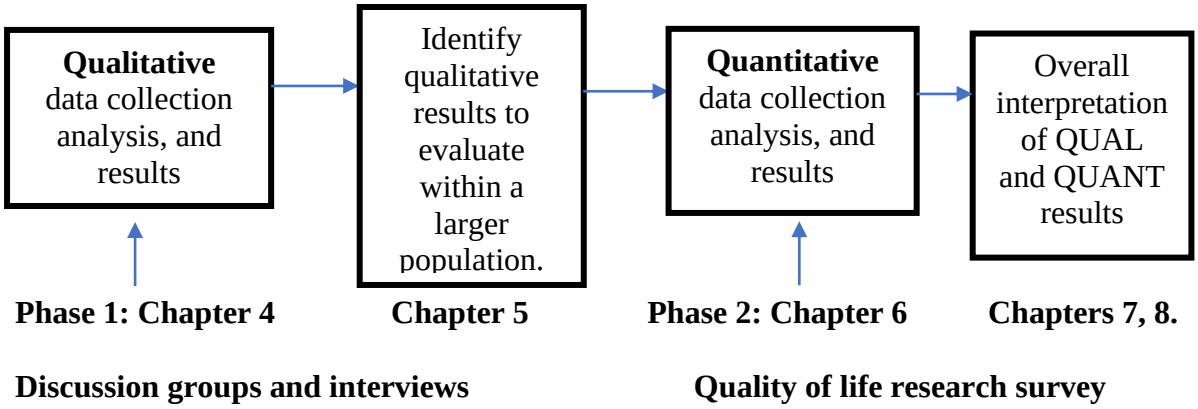
Recommendations from Creswell's (2014) research design and analysis methodologies text were drawn upon to refine and guide the data analysis decisions at key points. Mixed methods research strategies were drawn upon to inform decisions about the methods of data analysis. Creswell's (2014) *Exploratory Sequential Mixed-Methods Design* best describes the overall design of this research study. This design attends to the interaction between the aims and methods of both Phase 1 and 2 of the research.

This broadly involved collecting qualitative data in Phase 1, using a mixture of qualitative methods to identify key themes. Further quantitative data collection and analysis then occurred in Phase 2, leading to a final interpretation and outcome that brought together the insights gained from Phase 1 and 2. Details of the methods used in each phase are reported in Chapter 4 (Phase 1) and Chapter 6 (Phase 2). Hesse-Biber (2010) presented a

diagram of exploratory sequential design presented by Fuentes (2008) that outlines how qualitative and quantitative phases are used to build upon one another towards the final results. Figure 5 is an adaption of this figure to show how this design was used in the current research to develop the MHRQoL module for the WHOQOL:

Figure 5

Exploratory Sequential Mixed-Methods Design



Adapted from Fuentes' (2008) sequential exploratory mixed methods design. From "Qualitative approaches to mixed methods practice," by S. Hesse-Biber, 2010, *Qualitative Inquiry*, *16*(6), p. 459. https://doi.org/10.1177/1077800410364611. Copyright 2010 by S. Hesse-Biber used by permission granted by the author 2023.

The mixed-methods research approach was recommended for PROM development in the HRQoL field (Reeve et al., 2013; Regnault et al., 2017; Weiring et al., 2016, 2017) and for mental health recovery or outcome measurement research (Coffey et al., 2016; Donnelly et al., 2011; Happell & Roper, 2007). The recommendations of research studies reviewed before the study began have also influenced how this study was approached and the issues that were seen as salient to address.

Replication of Standardised Methodological Protocols

The WHO developed standardised protocols for researchers developing adjunct health and population-specific modules for the WHOQOL within the WHOQOL Study Guide (WHO, 1993). The WHOQOL Study Guide is in keeping with the WHO aim to encourage consistency in research design, methods, and style of question writing with the core WHOQOL instrument. Appendix B provides tables that detail how the WHO study protocol

informed the decisions made in the current research and where departures from the procedure occurred for this research.

Statistical procedures for identifying the most robust items to include in a module for the WHOQOL were developed in NZ during the development of the NZ national items study (Krägeloh et al., 2015, 2016). The current research involved replicating these data analysis methods in Phase 2. The use of these CTT and Rasch IRT methods in Phase 2 (Krägeloh et al., 2016) optimised item selection to strengthen the internal validity and measurement precision of the QoL construct as recommended by QoL PROM development standards (Aaronson et al., 2002; Reeve et al., 2013). Some minor modifications were made to suit the different sample populations, aims, and purposes of the current research, such as new conceptual criteria and variables for an MHRQoL module.

The purpose of Phase 1 was to generate as many potential candidate items as possible from all relevant sources. Reviewing the literature for themes of potential relevance and collecting data from discussions and importance rating exercises with people who have lived experience of recovering from mental health issues and the experiences of key stakeholders when supporting people to restore their QoL during recovery sought to achieve this aim. The involvement of multi-stakeholder perspectives in the methods of Phase 1 was influenced by literature read in the literature review, collaborative practice principles within mental health services, and the perspective of critical realism that values more than one perspective when seeking to answer a research question.

During the literature review, previous researchers discussed using similar methods to establish relevant content for a mental health or quality of life outcome measure. Connell et al. (2012) systematically reviewed qualitative research on personal recovery to identify six critical factors affecting QoL. They verified these during non-cued interviews with mental health service users, adding the seventh domain of physical health after these interviews

(Connell et al., 2014). They then used these seven domains to develop the candidate items for an MHRQoL measure called the ReQoL (Keetharuth et al., 2018). Using key stakeholder groups to find relevant content for a mental health outcome measure and exploring convergent themes to consider what was essential to recovery during that process was discussed by Siggins Miller Consultants (2003).

The WHOQOL PROM development principle of using person-centered approaches that incorporate the language and concepts of users into the measure development process (Skevington et al., 2004b) was a principle used in the current research. Secondly, from a recovery movement perspective, items generated from people's actual life experiences not only increase the relevance of the measures content but also strengthen the lived experience voice within research when it communicates the issues impacting their lives and enables this mechanism to continue in services when the measures are used (Campbell, 1989, 1997; Carlton et al., 2022; Crawford, 2011; Gordon & Ellis, 2013; Happell & Roper, 2007; Keetharuth et al., 2018; Rose, 2011; Siggins Miller Consultants, 2003; Onken et al., 2002; Philips, 2006; Trauer et al., 2004; Waks et al., 2017). Recommendations for conducting research with vulnerable or marginalised groups in society also influenced the research process (Happell & Roper, 2007; Wrigley & Dawson, 2016).

Conclusion

This chapter explored the WHOQOL's underpinning HRQoL theory, the ICF model, which the WHO uses to explain the ways that health problems impact people's lives through a dynamic interaction between a health condition, biological factors, functional activity changes, and contextual factors related to the person, their relationships, and the environment. Personal recovery theory and well-respected conceptual models were reviewed to examine the critical determinants of recovery that drive the recovery process. An overview of the intersection of QoL and mental health recovery was discussed. Factors within the CHIME

model and the work of other researchers who synthesised the personal recovery literature highlighted the type of content an MHRQoL module would need to include to identify that the module's content aligned with the mental health recovery and QoL constructs.

Links between the aims of this research and the theoretical and conceptual frameworks underpinning both HRQoL and the tenants of personal recovery were reviewed in this chapter. Further discussion that examines the MHRQoL items generated against the principal determinants of personal recovery and another measure of MHRQoL is explored further within Chapter 8.

This chapter discussed the underlying methodology of the current research as being founded on critical realism and how this methodology influenced the design and decisions made through the research process. This was followed by an overview of the design of this research as an exploratory sequential mixed methods research study consisting of two phases: (1) a qualitative phase aiming to generate themes important to mental-health-related QoL and (2) a quantitative phase that tested candidate items reflecting those themes to identify the final items for the MHRQoL module using Rasch analysis. The next chapter outlines the qualitative phase of the current research, where MHRQoL was explored with participants to identify the predominant MHRQoL themes that could go forward for testing in Phase 2.

Chapter 4

Phase 1

Phase 1 Aims

The purpose of Phase 1 was to identify potential recovery determinants for an MHRQoL module that can be used with the WHOQOL-BREF using qualitative research methods. Three aims of Phase 1 related to this overarching purpose were to: (1) identify as many potential candidate items as possible, (2) identify which of the recovery themes identified in Phase 1 should go forward for further testing in Phase 2, and (3) for participants to evaluate the face validity of the WHOQOL-BREF as an HRQoL survey for use in Phase 2.

These aims were achieved through three explorative data gathering activities: (1) semi-structured discussions with people who had lived experience of mental health issues and representative key stakeholders closely involved with supporting people to recover their QoL, (2) an importance rating exercise to see which recovery determinants were more important to QoL, and (3) a WHOQOL importance rating exercise to examine the relevance of the generic core tool for use as a mental health recovery PROM. Triangulation of the data from these activities identified the selection of recovery themes to go forward to Phase 2 and supported the use of the WHOQOL-BREF as a recovery orientated QoL PROM for use in Phase 2. The following section outlines the methods used in Phase 1.

Methods

The WHO study guidelines (WHO, 1993), methods used in the development of NZ WHOQOL national items and validation of the NZWHOQOL-BREF research (Krägeloh et al., 2013; Krägeloh et al., 2015, 2016) and best practice recommendations for developing PROMs for mental health service users (Connell et al., 2018; Donnelly et al., 2011) and HRQoL assessment (Reeve et al., 2013; Weiring et al., 2016, 2017) all recommend using a mixed-methods design that identifies potential items for a PROM from the intended end users to improve the relevancy of the measure's content.

The WHOQOL study protocol (MNH/PSF/93.9) was developed by the WHO for researchers interested in developing WHOQOL health or population modules (WHO, 1993). The study guide was used for planning the methods and recruitment objectives within this phase of the research. A detailed examination of how the methods used in the current research replicated and adapted methods outlined in the WHOQOL Study Guide can be reviewed in Appendix B: Tables B1, 2, 3. Standards for the development of PROMs developed by the ISOQOL (Reeve et al., 2013) were reviewed to establish whether the research design and methods planned for use in the current research aligned with these more recently developed PROM measure development standards. Appendix C reviews how these requirements were met within the current research.

The previous methods used in NZ research that: (1) validated the WHOQOL-BREF for use in NZ (Hsu, 2009; Krägeloh et al., 2013**)** and (2) developed the NZ national items (Krägeloh et al., 2015, 2016) also influenced decisions about the methods to use in this phase of the research, namely collecting data through discussion groups and using an importance rating exercise to establish relevant themes to go forward for question writing and further testing as candidate items in Phase 2.

Tong et al. (2007) have outlined 32 types of information to provide when communicating the methods used in qualitative research within a summarised checklist called the consolidated criteria for reporting qualitative research (COREQ) guidelines. Appendix E1 summarises all 32 COREQ topics with information about how Phase 1 of the current research addressed each topic. Chapters 3, 5 and 8 and the Appendices of this thesis detail 22 of the 32 COREQ topics. Table 3, presented below provides information about the remaining 10 COREQ topics relevant to the background of Phase 1, to reduce repetition. Direction to the information covering the 22 other COREQ topics is provided after Table 3.

Table 3

COREQ Reporting Guidelines

COREQ topic	COREQ information requested	COREQ information provided
Domain 1: Research team and reflexivity.	Interviewer facilitator	Melissa Rowthorn, primary researcher, PhD candidate
1. Personal Characteristics	Supervisors	Dr Rex Billington, primary supervisor, Phase 1 Dr Chris Krägeloh, secondary supervisor, Phase 1
2.	Interviewer Credentials	A master's degree in social science MSocSci (Psychology); Postgraduate diploma in Cognitive Behavioural Therapy (PGDipCBT). Registered in the counselling psychologist scope of practice with the New Zealand Psychologists Board. Dr Rex Billington: Adjunct Professor Dr Chris Krägeloh: Associate Professor
3.	Occupations	Counselling psychologist Rex Billington: Health psychologist Chris Krägeloh: Research psychologist
4.	Genders	Female (discussion facilitator) Male (attending supervisors)
5.	Experience and training	The PhD candidate had previous focus group facilitation experience within their master's degree; focus groups were held with staff in nursing homes for the elderly to investigate items for a pain assessment measure to be used with older adults who have varying degrees of aphasia due to dementia. Behavioural observation, psychometric assessment and interviewing of older adults was involved in that prior research study. Prior to involvement in the current research, the PhD candidate had experience in the social service and mental health sector since 1995; registering as a psychologist in 2006. Initially this involved working as a support worker in the NGO sector supporting people to recovery their lives from the negative effects of mental health and disability problems, then to roles that involved training staff, reviewing recovery plans, and providing recovery orientated consultancy services requested by the organisation to support staff. Post registration as a psychologist, employment tasks included a therapeutic caseload, i.e., providing therapy services to people recovering from mental health problems, project

COREQ topic	COREQ information requested	COREQ information provided
		management (inclusive of the outcome measurement project when the organisation decided to use the WHOQOL-BREF as PROM), programme development of various psychological intervention programmes that taught self-help, stress, change and symptom management skills to people with severe mental disorders, youth, and the general public, running and cofacilitating recovery groups and training group sessions, and providing coaching, programme development and psychological consultancy services for the organisation's social enterprise a change management consultancy. The researcher has lived experience of mental health issues within their family and personal life experiences. Dr Rex Billington provided guidance and training around implementing the WHOQOL study guide focus group and question-writing procedures. Dr Billington has had extensive experience working for the World Health Organization as the Director of Mental Health 1996-2000 and with research related to both mental health and quality of life.
Domain 2: study design 13.	Non-participation	No participants dropped out. There were likely to be people who saw adverts or were told about the research by people they knew who decided not to participate. There was an emphasis on choice and there being no consequences for the person or the services they received for saying no to the invitation. There was also a choice to attend a group or a 1:1 interview which may have retained people who could have dropped out if only focus groups were provided. Participants who chose 1:1 interview disclosed their reasons for this choice being: challenges with being in a group situation or with leaving their home, staff at times discussed additional commitments that resulted in being unable to attend set discussion group days and times. Potential recovery supporter participants that declined participation declined due to workload and perceived service disruption if discussion groups were held in their work setting. In one case an Asian mental health service stated that their clients were unlikely to have sufficient English to fully understand and participate in the discussion and staff were unable to provide translation support due to their work demands. The time and travel costs could be potential reasons for people not participating. A travel voucher was given and holding group meetings in places closer to where participants lived was planned in the Phase 1 recruitment strategy to offset travel barriers. People within more intensive secondary mental health services could attend with a support worker to offset possible challenges for them to attend discussion meetings or needs for support within meetings.
18.	Repeat interviews	No repeat interviews were carried out.
20.	Field notes	Records were kept of the discussion location, type (lived experience, recovery supporters as family, clinician, expert, or staff), the date of the meeting, and who participated as interviewers. Tape recordings of each discussion were kept and converted to MP3 files for long term storage. Consent forms signed by participants for each group were stored in a file with Phase 1 surveys.

COREQ topic	COREQ information requested	COREQ information provided
20 continued.	Field notes	Discussions with supervisors attending, or after group sessions occurred, for learning, feedback on shared perceptions and process issues, and as a way to consider when data saturation had been reached. Communications between the PhD candidate and their supervisors via email and meeting notes were stored as part of the field notes. Process documents recording the Phase 1 steps and decisions made at each analysis point maintained records of the methods and procedures used to establish the final results.
23.	Transcripts returned	Transcription was not part of the Phase 1 procedure. Transcripts of the LE discussions were later made for data interpretation purposes within the thesis as a way to identify relevant quotes that provided a context for each of the MHRQoL items identified within the final research result. The purpose of data collection in Phase 1 was not to explore the context or reasons for the QoL issues being identified. Coders identified themes from discussion tapes, summative frequency analysis was used to identify predominant themes. These were checked by consulting with a LE coder and LE volunteers prior to finalising the Phase 2 research survey.
27.	Software	A code book designed by a software engineer who was part of the WHOQOL special interest group. The code book enabled the creation of a summative frequency score for each item coded to be generated. An Excel workbook was used for side by side analysis of between group results. The software engineer who designed the code book was Jillian Pemington, who worked for a company (*Wild Bamboo*) that developed *Recordbase*, a client management system that two organisations using the WHOQOL-BREF were using to store and manage WHOQOL data at the time of the research. Wild Bamboo was part of the WHOQOL special interest group.

Remaining 22 COREQ Guideline topics and where to locate them. COREQ 6: Relationship with participants established. Information related to this guideline can be found in the Phase 1 procedures and discussion protocol in Appendix G. COREQ 7: Participant knowledge of the interviewer. Information related to this guideline can be found in the information sheet (Appendix F) and in this chapter within the participant recruitment section.

COREQ 8: Interviewer characteristics. This information is outlined in the information sheet (Appendix F) and is discussed in Chapter 3, when considering potential biases from prior experience with the WHOQOL-BREF, experience working in the mental health sector, the interviewer's family experiences of mental health and addiction issues and personal lived experiences of mental distress, and the counselling psychology lens used to consider people's mental health problems and well-being. Attempts to reduce biases are discussed in the methods section of Phase 1. These included using multiple coders, data triangulation, codes originating from internationally objective sources i.e., personal recovery research, use of frequency analysis to reduce the potential for psychological biases that could be greater if an alternative method was used involving only the researcher's perception of themes within the data gathered in Phase 1. The presence of supervisors within discussion meetings to review the process and check for any observed biases during data collection also controlled for bias.

COREQ Domain 2: Study design, under the heading of theoretical framework COREQ topics 9–12. COREQ 9: Methodological orientation and theory. This is discussed in Chapter 3 and the methods section of Chapter 4. COREQ 10: Sampling. This is discussed in the participant recruitment section of Chapter 4. COREQ 11: Method of approach. This is discussed in the participant recruitment section of Chapter 4. COREQ 12: Sample size. This is displayed in Figure 1, Table 4, and discussed within the methods section of Chapter 4.

COREQ guidelines related to the research setting. COREQ 14: Setting for data collection. This is discussed in the methods section of Chapter 4. COREQ 15: Presence of

non-participants. This is discussed in the methods section of Chapter 4. COREQ 16: Description of the sample. This is outlined in the methods section and Table 4.

COREQ guidelines related to data collection. COREQ 17: Interview guide. This is briefly outlined in the method section of Chapter 4 and fully detailed in the discussion protocol (Appendix G). COREQ 19: Audio visual recording. This is outlined in the methods section of Chapter 4. COREQ 21: Duration. This is discussed in the Chapter 4 methods section, discussion protocol (Appendix G), and Phase 1 information sheet (Appendix F). COREQ 22: Data saturation. This is discussed within the Chapter 4 methods section.

COREQ domain of analysis, findings**,** and data analysis, COREQ 24: Number of data coders. This is discussed within the methods section of Chapter 4. COREQ 25: Description of the coding tree. The code book can be reviewed in Appendix L. This is discussed within the methods section of Chapter 4. COREQ 26: Derivation of themes. This is discussed in the methods section of Chapter 4 subheading data analysis. COREQ 28: Participant checking. This is discussed in Chapter 5 within the section titled consultation and pilot testing. Wider stakeholder engagement also occurred where the results of Phase 1 were evaluated by the Platform Trust WHOQOL special interest group that included Peer Support services. This is discussed at the end of Chapter 4 in the section titled Wider Stakeholder Engagement.

COREQ sub-domain of reporting. COREQ 29: Quotations presented. This is discussed in Chapter 7, which predominantly focusses on the first-person accounts of Phase 1 participants in relation to the final research results. Anonymous codes were allocated to represent participants. COREQ 30: Data and findings. This is discussed in the results section of Chapter 4 in relation to subsample triangulation side-by-side analysis of convergent and divergent results. Phase 1 results (qualitative themes) are considered against Phase 2 (quantitative) results in Chapter 7 and 8 discussion sections. COREQ 31: Clarity of major themes. Table 8 summarises the major themes of Phase 1 and these are discussed within

Chapter 4 results section and the Chapter 8 discussion. COREQ 32: Clarity of minor themes. This was discussed in the results section of Chapter 4 when themes were subsumed under major themes presented in Table 9 and in Chapter 5 when minor themes were inadvertently also addressed by questions that focused on major themes. Chapter 7 contains some of the minor themes that came out during discussions about the effect of mental health problems on QoL. Appendix M gives participant examples of MHRQoL candidate items (minor themes) excluded from the module when they did not meet relevant IRT and Rasch criteria.

Phase 1 required a recruitment strategy to invite relevant stakeholders to participate in Phase 1 to provide information about QoL during mental health recovery. This was planned to occur through discussions and importance rating methods that aimed to generate and prioritise themes for potential MHRQoL items. The following section discusses the participant recruitment planning and approach.

Availability and Recruitment of Participants

The first objective was to consider what constituted a representative sample of people currently identifying as having mental health problems in NZ. The NZ Ministry of Health's (MOH) programme for integrating mental health data (PRIMHD) began in 2008. The PRIMHD programme systematically collects data about who accessed mental health services and the primary services provided. PRIMHD statistics are a reliable source of demographic information about people with a formal mental health diagnosis, a criterion for access to mental health services.

Statistics published by the MOH from the PRIMHD programme (2009–10) identified that 120,293 people accessed mental health services during that time. These were the statistics available at the initial planning and proposal stages of the research. It takes several years for data collected to be formally published to the public (MOH, 2016b). Phase 1 data collection occurred in 2015. By the end of the research, statistics published in 2018 reported

service use demographics during 2015–16 (MOH New Zealand, 2018). These statistics are used instead of the 2009–10 statistics. The 2009–10 statistics were used at the start of this research when developing a participant recruitment plan, documented in Appendix B. These later PRIMHD demographic statistics provide better comparison information to consider the representativeness of the research sample against, as Phase 1 data gathering occurred within the 2015–16 reporting period. The 2015-2016 statistics for the foundation for discussing the representativeness of the Phase 1 sample in the thesis. Not everyone in NZ with mental health issues will receive a mental health service. These figures can be considered an underestimate of the actual number of people in NZ with these health problems.

PRIMHD data for 2015–16 identified that 171,033 people accessed mental health services within NZ during that time. The population of NZ in 2015 and 2016, respectively, was 4.609–4.714 million people. The total number of people accessing mental health services in 2015–16 (171,033) represents 3.67% of the NZ population; the rate of Māori receiving mental health services was 6.2% of the total Māori population. The total number of Pasifika and Asian people accessing mental health services was 3.3% of the Pasifika population and 1.1% of the Asian population, according to the Statistics New Zealand data PRIMHD reporters referred to then.

The PRIMHD statistics reported that of the 171,033 receiving services, 89,379 (52.3%) were male, 81,654 (47.7%) were female, 45726 were Māori (26.74%), 9,980 were Pasifika (5.84%), 7,122 (4.16%) were Asian, and 108,205 (63.27%) were New Zealand European or other ethnicities. Of the 171,033 people accessing services, 142,039 received District Health Board services (DHBs) (83%), and 63,682 people (37%) received community-based NGO services.

The limitations of the data collected included the underreporting of NGO data, incomplete data for older adults, and coding changes. This underreporting of NGO data

makes the NGO data above an approximate guideline for the minimum percentage of participants aimed for during recruitment. For example, suppose the research sample comprised 52% males, 48% females, 26% Māori, 6% Pasifika, 4% Asian and 63% New Zealand European or other nationalities. In that case, the sample may be considered to represent similar gender and cultural demographics to those accessing secondary mental health services during 2015–16.

The following practical recruitment problem was where to find participants. The MOH identified five broad service types outside of hospital-based care. These were community-based mental health services, cultural services, alcohol and drug services, residential services, and others (specialist services). Some of these services are NGOs; the DHB mental health system funds community mental health centre (CMHC) and some specialist mental health and addiction services.

People receiving additional mental health services to a primary health service are referred to as receiving secondary mental health services. Secondary mental health services enable access to psychiatrists, multi-disciplinary mental health clinicians and the eligibility to receive intensive conjunct NGO mental health services. The PRIMHD statistics (MOH, 2018) reported that 37% of people received NGO services in 2015–2016. It is noted that the NGO data was underreported, so more than 37% of secondary mental health clients likely receive adjunct NGO services. The PRIMHD service data provided information about the types of services to approach during recruitment.

NGOs provide adjunct community-based rehabilitation services to people receiving secondary mental health services to address the following rehabilitation needs: community engagement, work, housing, practical assistance with activities of daily living, support to improve social networks, and individualised recovery support to achieve personal rehabilitation goals (Blake, 2020). Sometimes, a few people can also be referred to an NGO

service by their primary health practitioner for minimal adjunct support if they have a diagnosed mental health condition and a doctor who can respond to medication and crisis support needs. The research participants would ideally involve people who had a mental health diagnosis, received primary or secondary mental health services, and may have also accessed a range of adjunct NGO services, historically or currently.

Convenience sampling methods may introduce bias if only NGO participants from services using the WHOQOL-BREF participated. A more comprehensive recruitment strategy invited participants in the Tāmaki Makaurau region who had no prior experience with the WHOQOL-BREF as a PROM. The overall population of people receiving mental health services in NZ in 2015–16 was 171,033. The most significant number of these people, 55,448 (32.42%), received mental health services within the Tāmaki Makaurau region. For practical reasons, Phase 1 participants were recruited only from Tāmaki Makaurau. The Phase 2 recruitment plan included a broader regional recruitment strategy.

Phase 1 recruitment occurred within NZ's largest metropolitan region, in both population size and geographic region Tāmaki Makaurau (also known as Auckland). Tāmaki Makaurau is an ethnically diverse region with a mixture of rural, small-town, urban, and metropolitan areas. Targeted recruitment of participants from different regions within Tāmaki Makaurau supported obtaining a good cross-section of ethnic groups within the participant sample.

Different regions within Tāmaki Makaurau include higher numbers of some ethnicities than others. In the North, the population has more significant numbers of Pākeha (NZ European) and Asian cultures. In the East, there are greater Pākeha and Asian cultures; in the West, there are greater Pasifika, Indian, and Māori cultures; and in the South, there are more Pasifika, Indian, Māori cultures. Some regions are rural, and others are urban city or

town environments. Discussion meetings held in the regions where participants received services reduced travel costs and time barriers for participants.

The third practical recruitment problem was how to invite participants. Several NGOs that provide mental health recovery services across NZ were piloting the WHOQOL-BREF as an outcome measure. Under the umbrella of Platform Trust, these organisations met twice a year in a special interest group (SIG) facilitated by Lattice Consulting within the Te Pou (a mental health research organisation) site. Several organisations that were part of the SIG were willing to support participant recruitment in their organisations. Participants within these organisations were familiar with the WHOQOL-BREF tool and the concept of HRQoL changing in the context of mental health problems and their recovery.

Participating members of the SIG who used the WHOQOL-BREF as a PROM in their services were interested in further research into improving the precision of the WHOQOL-BREF for this purpose within the mental health field. Their willingness to support the research improved the recruitment drive for participants receiving secondary mental health services receiving residential and community-based mental health services and their staff members as recovery supporters. Recruitment and participation from people living in the north, west, south, and east areas was able to occur through their assistance as different NGOs had contracted services within each of these regions. Family members were recruited through NGO services specialising in supporting the families of people diagnosed with mental health conditions.

Several types of convenience sampling methods were used to invite participants: maildrop flyers, forum presentations to various services and stakeholder groups, noticeboard adverts within the community, word of mouth advertisement within the mental health sector, snowball marketing, and emailed letters of invitation to Tāmaki Makaurau-wide mental health DHB, NGO, cultural, and peer support agencies.

Recruitment did not occur within acute or forensic mental health settings. The research sample did not include people in acute phases of their mental health crisis for ethical reasons. Incarceration in a forensic environment naturally constrains the relevance of many facets asked about within the two-week time frame and the multi-faceted construct of QoL assessed by the WHOQOL facets. Within acute mental health settings, people are often in acute distress; focusing on their dissatisfaction with their lives and unmet needs could potentially increase risk issues or exacerbate their distress. However, information about the impact of acute mental health symptoms on QoL occurred during Phase 1 discussions in response to Question 1. Participants spoke about the changes to QoL during acute phases of their illness, during acute admissions, or when they had legal problems in the past, and the QoL impact of chronic mental health symptoms that remained unresolved by treatment.

Purposeful sampling targeting the recruitment of senior or clinical service providers who provided mental health support services to Māori, Pasifika, LGBTi, and younger people occurred to try to offset the lower response rate to the initial invitation to participate from members of those demographic groups. A key informant interview with a participant who had previously worked in forensic and acute in-patient settings included their comments on the QoL issues of people within those settings. Key informant interviews for underrepresented groups asked representatives to speak to their experiences of the QoL issues of service users as an opportunity to include any unique and relevant HRQoL issues important to these groups.

An adapted *About You* section was added to the Phase 1 WHOQOL-BREF importance rating survey in Phase 1 to collect participant demographics. Additional demographic questions added to the standardised WHOQOL-BREF *About You* questions supported the aims of the current study. Namely, these asked: (1) whether a participant identified as a person with lived experience of mental health issues and (2) what stage of

recovery they felt they were in at their time of participation. Weeks et al. (2010) write that STORI asks a person to rate their current stage of recovery using questions that translate to five progressive stages of recovery: (1) moratorium, (2) awareness, (3) preparation, (4) rebuilding, and (5) growth. The Phase 1 *About You* section included STORI (Andresen et al., 2006) questions to establish how many participants rated themselves in early, mid, or later stages of recovery (a complete outline of the demographic questions is in Appendix H).

Participant Characteristics

Eighty-eight participants contributed to the discussion data collected in Phase 1. The demographic section of the *About You* questionnaire identified 55 participants as people with lived experience of mental health issues. Forty-two of those were people receiving secondary mental health NGO services at the time of their participation. The number of participants from different Tāmaki Makaurau regions were: Central (22), West (10); South (11); North (34) and mixed regions (11).

Despite the aims and efforts to attain a representative sample during recruitment, the research sample did not match all of the 2015–16 PRIMHD population demographics. The demographic groups of females (59%) exceeded the aim of 47.7%. Asian participants (6%) exceeded the aim of 4.16%. New Zealand Europeans and other Europeans collectively (81%) exceeded the aim of 63.27%. However, the sample contained a lower percentage of males (41% as opposed to 52.3% aimed for), Māori (12% as opposed to the 26.74% aimed for), Pasifika (2% as opposed to the 5.84% aimed for), and fewer younger people (within the 18–30 age) responded to invitations to participate. A decision was made at the end of Phase 1 to plan to increase Māori participation in Phase 2 through the targeted recruitment of cultural services and geographic regions with higher numbers of Māori in keeping with Te Tiriti o Waitangi and research ethics to ensure adequate representation of Māori within this research. Table 4 presents the Phase 1 sample demographics.

Table 4

Phase 1 Participant Demographics

Participant demographic	Whole sample	
	N = 88	Valid %
Lived experience sample	55	63.2
Recovery supporter sample	33	36.8
Gender		
Female	50	58.8
Male	35	41.2
Age range (years)		
18–30	15	17.6
31–40	16	18.8
41–50	23	27.1
51–60	16	18.8
61–70	11	12.9
71+	04	4.7
Marital status		
Single	35	40.2
Married, living as married	37	42.5
Divorced, widowed	10	11.4
Separated	05	05.7
Ethnicity		
New Zealand European	52	59.8
Māori	10	11.5
Pasifika peoples	02	02.3
Asian	05	05.7
European (other)	18	20.7
Highest educational level		
Primary school	2	02.3
Secondary school	19	21.8
Tertiary	64	73.6
Other	02	02.3
Employment		
Full-time work	37	42.5
Part-time work	15	17.2
Unemployed	15	17.2
Student	01	01.1
Retired	06	06.9
Other	13	14.9
Physical health problems	31	46.3
Mental health problems		
Mood disorder	30	62.5
Psychosis	15	31.3
Personality disorder	02	04.2
Addiction issues past or present	16	25.0

Note. There were more missing values for some demographic categories than others. Gender = 3; Age = 3; Ethnicity = 1; Education = 1; Marital status = 1; Employment = 1; Physical health condition = 21; Addiction = 24.

Research Location

The sites of participating organisations where participants and staff were members provided a site for discussion meetings. Data collection outside of this was conducted in a

meeting room within Auckland University of Technology (AUT), in a community centre, once in the researcher's office, and once in a person's home setting.

Data Collection Methods

Thirteen discussion groups and 10 individual interviews (23 participant discussions) collected data about the impact of mental health problems on QoL and what supported the restoration of QoL during recovery. There were 11 discussions with people with lived experience (six group discussions and five interviews) and 11 discussions with recovery supporters focused on what they had noticed about people they had supported (seven group discussions and four interviews). The order of tasks within the discussion meetings was structured similarly, with the same three questions and meeting structure for all participants, regardless of whether it was an interview or a discussion group (refer to this protocol in Appendix G).

One additional outlier interview occurred with a recovery supporter who worked in workforce development. This participant discussed recovery determinants and QoL issues within their interview, so their data was included in the recovery supporter sample data (bringing this to 12 and the total interviews to 23). They did not participate in the WHOQOL survey and recovery card sort exercise. The interview provided additional contextual relevance to the study: the workforce development aims by which staff participating in the research were working and the workforce environment surrounding participants when receiving secondary mental health services. The workforce culture surrounding participants provided a service delivery context for participants' comments. Therefore, data collected in Phase 1 came from 88 participants in 23 semi-structured discussion meetings. Eighty-seven participants provided data for the two importance-rating data collection activities. Pages 152–153 describe the importance-rating activities in more detail.

Discussion Meetings

Discussion data was gathered in a semi-structured focus group or 1:1 interview format using the protocol outlined in Appendix G. This data collection method will be referred to using a generic term of *discussion meetings*. The researcher tape-recorded discussion meetings for later coding. Discussion meetings were part of replicating the methods used in the NZ WHOQOL research. Individual interviews supplemented the discussion meeting interviews in instances where people were too nervous to participate in a group situation, unable to attend, or interviewed as a member of an unrepresented demographic group as key informants.

Discussion Meeting Procedure. Before the research began, the preparatory stages involved developing a discussion meeting protocol as part of the ethics application. This protocol guided consistency across discussion formats (interview or group) and settings (see Appendix G for the complete protocol). The protocol involved the following process:

Multi-stakeholder discussions occurred, yet all discussion meetings were homogeneous. Participants discussed their recovery and QoL issues in a group with their peers. There were discussion groups of people with lived experience of mental health issues, staff groups, family members, and a small expert advisory group. This last group shared broader population-based views, as they had exposure to an observation of themes within more significant aggregated mental health service level QoL data sets or mental health research experience. That may identify important recovery determinants not discussed by a small sample of people in Phase 1.

Participants feeling comfortable sharing their life experiences was integral to the aims and purpose of Phase 1. Homogenous groups aimed to improve participants' comfort and the quality of discussions by reducing potential power relationships between clients, staff, clinicians, experts, or family members. People with similar life experiences may provide one

another with a more validating and supportive environment conducive to discussing life experiences where people may have felt very vulnerable. They may be able to discuss those times more safely, with more depth, or to build upon each other's discussion points naturally when among peers.

Participants had read the information sheet before attending the discussion meeting. Participants could ask questions after reading the information sheet and again when arriving at the meeting venue (see Appendix F for the information sheet). Participants signed a consent form outlining the day's activities upon arrival and confirming participation (see Appendix F for the consent form). Participants were reminded that the discussion would be tape-recorded, their names and identifying details would remain anonymous, and they were free to leave at any point in the meeting to address personal needs, a smoke break, or to discontinue their participation.

The discussion meetings began with an introduction to the meeting process and an orientation to the discussion, i.e., what was going to happen and what was expected of participants. The researcher developed a shared agreement with participants that addressed the nature of the discussion process's interpersonal dynamics and culture to reduce power dynamics and improve the potential for an egalitarian culture within the meeting.

The foundation for these guidelines was a poster brought into each discussion meeting and displayed on the wall where all participants could view it. A person with lived experience drew this poster. It highlighted the principles of a recovery dialogue. The artist was Sabine Tibbett. Daniel Fisher of the peer support organisation called the National Empowerment Centre in the United States permitted reproducing the poster from his website. A copy of the poster can be reviewed in Appendix G. The recovery principles named in the poster were: "Recovery Dialogue = Equality- leave your hat at the door; Suspend your beliefs (*exampled*

in thought bubbles as “I believe that xxyyxx”, “I believe that ooxxoo”); Enter a neutral place; Heart to heart; Respect differences; Use your authentic voice.”

An invitation to add to these recovery dialogue principles, as outlined on the poster, occurred at the start of each group. The researcher asked participants if they had any specific requests of each other to improve their personal feelings of safety and the capacity to feel that they could share openly without fear of destructive levels of conflict or judgment. The poster and invitation to discuss what constituted a safe, open, supportive conversation were presented in all discussions to maintain procedural consistency.

The discussion session involved three questions. The researcher wrote each question on an A1 piece of white paper attached to the wall. A visual representation of the question supported participants to remember the question and maintain focus on each question during the discussion. The participants could identify where the shift to a new question had begun when the researcher put a new question up on the wall when the time to focus on a new question occurred. The three discussion questions were:

1. What parts of life are most affected by mental health problems?
2. What presents as a barrier to mental health recovery or assists recovery to progress?
3. What unique QoL issues emerge when recovering from mental health problems?

These questions were repeated in all groups and interviews, using the same materials to reduce variations in the structure of the discussion meetings or how questions were asked. However, variations in subtopics evolved among members after asking these core questions based on the nature of the conversations that ensued or in response to participating members’ comments to seek clarification or reflect on each other’s comments.

The main aim of the qualitative data collection activity was to explore the interplay of changes to QoL in the context of mental health recovery. The group facilitator maintained the focus on this objective during the discussion meetings as much as possible. Interviews

naturally allowed for a more complete sharing of one person's recovery journey than each member of a discussion meeting could share at the same time. The aim of data collection and, therefore, analysis was frequency-based, to identify as many potential candidate items as possible and to identify the themes *most often* discussed within and across the different groups. Data convergence could identify the more critical themes if all groups discussed specific recovery determinants more often.

Importance Rating Exercises

Relevance of the WHOQOL-BREF. The fist importance ratings exercise immediately followed the discussion meetings. Participants were asked to complete a pen and paper survey. The survey was an adapted version of the NZ WHOQOL-BREF survey tailored to the aim of this exercise in Phase 1. An adapted version of the NZ WHOQOL-BREF survey, assessing for importance rather than satisfaction with each facet was used in previous NZ WHOQOL research (Krägeloh et al., 2013). The initial words of the WHOQOL-BREF such as: "how satisfied are you …" were changed to "how *important* has (the facet) been", in this case, *to your recovery*. A copy of the WHOQOL-BREF importance survey can be found in Appendix H.

A slight modification to the instructions in the importance survey was made for different participant groups, to ensure that the survey remained relevant to their circumstance. Participants with no personal experience of mental health issues were asked to answer the questionnaire in reference to one specific family member or a specific client they had supported, without naming that person specifically. Participants with mental health issues were asked to answer the questions about their own personal experiences.

Theoretically the QoL issues during acute phases of mental health problems could be quite different from those in later stages of recovery when people are returning to work, independent of services, or at mid-stages of recovery when they are still receiving intensive

community outreach or residential rehabilitation services. The self-report measure – The Brief Stages of Recovery Instrument (STORI) (Andresen et al., 2006; Weeks et al., 2010) was used within the *About You* demographic questions of the NZ WHOQOL-BREF Importance Survey to identify whether participants perceived themselves to be in early, mid, or later stages of their recovery journey. This helped to contextualise the ratings people gave on the importance survey and to consider how QoL is affected at different stages of recovery.

Discussion Questions. The researcher invited participants to reflect upon their lived experiences in response to three main research questions: (1) Participants were asked to reflect on first becoming unwell and to discuss the QoL challenges that emerged for them during that time. The impact of mental health problems on reducing QoL and the differences between the HRQoL issues emerging during acute stages of illness, compared to later phases of recovery asked about in later questions, could be assessed by answers to this question. This question could help to identify whether any recovery determinants belonged to acute stages of mental health issues, assisted with turning points, or emerged later in recovery when comparing participant answers to the three questions.

Participants were then asked: (2) how recovering from mental health problems impacted their QoL. People considered turning points and what changed when they started moving forward in a recovery direction. Participants often spoke about the recovery factors that changed their HRQoL for the better in response to this question. The insights they started to have and the experiences that led to making progress were shared at this point of the discussion, referring also to times they relapsed as part of the recovery process or gained more insight into what they needed to do to move forward, critical supports that made a difference, and emerging experiences of self-determination that led to taking more control of their life and recovery that in turn improved their QoL the most.

The next question asked participants: (3) whether they felt there were any unique HRQoL issues more pertinent to recovering from mental health problems than ones that could emerge when recovering from other health problems. This question attempted to narrow the discussion focus more specifically on the HRQoL issues experienced as a direct result of mental health issues compared to other health problems. This question was challenging for participants. They spoke about subjective distress states, perceptions-of-reality altering, self-assessed identity changing, the relational and social consequences of mental health problems, the cognitive disruptions they experienced, and shared experiences with recovering from other health problems.

Recovery Factors Affecting QoL. The second importance rating exercise was a card sort exercise introduced to participants in two different ways: (1) lived experience (LE) participants completed the exercise about *their* recovery, not about what they thought was generally experienced by all people with mental health problems; (2) Participants who were family members, were asked to recall their family member with mental illness when completing the exercise. If they were a staff member, to recall a specific service user they had supported. A staff member or family member with lived experience referenced their own recovery. This instruction aimed to create consistency among participants at each data collection point and to maximise the collection of data about the lived experiences of people with mental health issues by focusing the recovery supporter participants on the lived experiences of known people in recovery rather than upon abstract views of what they thought was important.

Participants were given a pack of laminated recovery cards with a recovery factor named on one side and a brief definition of what that recovery factor referred to on the back of the card. Appendix I shows the 48 recovery determinants participants reviewed with the definitions on the back of the cards. The researcher asked participants to choose the recovery

determinants from the selection most relevant to their QoL from the pack. Secondly, order the cards selected in order of importance to the recovery of their QoL or that impacted their QoL the most.

Participants discussed why they rank-ordered the cards. The researcher took a photo of each person's card sort result with a participant code beside their selection for ease and time efficiency. The code indicated the first initial of the location of the discussion meeting the participant attended and a second letter indicating what type of group it was (i.e., family (F) or client (C), staff (S) or expert (E)). The code and number assigned to each pack of laminated cards differentiated participants from one another. The code given to each participant's result was entered onto a spreadsheet after the session for later between-group analyses. Appendix J shows an example of the photos of card sort exercises completed by different members of different participant groups with their codes attached.

Participants discussed why they ranked the cards the way they did. Time constraints, the additional volume of qualitative data it would generate to analyse, and exploring why participants chose a recovery factor not being an aim in this research phase resulted in deciding not to tape these explanations. The exercise focused more on what was important than why or how it affected a person's recovery.

At times, participants chose and ranked the indicators to show which recovery factors were more critical to their recovery in different ways than anticipated by the instruction. The clustering of recovery determinants on one rank position increased the complexity of later data analysis. However, it also added to the richness of understanding about how these determinants affected people's QoL for the researcher.

Initially, the rank ordering part of the task aimed to show whether any specific recovery determinants were more often ranked within the top-ranked positions by all participants or by LE participants as an indicator of some recovery determinants affecting

QoL more often than others. However, the way that participants ordered their cards was recognised as authentic to their experience and represented what they wanted to communicate about how these recovery issues affected their QoL. The researcher decided to alter the method of identifying importance within the data analysis of this exercise rather than ask the participants to repeat the exercise. The analysis focused on whether a recovery determinant was chosen more frequently than others rather than *where* the recovery determinant was placed within a participant's rank order as the relevant data point to resolve this data analysis challenge.

The researcher gave participants a voucher of choice to thank them for participating in the form of a $20 bus card or a $20 petrol voucher. The LE participants were also given a gift bag with recovery-orientated content as an additional acknowledgement and appreciation for participating.

Data Analysis

Discussion Data

The researcher and primary supervisor analysed all discussion meeting tapes. Additional volunteer coders were recruited within the university setting to increase the number of people listening to and coding the LE discussion tapes. These additional coders were year three psychology students interested in mental health recovery. Therefore, five listeners coded the LE audio tapes, and two recorded the audio tapes of recovery supporter discussions.

A codebook introduced a consistent method of identifying themes across listeners. The code book was in the form of an Excel spreadsheet that recorded themes noted by listeners and collated tallies of each time each code was noted as being discussed on a final theme's 'summary' tab. The codebook summed the frequency of codes to each codebook item. Each codebook item had a tally representing the total number of times it was discussed

that had been recorded by each coder within each discussion session. Codebook items were the 26 WHOQOL-BREF items, the five NZ national items, and the 48 personal recovery determinants used in the card sort exercise. A column headed *other* was included in the code book for coders to record themes that did not fit within the provided codes and their facet descriptors. Appendix L 1–4 displays the different pages of the code book. Jillian Pennington, a software research specialist (from *Wild Bamboo* – a company that developed the *Record Base* software adapted to record WHOQOL data for several NGOs), developed this code book Excel tool for Phase 1 of the research.

Coders listened to the audio tapes and indicated on the spreadsheet whenever they heard any code book topics discussed. Coders typed a name for a topic they felt was new or different from the existing codebook items into the *other* table on the Excel page.

The codebook generated a final tally for each code in the codebook for each group or interview tape coded. Final tallies highlighted which themes were discussed most often within each discussion. Side-by-side analysis of total tallies for each code in the LE discussions versus the whole sample and recovery supporter discussions showed where data convergence and divergence of the number of times various codebook items were discussed between and within groups.

The researcher analysed the *other* category of themes separately. At times, topics in this *other* category duplicated content named within the facet descriptors of the NZ WHOQOL or met definitions included within the facet descriptor of the recovery determinants. The researcher recoded these *other* codes into the appropriate WHOQOL or recovery codes where this was evident. Initial recoding reduced the number of *other* themes. Those remaining in this category remained *other* themes. These new codes were typically not frequently mentioned across groups and were idiosyncratically named by different coders, with their relevance therefore being harder to assess. These items had no across coder tally.

Their importance could not be evaluated using the same methods used with the codebook items. These items were, therefore, initially included for consideration during question writing. The research team reasoned that the significance of any items developed from these *other* themes by the ways they performed during item analysis in Phase 2.

Some themes showed evidence of being closely related or interchangeably referred to when people discussed their experiences. The question writing team considered this when writing candidate items. An example of this was stigma and discrimination discussed amongst topics of self-stigma, social acceptance, and non-patient identity themes.

The researcher transcribed most of the LE discussion tapes using a transcription software service (REV.com) reviewed to improve the transcription accuracy against the words used in the tape. A volunteer with transcription experience transcribed two discussion tapes. Discussion transcripts from the LE participant sample provided the context for how and why the recovery determinants altered QoL for the better or worse during a person's recovery. Transcribing the LE audio tapes provided participant quotes for inclusion in the thesis. The first-person accounts that Phase 1 participants provided were used to support the interpretation and discussion of the final findings.

Importance Data

The Relevance of the WHOQOL Content to Mental Health Recovery. Eighty-eight participants completed a WHOQOL-BREF importance survey. Each WHOQOL-BREF question was rated importance by the participants from 1-5, where five was the most important. Each participant had a code to identify their survey. The researcher entered the scores that participants gave each NZ WHOQOL-BREF facet onto a spreadsheet against that code. The researcher calculated mean ratings from the participant responses to each WHOQOL-BREF facet.

The researcher examined the results to identify if the tool's content appeared relevant to recovering from mental health issues. A criterion for assessing importance was set at scores of 3–5, indicating a facet relevant to mental health recovery by being rated as moderately to extremely important on the WHOQOL Likert scale. Scores of 4–5 indicated higher importance to recovery. The WHOQOL-BREF facets could now be rank-ordered by mean ratings and side-by-side analysis between the raw score means of each sub-sample compared. It was unknown how meaningful the observed differences were between the two samples from these raw score results.

To consider whether these differences were significant on any of the WHOQOL-BREF facets, the researcher entered the Excel dataset of mean ratings into SPSS (version 25). A Mann–Whitney *U* test explored the differences between the mean ratings of importance that LE participants gave to each WHOQOL-BREF facet compared to the mean ratings recovery supporters gave to these same facets.

The researcher also explored the mean score results obtained from the importance ratings on the WHOQOL-BREF survey against how often these facets were discussed within the LE and recovery supporter groups. The frequency of times each coder had noted their mention in a discussion group could be tallied for each facet item. The number of groups that each facet was noted to have been discussed within by more than one coder could also be summed for each WHOQOL-BREF facet. The researcher calculated a percentage of groups each WHOQOL-BREF facet was discussed within Excel from the across-groups results of each facet item. The facets were rank-ordered by the number of groups each facet was discussed to compare the results between the whole sample and the LE subsample. Side-by-side analysis of the two datasets allowed for comparison between groups and the whole sample result to assess the reliability of the whole sample result, considering the LE result.

Some WHOQOL-BREF facets were spoken about more often by LE participants in their discussions and others by recovery supporters, as well as some WHOQOL facets being discussed as often by both groups. Those facets were calculated as being discussed 100% across all discussions, i.e., all LE and recovery discussion groups discussed this facet, resulting in it obtaining the highest rank order. These facets may indicate more QoL impact for people recovering from mental health problems than those discussed less often in either group or by people with LE. However, this cannot be ascertained from a small sample result.

It may be interesting to explore further within the WHOQOL-BREF survey responses within the Phase 2 dataset within a broader question the current research question sits within, i.e., what QoL items are most affected by mental health issues and recovery from them. An exploration of differences between methods of assessing importance between these two data collection methods occurred to consider which data set may be more reliable for reporting. The researcher compared the rank order position of each WHOQOL facet once they were ordered by frequency of groups the facets were discussed versus the mean average ratings of importance given to each facet provided by participants.

The rank order of facets changed between the discussion group result and the importance rating exercise, which was to be expected given the different instructions and processes involved with collecting data in these different ways. All 88 participants completed the importance rating exercise and were asked to focus specifically on the WHOQOL and NZ national items. Participants were asked to speak to their lived experiences within discussions. The coders coded these themes as they naturally arose in discussions. Not all of the 26 WHOQOL or five national items and 48 recovery determinants could be brought up in each group with equal prioritisation by all participants within 60–90-minute discussion meetings.

Nevertheless, topics discussed more often across the whole sample and by those with LE were still of interest when considering their potentially higher relevance as HRQoL issues

for this population. Triangulation of the importance data with the discussion data explored whether some WHOQOL-BREF facets were discussed more often and rated more highly by receiving a similar rank of importance. Others were examined to see if they were discussed less often and rated less highly by LE participants and across the whole sample.

Reflections on the reasons for these differences are broader than the scope of the current research when examining whether this is an indication of universal importance per se, as some personal issues may be less likely to be discussed within groups or with strangers, as noted by more significant numbers of missing values to some WHOQOL-BREF items compared to others. Given the limitations of both data collection methods, it may be worth considering whether focus groups are the best methods to research QoL in this population.

Similarities and differences between the importance exercise data and qualitative discussion data were exploratory to consider what generic facets of life represented in the WHOQOL-BREF may be more relevant to people with LE. However, these results only contributed to the final results of Phase 1 by establishing that people with LE, on the whole, perceived the WHOQOL-BREF to have content relevant to their recovery.

The Relevance of Specific Recovery Determinants to Quality of Life. The researcher entered card sort data into Excel. Recovery determinants were listed on the spreadsheet in rows, with participants identifying codes as column headers. Exploratory data analysis occurred to consider the best way to use the data, given the variability of participant responses to the ranking component of the exercise.

Eighteen of 88 participants (12 LE and six recovery supporters) rank ordered all 48 cards. In contrast, 70 of 88 participants selected only the recovery cards relevant to their recovery or the recovery of the person they supported during the rank-ordering task. Sixty-four participants ranked ordered the cards linearly as instructed; 24 participants (15 of the total 55 LE and nine of the total 33 recovery supporters) chose to put more than one card at

the identical rank position. Therefore, 24 out of 88 participants clustered more than one recovery determinant at the identical rank position. These participants explained that the card sort issues chosen were all present and cooccurred together at a specific time they were recalling. Some participants referred to how they had completed the rank ordering task as steps on their journey towards recovery. One participant mapped all 48 cards in a spiral to show that their recovery was a progressive journey.

The researcher decided to use the common denominator of whether a recovery determinant was chosen rather than to use the rank order placement as an indicator of importance within participant results. Frequency data could be calculated and summed for each recovery determinant based on how many participants chose the determinant featured as significant to their QoL during this exercise. A rate of one was put against each recovery indicator when a participant chose it within their rank-ordered selection. The recovery indicators could then be ranked based on how frequently any card was chosen, with the highest possible result being 87 (total number of participants doing the exercise). The lowest was not 0 (as some participants ranked all cards). The importance and discussion meeting data were now rank-ordered frequency data sets for side-by-side analysis and triangulation when considering which items should go forward to Phase 2.

Data Triangulation

Triangulation of data sets and convergent analysis identified the recovery determinants that may be more relevant to MHRQoL as themes for candidate item writing. Discussion, WHOQOL importance rating, and recovery determinant importance rating data sets were compared by combining the three data sets to analyse similarities and differences.

The Phase 1 data collection methods were now all frequency datasets as described in the previous sections. The frequency summations were rank-ordered from highest to lowest frequency based on: (1) frequency of selection in the card sort exercise, (2) rating of

importance in the importance survey, and (3) frequency of groups the topics discussed within across the sample and between subsamples.

Frequency scores were converted into percentages for each WHOQOL-BREF facet and each recovery determinant to examine the results across the whole sample and to explore between-group similarities and differences. The researcher calculated the percentage of participants within the whole sample, LE and recovery supporter subsamples that chose each recovery determinant. The researcher calculated the percentage of discussions each recovery determinant discussed within the whole sample, LE discussions, and recovery supporter discussions. The researcher then explored convergent patterns to note the most frequently discussed recovery determinants in discussions and the most often chosen recovery determinants affecting QoL during the importance ratings activities. The researcher also explored the data to examine where divergence occurred.

Side-by-side analysis and data triangulation methods showed which recovery themes were stronger candidates for consideration for question writing and further analysis in Phase 2. Recovery determinants most often chosen and discussed across the sample were themes more relevant to develop into candidate items to evaluate their performance within a larger dataset in Phase 2 to see how they perform as potential MHRQoL items. Recovery determinants chosen more often by the LE sample in the recovery importance rating exercise and most often mentioned in the LE discussions were used to resolve differences between the data sets where determinants ranked higher or lower by the whole sample were ranked more highly by those in the LE subsample when deciding where the cut-off point should occur for themes to go forward for question writing once the data was rank ordered.

Decision-Making Criteria for Phase 1 Results

There were several criteria for a theme to meet to go forward to the question-writing phase. At this research stage, a conservative approach avoided eliminating potentially

relevant indicators. The Phase 2 methods would identify the most relevant items for inclusion in a proposed module without reducing the number of themes to go forward to candidate writing at this phase of the research. However, only some items could be included to reduce the survey burden for Phase 2 participants, given that 31 NZWHOQOL-BREF items formed the foundation of the Phase 2 research survey. An initial cut-off set at 75% of discussions was recognised as eliminating some items that were noted in triangulation to be ranked higher by LE participants in the card sort exercise or were spoken about more often in the LE discussions. The research team prioritised LE participant results when setting the cut-off point for themes to proceed to the candidate item writing phase in preparation for further item evaluation in Phase 2 by resetting this to 50%. The following criteria for theme inclusion for the question-writing phase were used: (1) the majority of coders recorded the theme as discussed in discussion meetings, (2) the theme was discussed in over 50% of LE discussions, (3) the theme is in the top 50–100% of items selected in the whole sample card sort, (4) LE participants ranked the theme in the top 20 of the recovery determinant importance rating card sort exercise when triangulation was used to consider the cut off for a themes inclusion.

Phase 1 Results

Discussion Data

The researcher set aside the discussion results for the WHOQOL-BREF and NZ national item codes as these themes did not require question writing; existing items reflecting these themes formed the foundation of the Phase 2 research survey. There were 55 LE participants and 33 recovery supporters within the 23 discussion meetings and 55 LE participants within the 11 LE discussion meetings. Table 5 displays the percentages of groups that discussed the themes going forward for question writing. The recovery determinants discussed in 75%–100% of all 23 discussions are in the first section of Table 5. Those discussed in 50%–75% of all 23 discussions are in the second section of Table 5. The third

section of Table 5 lists the recovery determinants affecting QoL discussed in under 50% of all discussion sessions. The right column shows the LE results for comparison.

Table 5

Discussion Results

Recovery codes rank ordered by the percentage of discussion meetings within which they were discussed	Percentage of 23 discussions	Percentage of 11 lived experience participant discussions
1. Recovery progress	100.0	100.0
2. Stigma or discrimination	95.7	100.0
3. Illness symptoms	91.3	100.0
4. Interventions other than medications	91.3	90.9
5. Recovery readiness or determination	91.3	90.9
6. Self-awareness	91.3	100.0
7. Hope	87.0	81.8
8. Personal growth or change	87.0	90.9
9. Understanding	87.0	100.0
10. Acceptance	82.6	100.0
11. Goals	78.3	81.8
12. Peer support	78.3	81.8
13. Inner strength	73.9	63.6
14. Social networks	73.9	63.6
15. Spirituality	69.6	72.7
16. People skills	65.2	63.6
17. Well-being	65.2	45.5
18. Healing	56.5	72.7
19. Self-care, self-nurturing, self-help	56.5	63.6
20. Having things to do	52.2	72.7
21. Others recognising strengths	52.2	54.5
22. Exercise	43.5	54.5
23. Unmet needs	43.5	45.5
24. Time out	17.4	36.4

The topics of spirituality, healing, and having things to do were discussed in over 70% of the LE discussions. This observation resulted in a revised decision to lower the cut-off threshold criterion from an initial one set at 75% of the whole sample, to a renewed criterion of the theme needing to be discussed within 50% of the LE discussions to be included for candidate item writing.

Importance Data

WHOQOL-BREF Relevance to Mental Health Recovery

All participants were instructed to focus on the relevance of the items within the WHOQOL-BREF to people with LE; either themselves if they were part of the LE sample or a specific person with lived experience if they were a recovery supporter. All participants identified the WHOQOL-BREF items as relevant to mental health recovery evidenced by a mean score of over three for all facets. The item satisfaction with one's sex life had the most missing values; only 81 out of 87 participants rated this item as relevant to their recovery.

A Mann-Whitney *U* test assessed whether the importance ratings of LE participants differed from those of recovery supporters. The Likert scale response options in the importance survey named a score of 3 as moderately important, 4 as 'very important', and 5 as 'extremely important' to the person's mental health recovery. Thirty of the 31 facets in the WHOQOL-BREF importance measure showed no significant differences between the subsamples. Differences occurred for one item asking about accepting bodily appearance. LE participants rated this more relevant (4.00) than recovery supporters (3.00). Four of the five NZ national items were within the top 10 ranks of relevance to mental health recovery: (1) control over life, (2) feeling respected by others, (3) being able to manage personal difficulties, and (4) feelings of belonging. Meeting others' expectations of you (5) ranked lower at the nineteenth position. Table 6 displays the average raw score results of LE participants ratings of relevance to each of the 26 WHOQOL-BREF and five NZ items.

Table 6

Mean WHOQOL-BREF Importance Ratings: Lived Experience Participants

Rank order as identified by those with lived experience	WHOQOL-BREF facet item **New Zealand national item**	Average rating given by those with lived experience
1	Feel life to be meaningful	4.21
2	**Feel I have control over my life**	**4.17**
3	Get around physically	4.11
4	Satisfaction with myself	4.09
4	Feel safe in your daily life	4.09
4	Enjoy life	4.09
5	Satisfaction with personal relationships	4.08
6	Overall quality of life	4.06
7	**Feel respected by others**	**4.02**
7	**Able to manage personal difficulties**	**4.02**
8	**Have feelings of belonging**	**3.98**
9	Access to health services	3.96
9	Performance of activities of daily living	3.96
10	Healthy Physical environment	3.94
10	Satisfaction with sleep	3.94
11	Satisfaction with living conditions	3.91
11	Enough Energy for daily life	3.91
12	Availability of Information	3.89
13	Enough money to meet needs	3.88
14	Overall physical health	3.87
15	Leisure activity opportunities	3.83
16	Not have negative feelings	3.81
16	Physical pain	3.81
17	Satisfied with support from friends	3.70
17	Transport	3.70
18	Capacity to work	3.69
18	Concentrate well	3.69
19	**Meet expectations placed on you**	**3.58**
20	Acceptance of body appearance	3.57
21	Dependence on Medical Treatment	3.29
22	Satisfaction with sex life	3.23

Facets ranked in the top five levels of relevance by LE participants in the WHOQOL-BREF importance rating exercise were: (1) life being meaningful, (2) having control over life, (3) mobility, (4) satisfaction with oneself (self-esteem), (5) safety and security, (6) enjoying life, and (7) satisfaction with personal relationships.

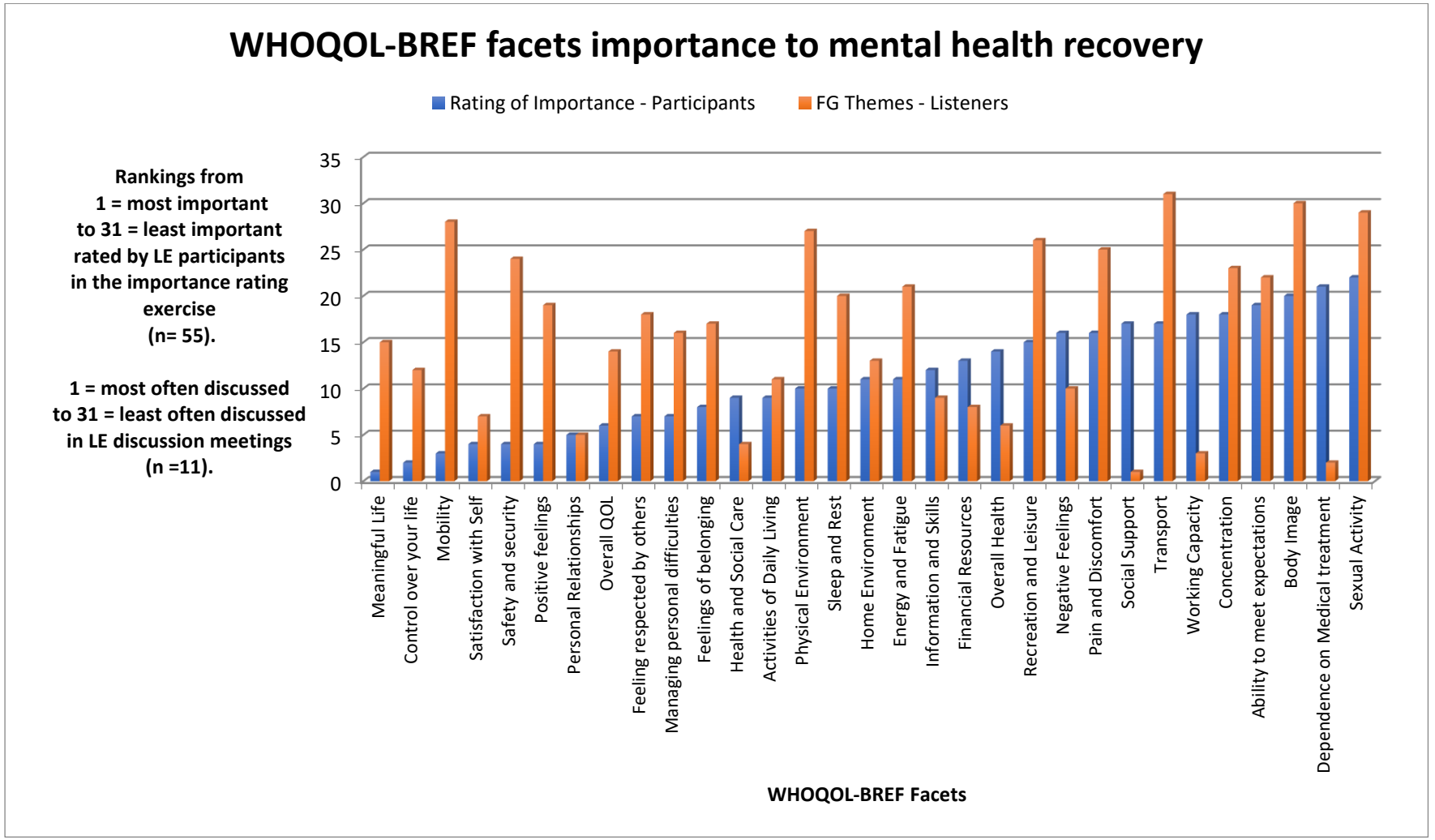
Some WHOQOL-BREF and national items topics were discussed more often within the discussions. Satisfaction with personal relationships was in the top five of LE discussions. The top five topics spoken about in LE groups were: (1) challenges and changes within personal relationships, (2) experiences of health and social care services, (3) social support needs, (4) capacity to work, and (5) difficulties arising from dependence on medical treatment. The least often discussed topics in the LE discussions are represented by ranks above 25 (of the 31-item measure). These were: (1) mobility, (2) one's environment, (3) recreation and leisure, (4) transport, (5) body image, and (6) sexual activity.

Figure 6 displays the triangulation of discussion data results and WHOQOL-BREF importance rating results amongst LE participants. This figure shows the degree to which each WHOQOL-BREF facet was discussed within the LE discussions, compared to how LE participants rated these same facets as relevant to their recovery in the WHOQOL-BREF importance rating exercise. Orange represents the rank order given to discussion group data. The lower the score translates to higher rank importance, meaning coders noted this WHOQOL-BREF facet more often in discussion sessions. Facets discussed less often are ranked lower, so they have higher scores in Figure 6.

Blue represents the rank order given to WHOQOL-BREF importance data. Again, the lower score translates to higher rank importance, with higher bars equating to lower importance. Low blue and orange bars identify facets discussed most often and ranked most important. Higher blue and orange bars identify facets least often discussed and ranked less important by LE participants.

Figure 6

Triangulation of LE WHOQOL-BREF data



The WHOQOL-BREF facets rated as having the lowest recovery relevance ***in the importance rating exercise*** were***:*** (1) dependence on medical treatment and (2) sexual activity. Some topics may be too personal for people to highlight in a survey, sexual activity potentially being one of these as it was noted that this item had the highest missing values. However, both items were still on average rated as moderately relevant to personal recovery.

Recovery Determinants' Importance to QoL

Participants identified which recovery determinants affected their QoL the most in two data-gathering activities: (1) by more participants choosing the recovery determinant and (2) by repeatedly discussing specific recovery determinants in more meetings. The researcher created two data sets. The recovery determinants were rank-ordered by the percentage of participants choosing each recovery determinant; the determinant that more participants chose obtained the highest rank. Secondly, the recovery determinants were rank-ordered by the percentage of groups coders noted the recovery determinant as being discussed; the determinant discussed in more groups obtained the higher rank.

Table 7 displays the results of triangulating the recovery determinant card sort and discussion data. The far-left column displays the rank order assigned to the recovery determinant based on the percentage of discussions it was discussed across the whole sample. The third column displays how often LE participants chose each recovery determinant as having affected their QoL in the card sort exercise. The fourth column compares this with how often the whole sample chose the recovery determinant in the card sort exercise. The whole sample result comprises 55 participants with lived experience (62.5%) and 33 (37.5%) recovery supporters. One discussion group participant did not participate in the card sort exercise, reducing the total sample for the importance rating exercise to 87 (32 recovery supporters and 55 LE participants). This changes the composition of recovery supporters to LE participants (63.2%) LE and recovery supporters (36.8%) in the card sort data analysis.

Table 7

Triangulation of Importance Data: Themes Discussed versus Cards Chosen

Rank order based on how often it was discussed in all discussions (*n* = 23)	Recovery determinants impacting QoL rank ordered by lived experience participant card sort results (*n* = 55)	Percentage of lived experience participants choosing the recovery determinant (*n*= 55)	Percentage of all participants choosing the recovery determinant (*n* = 87)
07	1. Hope	78.2	79.6
09	2. Understanding	76.4	78.4
17	3. Well-being	72.7	68.0
20	4. Having things to do	72.7	67.0
06	5. Self-awareness, insight	70.9	68.2
19	6. Self-care	70.9	68.0
08	7. Personal growth	69.1	68.2
10	8. Acceptance	69.1	73.9
01	9. Recovery progress	67.3	61.4
11	10. Goals	65.5	62.5
22	11. Exercise	65.5	61.4
14	12. Social networks	63.6	71.6
12	13. Peer support	61.8	53.4
13	14. Inner strength	61.8	60.2
15	15. Spirituality	61.8	62.5
18	16. Healing	60.0	56.8
21	17. Recognising strengths	58.2	64.8
04	18. Interventions other than medication	56.4	69.3
05	19. Recovery readiness, determination	56.4	54.6
16	20. People skills	52.7	52.3
24	21. Time out	50.9	45.5
23	22. Unmet needs	43.6	44.3
02	23. Stigma and discrimination	38.2	42.0
03	24. Mental illness symptoms	38.2	39.8

The pink highlight identifies recovery determinants coded in 70%–100% of all 23 discussion meetings (ranks 1–12). The blue highlight identifies recovery determinants coded in 50–70% of all 23 discussion meetings (ranks 13–21). The yellow highlight identifies the determinants coded in less than 50% of the 23 discussion meetings (ranks 22-24).

Some recovery determinants moved from moderate relevance when considered within the discussion data to higher relevance when compared to the card sort data. When determining the most reliable result from the Phase 1 data sets, exploring group differences showed similarities and differences between the LE and whole sample card sort results.

Items showing more significant disparity in the card sort results were: (1) recovery progress, (2) social networks, (3) having things to do, (4) peer support, and (5) interventions other than medication. Having things to do, recovery progress and peer support were often chosen by people with lived experience. Social networks and interventions other than medications were more often chosen when adding recovery supporter data.

Convergence between datasets was observed. Determinants coded as discussed often in the discussion data were also chosen often, i.e., by over 70% of LE participants. These were: (1) hope, (2) understanding, and (3) self-awareness, closely followed by (4) personal growth, and (5) acceptance at 69.1, and (6) recovery progress at 67.3%.

There was data divergence between the card sort and discussion data. The importance of exercise was chosen by 65.5% of LE participants. However, it was not often coded as discussed. Exercise ranked 22 out of 24, based on how little it was coded across all groups. Some recovery determinants that ranked lower, based on the frequency in which they were coded in groups, were chosen by over 70% of LE participants during the card sort exercise. Self-care (rank 19) and having things to do (rank 20) exemplify this data set divergent result.

Between groups, differences were not analysed to consider whether they noted anything meaningful between participants. The data exploration and triangulation methods

showed that the LE card sort data provided a mechanism for a whole sample comparison with the discussion group data to consider what themes were best to take forward into Phase 2.

There was no consensus process in the discussion meetings to ascertain the importance of a theme; importance was established by the determinant's frequency of mention across groups and depended on it being recognised by coders. The card sort importance-rating exercise provided a further indicator of how many LE participants experienced each recovery determinant affecting their QoL when LE participants chose it themselves. The criteria of ensuring the majority of coders noted the determinant as present controlled for bias to some extent. Yet, balancing the possibility of error caused by perceptual bias and interpretation of the discussion group data, which may itself limit the opportunity for some discussion topics to arise or result in others being favoured, with the card sort results strengthened decision-making processes when identifying themes to go through to Phase 2.

Differences between the discussion and card sort datasets may reflect differences between data collection methods that are to be expected in small samples. Triangulation merely identified that weighting the decision-making about discussion themes to go forward for question writing against LE card sort results improved the potential that the most salient themes were determined in the final result from Phase 1. Triangulation methods addressed the risk that a whole sample result based only on discussion data did not inadvertently remove recovery determinants identified as necessary to the QoL of LE participants.

Phase 1 Conclusions

Triangulation of discussion and importance data identified 24 themes for question writing at the end of Phase 1. Table 8 summarises the final results along with their code descriptors. These recovery determinants verified by participants during non-cued discussion sessions in Phase 1 came out of a review of the personal recovery literature. The researcher attempted to simplify the language and make the terms more accessible for a non-academic

participant population when writing definitions for the back of the cards used in the importance exercise and for coding purposes.

Table 8

Recovery Determinants Affecting QoL: The 24 Phase 1 Themes

Recovery determinant	Definition
1. Hope	Able to believe solutions or positive changes will happen in the future. Having an optimistic view of my future; believing recovery is possible.
2. Understanding	The experience of understanding. Understanding my illness, feeling understood by others; or the issues I have being understood.
3. Well-being	A sense of being well within myself
4. Having things to do	Activities to keep me busy so I don't get bored and can keep myself active.
5. Self-awareness	Recognising thoughts, feelings or patterns of coping that are helpful to my recovery or that keep me stuck or create problems for me in life.
6. Self-care, self-nurturing, self-help	Being able to take good care of myself. Making sure my health, mind, feelings, body, and well-being are cared for. Taking responsibility for my own recovery and helping myself more. Learning how to rely on myself more independently or use self-help tools.
7. Personal growth or change	Feeling I am developing, growing, discovering who I am or changing as a person. I know myself more, am more able to do things I used to find difficult or have grown out of old ways of feeling or thinking.
8. Acceptance	Turning point in how I see myself, my illness or my symptoms that helped. Able to adjust to, accept, or adapt to things I can't change. Letting go, to move forward.
9. Recovery progress	Being able to look back and see I have made progress.
10. Goals	Having plans and things to work towards for the future. Could also be a vision for the future that I want to achieve or changes I am planning to make.
11. Exercise	Physical activity done to get fit or healthy or help my recovery.
12. Social networks	Having different groups of people as friends, contacts or supports
13. Peer support	Support from people who have experienced mental illness or addiction.
14. Inner strength	Feeling strong on the inside and being able to draw on this when I need to.
15. Spirituality	A personal belief, set of values or inner experiences, that helps me to see the bigger picture, transcend what is happening, and maintain my recovery. Could be through religion or other practices, values, or beliefs you call spiritual.

Recovery determinant	Definition
16. Healing	Old hurts, trauma, or relationships are no longer getting in the way of my life or happiness or don't cause the same pain they used to.
17. Recognising strengths	Being able to see strengths that help me move forward or recover. Other people recognising or showing me my strengths and abilities.
18. Interventions other than medication	Things that help my recovery that are not related to medication or medical services, e.g., therapies, groups, work support, social support, practical help, etc.
19. Recovery readiness or determination	Being ready to make changes or work towards my recovery. Being determined to recover and do whatever it takes.
20. People skills	Being able to get along with others, e.g., could involve asserting myself, managing relationships at work, home, socially, with friends, work mates, or family.
21. Time out	Time away from all the responsibilities of my life. Needing to depend on others, withdrawing from my roles or life activities, stopping my life as it is, respite or hospital time.
22. Unmet needs	Important things necessary for survival are restricted by a certain life situation, e.g., food & water, shelter, clothing, healthcare, safety, relationships, money, freedom, etc.
23. Stigma and discrimination	Feeling people judge me, see me as less able to do things, or are nervous about me, because of my history or current experiences of mental illness.
24. Illness symptoms	Experiences my illness brings that gets in the way of my recovery, e.g. – voices, mood swings, tiredness, certain beliefs, or thoughts that concern me or others, fears, highs …

The next step of the current research involved developing candidate items and a research survey to evaluate these themes in Phase 2. The research tasks that bridged Phases 1 and 2 are discussed in the next chapter, Chapter 5.

Chapter 5

Question Writing and Survey Development

Preparation for Phase 2

The aim of Phase 1 was to identify potential content for a mental health recovery module for the WHOQOL-BREF. The aims of Phase 2 were to survey how the candidate items developed to assess Phase 1 themes performed statistically, from an CTT and item response theory (IRT) perspective, within a larger population of people recovering from mental health problems. Question writing and survey development, occurring between the qualitative and quantitative phases of the current research, created the materials required for Phase 2. This chapter explains how a question-writing team turned the themes from Phase 1 into candidate item questions. The second part of the chapter describes how a research survey was developed to gather data about how these items performed in Phase 2.

The existing WHOQOL-BREF and NZ national item questions formed the foundation for the research survey. They did not require new question writing for the Phase 1 themes that had been coded against the WHOQOL-BREF or NZ national items. Table 8 in Chapter 4 displayed the results of Phase 1, the recovery determinants most often discussed in meetings and most often chosen by LE participants as impacting QoL during recovery. The definitions available to coders when listening to the tapes and on the back of the cards in the importance rating exercise are displayed on the right-hand side of Table 8. The question-writing team considered these definitions and referenced how participants discussed these themes when developing candidate item questions for the research survey.

At times, a question written for one theme also covered another sub-theme, an existing WHOQOL-BREF item, or was a health status question not a QoL question. Therefore, the final 24 questions developed for the research survey do not map explicitly onto the 24 themes emerging from Phase 1 listed in Table 8. Table 9 shows the minor themes integrated into major themes during question-writing. Items were written for the themes listed on the left; the subthemes subsumed into those higher-order themes are depicted underneath.

Table 9

Recovery Determinants: Major and Minor Themes

Recovery determinant	Definitions used in the discussion meeting code book and the importance exercise associated with these recovery determinants
Mental health status	Experiences my illness brings that gets in the way of my recovery. e.g. – voices, mood swings, tiredness, certain beliefs, or thoughts that concern me or others, fears, highs.
- Illness symptoms	
- Well-being	A sense of being well within myself.
Acceptance	Turning point in how I see myself, my illness or my symptoms that helped.
- Peace of mind	Able to adjust to, accept, or adapt to things I can't change Letting go, to move forward.
	A state of peace inside myself, with myself or my life as it is, or has been. Not worried about things all the time or focused on my problems, past experiences, or issues.
Understanding	The experience of understanding.
	Understanding my illness, feeling understood by others; or the issues I have being understood.
Hope	Able to believe solutions or positive changes will happen in the future. Having an optimistic view of my future; believing recovery is possible.
Self-awareness	Recognising thoughts, feelings or patterns of coping that are helpful to my recovery or that keep me stuck or create problems for me in life.
- Personal worldview	
	Having my own way of seeing things that helps my recovery.
Recognising strengths	Being able to see strengths that help me move forward or recover.
- Others recognising my strengths	Other people recognising or showing me my strengths and abilities.
- Inner strength	Feeling strong on the inside and being able to draw on this when I need to.
People skills	Being able to get along with others, e.g., could involve asserting myself, managing relationships at work, home, socially, with friends, work mates, or family.

Recovery determinant	Definitions used in the discussion meeting code book and the importance exercise associated with these recovery determinants
Recovery progress	Being able to look back and see I have made progress. Recognising how far I have come from the past. Moving forward or closer to where I want to be in my life.
Peer support	Support from people who have experienced mental illness or addiction.
Personal growth or change	Feeling I am developing, growing, discovering who I am or changing as a person.
- Healing	I know myself more, am more able to do things I used to find difficult or have grown out of old ways of feeling or thinking. Old hurts, trauma, or relationships are no longer getting in the way of my life or happiness or don't cause the same pain they used to.
Fear of relapse - Self-trust	Being able to believe in myself and trust myself at a deeper level. Knowing I can trust my mind, emotions, or thoughts. I can trust myself to manage my life & future.
Goals	Having plans and things to work towards for the future. Could also be a vision for the future that I want to achieve or changes I am planning to make.
Recovery readiness or determination	Being ready to make changes or work towards my recovery. Being determined to recover and do whatever it takes.
Coping skills	Taking responsibility for my own recovery and helping myself more.
- Self help	Learning how to rely on myself more independently or use self- help tools.
- Self-care, self-nurturing	Being able to take good care of myself.
Work readiness - Role functioning	Able to do what I need to do, to maintain important roles in my life, e.g., parent, family member, worker, friend, student, church goer, team-player.
Loneliness	
- Community integration	Living in and being part of my local community.
- Social networks	Having different groups of people as friends, contacts or supports.

Recovery determinant	Definitions used in the discussion meeting code book and the importance exercise associated with these recovery determinants
Stigma and discrimination	Feeling people judge me, see me as less able to do things, or are nervous about me, because of my history or current experiences of mental illness.
- Social acceptance	People I meet that make me feel like they accept me as I am.
- Self-stigma	Ways they talk to me or involve me in things, like there is no difference between me and others.
- Non-patient identity	Seeing myself as less of a person or socially rejectable because I have a mental illness or addiction, even if others don't, or say I am not.
	No longer thinking of myself as someone with a diagnosis or illness. Having a positive sense of self.
	Others see me as a person with other roles in life more than a patient or a person with this illness.
Social networks	Having different groups of people as friends, contacts or supports.
Spirituality	A personal belief, set of values or inner experiences, that helps me to see the bigger picture, transcend what is happening, and maintain my recovery. Could be through religion or other practices, values, or beliefs you call spiritual.
Health system issues	Things that help my recovery that are not related to medication or medical services, e.g., therapies, groups, work support, social support, practical help, etc.
- Interventions other than medication	
- Unmet needs	Important things necessary for survival are restricted by a certain life situation, e.g., food & water, shelter, clothing, healthcare, safety, relationships, money, freedom, etc.
Having things to do	Activities to keep me busy so I don't get bored and can keep myself active.
- Structure	Having a regular daily routine or weekly plan that helps me to feel stable.
Exercise	Physical activity done to get fit or healthy or help my recovery.

Some significant themes had more than one candidate item written to assess them, so Phase 2 could evaluate the nuances in how participants discussed them during Phase 1. The various tasks involved in question writing are written under headings like a small study in this chapter to outline the ways that the candidate items and research survey were developed between Phases 1 and 2 of the current research.

Methods

Participants

A question-writing team developed the candidate items for the Phase 2 research survey. Auckland University of Technology was fortunate to have Dr Rex Billington as an Adjunct Professor, who had previously worked at the WHO as the Director of Mental Health and was familiar with the WHOQOL development project and the process of developing subsequent health modules for the WHOQOL. Dr Billington was the primary supervisor for Phase 1 of this research. Dr Billington mentored and guided the research discussion meeting analysis and question writing phases to ensure that the question writing process aligned with the WHO study protocol guidelines. Dr Billington had experience and knowledge of how to word QoL questions within the WHOQOL-BREF and QoL assessment context.

The additional people participating in the question writing panel included two researchers with expertise in QoL and mental health research, as well as the PhD candidate who had service delivery experience within the QoL and mental health fields and experience using the WHOQOL-BREF as a PROM within secondary mental health services, as well as lived experience of mental health problems within their family and personal life experiences.

Three out of four members of the question writing team attended the LE discussion meetings. Two of the question writing panel had attended all the LE discussion groups – the PhD candidate and Dr Billington. The PhD candidate attended all LE discussions and recovery supporter meetings as the discussion facilitator. Another panel member attended one

LE discussion group and one group of recovery supporters – the secondary supervisor for Phase 1. A fourth panel member provided expertise in the fields of addiction and QoL research. Dr Billington and the PhD candidate had listened to and coded all the discussion tapes before engaging in the question-writing task. The panel members considered how the LE participants discussed each item's context when considering how to phrase a question related to an emergent theme from the Phase 1 results.

Procedure

The question-writing team met several times and communicated about further work completed between panel meetings by email. The question-writing team scrutinised the recovery determinant themes and proposed items against several criteria and principles:

1. **Items captured the HRQoL focus required of WHOQOL items**. Through the question-writing process, a theme discussed in the discussion meeting identified a health status issue, not an HRQoL issue. An example of this was the theme of illness symptoms. The WHOQOL is not a health status questionnaire; therefore, this item became a QoL and criterion measure question, asking about satisfaction with mental health, solely for use within the data analysis procedures of Phase 2.
2. **Reference to discussion meeting dialogue occurred during question writing.** The candidate item must reflect the context and meaning of the theme described by people recovering from mental health problems in Phase 1. The team used a cautionary approach to ensure that any nuances in how participants spoke about existing WHOQOL-BREF items were considered. Existing facet areas might be experienced differently within the context of mental health recovery. The WHOQOL-BREF question may require a further question to evaluate whether a different way of asking about these QoL issues could better capture the experiences that participants described. The significance of these nuances could be evaluated within a correlational

analysis of participant responses to WHOQOL-BREF versus candidate items within Phase 2 data analyses. An example of this type of nuance was an existing WHOQOL question about work readiness versus participants referring to problems accessing work opportunities, being well enough to work, or reduced career pathways with glass ceiling limitations imposed after a mental health diagnosis. People spoke about being pressured to get work when not well and their diagnoses or history of mental health problems narrowing their options for work, or a career pathway compared to peers without mental health issues.

3. **Questions needed to be written to be equally applicable to people with and without lived experience of mental health problems.** Phase 2 involved analysing items for their discriminant validity by comparing the responses a comparison group without mental health problems gave to each item with the responses given by people with mental health problems. The mental-health-specific words required modifying for candidate items that would lose their discriminate ability when overtly worded as a mental health item. Phase 2 comparison group participants would know they were comparison group participants; this may influence how they answered those items if they could easily recognise those items were relevant only to people recovering from mental health issues, for example, asking, “How satisfied are you with your mental health recovery?” instead of asking about recovery in ways that could relate to recovering from anything. The team, therefore, worded candidate items generically. Some themes, such as stigma and discrimination, were relevant to a non-mental health sample. People can experience stigma or discrimination for any reason, such as membership in any minority or marginalised social group. Some themes, therefore, did not require modification to be equally relevant to the comparison group.

4. **Questions were primarily worded positively, in line with the WHOQOL study protocols.** Items related to difficult life experiences required negative wording. Items asking about stigma, loneliness, and boredom are examples of these. The WHOQOL-BREF includes some negatively worded facet items. Negatively worded items are managed through reverse scoring procedures when WHOQOL surveys are analysed. An item identifier, the letter ‘r’, was placed after the numeric identifier to highlight when to reverse-score an item within the analysis.
5. **Candidate item prefixes were assigned according to how questions were asked within the existing WHOQOL-BREF format.** The prefixes used when asking QoL questions within the WHOQOL-BREF include: (1) how satisfied are you, (2) how much, (3) to what extent, and (4) how often. Idiosyncratic prefixes are also used, such as: (5) how, (6) do you, (7) are you, (8) have you, and (9) how available is. The team chose the most appropriate prefix to suit the nature of the candidate item and how best to ask about it. Once chosen, the prefix also determined the candidate item question’s placement within the existing WHOQOL-BREF survey structure. Questions of a similar prefix were placed together. Candidate items asking about, for example, *how satisfied* a person was with a specific facet area were grouped with existing WHOQOL or NZ items that also asked about *how satisfied* people were with the areas of their life asked about in the WHOQOL-BREF questionnaire.
6. **Each question had a descriptor and visual analogue Likert scale numerical equivalent** to ask the respondent to indicate their answer from the lowest to highest QoL rating a person could give across a continuum of possible response options when answering each question in the survey. These response options are scored from 1–5, where one indicates the lowest QoL and five the highest QoL rating. Candidate items needed to make sense in light of this request to survey respondents.

Results and Discussion

The themes from Phase 1 were at times covered by one candidate item during question writing. Some themes collapsed into one item when attempting to write questions for both and recognising similar questions were being generated for two themes. An example is the recovery theme of stigma and discrimination, closely related to the recovery themes of social acceptance, self-stigma, and a non-patient identity. The existing WHOQOL-BREF item asking about self-satisfaction (self-esteem) was considered as already asking about identity and could cover issues of self-stigma or a non-patient identity. However, the subtheme of discrimination was not adequately covered by existing items. A candidate item asking about discrimination was written to assess this Phase 1 theme.

The hope theme, although covered in the facet descriptor of an existing WHOQOL item asking about life enjoyment, was still included for further question writing for three reasons. This theme was discussed often in Phase 1, chosen by most LE participants in the card sort activity, and was a predominant and recurring theme within the international personal recovery literature. The team wrote three candidate items to address the different ways participants discussed hope in Phase 1: (1) making recovery progress (the hope inspired by seeing that things are getting better, so could be better in the future), (2) holding a hopeful belief that recovery was possible, and (3) an optimistic view of one's future. Opposed to the themes of an uncertain future or fear of relapse indicative of holding a poor future prognosis.

The theme of strengths was split into two questions. Participants discussed this theme in two different ways. The importance of recognising one had strengths or inner resilience to recover, compared to other people identifying that they had strengths, which then opened their eyes to see these strengths. It was unclear which of these was the more significant issue that affected a person's QoL during their recovery from mental health problems. Therefore, the team generated two items to examine this theme's nuance during Phase 2 data analysis.

Some themes were not QoL questions per se, as they related more specifically to symptoms of the health condition or its treatment. A mental health status question became a construct variable for statistical analysis in Phase 2. Health system issues were recognised as potentially covered by the existing WHOQOL-BREF item asking about access to required or desired health services. However, the nuance of non-medical interventions may not be, as funded healthcare systems do not ordinarily provide alternative healthcare. Therefore, the team formulated a question to assess the need for alternative healthcare interventions a person could not receive from the current health system that could identify unmet treatment needs.

Loneliness is another example discussed in the context of a lack of social networks and low levels of community integration, resulting in social isolation and a lack of capacity or opportunity to connect to others in meaningful ways. Wang et al. (2020) reported that loneliness at baseline affected four mental health outcomes, including QoL, four months after a mental health crisis and was a better predictor of clinical outcomes than social isolation or social capital. Two social support facets exist in the existing WHOQOL-BREF (satisfaction with support from family and personal relationships). The team created a new candidate item to capture how participants discussed their existential aloneness beyond the two social support items in the WHOQOL-BREF. Items asking about two nuances to this theme, inner felt loneliness versus objective experiences of low social connection (wider social networks), could further evaluate the nuances of this theme during Phase 2 analysis.

The item coping skills was another example. The themes of self-help (to address symptoms) and self-care (to restore well-being) that is different from the existing WHOQOL-BREF items of: (1) being able to manage activities of daily living or (2) the NZ item about meeting the expectations of others were considered. The literature promotes self-help and self-care practices to empower people (Fisher, 1994; Mental Health Foundation, 2006; Slade, 2013). Their use helps people to moderate symptoms and the ups and downs of life that can

present as barriers to recovery and interfere with meeting the demands of everyday life. Self-help skills can develop coping skills that improve people's capacity to manage symptoms and meet the expectations of life (Brown & Wituk, 2010; Slade, 2010; Spaniol et al., 1994). The team wrote a question about *coping* to use the words that participants used when discussing the themes of self-help, meeting others' expectations, and managing activities of daily living.

Connell et al. (2018) found that service users can interpret items within QoL measures within the context of their mental distress, which can alter what an item intends to measure. They gave the example of an item asking about pain being answered in the context of emotional pain, not physical pain (Connell et al., 2018). The team considered that the mobility, pain, and safety items within the WHOQOL-BREF could be interpreted differently in the context of mental health problems. Safety in the WHOQOL-BREF asks about physical safety, such as the impact of war, building integrity, or extreme environmental conditions.

Research highlights that many people within the mental health population have a trauma history (Read et al., 2008). Floen and Elklit (2007) found that 91% of people admitted to a psychiatric service had a history of at least one trauma, with 69% repeatedly exposed to chronic trauma over time and comorbidity of PTSD symptoms for 78% of those in their study. A SAMHSA (2014) literature review highlighted the link between trauma, mental health, and substance use issues. The SAMHSA review associated experiences of past trauma with higher vulnerability to substance abuse problems, citing studies that showed 86.6% and 82.7% of people receiving outpatient substance use programmes had a history of at least one trauma (Farley et al., 2004; Reynolds et al., 2005, respectively).

Koenen et al. (2008) conducted a longitudinal study in NZ that was discussed in the SAMHSA review. Koenen et al. (2008) found that people diagnosed with mental health issues have often experienced multiple traumas. The Koenen et al. (2008) review cited studies showing trauma increased people's vulnerability to mental health problems.

Researchers have discussed the link between trauma and mental health problems for depressive and all affective disorders (Kessler, Berglund et al., 2005; Kessler et al., 1995), personality disorders (Pietrzak et al., 2011a); eating disorders (Brewerton, 2007; Swinbourne & Touyz, 2007); and severe mental disorders such as schizophrenia, bipolar affective disorder, or schizoaffective disorder (Bebbington et al., 2004; Garno et al., 2005; Read et al., 2008). Koenen et al. (2008) also highlighted that the experience of severe mental disorders requiring hospitalisation or forced treatment was also reportedly linked to the development of trauma symptoms and diagnoses in studies by Beattie et al. (2009) and Sherrer (2011).

The research team considered whether the nuances of some existing WHOQOL-BREF questions may need to be evaluated to see whether they meant something different to people in recovery from what the WHOQOL survey intends them to measure. The team thought about the value of a global mental health question in a mental health module.

A global item offered several benefits to the research study. Firstly, this item could serve as a criterion question to identify those with mental health issues. Secondly, it could perform a function for the module similar to the general QoL and physical health items in the WHOQOL. The general items are umbrella items, i.e., represent the sum result of all the other facets that make up what we call health and QoL that are evaluated within the WHOQOL surveys. A mental health item could operate as a general item for later statistical analysis as a criterion variable. Thirdly, it could collect data to assess how dissatisfaction with mental health affected overall QoL, specific domains, or certain facets more than others.

The team considered how the wording of some questions might encourage a bias towards people with a particular injury, chronic health, or social marginalisation issue, such as asking directly about satisfaction with recovery, mental health, and stigma. The team considered the risks and benefits of generic language versus words rooted in the mental health experience, cognisant of the potential bias towards the research sample versus risks of

obscuring an item's meaning and reducing its comprehensibility for the mental health sample. The latter could impact item performance in Phase 2 data analysis or its discriminative capability. Making items fit for a comparison group conflicted at times with trying to capture nuances of participant meaning when wording questions to make items equally relevant to non-mental health populations. Although some items may be chosen more often by people with mental health issues, the team also considered the item would need to meet several robust statistical criteria during psychometric analysis for inclusion in the final module.

When striving to meet the criterion objectives for question writing, the team considered additional reference points during the question-writing process: the WHO definitions of HRQoL, mental health, and mental disorders, and the existing WHOQOL-BREF and recovery determinant definitions. Skevington et al. (2004b) reported that translatable poles for every language across cultures were developed during the original WHOQOL question writing process, such as: (1) intensity (how much), (2) capacity (how completely), (3) evaluation (how satisfied, happy, or good), (4) frequency (how often), and (5) how important. The team used these same question stems when writing candidate items for the Phase 2 research survey. The team needed to maintain focus on the research's primary aims and purpose to ask about MHRQoL in ways that maintained the WHOQOL ethos of incorporating the language and concepts of end users in the PROM development process (Skevington et al., 2004b) when writing candidate item questions. Reference back to how participants spoke about existing WHOQOL-BREF, national items, and recovery determinants assisted with this aim when developing candidate items.

Table 10 displays the 24 candidate items that the question-writing panel developed alongside the Phase 1 discussion themes related to these items.

Table 10

Mental Health Module Candidate Items Against Phase 1 Themes

Item code	Candidate item questions evaluated in Phase 2	Phase 1 themes aligned with candidate items
MH 1	How would you rate your mental health?	Illness symptoms, well-being
MH 2	To what extent do you feel lonely?	Social networks, community integration
MH 3	To what extent have you made changes for the better?	Personal growth, healing
MH 4	To what extent do you believe you can recover from illness?	Hope
MH 5	To what extent do you recognise positive strengths you have?	Recognising strengths, inner strength
MH 6	To what extent do spiritual values help guide your life?	Spirituality
MH 7	To what extent are you determined to recover?	Recovery readiness, determination
MH 8	To what extent do you feel you are able to cope with daily life?	Self-help, self-care
MH 9	To what extent does understanding why you have a problem help you to resolve it?	Self-awareness
MH 10	To what extent do the health and social services meet your needs? *	Unmet needs, alternative holistic healing
MH 11	How well have you been able to adjust to what has happened in your life?	Acceptance, self-stigma
MH 12	How well do you feel you can relate to others?	People skills
MH 13	To what extent do you consider that you are fit and able to work? *	Role functioning
MH 14	How confident are you that when well, you can stay well?	Self-trust, hope
MH 15	To what extent do you feel positive about your future?	Hope
MH 16	To what extent are you motivated by people who have overcome similar problems that you have?	Peer support
MH 17	To what extent are you confident you can attain your goals in life?	Goals
MH 18	How satisfied are you that people really understand you?	Understanding
MH 19	How satisfied are you with your recovery?	Recovery progress
MH 20	How satisfied are you that other people recognise your strengths?	Recognising strengths
MH 21	How satisfied are you that there are people there for you when you need them?	Social networks
MH 22	How much do you feel discriminated against?	Stigma, discrimination
MH 23	How frequently do you feel bored?	Having things to do
MH 24	How satisfied are you with the amount of physical activity you engage in?	Exercise

**Note*. These candidate item questions evaluated for interpretive nuances within existing WHOQOL-BREF items. MH refers to mental health as an identifier for candidate items within the 55-item survey.

The team evaluated the similarity of Phase 1 themes to those asked about within existing modules, i.e., WHOQOL-100, WHOQOL Disability (WHOQOL-DIS), WHOQOL-OLD, WHOQOL-HIV, WHOQOL-PAIN, WHOQOL-Spirituality, Religiousness, and Personal Beliefs (WHOQOL-SRPB) and the New Zealand national items during the question writing process. The team considered the wording of questions within other modules asking about the same Phase 1 themes. The team explored the pros and cons of using existing module questions versus creating unique questions for these themes. The team decided to phrase the questions for the mental health module more closely to how LE participants discussed the item themes in Phase 1. This decision ensured that the lived experiences that LE participants described founded the item wording. Despite the themes being the same, the items from the other modules related to the lived experiences of different health populations.

The WHOQOL tool is primarily a survey that asks about life experiences positively. Connell et al. (2012) critiqued using predominantly positive psychology methods of asking about HRQoL within mental health populations. These researchers highlighted the risk of invalidating the problematic aspects of recovering from mental disorders by primarily using positive psychology terminology within QoL measures for people recovering from mental health problems. The team considered the Connell et al. (2012) advice during the question-writing phase.

WHOQOL-BREF survey questions cover both perceived objective and perceived subjective QoL facets across a continuum of ill-being and well-being (Skevington et al., 2004b). The WHOQOL is well-being-focused to avoid the problem-focus of other HRQoL measures, creating items that move towards well-being within their continuum (Skevington et al., 2004b). These authors gave examples of naming a domain level of *independence* rather than levels of *dependence* and using the term *energy* levels rather than *fatigue* levels. Using a

Likert scale to measure the QoL issue ensured that both ends of the positive and negative continuum of a QoL facet's dimension could be evaluated (Skevington et al., 2004b).

Some items within the WHOQOL-BREF and the candidate item selection ask about negative experiences. These were not able to be positively worded. Negatively worded items include WHOQOL questions about negative emotions, pain or discomfort, and the need for medical treatment and MHRQoL candidate items asking about stigma, boredom, and loneliness. The team considered the consequences of adding complexity for end users when scoring and for respondents answering these questions amongst positively worded items when writing items for these themes.

When referring to the literature on this topic (Connell et al., 2012), the team recognised that some questions need to be negatively worded to capture the experience of difficult life experiences. The loneliness item captured the sense of existential aloneness brought about by marginalisation, loss of social connection, relational disruptions, and difficulties building wider social networks or new relationships discussed by participants in discussion meetings. Although Wang et al. (2020) cited loneliness as a predictor of mental health outcomes and Hawkley & Cacioppo (2010) noted loneliness affected mental health in the general public, it may not be the best way to ask about this experience when considering the review of loneliness by Ortis-Ospina (2019). The review highlighted that aloneness and loneliness are two different and only at times related concepts. Asking about this in two ways, within items asking about loneliness and having sufficient social networks, allowed for further Phase 2 evaluation of this theme's nuances, each item's discriminative ability, and their relevance to MHRQoL when analysing the Phase 2 data.

The existing WHOQOL-BREF has reverse scoring protocols to help users manage the inclusion of negatively worded items during data analysis. Items could be reverse-scored if they became part of the final module. The team gave these items an "r" identifier to show that

they would be reverse-scored during data analysis to ensure that the answers given by participants to those questions would be comparable to the answers given to positively worded items within the candidate item list.

Research Survey Development

Survey Construction

The team reviewed the candidate items for linguistic and structural fit within the WHOQOL-BREF survey. Candidate items were placed randomly within the existing structure of the WHOQOL-BREF among items with similar question prefixes. Adding 24 candidate items to the existing WHOQOL-BREF measure and the five NZ national items resulted in a research survey with 55 items. The WHOQOL-BREF has a demographic question section named *About You*. These demographic questions include age, gender, ethnicity, education, marital status, and employment. The demographic questions were asked at the end of this research survey.

Two demographic standards were referred to when writing demographic questions for the research survey: (1) the existing WHOQOL demographics routinely collected in their '*About You'* section of the WHOQOL-BREF survey, and (2) consultation with and the use of the Statistics New Zealand criteria for the other demographic questions relevant to this research. Standardised ways of asking demographic questions meant results from the current research could be later compared with the sample characteristics of other WHOQOL mental health studies or against NZ Census and PRIMHD demographic data when considering the representativeness of the Phase 2 sample.

The researcher added demographic questions to the *About You* section of the research survey that asked about demographic variables relevant to the current research. These asked people if they had current or past experiences of mental health problems or addiction. Participants answering yes to this question were also asked to identify the type of mental

health problem they had among a range of common mental health issues or to specify "other" if the broad category of mental health or addiction issue was not named on the form. These questions functioned to differentiate the mental health sample from the comparison group.

This section also asked about other variables that can affect QoL or mental health treatment needs: if they had coexisting health and disability issues, whether they lived in a rural, small town, or city environment and where in NZ they lived within broad geographic regions. These additional questions allowed for a comparative analysis of survey answers among comparison group participants. Collecting this data allowed for a future examination of whether participants registered poorer QoL with coexisting health issues, minority group status, or who had other demographic factors associated with reduced QoL in the comparison and research samples. These sample characteristics in the comparison group provided data to later explore differences between extraneous variables that affect QoL if any items did not adequately discriminate between those with and without mental health issues.

Survey Formats

The research survey contained 55 items, which could create fatigue effects for participants. The researcher created two forms and two formats of the survey. One form was reverse-ordered with the other to manage this risk. The researcher developed paper formats of this survey in preparation for their random assignment to participants who preferred a pen-and-paper format or did not have internet access to complete an online survey. Appendix N1 displays the paper version of the research survey.

The researcher also developed an electronic form of the survey. Wider survey distribution across NZ could occur if surveys could be completed online or on mobile phone devices. The researcher explored and trialled three online platforms to consider which platform offered the best software design and confidentiality protections for this study. The researcher chose the *Qualtrics* survey platform for the online research survey. The researcher

developed two forms of the electronic survey, with reverse and non-reverse ordered items. Screenshots of the online survey can be viewed in Appendix N2.

Response Options

The WHOQOL includes five response options presented in two ways: (1) along a descriptive continuum and (2) for scoring purposes, a numerical continuum. A satisfaction question, for example, ranges from “very dissatisfied” to “very satisfied”. It has response options of “dissatisfied”, “neither satisfied nor dissatisfied”, and “satisfied” between these two anchor points. For scoring purposes, a visual analogue 5-point Likert scale equates these item descriptors with numerical equivalents ranging from one to five. One equating to low QoL and five to high QoL on each item asked about in the survey.

The software for the electronic format of the research survey did not allow for a numeric continuum to be observable to participants. A question was answered by clicking on the descriptive response option alone. This way of answering questions differed from circling a number on the paper format of the WHOQOL-BREF survey that matched a descriptive response option. The researcher modified the paper survey to match the online format to reduce the potential of introducing added complexity for respondents completing a paper survey.

In its usual form, the paper format requires a person to cognitively consider both a numerical rating and a written descriptor when answering a question. Leaving the survey in its original format may introduce an extraneous variable of increased cognitive burden for respondents compared to the requirement of respondents in the online format. Those answering the paper survey formats may more often be participants who receive more intensive services. Online responses only required a click on a verbal descriptor without additionally considering a numerical rating assigned to an answer. This modification removed the 5-point Likert scale numbers from the paper survey format, leaving only the Likert

narrative descriptors for participants to read. The researcher modified the paper survey to resolve this potential issue. Paper survey respondents could tick an empty box under their chosen descriptor, akin to clicking the descriptor on the online format.

Removing the visual presence of Likert numbers for respondents is a departure from the design of the traditional paper format of the original WHOQOL surveys. Future researchers need to consider this when comparing the results from the current research against other WHOQOL research using the traditional numerical format of the survey with people with mental health issues. The 5-point Likert descriptors on both surveys retained their numeric equivalents from 1–5 for each descriptive response option in the background of the software and data entry process when data was entered into an Excel spreadsheet for later data analysis.

Consultation and Pilot Testing

Cultural Consultation

The WHOQOL-BREF survey is a cross-cultural measure designed to include facets of HRQoL common to all cultures. This research did not aim to develop a module targeted at unique MHRQoL facets specific to a particular culture; however, ideally, the final measure would contain items that apply to broad cross-cultural aspects of well-being and MHRQoL.

As part of the commitment that all health services in NZ have to Te Tiriti o Waitangi, actions were taken during the research to check that the research process, questions asked, and the research survey had content relevant to Māori. A commonly cited model of Māori health is the Te Whare Tapa Whā model (Durie, 1994). This model depicts the four cornerstones of well-being for Māori as taha hinengaro (mental health), taha whānau (family), taha wairua (spirituality), and taha tinana (physical health) (Rochford, 2004). The 55-item Phase 2 research survey contained items about these four issues: mental health, family, spirituality, and physical health.

Cultural consultation occurred at different stages of the current research. A Kaumatua offering services to an NGO (*Connect Supporting Recovery*) in Tamaki Mākaurau reviewed the WHOQOL-BREF before its use in Phase 1 as an importance survey. The consultation also included reflecting on process issues relevant to Māori for inclusion in the discussion group protocol. The Kaumatua found no problems with the content of the WHOQOL-BREF. A key informant interview with a Māori clinician working in a Kaupapa service occurred within Phase 1 to enquire about personal recovery and QoL issues important to Māori to offset optimal Māori participation in Phase 1.

The Northland District Health Board (NDHB) Kaumatua reviewed the two formats and the content of the Phase 2 research survey to ensure that the content was perceived to be relevant to Māori and that the language was acceptable within the questions from a cultural perspective. The Kaumatua stated that the measure and research process was inclusive and presented no barriers to Māori participation. A request for feedback about the relevance and appropriateness of the content of the research survey was reviewed with a Kaupapa service provider in Northland when approaching them about inviting their service users to participate in the research during Phase 2. The content was non-offensive and perceived to be relevant to their service user population.

Pasifika service users and staff gave feedback on the survey content during Phase 1 when approaching Pacific service providers during recruitment. The content was relevant; however, the sexuality item was identified as potentially sensitive if the person asking for the response was present and unknown to the service user. The *Fonofale Model* (Ioane & Tudor, 2017), a well-known Pasifika model of health and well-being, highlights the corner posts of physical health, mental health, spiritual health, and other impacts on health, on the foundation of family and people cared about and ceiling impacts of culture, values and beliefs. These domains occur within an ecological framework of time, environment, and context for the

person. The research survey included questions about elements critical to Pacific people's well-being named within this model: physical health, mental health, family, belonging, and spirituality. The survey asks respondents to evaluate their lives over the time frame of the last two weeks. A person's ratings are considered context dependent and are made in reference to how their priorities are able to be sustained within current environments at any one time.

Consultation with two participants from two Asian cultures (one Chinese, one Korean) occurred to request feedback about the survey questions and how to increase Asian participation during Phases 1 and 2. Both of these people also participated in Phase 1 as key informants. They spoke to working with Asian mental health service clients and, in one case, about family responses to mental health issues within family members. Although no content changes were requested by those approached, using a survey written in English with people who have English as a second language, are illiterate, unable to read English, and need access to translators were noted as barriers to participation. The method of gathering data using a survey would limit Phase 2 participation to those who could read English or had support from translators in their service or home environments.

Many different models of well-being can be referred to when considering the well-being of different cultures. The researcher considered those cited above to examine at a superficial level whether some critical determinants of well-being for different cultures were evident within the items asked about within the 55-item Phase 2 research survey. Examining candidate item questions against cultural and other demographics was part of the Rasch analysis step in Phase 2. Differential item functioning analysis (DIF) examines whether any items do not adequately work for specific demographic groups within the sample.

Consultation with Lived Experience Participants

The researcher sought consultation as an objective fidelity check against any drift away from the participants' lived experiences that could have occurred during the question

writing stage or the data analysis stages in Phase 1 when aggregating frequency data and using triangulation methods to establish the final Phase 1 results. A listener who had: (1) listened to all the LE participant discussions as a coder of the LE discussion meeting data, (2) participated in a discussion meeting as a family member of someone with addiction issues, and (3) who was a person with lived experience of mental health issues themselves, reviewed the list of 24 candidate items resulting from Phase 1. This person offered feedback about whether the Phase 1 results reflected the themes that this person recognised as necessary when listening to all the discussions as a coder. This person felt the 24 Phase 1 themes reflected the essential points spoken about by people with lived experience in the groups they both coded and attended. The questions were reviewed with feedback given that they made sense and reflected issues relevant to people with mental health problems.

A small sample of people who shared various demographic characteristics of Phase 2 participants agreed to complete the survey and offer detailed feedback in an interview with the researcher. The researcher enquired about the time taken to complete the survey, the comprehensibility of survey questions, and perceived relevance or any missing items that should be there when piloting the survey with these volunteers.

People who participated in this consultation were: (1) a person with high and complex needs receiving residential mental health services; (2) a person recovering from addiction problems only; (3) a person recovering from a mental health problem who was older; (4) a person recovering from a mental health problem who was younger; (5) a person without mental health or addiction problems; (6) a person with physical health problems as well as mental health problems; and (7) a person with mental health and addiction problems. Feedback resulted in minor changes to the questions' grammar and language to improve clarity.

The average time for survey completion was 7–15 minutes, depending on how long a person took to reflect upon and consider each question. A more extensive pilot study was not possible within the limited time and resources of the PhD-resourced study. The researcher checked for any recurring patterns in the feedback between volunteers, problems with and perceived relevance of the items, and assessed completion time and concentration burden within these consultations before launching the survey. Word processing software assessed the approximate reading age required to answer the survey. The Flesch-Kincaid readability statistics for the research survey were: (1) Flesch-Kincaid Grade Level 8.3, (2) Flesch-Reading Ease 60.8, passive sentences 0%.

Wider Stakeholder Engagement

Communication of the results of each phase of the research with an opportunity for feedback from the wider sector occurred through: (1) regular presentations at each stage of the research to the SIG – Mental Health and Addictions NGO Outcomes Group, within Platform Trust; (2) a presentation of the results of Phase 2 with representative managers from the NDHB; (3) a presentation of the research and its findings within a Counties Manukau research presentation day; (4) service presentations during participant recruitment. Appendix Q contains screenshots of the PowerPoint presentation slides of the consultations with wider stakeholders between 2014–2018 that communicated the results during data collection and when finalising the results.

Conclusion

Following the task of question writing, survey development, and pilot testing of the survey, Phase 2 was ready to begin. Chapter 6 documents the rationale for the Phase 2 methods used, participant recruitment, the survey distribution processes, and psychometric analysis methods used to arrive at the seven items finally proposed for a MHRQoL module to use with the WHOQOL-BREF.

Chapter 6

Phase 2

Rationale for Phase 2 Methods

The results described in this chapter and from this research study have been published previously in ***Quality-of-Life-Research*** (Rowthorn et al., 2019). This chapter details Phase 2 of the published study more extensively. The structure of this chapter begins with a brief literature review that provides relevant background to the rationale for the methods used to identify the final module items. The chapter then outlines the aims and data collection methods used in Phase 2. The chapter concludes with a detailed account of how the stepwise application of specific psychometric methods, CTT and IRT criteria led to identifying MHRQoL items for use with the WHOQOL-BREF.

Standards for the Development of QoL Measures

The need to develop reliable and valid QoL measures has been highlighted as important when collecting QoL data about different health populations (Taillefer et al., 2003). Taillefer and colleagues reviewed QoL instruments and models developed prior to 2003 and stated there are a limited number of psychometrically sound QoL instruments. They offered specific recommendations for research design and data analysis to improve the reliability and validity of QoL measures during their development.

The ISOQOL research team outlined a set of criteria to improve the validity and reliability of PROMs for health service and HRQoL research (Reeve et al., 2013). The ISOQOL research group recommended a mixed-methods research design that collects the content for a PROM from the lived experiences of the intended users of the measure. The ISOQOL guidelines state that this improves the likelihood of the content being relevant to the people who will use the measure. This has been further recommended by other PROM development researchers (Weiring et al., 2016, 2017). A number of psychometric criteria are outlined that measures need to meet to ensure the content is valid and reliable for PROM use.

A mixed-methods approach with content identified as relevant by the intended end users and psychometric item analysis to finalise item inclusion in the measure were methods used when developing the WHOQOL tools (Skevington & McCrate, 2011; World Health Organization, 1993). The CTT and IRT methods used in Phase 2 were successfully applied within previous research that identified New Zealand national items for use with the WHOQOL-BREF outlined in publications by Krägeloh et al. (2015, 2016). These were the most recently published IRT methods for the identification of items for a WHOQOL-BREF module available when the research began.

The History of Item Response Theory

The choice of data analysis methods can improve the precision and effectiveness of a measure during its development (Boone, 2016). Boone reviewed the history of measurement development methods and explained that traditionally, CTT methods were used to identify relevant items when wanting to assess various human traits and abilities. Item analysis methods within CTT include descriptive and inferential statistics that explore the relationship between items and their performance against population variables.

McDowell (2006) explained that CTT statistical methods were used to establish an item's internal consistency, ability to discriminate between members of a population, and to identify items relevant to a specific population or concern. These authors explained that typical CTT methods used in item analysis include tests of skew, analyses of item correlation, and factor analysis. Assigning confidence intervals can determine a reliable selection of items with internal consistency assessed by using Cronbach's alpha (Boone, 2016).

The origin of IRT can be traced back to 100 years ago (Thissen & Steinberg, 2020). IRT began with the idea of a normal ogive model developed by Thurstone in 1925 who proposed that items of various levels of difficulty that allow for a right and wrong answer can

be normed against age data, to assess where a person was placed on an ability hierarchy in relation to their peers (Thurstone, 1925).

Thurstone developed a procedure called developmental scaling that was initially applied to measuring intelligence among children. Thissen and Steinberg (2020) stated that this idea of latent traits being normally distributed, and values attributed to responses along a continuum of all possible responses, was an idea that evolved more in IRT in later years through the ideas of other statisticians. This started with the work of Symonds who graphed the relationship between the level of ability and percent of correct items within identical item sets (Symonds, 1929).

Further development of IRT occurred through the work of Guilford (1936) who added the dimensions of item difficulty, and item discrimination, that were based on the steepness of the item's curve within item responses within a test. Guilford noted that the differences between the slopes of each item's curve could give an item diagnostic value. This could be assessed by an item's median response value within a test population (Guilford, 1936). Guildford recognised that each item within a test could potentially be reviewed to select easy, moderate, and hard items to better assess an ability within a test. Thissen and Steinberg (2020) wrote that achieving this took another 50 years to refine, yet by the 1980s IRT had achieved this goal. The developments of IRT were further evolved through this time by the work of Richardson (1936), Ferguson (1943), Lawley (1943) and Tucker (1946).

Lazarsfeld was acknowledged as being the first to have had the idea of being able to predict a response to an item within a sample (Thissen & Steinberg, 2020). Lazarsfeld did this using trace lines for an item that were compared against population distributions for a latent variable (Lazarsfeld, 1950). Lazarsfeld's work initiated the idea of a "pure test" where item responses fit a model with unidimensional properties and local independence (Thissen & Steinberg, 2020). In a unidimensional model, an item can be assessed to examine if it is

independently related to the central construct being measured, more than it is related to other items within the measure, or to characteristics of the test taker. Lord (1952) noted the difference between a score on a test is, at best, a pseudo approximation of an ability, rather than the measurement of that ability; highlighting that latent abilities and test scores were two separate entities (Lord, 1952).

Thissen and Steinberg (2020) explained that the findings and ideas of these early psychometricians contributed to the conceptual foundations of IRT. Although these ideas were being used, there was still no way to estimate item parameters (location and discriminative ability) from the data gathered in psychological tests. Thissen and Steinberg (2020) stated that the emergence of computers enabled more sophisticated computation methods to be developed, which supported further development in IRT from being a conceptual model to something that could be practically applied.

The next development step for IRT was Lord and Novick's (1968) theory, which described the relationship between the latent variable, unobserved response processes, threshold parameters, and the probability of a correct response for any item in a test (Lord & Novick, 1968). They were also able to plot population distributions that transformed Thurstone's ogive curve in ways that enabled the observation of an underlying trait being measured that was not observable from the test scores alone (Thissen & Steinberg, 2020).

Birnbaum (1968) highlighted that replacing the ogive curve for this alternative logistic model was already occurring within biometric research when measuring physical phenomena. Birnbaum developed IRT further when providing mathematical formula to account for the possibility that people can guess a correct response on a multiple-choice item rather than their response being evidence of them having an ability that is assessed by an item. Birnbaum stated a probability equation can be calculated to account for this possibility for each item (Birnbaum, 1968). The response to an item must show evidence of transcending

this possibility before it is recognised as a response that indicates the latent trait is the reason for their response to that item. Yet, at this point in the history of IRT development, the logistic models available still relied on two to three parameters for consideration when evaluating an items performance within a test.

Wright et al. (2008) reviewed the history of IRT through to the development of Rasch analysis, in the preface of their book *Best Test Design.* Wright et al. (2008) stated traditional CTT methods of test construction have continued to be used, despite evidence that there are more effective item analysis methods available to improve the content and measurement capability of measures. They highlighted that the two-parameter logistic model remained problematic, by including both item difficulty and item discrimination. Wright et al. (2008) explained that only one parameter, item difficulty, can be estimated consistently and sufficiently within ability tests. They stated that the work of Georg Rasch resolved this problem, by finding a mathematical way to establish a truly objective method of measuring a variable by using a unidimensional logistic probability model to ascertain an item's true measurement capability to independently identify the presence of a latent trait of interest.

Wright (1967) stated that Rasch's rationale for the development of his approach to item analysis involved illustrating that any ruler will measure height the same, as the measurement tool of the ruler has equal measurement points that remain constant over time, regardless of an object to be measured. Any colour, size, or styled ruler of the same height will obtain the same height result, the tool will give the same accurate result, independent of any other characteristics of the ruler being present other than its ability to measure height.

Wright (1967) stated that Rasch's (1960) model provided a way to create 'sample-free' items and measures free of internal measurement error problems during the process of test construction, in the same ways that measurement tools are used in the physical sciences.

Wright stated that this was what psychometric measurement tools always wanted to do, yet prior to the work of George Rasch were not able to do so.

Thissen and Steinberg (2020) outlined that Likert (1932) developed the Likert-response scale, which increased the complexity of item analysis when there is more than one response option for each item; explaining polytomous item response data did not initially have well developed methods for data interpretation. Likert developed a scaling method to improve the ways test items could be scored by giving each response a number that represented an average standard deviation of a percentile rank within a normal distribution called ‘sigma scoring’. Although this scoring method was not maintained Thissen and Steinberg (2020) wrote the development of Likert scales led to the later development of the polytomous IRT methods.

The work of Andersen (1977) and Andrich (1978, 2016) was attributed to further mathematical developments that allowed for the overall difficulty of an item to be identified alongside properties of the scale. The calculation of thresholds allowed for an observation of the relative widths of categories on a polytomous scale as a scale property when the rating scale structure is the same for all items. The only difference between items on their ratings-scale model, is the response to the item, unaffected by the properties of the scale itself. Thissen and Steinberg stated that Masters (1982, 2016) further developed a partial-credit Rasch model for use with polytomous scales in situations where items within a scale are not all the same and instead have a varied scale structure.

Health Measurement

Rasch analysis has been highlighted both as an effective way to develop reliable and valid items for inclusion in a range of health measures and to improve the measurement precision of a test (Apezetxea et al., 2018; Apon et al., 2021; Chang et al., 2013; Medvedev & Krägeloh, 2022; Medvedev et al., 2018; Vaganian et. al., 2021). Medvedev and Krägeloh

(2022) explained that when data fit the Rasch model ordinal scores within a measure can be transformed to interval scores. When this is done, changes on a latent trait can be measured in similar ways that any other interval measure can measure an object such as length or height. This improves the measurement scale beyond what CTT can produce, by adhering to more fundamental measurement principles. Rasch analysis has been shown to improve scales that explore aggregated data across subgroups (Khan et al., 2013; Lundgren-Nilsson et al., 2013) as well as scales that measure individual changes, such as patient responsiveness (Hobart et al., 2010).

Prieto et al. (2003) compared CTT and Rasch analysis methods when reducing the items within a HRQoL measure. They found that both methods effectively reduced the items of a longer HRQoL measure, yet the methods selected different items to best measure the latent trait of HRQoL. The Rasch analysis selection was chosen as the preferred selection because the method of analysis also provided the added benefits of being able to examine the hierarchical structure of items, establish the unidimensionality of a specific group of items against the construct, ensure the value additivity of items within the HRQoL measure, deal with missing items effectively, and by being able to produce a true interval scale measure for use when measuring the construct.

Brief Overview of the WHOQOL

The WHOQOL-BREF is the brief form of the WHOQOL-100 (The WHOQOL Group, 1998), a cross-cultural HRQoL survey. The WHOQOL-100 was developed by an international collaborative research project team involving 16 field centres coordinated by the World Health Organization (The WHOQOL Group, 1998). The WHOQOL tools have been used in over 40 countries (Skevington et al., 2004b) and currently there are 76 language versions listed on the WHO's website (WHO, 2022a).

The WHOQOL tools are self-report surveys that can be used as PROMs within health services (Skevington & McCrate, 2011). Skevington et al. (2004b) highlighted that the WHOQOL tools do not measure health status, they measure the consequence of health status on a person's subjective state, experience of life, and well-being. The tools capture generic QoL issues affected by health problems, they were not designed to contain items relevant to recovering from any specific health condition (Skevington et al., 2004b).

The WHOQOL-BREF, has proven to be a psychometrically robust PROM for use across diverse health populations when analysed with CTT methods (Skevington & McCrate, 2011). The content of the WHOQOL-BREF has also been validated as a reliable HRQoL measure when analysed with Rasch analysis (Balalla et al., 2019). The WHOQOL-BREF was found to be a psychometrically sound QoL assessment measure for use in NZ, using both CTT and Rasch analysis methods (Krägeloh et al., 2013).

Within the WHOQOL population norms study, the QoL of people with mental health problems was found to be 50% lower than those without mental health problems (Hawthorne et al., 2006). People with mental health issues have been identified as having the poorest QoL compared to those with other health conditions (Masthoff, Trompenaars, Van Heck, De Vries et al., 2006; Masthoff, Trompenaars, Van Heck, Hodiamont et al., 2006; Medici et al., 2015; Ohaeri et al., 2007; Orley et al., 1998; Priebe et al., 2010; Prince & Prince, 2001; Skevington & McCrate, 2011). The WHOQOL have been identified as reliable and valid measures to assess the generic QoL issues that people recovering from mental health problems experience (Fleck, 2013; Garcia-Rea & LePage, 2010; Ginieri-Coccossis et al., 2009; Mas-Expósito et al., 2011; Masthoff et al., 2005; Oliveira et al., 2016; Rocha & Fleck, 2009; Rocha et al., 2011; Trompenaars et al., 2006b).

The WHOQOL's capacity to assess QoL issues experienced as a direct result of mental health issues could be improved by adding adjunct items to the generic HRQoL tool

that are specific to recovering from mental health problems. Prior to this research, a mental health module for the WHOQOL tools had not been developed to increase the sensitivity of the WHOQOL to the needs of people recovering from mental health problems.

Phase 2 Aims

The research design used to identify the content for a mental health module was an exploratory sequential mixed-methods design. People with lived experience of mental health problems provided the data for both phases of this research. The purpose of both phases was to find relevant content for an adjunct mental health module for the WHOQOL-BREF. Phase 2 involved inviting people with lived experience of mental health issues and a comparison group without mental health diagnoses to answer QoL questions within a research survey. The survey included mental health candidate items identified from themes collected from participants with lived experience in Phase 1, along with the 26 generic WHOQOL-BREF items, and the five NZ national items. The answers that Phase 2 lived experience participants gave were psychometrically analysed with both CTT and Rasch analysis, to see which Phase 1 candidate items were the most robust measures of MHRQoL for this population in Phase 2.

Item Response Theory in Phase 2

The overall purpose of the research was to develop a mental health recovery module to be used in conjunction with the WHOQOL-BREF. Phase 2 was the quantitative phase of this two-phased study that aimed to refine the results obtained from the earlier qualitative phase of the current research to achieve this purpose. The objective of Phase 2 was to identify which items, within the 24 candidate items developed from Phase 1 themes, were more effective measures of HRQoL within the context of recovering one's mental health.

That more advanced psychometric analysis methods such as Rasch analysis are now available to improve the item selection and test construction process meant that these methods could be used to improve the process of developing the MHRQoL measure within

this research. The NZ national items study (Krägeloh et al., 2015, 2016) outlined statistical criteria for developing a module to be used with the WHOQOL-BREF. These criteria and a combination of CTT and Rasch analysis methods used within the NZ national item study were replicated in this research to facilitate the item selection process with the aim to develop a reliable and valid measure of MHRQoL. Additional conceptual criteria and variables were also created to meet the unique needs for item inclusion specific to the current research aims.

Phase 2 involved collecting QoL data from people with lived experience of mental health issues and a comparison group through answers to a 55-item research survey. The survey included 26 WHOQOL-BREF questions asking about generic HRQoL issues, five NZ national items asking about non-health-related QoL issues, and the 24 candidate items from Phase 1asking about MHRQoL issues. Data was analysed using both CTT and Rasch analysis methods to find the items that discriminated between those with and without mental health issues, were not redundant in the presence of other survey items and had the best measurement properties for an MHRQoL module to be used with the WHOQOL-BREF.

The 24 items developed from Phase 1 themes needed to meet specific statistical criteria to be included within the MHRQoL module such as discriminatory ability, statistical robustness, IRT measurement criteria, and HRQoL relevance. Including the existing 26 WHOQOL-BREF questions along with the five NZ national items in the research questionnaire provided an opportunity to analyse each candidate item against existing items within the BREF. Inclusion of the NZ national items also provided an opportunity to compare candidate items against non-health-related QoL items important to NZ participants. The next section details the methods used to recruit participants, collect, and analyse the Phase 2 data to identify the final items proposed for a MHRQoL module for the WHOQOL-BREF.

Methods

Participants

Participant Recruitment

Adult participants were recruited NZ-wide through convenience sampling methods. These included social media marketing, research participant site advertising (namely, *White Cloud*), flyers dropped into mailboxes, notice board posters, word of mouth advertising through presentations to local mental health and social services, mental health forum presentations, and snowball marketing from people who knew about the research from these prior promotions, emails with letters of invitation to mental health service providers, and newsletter advertising among relevant mental health service agencies.

Marketing and advertising material included a quick-response (QR) code for quick access to the online survey from posters and flyers, and the ability to request paper surveys via text, email, or post. Marketing material included an invitation for survey participants to enter a draw for a $50 food voucher; there were 10 vouchers to give away.

Respondents for the draw were selected randomly by a person not connected to the research by selecting a participant number from 1-667 within the data base of respondents entered onto a spreadsheet when their surveys were returned. The people selected were informed by email of their success, postage of the voucher was sent to them via tracked courier post. The marketing material used to invite participants can be reviewed in Appendix O. An information sheet introducing the aims of the research to prospective participants and a consent form for participants, were developed for Phase 2 participants. The Phase 2 information sheet and consent form can be reviewed in Appendix P.

Non-government mental health organisations (NGOs) currently using the WHOQOL-BREF were collaborating in a special interest group (SIG) to work through roll out, training,

and data interpretation issues (Andrews & Rowthorn, 2013). The members of this SIG supported participant recruitment by sending invitations to participate to services and clients.

Other organisations within the mental health sector such as the *Key to Life* charity, *Supporting Families in Mental Health*, the lived experience service user network *DRIVE*, and consumer organisation *Changing Minds* also assisted. These organisations invited the researcher to speak about the research to their networks and sent links to the survey out to their networks. Social media was used to extend the reach of the research to potential participants in NZ. Other advertising involved placing posters in social service centres, libraries, and mailbox flyer drops within the Northland and Auckland areas.

NDHB offered to support participant recruitment within their CMHC services and provided staffing support to achieve promotion, survey dissemination, and collection support through the aid of their Consumer Advisor, a peer support lead in the CMHC. This improved the potential for the research to reach Northland Māori as well as to reach those currently receiving mental health services in DHB residential and community settings. Midland District Health Board and services in Southland District Health Board regions were also open to the research being advertised in their services to support a wider degree of participation across NZ in this phase of the research.

The researcher visited the NDHB region for a week and was taken to a variety of sites by the Consumer Advisor lead (peer support advisor) for NDHB from Whāngarei to the far north of this region. The researcher was introduced to clinical teams, peer service groups, and NGOs. When visiting these sites, the researcher gave presentations about the research, invited participation, answered questions, and requested word of mouth marketing to support greater awareness of the opportunity to take part in the research among staff and service users within the mental health services of this region. Posters and a random assignment of survey formats and a survey return box were placed in sites willing to support the promotion of the research.

Survey Distribution and Formats

Paper surveys were provided for people without access to the internet or smart phones. Paper surveys were completed by both staff and people receiving services through their distribution in Community Mental Health Centres (CMHC), service by service, in the NDHB region and within participating NGO organisations during recruitment. Online surveys were completed by people receiving links from participating mental health service organisations or community and social media advertising sources outlined previously. Reverse order surveys of both formats reduced the potential for item responses placed at the end of the survey being affected by fatigue. The inclusion of reverse and linear ordered surveys therefore controlled for fatigue-based order effects in this study.

The paper and electronic versions of the research survey used in Phase 2 can be reviewed in Appendices N and O, respectively. The QoL questions were not expected to be distressing to participants. Ethical consideration was given to participant's mental health for anyone facing realisations of low life satisfaction across many areas of life, as this has been linked to suicidal ideation and actions (Alves et al., 2016; De Abreu et al., 2012; De Freitas Melo et al., 2022; Ponizovsky et al., 2003). Links and contact information for mental health support services were supplied for online survey participants if needed. People completing paper surveys had access to staff if they needed support after completing the research survey.

Paper surveys were distributed by alternating the survey formats when they were given to a site. Staff distributed these surveys via a process of random allocation of reverse and non-reversed ordered surveys. This random alternative distribution method was also used when links to the online survey format were sent out to services. A survey box was left in CMHCs and participating Citizen's Advice Bureau community outlets. People could return anonymous surveys by placing them within this box within participating CMHCs and community agencies, or by return post with a pre-stamped and addressed envelope. The

Consumer Advisor collected the completed surveys from these sites and returned them to the researcher at an agreed date. Absolute equality of survey randomisation could not be retained as the snowball method included individuals choosing which of two links to send out and different numbers of participants responding to different formats and forms when invited.

Participant Characteristics

The survey responses of 667 participants were included in the data analysis. Participants were people with and without lived experience of mental health issues recruited nationwide from four regions. Table 11 displays Phase 2 participant demographics.

Table 11

Phase 2 Participant Characteristics

Demographic category	Lived experience (n = 389)	Comparison group (n = 278)	Whole sample (N = 667)
Age range (years)	%	%	%
18–35	29	34	31
36–50	37	27	33
51+	34	39	36
Gender: Males	31	28	30
Ethnicity			
New Zealand European	72	70	72
Māori	21	18	20
Pasifika	3	3	3
Asian	3	6	4
Other	1	2	1
Health issues			
Physical health diagnoses	30	20	26
Physical disabilities	33	20	28
Addiction	30	0	30
Mental health diagnoses			
Mood disorder	66	0	66
Psychosis	17	0	17
Personality disorder	7	0	7
Other	2	0	2

Note. Percentages are valid percentages rounded up to the next whole number.

There were two primary groups of participants in Phase 2. One was a lived experience sample (LE). These are people who answered the *About You* question asking about having current or past mental health and or addiction problems with a "yes" answer and named their diagnosis. The comparison group answered "no" to this question. The comparison group included participants with health, injury, or disability issues that could affect their HRQoL. The LE group also identified coexisting health problems. Participants recruited from secondary DHB and NGO mental health services were people with a psychiatric diagnosis. It is unknown whether participants who responded to wider community-based advertising who answered "yes" were receiving mental health services at the time of their participation.

Participants were fairly evenly distributed across four main regions of New Zealand: Auckland (Tāmaki Makaurau) (186, 28%); Northland (184, 28%); Central and lower North Island (147, 22%); South Island (152 participants, 23%). Participant education level was high school (407, 60%), primary school (100, 14%), no education (25, 3%), and university (125, 18%); with six participants not answering this question. Participant employment status was unemployed (411, 61%), employed full-time (293, 44%), employed part-time (230, 34%), students (220, 33%), retired (145, 22%), volunteers (156, 23%), and 70 people marked "other" to this question (10%). Relationship status of participants was single (282, 42%), married (187, 28%), living with a partner (112, 17%), separated (24, 4%), divorced (42, 6%), and 11 people were widowed (2%).

Across the whole sample there were (7, 1%) gender diverse people and in the LE sample (6, 2%). In the whole sample there were (454, 67%), females, in the LE sample (242, 63%) were female compared to (213, 71%) in the comparison group. Sexuality results: heterosexual people were (549, 81%) of the whole sample; homosexual (21, 3%), bisexual (46, 7%), transexual (11, 2%) and other (16, 2%). In the LE sample there were (286, 75%) heterosexual, (16, 4%) homosexual, (36, 9%) bisexual, (4, 1%) transexual and (13, 3%) other.

In the comparison group (264, 88%) identified as heterosexual, (5, 2%) as homosexual, (10, 3%) as bisexual, (7, 2%) transexual and (3, 1%) as other.

Rural versus city results were for the whole sample, urban areas (530, 80%) and rural areas (125, 19%); of the LE sample, urban areas (304, 80%) and rural areas (56, 15%). For the comparison group, urban areas (226, 76%) and rural areas (69, 23%).

Data Cleaning and Preparation for Data Analysis

Initially, there were 759 survey respondents. There were two reasons for excluding surveys from the analysis: (1) when the demographic section of a participant's survey was not answered, as this prevented participant allocation to the appropriate research sample group or (2) if a person answered too few questions. This was addressed by nominating a cut-off criterion, i.e., deciding on a set number of items that had to be answered in a survey for the survey to be included. The WHOQOL-BREF manual recommended discarding a survey for analysis within aggregated datasets if more than 20% of survey questions were unanswered (New Zealand World Health Organization Quality of Life Group, 2014). Although missing scores can be transformed the team did not want to do this as it may skew the actual results. The total number of surveys after data cleaning was 667, where 251 were paper surveys and 416 were online surveys, 393 of which were ordered in the first format and 274 reverse ordered.

Qualtrics survey data was downloaded into an Excel file. Paper survey data was manually entered into this file. Columns in the Excel file were added to identify reverse or non-reverse-ordered surveys, and which were paper or online formats. This enabled later examination of any differences in results due to format and to assess for order effects.

An audit of paper surveys data that had been entered into excel checked that the manually entered paper survey data matched the paper record of the respondent's answers. The researcher and a volunteer went through each survey, the researcher reading the answers

on the paper survey, and the volunteer comparing the number read out to the data on the screen. The volunteer verbally identified and then corrected an entry when errors were found. A second volunteer reviewed the demographic data entered from the *About You* section of the WHOQOL importance survey that had been entered into the spreadsheet. Written stepwise instructions were provided when checking the demographic information on the paper survey against the data entered onto the spreadsheet. The volunteer corrected any errors when found. This completed data cleaning prior to data analysis.

Data Analyses

Classic Test Theory Analysis

Descriptive and inferential analyses were conducted using the statistical software SPSS (version 25*)*. The CTT methods used in Phase 2 replicated the statistical methods used in two prior studies within NZ (Krägeloh et al., 2013; Krägeloh et al., 2015, 2016). The current research replicated five of the CTT steps and their conceptual criteria from this previous research and added several additional conceptual criteria relevant to the mental health focus of the module. The details of this are discussed within the CTT analysis steps.

Rasch Analyses

Items retained after the initial CTT analysis phase were subjected to Rasch analysis using the software RUMM2030 (Andrich et al., 2009). Medvedev and Krägeloh (2022) describe the RUMM software as having a range of data analysis tests that can explore model fit statistics, develop graphs, and examine threshold parameters and invariance across individual items. Rasch analysis was used to identify the most suitable items for inclusion in the final module, based on their measurement capability and fit with the construct of QoL.

Medvedev et al. (2017) wrote that Rasch analysis improves a measure's precision to measure what it sets out to measure by analysing each item's performance on a range of Rasch mathematical criteria. The criteria identify how an item performs within a test and

within a population independent of the inherent biases within that population. A likelihood-ratio test on the initial analysis established whether the difference between item thresholds were uniform or varied significantly ($p<.05$) between items to establish whether the Rating Scale Model (Andrich, 1978) or unrestricted Partial Credit model (Masters, 1982) was to be used (Medvedev & Krägeloh, 2022). The initial analysis revealed that the Partial Credit model (Masters, 1982) was the most suitable foundation model for data analysis. A stepwise process of iterative steps occurred within the Rasch analysis phase to evaluate each item against specific Rasch item-exclusion criteria. Siegert et al. (2010) outlined the criteria as:

1. A test for overall data fit to the Rasch model.
2. Identifying items with disordered thresholds and rescoring them.
3. Deletion of items with poor fit to the Rasch model.
4. Retesting individual item fits and overall fit to the Rasch model.
5. Analysis of DIF for gender, age, sample population, and other personal factors.
6. Examination of local dependency based on the residual correlation matrix.
7. Unidimensionality testing.
8. Distribution analysis of the participant-item thresholds.
9. Comparison of Rasch results with more traditional psychometric tests (e.g., item-to-total correlations and factor analysis).

A definition of these Rasch criterion terms and methods of analysis will be briefly given here, to explain the item elimination tasks conducted in this research. A test for overall item-trait interaction and fit with the Rasch model is initially performed by a chi-square test. Chi-square results with a p-value $\leq .05$ are considered statistically significant. The chi-square statistic is assessed at the start of each step of the analysis and after each modification of a scale during its development (Balalla et al., 2019). These researchers stated when a chi-square statistic is lower than .05 the source of measurement error is explored; item fit-

residuals outside the range of -2.50 to +2.50 are indicative of problematic fit to the Rasch model. Balalla et al. (2019) explained when the chi-square is significant this reflects that a selection of items shows an adequate spread of item difficulty across the construct measured.

Threshold maps of the RUMM software output are used routinely to identify items with disordered thresholds (Medvedev & Krägeloh, 2022). Medvedev and Krägeloh (2022) explained that a threshold is disordered when people with greater amounts of a construct (e.g., QoL) are not consistently rating QoL items in ways that demonstrate their greater QoL. Items showing evidence of this are identified within the disordered thresholds analysis in the RUMM software. An item with disordered thresholds would generally be considered for elimination, as this would indicate it was not a stable item to best measure a construct. Tennant and Conaghan (2007) provided a solution to resolving disordered thresholds, when necessary, by collapsing relevant response options during analysis, then rescoring the item.

Medvedev and Krägeloh (2022) described DIF as a situation where participants with the same ability on the latent trait (e.g., QoL) who belong to different demographic groups (e.g., gender or ethnicity) are responding differently to an item. This can indicate that an item may mean different things to different people based on their demographic variables, rather than from distinct levels of QoL. This is not desirable as items included in a measure need to be free of response bias for any specific demographic group. DIF analysis is conducted for users within the RUMM software by using ANOVA to compare individual score distributions aggregated by class interval mean scores for each demographic group. Examination of the item characteristic curve of each item with the class interval means for each demographic group, reveals whether there are consistent (uniform DIF), or inconsistent mean differences (nonuniform DIF), across observed class intervals (Medvedev & Krägeloh, 2022).

Medvedev & Krägeloh, (2022) explained that local dependency refers to a situation where two or more items are strongly associated in some way unrelated to an items'

relationship to the latent trait. They exampled a situation where two items may show local dependency, such as a questionnaire that asks about negative emotions. It may use a term such as upset in one item and a term angered in another. These two items may be locally dependent if a correlational analysis reveals that the two items showed evidence of residual correlation. In this instance, the items may be perceived as measuring the same thing by participants, more than the two items measuring two distinct factors involved with negative emotions. A valid reliable scale has no local dependency evident between individual items. Checks for local dependency can be made by using a residual correlation matrix.

Any item with a residual correlation of >.20 compared to the mean of all residual correlations, is regarded as a sign of local dependency (Medvedev & Krägeloh, 2022). Lundgren-Nilsson et al. (2013) discovered that creating subtests reduces measurement error from combining items together and was a more accurate estimation of latent traits than can be obtained through comparing individual items. Items with residual correlations can therefore be added together to form a subtest to solve local dependency issues (Medvedev & Krägeloh, 2022). This is like developing one item that measures getting upset and angered together. They advised if the local dependency disappears with the development of a super-item like this, it confirms these items as measuring the same thing. Decisions about which item to retain can then be made, based on examining the other measurement criteria of each item.

Medvedev and Krägeloh (2022) stated that establishing unidimensionality refers to an analysis within RUMM that involves running an independent paired samples *t*-test to compare person-estimates with two subsets of the item data. The data is rank ordered and then divided into two subsets of data. Once the latent factor has been removed one set has the highest positive factor loadings, the other set has the highest negative factor loadings on the first principal component of the residuals. This is referred to as ‘Smith’s test’ (Smith, 2002). Table 12 outlines the CTT and Rasch analysis criteria used for item selection in Phase 2.

Table 12

CTT and Rasch Criteria for Item Elimination or Retention

Step	Methodological aim	Criterion description
1	Check for floor and ceiling effects.	The item's mean is between 2.00-4.00 on the 5-point Likert scale. Kurtosis and skewness scores are between -1.00 and +1.00.
2	Discriminant validity of each item is assessed	Items discriminate between those with and without mental health issues. Any item with a result of p >.05 (Mann Whitney U test) is red flagged for elimination, if failing the next criteria.
3	Construct validity of each item is assessed	Using the mental health data set only an item's correlation (Spearman's *rho*) above .30 with 1) Total QoL 2) the two *g* facets 3) MH *g* Facet, and 4) Mental Health QoL and 5) MH1 as mental health status question.
4	Ensure no duplication with existing WHOQOL-BREF items	Spearman's item correlations are below .60 with any existing WHOQOL item or NZ National item.
5	Ensure no duplication with existing candidate items	Spearman's item correlations are below .60 with any existing mental health candidate items.
6	Rasch criteria for item inclusion assessed	Items are removed if they are identified as having disordered thresholds, differential item functioning (DIF) by demographic characteristics, fit residuals $p>\pm.30$ or evidence of residual correlation >.2 with existing items. Nonsignificant chi-square >.05 and a Person Separation Index (PSI) over .70 when extreme persons are included. Rasch unidimensionality analysis needs to show an acceptable fit to the Rasch model expectations. Person-Item threshold distribution, with extreme persons included, shows acceptable item difficulty distribution for individuals with adequate spread of measurement capability across the sample.
7	Internal consistency checked	PSI is above the cut-off of >.80 so that the module can be used for individual or aggregated data analysis.
	Conceptual criteria considered throughout	The item's practicality for redress within mental health service environments, question complexity considered, items are aligned with the WHO definitions of HRQoL and mental health. Items can be used in aggregated organisational data sets or individual recovery planning applications. Module length is kept as short as possible, without losing reliability or validity for subsamples of the population. Items are sensitive to change and relevant to the subjective processes involved with recovering one's life following mental health problems.

Results

Classical Test Theory

All 24 mental health candidate items from Phase 1 were analysed against the five CTT criterion methods outlined on Table 12. The aims were to identify and progressively eliminate items that: (1) failed to discriminate between those with and without mental health problems, (2) were not correlating with the variables of interest (HRQoL and MHRQoL), and (3) evidenced redundancy by correlated with existing WHOQOL-BREF items or existing mental health candidate items. This would leave a set of items that were more strongly correlated with MHRQoL that did not duplicate any existing items.

CTT Criterion 1

There was no evidence of floor or ceiling effects within the 24-item selection. All items had acceptable kurtosis, and mean scores between 2.00 and 4.00. The comparison group showed some skewness in candidate items. This was to be expected as an early indicator that module items were showing some degree of differentiation between those with and without lived experience of mental health issues. Of the 24 candidate items, 23 differentiated between participants with lived experience and those in the comparison group.

The candidate item asking about spirituality did not meet this criterion. A conceptual criterion was developed at this point: an item needed to fail two consecutive criteria as part of a careful and considered process of decision-making when eliminating items. Given the significance of spirituality to people with mental health problems and recommendations for its inclusion within QoL measures for this population (Connell et al., 2012), this item was kept avoiding eliminating a potentially important item to people recovering from mental health issues.

CTT Criterion 2

The purpose of the second criterion step was to rule out any of the candidate items that did not discriminate between those with and without mental health issues. A non-parametric Mann–Whitney *U* test within SPSS was used to analyse the complete data set. The Mann–Whitney *U* test compares the differences between two independent groups (in this case the comparison group and the lived experience group) when the dependent variable is either ordinal or continuous, but not normally distributed.

This test was considered because the items were ordinal and previous analysis showed evidence of skewedness. Any item that scored over .05 in a (two-tailed) test result was red flagged as being equally relevant to both groups. An item not meeting this confidence interval would be identified as an item that could be less specific to MHRQoL. MH6-spirituality was red flagged for elimination, if it did not meet criteria for inclusion at step 2.

Question 6 within the WHOQOL-BREF is an item that aims to assess spirituality through asking about life being meaningful. Eliminating this candidate item does not prohibit spirituality from being covered in a QoL assessment for people recovering from mental health problems, as the module will be used in conjunction with the WHOQOL-BREF.

CTT Criterion 3

The third criterion step objective was to find items that showed evidence of being aligned with the HRQoL construct in the context of mental health recovery. Following the methods of Krägeloh et al. (2016) five variables were calculated that were used to identify which items were correlated with mental health, generic health, or QoL variables.

The first was a Total QoL score. This was calculated by summing the scores from all WHOQOL-BREF questions from questions 3–26 (excluding the first two WHOQOL-BREF *g* items of overall QoL and physical health). The average QoL score was then calculated for each participant from the total score obtained, to resolve any missing values, to create a Total

QoL score for all participants. The second variable created was a new *g*-facet to be used as a construct variable for a health module that could represent HRQoL. This was calculated by summing the WHOQOL-BREF *g*-item questions, which ask about general satisfaction with overall QoL and satisfaction with one's physical health, then calculating a mean score.

The third variable was created from the participants' responses to the G1 question in the WHOQOL-BREF which asked about one's overall satisfaction with QoL. This variable represented overall QoL. The fourth variable was newly created for this research study from a participant's response to the mental health candidate *g*-item, or otherwise identified as question 1 of the candidate items, coded as MH1. This represented a participant's overall satisfaction with their mental health, as a mental health status question. The fifth variable was another newly created *g*-facet calculated for this research that represented MHRQoL. This variable was calculated from summing the data from the WHOQOL GI question asking about overall satisfaction with QoL and the G3 question asking about overall satisfaction with mental health (MH1), then creating a mean score for each participant after this summation.

In criterion step 3, the lived experience dataset was analysed. Participant response to the candidate items were analysed using a bivariate correlational analysis, Spearman's *rho* against the five created variables: Total QoL, HRQoL, G1(overall QoL), G3(MH1) (mental health status), and MHRQoL. Each item needed to correlate with all five variables at a cut-off point established by Krägeloh et al. (2016) > .30 using Spearman's *rho* to be retained for further analysis in criterion step 4.

The spirituality item (MH6) was evaluated against these new variables to investigate whether it was correlated with MHRQoL. This item did not significantly correlate with the construct of MHRQoL, which confirmed that the ways this item was performing in the dataset was less specific to it being related to MHRQoL and could be sufficiently assessed as a generic QoL item within Question 6 of the WHOQOL-BREF.

Two further items did not meet criterion 3. Questions MH22 asking about stigma and discrimination, and MH23 asking about boredom. These two items were red flagged for further evaluation within criterion step 4. These items were identified as correlating >.30 with the module's *g*-item MH1. However, these items met inclusion criteria when analysed against the other four variables. These items were retained for further analysis in criterion step 4.

Exploratory analysis occurred within this criterion step to examine how items performed against the variable of overall satisfaction with physical health. Several candidate items did not meet the >.30 cut-off criterion against this variable. These were: MH2 (loneliness), MH7 (determination), MH9 (insight), MH12 (ability to relate), MH16 (peer support), and MH20 (others recognising strengths). This was interesting as these items did meet the >.30 criterion when evaluated against the HRQoL and MHRQoL variables, indicating relevance to the constructs of interest yet not to physical health.

CTT Criterion 4

The purpose of criterion step 4 was to reduce item redundancy by eliminating items that correlated too highly with a generic QoL facet already being asked about in the WHOQOL-BREF or five NZ national items. Spearman's two-tailed bivariate analysis was run in SPSS (v25), using two item data subsets; one being LE participants answers to the WHOQOL-BREF and NZ national items and the other being these participants answers to the 23 candidate items.

A Spearman's *rho* analysis was used to measure the strength of the association between candidate items and generic QoL items. Using the criterion cut-off established by Krägeloh et al. (2016) any items that obtained a Spearman's *rho* of >.60, were red flagged as correlating too highly with existing QoL items. The mental health candidate items (MH) not meeting the inclusion criterion at step 4 are noted below, along with the WHOQOL-BREF and NZ items (coded as N) that they correlated too highly with:

MH8: To what extent do you feel you are able to cope with daily life?

1. WHOQOL-BREF 10: Do you have enough energy for everyday life? (.617)
2. WHOQOL-BREF 17: How satisfied are you with your ability to perform your daily living activities? (.602)
3. N29: To what extent are you able to manage personal difficulties? (.619)

MH15: To what extent do you feel positive about your future?

1. WHOQOL-BREF 5: How much do you enjoy life? (.669)
2. WHOQOL-BREF 19: How satisfied are you with yourself? (.619)
3. WHOQOL-BREF 6: To what extent do you feel your life to be meaningful? (.616)
4. N31: To what extent do you feel you have control over your life? (.709)

MH10: To what extent do health and social services meet your needs?

1. WHOQOL-BREF 24: How satisfied are you with your access to health services? (.672)

MH13: To what extent do you consider that you are fit and able to work?

1. WHOQOL-BREF 18: How satisfied are you with your capacity for work? (.650)

MH21: How satisfied are you that there are people there for you when you need them?

1. WHOQOL-BREF 22: How satisfied are you with the support you get from your friends? (.608)

MH17: To what extent are you confident you can attain your goals in life?

1. N31: To what extent do you feel you have control over your life? (.672)

A conceptual criterion was developed at this point to ensure that the item elimination process would not inadvertently remove an item purely because it only correlated too highly with an NZ national item. Consideration was given to the possibility that a NZ national item may also be specifically relevant to MHRQoL. The module needed to be useful for people

outside of NZ, as well as within NZ. If an item only correlated >.60 with a NZ national item, it was retained for further analysis in criterion step 5. If an item correlated >.60 with an existing WHOQOL-BREF item and NZ national item, it could be considered for elimination.

MH8 asking about coping and MH15 asking about hope were red-flagged. The criteria used to evaluate items was: if the correlation between an item and the existing WHOQOL-BREF item was >.60, the item was identified as too similar to an existing WHOQOL-BREF item. These items also correlated >.60 with two existing NZ national items "manage personal difficulties" and "control over one's life". Item MH17, asking about goals, only correlated >.60 with one NZ national item asking about control over one's life. This item was not red-flagged, as it did not correlate >.60 with any existing WHOQOL-BREF item. It was also recognised that the Rasch analysis steps would further determine the robustness of remaining items using more stringent criteria. If an item, such as goals, met all the Rasch criteria during analysis, it could still become a candidate item for the final module.

At each step, conceptual criteria were considered as the results of each item's performance against the criterion were assessed. An item was retained if there was only a marginal failure to meet inclusion criteria and no strong conceptual reasons to discard it. If an item appeared to be asking the same question as an existing WHOQOL-BREF or NZ national item, this question would be discarded for conceptual reasons and statistical reasons.

An example of this was MH13 that asked about work which correlated >.65 with question 18 of the WHOQOL-BREF also asking about work. In this item's case, the two questions were not asking about anything vastly different from one another for the MH item to add further measurement value to warrant inclusion. This was similar to the question relating to social support (MH21) that correlated with the WHOQOL-BREF question 22, asking about social support. The candidate item MH10 asking about alternative healthcare also correlated highly with the existing WHOQOL-BREF question 24 asking about

satisfaction with health services. That this observation could be made can suggest that the cut-off criteria of >.60 was not too low for use in this step.

Nuances in how people discussed items warranted their inclusion for further testing in Phase 2 to avoid too early elimination of items that may be important when evaluated within a larger population. These items could now be safely eliminated based on both an observed similarity to existing WHOQOL-BREF questions and statistical support for this decision, not available at the question writing stage. This result confirmed the generic WHOQOL-BREF items asking about these issues were adequate measures of QoL for this population.

CTT Criterion 5

The aim of criterion 5 was like that of criterion 4, to reduce the potential for item redundancy due to unnecessary duplication. In this criterion step, a candidate item was evaluated to see if it correlated highly with another candidate item. One conceptual criterion occurring throughout criterion steps 4 and 5 was to ensure the final measure was as short as possible to reduce the potential for response burden, given that the module will be an adjunct measure to an existing 26, or with NZ national items added, a 31-item measure.

A correlational bivariate analysis using Spearman's *rho* and the cut of criteria established by Krägeloh et al. (2016) was again performed within the lived experience participant data set and remaining 20 candidate items. The items that correlated >.60 with other candidate items are listed below with the items they correlated with underneath:

MH8: To what extent do you feel you are able to cope with daily life?

1. MH15: To what extent do you feel positive about your future? (.618)

MH15: To what extent do you feel positive about your future?

1. MH8: To what extent do you feel you are able to cope with daily life? (.618)
2. MH17: To what extent are you confident you can attain your goals in life? (.752)

MH17: To what extent are you confident you can attain your goals in life?

1. MH15: To what extent do you feel positive about your future? (.752)

MH 19: How satisfied are you with your recovery?

1. MH8: To what extent do you feel you are able to cope with daily life? (.602)

At this point, items MH8 (coping) and MH15 (hope) were eliminated, as they had not met two successive criteria. These two items correlated: (1) too highly with three existing WHOQOL-BREF questions, and (2) with two candidate items (goals and recovery progress). A decision to maintain MH7 (goals) was made at this point, despite it not meeting criterion 4, by correlating >.60 with the NZ item, control over one's life. In criterion 5, this item only correlated >.60 with the candidate item MH15 (hope). As MH15 (hope) had now been eliminated and the criterion 4 fail was only against a NZ national item (control over life) there was insufficient compelling evidence to eliminate this item. The item was red-flagged to see how it performed under Rasch analysis.

MH19 (recovery progress) was also kept, as it met the previous four criteria, and only correlated >.60 in criterion step 5 with MH8 (coping). MH8 (coping) had now been eliminated, making MH19 no longer correlating >.60 with any remaining item. The elimination of MH6 (spirituality), MH21 (ability to work), MH8 (coping), MH15 (hope), MH10 (alternative health care), and MH 21 (social networks) left 17 items going forward for further Rasch analysis. MH1 (mental health) was not included.

The extent to which these 17 items met each of the five criterion variables can be reviewed on Table 13. Items with the higher scores correlated higher with each of the variables the result is compared against. The items bolded on Table 13 are the items that became the final module items. Most of these items correlated with MHRQoL >.45 to >.57 other than MH9 (insight) that correlated with the MHRQoL variable at .39.

Table 13

MHRQoL Item Correlations Against CTT Criterion Variables

Item code	Question	Mean total QoL score	HRQoL G1+G2	MHRQoL G1+MH1	QoL G1	MH status MH1
MH 2	To what extent do you feel lonely?	.55	.43	.49	.49	.39
MH 3	To what extent have you made changes for the better?	.45	.39	.41	.38	.32
MH 4	**To what extent do you believe you can recover from illness?**	**.58**	**.46**	**.54**	**.45**	**.49**
MH 5	**To what extent do you recognise the positive strengths you have?**	**.59**	**.46**	**.54**	**.46**	**.48**
MH 7	To what extent are you determined to recover your health when not well?	.46	.35	.40	.34	.35
MH 9	**To what extent does understanding why you have a problem help you to resolve it?**	**.47**	**.32**	**.39**	**.34**	**.34**
MH 11	**How well have you been able to adjust to what has happened in your life?**	**.61**	**.48**	**.52**	**.49**	**.44**
MH 12	**How well do you feel you can relate to others?**	**.45**	**.32**	**.45**	**.36**	**.42**
MH 14	How confident are you that when well, you can stay well?	.60	.49	.60	.50	.55
MH 16	To what extent are you motivated by people who have overcome similar problems that you have?	.39	.32	.37	.35	.31
MH 17	To what extent are you confident you can attain your goals in life?	.65	.54	.60	.57	.48
MH 18	**How satisfied are you that people really understand you?**	**.65**	**.52**	**.58**	**.48**	**.54**
MH 19	**How satisfied are you with your recovery?**	**.64**	**.53**	**.62**	**.49**	**.59**
MH 20	How satisfied are you that other people recognise your strengths?	.54	.38	.43	.39	.36
MH 22	How often do you feel discriminated against?	.38	.32	.32	.32	.23
MH 23	How frequently do you feel bored?	.38	.35	.35	.36	.26
MH 24	How satisfied are you with the amount of physical activity you engage in?	.45	.48	.39	.32	.35

Note. Items that obtained a Spearman's *rho* >.30 with a p<.01. Items bolded are the 7 MHRQoL module items. MH means mental health, the code for the mental health items.

Through CTT analysis steps these 17 items showed evidence of being MHRQoL items not covered by the WHOQOL-BREF. Table 14 lists the final 17 items retained after meeting CTT criterion analysis. These 17 candidate items were then examined for their MHRQoL measurement capabilities using Rasch analysis and set criteria previously used by Krägeloh et al. (2016).

Table 14

17 Items Meeting CTT Criteria

Item code	Candidate item question
MH2	To what extent do you feel lonely?
MH3	To what extent have you made changes for the better?
MH4	To what extent do you believe you can recover from illness?
MH5	To what extent to do you recognise the positive strengths you have?
MH7	To what extent are you determined to recover your health when not well?
MH9	To what extent does understanding why you have a problem, help you to resolve it?
MH11	How well have you been able to adjust to what has happened in your life?
MH12	How well do you feel you can relate to others?
MH14	How confident are you that when well you can stay well?
MH16	To what extent are you motivated by people who have overcome similar problems, that you have?
MH17	To what extent do you feel you can attain your goals in life?
MH18	How satisfied are you that people really understand you?
MH19	How satisfied are you with your recovery?
MH20	How satisfied are you that other people recognise your strengths?
MH22	How often do you feel discriminated against?
MH23	How frequently do you feel bored?
MH24	How satisfied are you with the amount of physical activity you engage in?

Note. MH means mental health, the code for the mental health items

Rasch Analysis

Utility of Rasch Analysis

Medvedev and Krägeloh (2022) wrote that Rasch analysis allows for a greater examination of a measure's internal construct validity than can be obtained from CTT

analysis alone. Each item needs to meet a range of Rasch analysis criteria for inclusion in a scale by evidencing specific measurement strengths. These include a stable relationship between an item's response and the latent variable, evidence of local independence, no item-bias among demographic variables, which when doing so produces a final selection of items within a measure that shows evidence of unidimensionality and adequate spread of item difficulty to be able to effectively measure a latent trait.

Dataset Preparation and Rasch Analysis Procedure

The Phase 2 lived experience dataset was extracted from the whole data set within SPSS (version 25). The following demographic variables were included in the SPSS data file: age, gender, education, employment, relationship, ethnicity, and physical health. An ASCII dat. file with local encoding was created. The researchers reviewed the dataset to ensure no errors; a new file and a project name were given to identify the analyses. When the file was opened within RUMM2030 (Andrich et al., 2009) the ID components were Person ID and Person Design within the programmes default of a single factor layout. The demographic variables were individually loaded as personal factors with a width and code of one. The 55 items of the research survey were then entered onto the spreadsheet with a width of 55 and item specifications given as Q1-26 for the WHOQOL-BREF items, N27-31 for the NZ items, and MH32-55 for the candidate items, in the same order these questions appeared in the SPSS spreadsheet, now in dat. file format. Analysis used six class intervals.

The 17 mental health candidate items arrived at by CTT analysis were now ready to be systematically analysed by Rasch analyses through a process of iterative steps and criteria used in Krägeloh et al. (2016) NZ national items study. The first criterion for a final selection of items was a chi-square probability. When the chi-square *p*-value for a model with a particular selection of items is $\leq$.05 exploration for the cause of poor fit with the Rasch model (or latent trait) is conducted. Several RUMM item statistics outlined previously by Siegert et

al. (2010) were explored to identify poor fitting items. Consideration of which item to eliminate was made before running the next chi-square analysis. Each iterative step began with a chi-square analysis of the remaining selection of items, followed by an examination of poor fitting items, then the successive elimination of items with the poorest fit throughout the analyses until the chi-square statistic of a selection of items reaches a $p \geq .05$. This selection of items is examined for unidimensionality by analysing whether they show an acceptable fit with the Rasch model. If not, further item analysis occurs to find the source of measurement error such as residual correlation or items loading on another principal component. Any items identifying measurement error are removed. The selection of items is evaluated again against Rasch analysis model fit statistics. The specific iterate process of item analysis and progressive item elimination decision-making processes used to arrive at the 7-item solution of this research are described below in the form of analysis steps numbered 1–12. Conceptual decisions made at each step are included, along with the source of measurement error found in each item eliminated, to explain the reasons for discarding an item.

Analysis 1

The selection of 17 candidate items retained after meeting CTT criteria were subjected to a chi-square goodness of fit analysis. This examined the degree to which all 17 candidate items together could operate as a MHRQoL module. The minimal requirement for a set of items to be considered for a module was a chi-square result of $p \geq .05$. The chi-square result for the 17-item set was $p < .001$. Further exploration to examine which items were problematic, showed residual fit problems on several items. The criterion cut-off to identify residual fit problems used by Krägeloh et al. (2016) was -2.5 to +2.5. Items not meeting this criterion were MH22r (discrimination, stigma) (5.32); MH 24 (exercise) (5.18); MH17 (goals) (-3.36); MH3 (personal growth, transformation) (2.59); and MH23r (boredom) (2.54).

Items were eliminated one at a time, rather than all problematic items removed collectively, recognising that the performance of some items may temporarily negatively impact the performance of others until the most problematic items are eliminated. A decision was made to set the cut-off point for residual fit problems slightly higher at ±3.00. This was to reduce the risk of eliminating too many items too quickly before their performance within the measure could be assessed.

A conceptual criterion was decided at this point. An item considered for elimination would be an item with the highest residual fit problems. If there were more than one item with residual fit problems (indicated by results of < ±3.0), additional item performance problems within each item would be explored. An item would be prioritised for elimination if it had residual fit and a greater number of additional problematic results compared to the other items. Items with residual fit at the border of the cut-off threshold were retained, yet these were red-flagged to see how they performed after an item was eliminated.

The following items were considered for elimination in Analysis 1, from higher residual fit problems: MH17 (goals), MH22r (discrimination, stigma), and MH24 (exercise). It was noted that MH24 (exercise) and MH14 (fear of relapse) also had disordered thresholds. MH24 was eliminated at this point, due to it having residual fit problems and disordered threshold problems. MH14 was red flagged to examine its performance in later analyses.

Analysis 2

There were now 16 items to analyse after removing MH24. The 16-item result was still problematic with a chi-square $p = .000001$. This indicated that removing MH24 had yet to resolve how the remaining items performed together as a selection for a final module. Further exploration revealed there were still residual fit problems on items MH22r – Discrimination, stigma (5.46); MH17 (goals) (-3.11); MH23r (boredom) (3.01); as well as now also on MH3 (personal growth, transformation) (2.70), although this was at a below

threshold level. MH14 (fear of relapse) presented with disordered thresholds for a second time, so again was red-flagged. MH22r (discrimination, stigma) was eliminated it had the highest residual fit problems and showed high residual fit problems in Analysis 1.

Analysis 3

Removal of MH22r resulted in an item selection of 15 items for analysis. Chi-square analysis obtained a result of chi-square $p = .000009$. Although this showed a minor improvement, residual fit problems were still evident on one item MH23r (boredom) (3.48). Other items also showed residual fit problems < $\pm$3.0 yet were at a subthreshold level, so they were red-flagged for observation in the following steps. They were MH2r (loneliness) (2.69), MH17 (goals) (-2.69), MH16 (peer support) (2.65), and MH3 (personal growth, transformation) (2.55). MH14, although not presenting with residual fit problems, did have disordered threshold problems, so it was also red-flagged. MH23r was removed because it had the highest residual fit problems and was red-flagged in Analyses 1 and 2.

Analysis 4

The item selection now comprised of 14 items with MH23r removed. The result was a chi-square $p = .0075$. This selection performed much better but still needed to meet the $p \geq .05$ criteria for non-significance. Further exploration of problematic items identified residual fit problems within the same items that were showing residual fit problems in previous steps: MH2r (loneliness) (3.56), MH16 (peer support) (2.94), MH3 (personal growth, transformation) (2.81), and MH17 (goals) (-2.52). MH14 presented with disordered thresholds so, again, was red-flagged. MH2r was removed as it had the highest residual fit problems.

Analysis 5

There were now 13 items with MH2r removed. This selection obtained a chi-square result of $p = .038$. Removing MH2r (loneliness) had resulted in an improved result. There

were still residual fit problems with MH16 (peer support) (3.18) and MH3 (personal growth, transformation) (2.63). MH14 no longer presented with disordered thresholds within this selection of items. MH16 (peer support), with the highest residual fit problems, was removed.

Analysis 6

There were now 12 items with MH16 removed. This selection obtained a chi-square result of p =.051. This was a significant improvement. Further exploration showed MH3 (personal growth, transformation) had an elevated residual fit result, however, at 2.96 it was not at the > $\pm$3.0 cut-off level for item elimination. This item's result was at a subthreshold level in this analysis. It had presented as problematic in all previous steps in similar ways, so it was red-flagged, to observe how it performed in later analyses. MH17 (goals) produced significant DIF results on the demographics of age, diagnosis, and ethnicity, yet there were no significant DIF problems on this item for the demographics of gender, education, and employment. A decision to remove MH17 was made, due to its significant DIF problems and because it showed higher residual fit problems in previous analyses.

Analysis 7

The item analysis was performed on 11 items with MH17 removed. This selection obtained a chi-square result of p = .32. Exploration of the items within this selection showed that MH3 (personal growth, transformation) was again elevated, compared to the other items, yet it was not meeting the threshold for elimination (2.57). Further exploration occurred to find the items that had measurement problems. No items had any significant DIF on any demographic variable other than diagnosis. One diagnosis group (psychosis) showed problematic DIF for MH3 (personal growth and transformation). The number of participants in this subgroup was too low to consider whether this result was due to the lower number of participants or was due to this item's performance for that population.

Residual correlational analysis was performed using an analysis of mean correlations of each item, to see if any items were correlating highly with one another >.20. It was discovered that MH4 (belief in recovery) and MH14 (fear of relapse) were correlated. Consideration was given to creating a super-item for MH4 (belief in recovery) and MH14 (fear of relapse) to resolve this, using a subtest.

This method was published within an article using Rasch analysis to assess the performance of the WHOQOL-BREF across injury groups and healthy populations (Balalla et al., 2019). Medvedev and Krägeloh (2022) describe the creation of super-items where item scores are added from a group of locally dependent items. If the super-item distribution is dependent on the same latent trait and satisfies Rasch model expectations, this provides evidence against multidimensionality. They state that the super-item subtest can resolve response dependency, such as those caused by method effects. When MH4 and MH14 were added as a super-item there were no disordered thresholds or residual fit problems.

An assessment of unidimensionality discovered an unacceptable Rasch model fit on this set of 11 items with upper limits at 8.74% and lower at 6.5%, which indicated further problems within this set of items to resolve. A decision was made to trial eliminating MH14 to see how the module performed with 10 items, once MH14 was eliminated. The rationale for this decision was that MH14 had been unstable within several analyses, it had been red-flagged for showing residual fit problems several times and had again presented with disordered thresholds and residual correlation problems in this analysis.

Analysis 8

There were now 10 items to analyse after removing MH14. This selection obtained a chi-square result of $p = .11$. There were no residual fit problems nor disordered thresholds within any items of this selection. This improved result was then evaluated for

unidimensionality. This set of 10 questions obtained an unacceptable fit with the Rasch model, indicating measurement problems remained within this 10-item selection.

Analysis 9

A decision was made to return to the 11-item solution, to examine the item selection again to check whether the removal of MH14 had been an error. Medvedev and Landhuis (2018) published a method of exploring the source of misfitting items. Their method examined whether some items were loading on a second factor or were less loaded on the primary factor of interest. Their method was used in this step to explore the possible reasons for the 11-item selection showing no evidence of unidimensionality.

The 11 items were analysed through Exploratory Factor Analysis (EFA) with a Promax rotation to explore where non-unidimensionality was coming from. Loadings closer to -1 or 1 indicate that the factor strongly influences the variable. The component being considered is HRQoL, with the variables being the module items. Table 15 displays items that loaded against the first principal component (QoL) and an unknown second component.

Table 15

Analysis 7: Exploratory Factor Analysis

Mental health module item code and question	Component	
	1	2
MH4: To what extent do you believe you can recover from illness?	.74	
MH11: How well have you been able to adjust to what's happened in your life?	.72	
MH14: How confident are you that when well, you can stay well?	.72	
MH19: How satisfied are you with your recovery?	.70	
MH5: To what extent do you recognise the positive strengths you have?	.70	
MH18: How satisfied are you that people really understand you?	.70	-.37
MH12: How well do you feel you can relate to others?	.66	
MH9: To what extent does understanding why you have a problem, help you to resolve it?	.65	
MH7: To what extent are you determined to recover your health when not well?	.61	.46
MH20: How satisfied are you that other people recognise your strengths?	.60	-.52
MH3: To what extent have you made changes for the better?	.59	.43

Crossloading was discovered for the shaded items on Table 15, which have been rounded to two decimal places on the table. The three decimal place result is included here

with the first number representing the result loading on the first principal and the second on the second component: MH18 (understanding) at .696 and -.370, MH7 (determination) at .609 and .462, MH20 (others recognising your strengths) at .596 and -.520; MH3 (personal growth) at .591 and 4.29. MH19 (recovery progress) obtained a three decimal place result of .703 with MH5 (self-recognised strengths) obtaining .700.

These subtle differences were considered when rank ordering items. The two items obtaining a negative result on the second component asked about other people's perceptions of them, whereas those with positive crossloadings asked about self-perceived levels of determination and change. This may reflect differences between items worded as perceived objective versus perceived subjective evaluations. Two items with previous residual correlation, MH4 and MH14, were no longer crossloading within this EFA analysis.

The Medvedev and Landhuis (2018) method involved progressively eliminating items with the highest crossloading factors, until unidimensionality was reached. Crossloading items are rank ordered on the first principal component then the item with the lowest loading are eliminated first. The rank order from lowest to highest loading on the first principal component in this item selection were MH3 (personal growth), MH20 (others recognising strengths), MH7 (determination) and MH18 (understanding). MH3 (personal growth) was removed initially, as it had the lowest factor loading on the first principal.

Analysis 10

A second 10-item selection with MH3 removed, produced a chi-square result of p = .53. When assessing this selection for unidimensionality it obtained an acceptable fit to the Rasch model, however the upper limit was 6.94, which was not ideal, as the upper limit should be under 5.0 (Krägeloh et al., 2016; Medvedev & Krägeloh, 2022). The lower limit was also high at 4.78. Conceptual requirements involved an objective to produce a module with the lowest number of items that still obtained a good fit with the Rasch model and met

all IRT criteria for well performing items. As this requirement was not yet achieved, further item reduction occurred that removed all three items from the earlier 11-item version with crossloading problems >.65 on the first principal – MH3, MH20, and MH7. This produced an 8-item solution for further testing in the next step.

Analysis 11

An 8-item selection after MH3, MH20, and MH7 were removed was analysed. This selection obtained a chi-square result of p=.62, an acceptable unidimensionality result, with a PSI of 0.84436 (with extremes) and 0.84050 (no extremes). There were no residual fit problems, no disordered thresholds, nor significant DIF on this 8-item solution. Residual correlation checks on this selection of items showed a reappearance of residual correlations over the mean average cut-off criteria of >.2 for items MH4 and MH14. MH14 (Fear of Relapse) was removed based on its unstable performance in more of the previous analysis steps than MH4. MH4 presented as a more stable item for inclusion.

Analysis 12

Removing MH14 resulted in a 7-item selection. This selection obtained an improved chi-square result of p=.43. There were no residual fit problems and no disordered thresholds, nor DIF on any demographic variables. PSI with extremes was 0.81853 and without extremes was 0.81391. This result obtained a strict fit with the Rasch model with upper extremes of 2.30 and lower extremes of 0.13.

Exploration of this selection with EFA resulted in a one factor solution indicated by only one eigenvalue above 1(Kaiser criterion). There were no crossloadings on the first principal using a criterion of p < .65. MH18 (understanding), crossloading previously, was no longer crossloading within this item selection. This 7-item result is displayed n Table 16 as the final selection of items proposed for a MHRQoL module.

Table 16

Principal Component Analysis of the 7-Item Mental Health Module

Mental health item code and question	Component 1
MH11: How well have you been able to adjust to what has happened in your life?	.79
MH5: To what extent do you recognise the positive strengths you have?	.75
MH18: How satisfied are you that people really understand you?	.75
MH4: To what extent do you believe you can recover from illness?	.74
MH12: How well do you feel you can relate to others?	.73
MH9: To what extent does understanding why you have a problem help you resolve it?	.71
MH19: How satisfied are you with your recovery?	.69

Medvedev and Krägeloh (2022) stated that when all the criteria for Rasch model fit are satisfied, the sample's person-abilities scores can be plotted against the item's thresholds on the same Rasch-derived interval-level scale. This is called a person-item threshold distribution.

The person-item threshold distribution shows the spread of item difficulties and how well they cover an individual's ability on a latent trait by calculating individual item thresholds. Figure 7 displays the person-item threshold distribution of the 7-item solution including extreme-person results for the final module. This figure shows that the items within the 7-item solution perform well as a module when analysed by item-thresholds, i.e., there is an adequate spread of item difficulty therefore allowing for the full assessment of individuals capability along a continuum of low to high MHRQoL for each item.

The results show that this 7-item selection can operate effectively within large, aggregated data sets that examine sub-sample results, for service evaluation applications and individual use within clinical recovery planning and treatment evaluation situations. The distribution displayed in Figure 7 includes extreme scores and shows the mean and standard deviation scores.

Figure 7

MHRQoL Module Person-Item Threshold Distribution

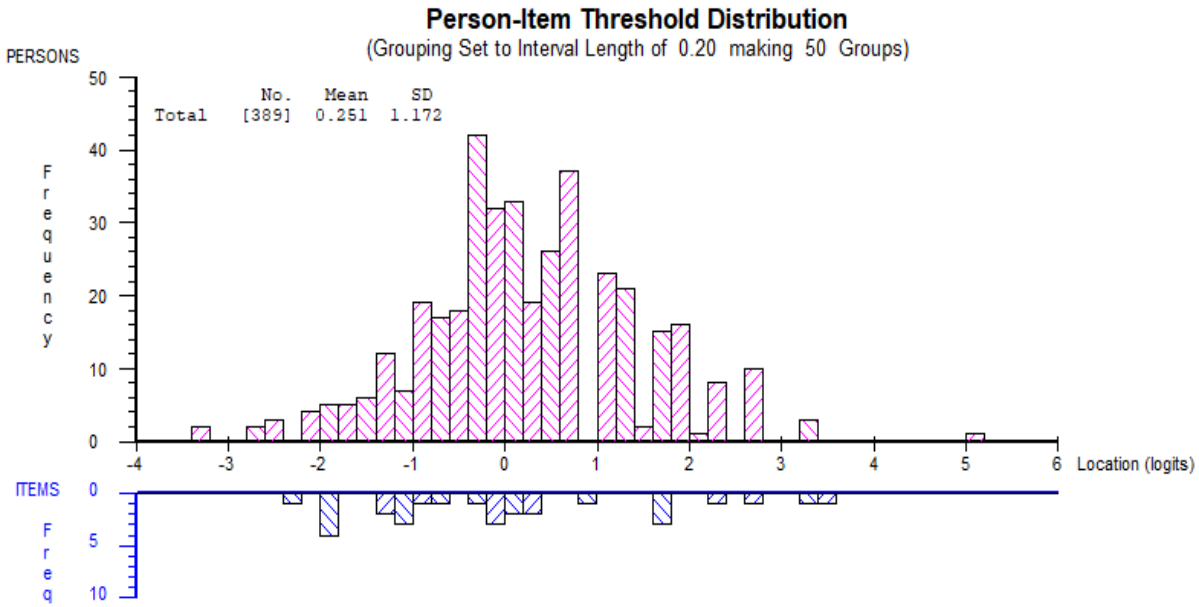


Table 17 displays the unidimensionality results of all item selections receiving an acceptable chi-square statistic starting from the unacceptable chi-square result of Analysis 1 through to the acceptable Rasch model fit of Analysis 12, including the first statistically significant chi-square result; the 11-item version discussed in Analysis 10.

Table 18 displays the 7-item solution alongside the Phase 1 discussion themes that these items represented. When an acceptable fit with the Rasch model has been ascertained ordinal-to-interval conversion scores can be computed (Medvedev & Krägeloh, 2022). Conversion algorithms are available for the WHOQOL-BREF and are consistent with scoring recommendations for WHOQOL use in NZ (Krägeloh et al., 2016). A 7-item module, where each item is presented on a 5-point Likert scale, results in a minimum score of 7 and a maximum score of 35, as a total module score. The interval scores are estimated in logit units. These are used as a universal metric for person-ability and item-threshold difficulty. Leung et al. (2014) explained converting ordinal raw scores into interval-level data increases measurement precision. Table 19 details conversion scores for the module's raw scores.

Table 17

Rasch Model Fit Statistics from Analysis 1 to Final 7-Item Result

Analysis step		Item-fit residual		Person fit residual		Goodness of fit		PSI	Significant *t*-tests		
	N	Value	*SD*	Value	*SD*	$\chi 2$ (*df*)	*p*	with extremes	%	Lower bound	Unidimensional
Analysis 1	17	.51	2.46	-.32	1.55	205.16 (85)	.00	.89	13.37	1.20	No
Analysis 7	11	.36	1.32	-.40	1.42	59.22 (55)	.32	.87	9.00	6.83	No
Analysis 11	8	.37	1.10	-.38	1.26	36.64 (40)	.62	.84	2.32	.15	Yes
Analysis 12	7	.39	.96	-.36	1.19	35.83 (35)	.43	.82	2.30	.15	Yes

Table 18

MHRQoL Module Questions and Phase 1 Themes

Module item code	Module question	Phase 1 theme
MH 4	To what extent do you believe you can recover from illness?	Belief in recovery (hope)
MH 5	To what extent to do you recognise the positive strengths you have?	Identifying strengths
MH 9	To what extent does understanding why you have a problem help you to resolve it?	Self-awareness, insight
MH 11	How well have you been able to adjust to what has happened?	Acceptance, adjustment
MH 12	How well do you feel you can relate to others?	People skills
MH 18	How satisfied are you that people really understand you?	Understanding, empathy
MH 19	How satisfied are you with your recovery?	Recovery progress (hope)

Table 19

Ordinal-to-Interval Conversion Scores for MHRQoL Total Score

Ordinal scale	Interval	
	Logit	Scale
07	-4.18	7.00
08	-3.36	9.49
09	-2.80	11.21
10	-2.41	12.39
11	-2.11	13.31
12	-1.85	14.09
13	-1.63	14.77
14	-1.43	15.38
15	-1.24	15.95
16	-1.06	16.49
17	-0.89	17.02
18	-0.72	17.53
19	-0.56	18.04
20	-0.39	18.55
21	-0.22	19.07
22	-0.04	19.61
23	0.15	20.18
24	0.34	20.77
25	0.55	21.41
26	0.78	22.10
27	1.02	22.86
28	1.30	23.69
29	1.61	24.63
30	1.95	25.69
31	2.34	26.88
32	2.80	28.26
33	3.34	29.92
34	4.06	32.11
35	5.01	35.00

On the above conversion table, a module user would consider a person's raw score total (from summing the Likert scale item answers to all questions contained within the

module) on the far left of Table 19 against its converted score on the far right of this table, to obtain an interval score. This interval score represents a more precise measure of MHRQoL for a person or group. The module user can use this table to calculate a more accurate measure of MHRQoL when using the module in research, clinical applications, or within aggregated service level data analysis. Table 19 presents raw scores with no missing values.

Conclusion

Twenty-three of the 24 items representing issues most often noted to affect QoL by 88 participants within Phase 1, when assessed for their relevance to HRQOL by 667 participants nationwide in Phase 2, showed good discriminative capability between people with and without mental health problems. CTT analysis identified that 17 of these items met criteria to be considered MHRQoL items, that were not redundant in the presence of either existing WHOQOL-BREF items or candidate items. Through a progressive process of item elimination using CTT and iterative Rasch analysis methods that were developed within other WHOQOL studies (Balalla et al., 2019; Krägeloh et al., 2013, 2016) and cited by experienced Rasch analysis researchers (Medvedev & Krägeloh, 2022; Medvedev & Landhuis, 2018) seven items were arrived at, as the proposed content for an adjunct MHRQoL module for the WHOQOL-BREF. Appendix R presents a proposed format for the MHRQoL module that can be used for research or practice applications.

The careful iterative stepwise process used in Phase 2 evaluated each item's performance individually as items were progressively eliminated. The scrutiny of each item against set item measurement criteria clarified the performance problems of each of the 10 items eliminated, before arriving at the 7-item solution as an outcome from the current research. This process provided a robust basis for item selection by requiring items to meet strict item measurement and performance criteria and assessing their fit with the latent trait of MHRQoL.

Items removed evidenced residual correlation with other items, problematic differential functioning within some demographic groups, poorer ability to perform as stable items to measure MHRQoL across the research sample, and poorer fit with the central HRQoL construct. Compared to the final seven items selected, they did not meet the Rasch model's item performance criteria. The 10 eliminated MHRQoL items may be relevant to include in item banks if individuals want to choose additional items relevant to their QoL or recovery to track in response to targeted interventions during service delivery. Appendix M contains participant quotes explaining how those 10 items affected their QoL. However, these 10 items do not perform well, from an IRT perspective, for use as PROM items in situations of service evaluation.

The following chapter offers an opportunity to interpret the results of this research in the context of how the seven issues underlying the MHRQoL module items affect the QoL of people recovering from mental health problems. Chapter 7 contains quotes from the discussions held with Phase 1 participants that outline how the seven issues explored by the final seven items affected their QoL, for the better or worse, during their recovery from mental health problems.

Chapter 7

Discussion of Phase 2 Results

First-Person Narratives

Chapter Overview and Aims

This chapter of the thesis presents first-person narratives that speak directly to the experiences of QoL being negatively impacted and restored during recovery from mental health issues. Including first-person narratives is common in mixed-methods research (Hesse-Biber, 2010) and personal recovery research (Hartley et al., 2014; Houghton, 1982). The researcher decided to include first-person narratives as the discussion section of the Phase 2 results to consider and discuss the final results through the lens of participant life experiences. The value of bringing qualitative and quantitative data together to support data interpretation is part of the mixed methods approach to explore how each method can contribute to the final outcome and offer unique benefits to a research study.

Participant quotes are raw data, unaltered by potential perceptions or interpretations made by researchers or coders involved in the coding of discussion meeting themes. First-person narratives empower the service user's voice within research in the same ways that PROMs give voice to the service user's experience within mental health evaluation suites. The placement of Phase 1 first-person accounts in Chapter 7 explains the meaning of the Phase 2 results through the lens of personal life experiences that exemplify each module item.

The information provided in this chapter parallels a process that can occur during PROM measure review. Namely, a better understanding of why a person may be rating a specific item the way they are in the context of their mental health problems, goals, life context, and concerns. The benefit of processing PROM results this way is that it can lead to increased insight within the service or for the provider about how a person's QoL has been affected by their mental health problems. Processing WHOQOL ratings with service users can increase the opportunity for more tailored interventions to arise that support people to recover their lives from the effects of mental health issues during service delivery and goal plan reviews (Andrews & Rowthorn, 2013; Llewellyn & Skevington, 2015).

In this chapter, first-person narratives provide experiential accounts from Phase 1 participants that illustrate how each MHRQoL issue within the 7-item module can be understood when recovering from mental health problems. Within the mixed-methods approach, this chapter provides a balance to the quantitative approaches of data analysis in Phases 1 and 2 to look more deeply into *how* these final seven MHRQoL items can assist the measurement of mental health-related QoL beyond the aims of *what* indicators to include in a MHRQoL module for statistical reasons that occurred in Phase 1 and 2. To better understand how mental health problems and recovery interventions impact people's QoL, we need to listen to people's lived experiences. When exploring the qualitative dimension of each module item, we hear how the different determinants of recovery, represented by the seven module items, interact with QoL and mental health recovery.

When a measure is used in an organisation, more than an aggregated numerical result is needed to offer clear direction for improving QoL for people. A greater understanding of *why* and *how* these recovery determinants affect people's QoL creates an opportunity for further clarity about how mental health problems, receiving services to support recovery, and the recovery process affect QoL. Improved understanding may help service providers better understand how using the MHRQoL module with the WHOQOL-BREF can assess and encourage the progressive improvement of QoL and recovery outcomes for service users when receiving mental health services.

This section aims to explore these issues with more narrative depth than the Phase 1 numeric analysis was able to provide about the final 7-item module result. Exploring first-person narratives reinforces how qualitative and quantitative methods within mixed-methods research can be combined to improve an understanding of a research question, interpret results, and offer an opportunity to appreciate participants' lived experiences concerning the research question under investigation.

The WHOQOL-BREF and the MHRQoL module require survey responders to indicate an answer that best fits their current experiences on a 5-point Likert scale continuum. The participants explained how the issues underlying the final seven items affected their QoL and recovery positively and negatively. The participants' comments reflecting satisfying and dissatisfying experiences about these themes can provide a sense of each item's low to high QoL continuum. Quotes juxtaposing the constructive and deteriorating ways that recovery issues impacted a person's QoL aim to illustrate each module item's individual expression, scope, and complexity. Examples included in this chapter may assist with the latter development of a MHRQoL manual to accompany the module that includes facet item descriptors that capture this complexity and scope from the authentic experiences and meaning that people with lived experience placed upon them when discussing them in this research. Phase 2 participants were not asked to explain how the candidate items within the MHRQoL survey affected their QoL, yet Phase 1 participants did speak to this issue.

The first-person narrative accounts occurred within an open, supportive, and connected conversation among peers, with one to two research interviewers attending. Unfortunately, this chapter cannot capture the value of the rich discussions that all 88 participants offered during these times. The quotes in this chapter will only include those made by participants within the LE sample, i.e., the 55 participants with lived experience participating in Phase 1. Participants included people in mid-stages of recovery receiving intensive community residential services and people in later stages of recovery, working as peer support workers and advisors within the field.

Peer support participants offered their own lived experiences and what they had heard and observed from their peers' lived experiences within their time in these roles. These examples also highlight some systemic complexities behind the lines when delivering a recovery-focused service that can negatively affect a person's QoL. Providing illustrative

quotes from those with lived experience of mental health issues aims to mirror the participatory conversational process that can occur during QoL conversations with people who have answered the MHRQoL module questions about their recovery during service evaluation or delivery reviews.

The structure of this chapter will follow the following format: The first section discusses the impact of mental health problems on overall QoL and the subthemes of that impact within the participant's discourse. A broad overview of how mental health problems negatively affect QoL, and examples of how mental health problems can result in a deterioration of QoL. This overview provides a background context for the sorts of issues people are trying to resolve while seeking to restore their QoL as they recover.

The next section of this chapter focuses on quotes that discuss the underlying themes represented by the final seven mental health module items. Each module item theme will be focused upon individually in the following order: (1) acceptance and adjustment, (2) understanding and empathy, (3) belief in recovery, (4) self-awareness and insight, (5) recognising strengths, (6) the people skills required to relate to others, and (7) making progress in recovery. Each module item theme starts with a broad overview of how people spoke about this item during discussions. It then presents quotes that illustrate the dissatisfying experiences related to the item, followed by quotes that illustrate the satisfying life experiences related to the item. This method explores the continuum of experience that people can have, akin to an item's Likert scale continuum, from feeling stuck to moving forward during their recovery in the context of the theme that the module item represents from the Phase 1 discussions.

The themes of items that met CTT criteria as candidate MHRQoL module items yet eliminated by Rasch analysis are not discussed in this chapter. Appendix M contains quotes about those items, with added discussion about themes of goals, spirituality and hope.

Appendix M presents those item themes in a similar format to the quotes in this chapter, with examples of satisfying and dissatisfying experiences discussed about those themes. The items discussed in Appendix M may be considered for individualised recovery planning and tracking, yet from an IRT perspective, they are not items to include in PROM evaluations for outcome measurement purposes.

The Impact of Mental Health Problems on QoL

Participants discussed how overall QoL was negatively affected by mental health problems in response to Question 1 of the Phase 1 discussions. Participants who spoke about how mental health problems changed their QoL spoke about their distressing experiences in the initial or acute phases of mental health problems. Within their discussions, they spoke to many existing WHOQOL facet areas and some of the recovery-specific issues that arose during these times of their life.

Participants spoke about the experience of a mental health crisis as an existential crisis or as a traumatic experience in and of itself at times. Participants spoke about the impact of mental health problems across many facets of their lives simultaneously, subjectively and objectively. The compounding impact of so much life deterioration and change occurring at once was overwhelming at a time when they had less internal resilience to manage the additional load of all these changes.

Participants discussed changes to their functioning within important roles, disruptions to personal and family relationships, and a sense of disconnect with a broader sense of social belonging and worries about how society viewed them. This section will include subthemes participants spoke about when responding to Question 1 of the Phase 1 discussions: How do mental health problems affect QoL?

Subjective World Changing

Participants illustrated how mental health symptoms affected their subjective state and how this affected their functioning within important QoL facet areas assessed by the WHOQOL-BREF. Participants often spoke about their QoL deteriorating within several specific WHOQOL-BREF facet areas: their ability to work, satisfaction with themselves (self-esteem), their mobility, cognitive capabilities, capacity to perform activities of daily living, meet expectations of others, their capacity to engage in personal relationships, or feel as socially connected as they had been, prior to the onset of these problems:

> AE: "Your ability to control how you think or how you feel is compromised, it's, just horrible. I just hate it. You're not able to be you, which I suppose, I don't know with everything else, you're still able to be the same person. I don't know, it sounds a bit weird, I don't know if that makes any sense."
>
> CC1: "Well, having a mental disability, let's call it schizophrenia, anyway, it doesn't help because you can't do things you should do every day, normally, so it is hard to get a job, dizzy spells, short of breath, that sort of thing … you have trouble doing things."
>
> CC2: "Your emotional side of things, some people have mood swings, anxiety, depression and sometimes struggle to communicate with others as well, yeah. It does affect your ability to work and think and feel, be with others, and enjoy creative things."
>
> TC3: "The other thing after that was, I didn't know what was real or not...That was scary, because I didn't know if what I was seeing, and hearing was real or not. Even if it's just day-to-day normal things. I think, 'Am I really here? Is this right?' So that was a bit startling."

Interruption of Life Direction and Vocational Goals

Participants discussed the negative impact of mental health symptoms on their capacity to study for and achieve vocational goals set before their mental health problems. Participants explained that the consequences of not being able to complete vocational goals impacted other WHOQOL-BREF facet areas such as income, commitments to family, and relationships. The onset of mental health problems culminated in an overall deleterious impact upon a person's life both immediately, in terms of not being able to continue with academic study or vocational training, as well as upon their chosen vocational and life paths being closed permanently in some cases.

> CC3: "I first got schizophrenia when I was 18 to 19, I was trying to get through university, and so, getting sick, affected me, getting my papers at university, I tried for two or three years to do university, I tried to write essays and I couldn't do that, I was too ill. So that affected my confidence, and my friends and peers, they were doing the papers, got through the degree, and started working. While I was still trying to figure out ways to do it."
>
> CC4: "I got bipolar at the age of 17, I was about four months into my nursing career, I had worked very hard to get into nursing through schooling, it was a real shame. I never went back there. It shaped my life, it affected what I chose to do with my life, and my working career. Sometimes those are hard pills to swallow, when you can't do what you wanted to do, or planned to do. I had a complete breakdown and burn out and ended up in Carrington (*institution*) for 12 months, so I was very extremely sick."
>
> CM8: "I found my studies were affected quite strongly. I was in high-school when I had one of my episodes, so I did not end up finishing high-school. And then when I began university, there was that motivation thing, where you are completely lacking all motivation, but you've got all these really high goals for yourself. Got to get those

A's; things like that. It was a bit weird, and it took me a while to get over bringing my confidence up and bringing my expectations down a wee bit, just so that I could survive a semester. But also, that socio-economic stuff was really difficult … just to support everyone else, family, relationships, work, and everything like that, it is really big, it's the whole life, everything."

RC1: "Well, when I became unwell, it was when I was a teenager. So, I went into a career, and then couldn't finish the training because I was admitted to hospital. And then, then for years, I was in and out of hospital. So, I never got back. When I tried to go back and said, "Can I sit the exams?" They said, "No, it's not possible." So, I never actually got any qualifications, like other people do, at that age."

Breakdowns of Relational Functioning

Participants spoke about the impact of mental health symptoms on WHOQOL-BREF-assessed facets, such as personal, family, or social relationships. Participants spoke about seeing how their difficulties relating to others also impacted other generic WHOQOL-BREF facet areas such as workplace relationships, being able to fulfil role expectations as they had done previously, and their relationship with themselves (self-esteem) changing.

PC1: "I was on drugs, and you know, violent towards my kids. I only had one child at that time. I became very violent and out of control, yeah, at my work, at my job and with family around me. I was losing it up here in my mind. Things that I take for granted I lost. I ended up losing everything so, you know, that was hard to accept, I think, in the back of my mind."

TC2: "My immediate reaction, without thinking too much about it, was relationships and roles. I guess I also equate that to physical health. What happens is that somehow your identity changes, not only for yourself, but in the eyes of other people. And there's a whole adjustment thing, or readjustment thing, that goes on. So, it's

something about identity within and without. And that's about a relationship and the kind of role that you have and play in life."

Overall QoL Affected

Participants spoke to the WHOQOL-BREF item "overall QoL" when describing the overall negative impact of having a mental health crisis affecting many or all domains of their lives simultaneously. Participants explained that this overall deterioration of QoL was part of the overwhelm and increased difficulty they were experiencing when acutely unwell, both in experiences of mild as well as severe mental health problems.

Participants provided examples to show that the overall impact of mental health issues on QoL was not determined solely by the symptoms of the illness a person had. Changes to QoL were brought about by how mental health problems created difficulties functioning in many domains of life concurrently, causing widespread consequences personally, socially, and with their ability to orientate themselves and direct their lives. People named existing WHOQOL-BREF facets of life when describing the personal impact mental health problems had upon their lives, such as items asking about satisfaction with work, accommodation, meaning and purpose in life, family support, and their satisfaction with themselves.

CM3: "It affected, for me, relationship, it affected work, it affected where I was living, it affected where I was going, it affected my sense of meaning for the future, it affected family, and a lot of this was a huge amount of change taking place."

CM6: "It becomes that vicious spiral …so all those parts of life are affected, it is almost, it can be every aspect I think that breaks down, and that is how severe depression and anxiety affects your life. I have never experienced schizophrenia or bipolar, or psychosis, so I am talking about the mild to moderate mental illnesses, and I know what that is like, at the top end."

> TC3: “I guess when you’re asking what parts of life are affected? It’s all of it. Your future, your past, the bit you’re in right at the moment. These are the stories we don’t tell. Or very rarely you’ll hear the stories about often the really obvious wrong side, people being secluded for weeks. I couldn’t imagine anything worse, quite frankly. But there’s all these other stories that we each have, that no one really hears. And there are big griefs, but in the scheme of things, they’re not that big. But to us, they feel like, the universe, at times.”

A Traumatic Experience, An Existential Crisis

Participants spoke about the experience being profoundly traumatic at times, like an existential crisis. In the case of a psychotic break, it felt like a sudden abrupt change to identity, occurring overnight, that affected their view of themselves and how others viewed them. Whereas for others, it occurred as a slow deteriorating progressive change of how they saw themselves and the world around them, which resulted in life-destabilising outcomes over multiple facets asked about in the WHOQOL-BREF.

Due to the co-occurring personal and objective losses that mental health problems brought, participants described experiencing a loss of overall confidence in themselves and their ability to know how to reorientate to their world or manage their lives as they had previously. Existing WHOQOL-BREF facets were discussed such as self-satisfaction (self-esteem), personal relationships, work, control over life, social support, and spirituality. Other themes represented by different candidate items were also discussed as a consequence of experiencing a mental health crisis, such as coping, stigma, its impact on goals, changed their views of their future and their sense of being able to progress in life as previously envisioned. The breadth of impact on their lives resulted in a health crisis also being experienced as an existential life crisis; participants noted this profound, extensive, and deep personal consequence as making it different from what occurs from other health crises.

TC3: “Especially, the first two kind of really clear episodes. Because there’d been touches and bits and pieces before that, probably all my life. But there was two really clear early episodes. One lasted a month, which was that psychotic time …and then when I had my son, who was my second child, I had a seven-year episode … I always felt that the experience was more traumatic than anything I’d ever had before. It wasn’t that different from a lot of people I talked to in hospital. They had terrible childhoods and things like that. This just came from nowhere …as far as I could tell. But listening to other people talk about their experiences, because I worked in the inpatient unit for a while as Consumer Advisor, they were very traumatised by sort of waking up in this alien world. Which is, my words, but it seemed a same, similar sort of experience. And that sense of helplessness. And there were quite a few people who got it suddenly. And then there were people who slipped into it. Which didn’t seem as traumatic. But the losses were traumatic … looking back, I think it would be. Because you realise what it stole at that time. So, I guess that’s a big question. But yeah, certainly lots of people I’ve talked to feel that way.”

WT8: “Confidence was a mess. I really was touched by this reality, for a long time. And how I was seeing the world was very different to how other people were seeing the world around me, and so I felt like I couldn’t trust other people around me because they weren’t seeing things how I was seeing it, so I became quite isolated, and I started to doubt every element of myself, essentially. I was just getting told that, that’s not how things are, you know, this is, that’s not what’s going on, so, it really shredded my confidence. I had to relearn stuff again.”

TC2: “Something amorphous and existential about it. That is on another plane than the physical material world. …So, if you look at it as an existential crisis, I think that it scares the living daylights out of a majority of the population. Because it’s of the

> unknown and it's talking to something that's in them. They know it it's just one step away, inside themselves. …It's not static. And you could say in some respects that those individuals are even more sensitive and that something's got in and touched it, touched the core of you and then come out and it manifests on the surface … on a deeply sort of existential level. Which is why I was saying, I think in some ways it's an existential crisis."

Changes to QoL Brought About by Treatment

Participants spoke about WHOQOL-BREF facets areas such as their experiences of not being able to access health services when needed, difficult experiences when receiving health and social services, and problems related to dependence upon medical treatment for mental health problems or being mandated into treatment through the *Mental Health Act* as having a disruptive impact upon the quality of their lives.

> PC7: "My life was affected for a while, by medication, I had psychologists. I was diagnosed with schizophrenia, and they were pumping me full of anti-depressants. What they would do is put me on highs and lows at the same time, like a guinea pig. And my life was just messed up."
>
> TC3: "It felt like forever, that month. But the next time it wasn't like that. It was like a switch in the beginning but went on and on and on and on and on. Interestingly, that was when I started taking psychiatric meds. And I've always wondered if they didn't slow it all down or something. I don't know."
>
> CC3: "I suppose, a change of medicine made me have time back in hospital I had treatment resistant schizophrenia, getting a medicine to work, you know."
>
> RC1: "I think, I've got more coping strategies these days and I'm much better able to cope with any stressors, than I used to be. So, I would like the opportunity to try and reduce and come off medication. …I had a Mental Health Act review, last week, and

> they said, under no circumstances, were they going to take that risk …and they put me under *The Act* for another six months."

The "Up-Side" of Mental Health Issues

When considering positive aspects of mental health problems, at times, participants reflected upon some paradoxically satisfying consequences of having a mental health diagnosis that improved their QoL at times. Participants explained that the break from life a mental health crisis resulted in allowed them to escape a way of living that had previously felt confining, pressured, or too complicated. Some participants commented that mental health stigma ironically led to getting their needs met on occasion. Other participants noted that mental distress had been a catalyst for making necessary constructive changes to their lives. Participants referred to existing WHOQOL-BREF facets areas (managing activities of daily living and access to health and social services), NZ national items (meeting the expectations of others) and candidate items (coping) when describing their experiences.

> AE: "I used to do this thing that I don't do anymore, which is really good. It sounds a little bit strange, but I used to sometimes let myself go mad, because it was the only time that I was completely free of responsibility. We have so many commitments and so many responsibilities and everything …and as I say, madness, was the only time that I was, free from all that. It used to be quite alluring. And each time I take longer to come back, so that scares me a little bit. But I don't do that anymore because it's not worth it. It's better to go out and have a massage or something."
>
> PC4: "I enjoy being unwell. I can cope very well. If I, if I was well, I wouldn't be able to cope at all, no. It would be hard to cope, too hard to cope. I'm glad I am unwell, and with the voices making me... I would find it hard to cope, if I was well, I would find it hard to cope. That's the advantage for me being unwell."

RC1: “WINZ used to say things like, “What are you on a benefit for anyway?!” And funny things like that [*laughs*] But I do, sometimes it worked to my advantage, because I would, if they wouldn’t give me a food parcel, or something like that, I’d just ended up getting upset, and they would say, “Here, here, take it, take it.” (*laughs*). And that was about the only time, ever, that it works to your advantage. So, yeah.”

RCG4: “You know it can actually be a blessing in disguise … mental illness can be a blessing in disguise.”

Participants identified WHOQOL-BREF facet areas such as satisfaction with health and social services or dependence on medical treatment to address symptoms, despite their challenges, helped to improve the quality of their lives, or facilitated areas assessed in other candidate items such as recovery progress, coping, and continued goal achievement. Participants explained that the services the health system offered helped through offering medication at times, at others, through the self-care choices encouraged, lifestyle changes made, or recovery-focused social support they received.

Participants also talked about how the relief of symptoms restored certain WHOQOL-BREF facet areas, such as their sense of satisfaction within themselves, reduced negative feelings, or their capacity to access positive feelings and enjoy life when they were no longer preoccupied with the effect of those symptoms. Their ability to focus on the outside world again enabled them to better cope with activities of daily living and subsequently to recover aspects of their roles and lives previously negatively impacted by mental health problems.

CC10: (*Context: history of substance addiction and psychosis*). “I just want to get my life back to normal again, as much as I can. I don’t want to be taken off my tablets because it does keep me sane when using them. I find it hard, because now I’m on drugs to control, to keep me sane, because I sort of, lost my way. I didn’t know what I was doing was very wrong and it was affecting my daughter. So, being on medication

now has started to stabilise me …and yeah, it makes it hard, because I've also got to rely on drugs now, to keep the pain under control. So yeah. I'm glad I am on it. It keeps me sane, and I don't lose it as much. If I become depressed or whatever, I've been told that I have to speak out and say something to somebody, because I get voices in my head telling me to do stupid things, and I'd most probably go and do it. The tablets try and help me with not doing the stupid things that I would do."

RC6: "I really believe in medication, provided it is the right one, and you take it, relay back to your doctor what is happening, it is just another issue, we just have mental issues, that's all. For me now. I take 16 pills a day, eight in the morning, one at lunch time, one at dinner time and six at night. It has taken years to do it."

AE: "Now, my parents didn't take any notice of that, and they facilitated and paid for wrap around mental health support to enable me to go to university. I had all my medication and all my treatment, and everything, focused around supporting me to do that, rather than focused on curing me, or whatever. Everything became revolved around that, rather than revolved around treatment for the sake of treatment. That's a very different model."

WT4: "Mine's probably, I would say 60% medication, and the rest of it, managing the stresses in my life and pushing myself to do social things as well."

Mental Health Recovery Module Items

This section will explore the first-person narratives about the underlying themes represented by the final seven module items and how these issues affected their QoL for the better and, at other times, were implicated in the deterioration of well-being or QoL. The core theme of the item is presented in the subheadings in this section to illustrate how each of the seven module items represented these Phase 1 themes. Their corresponding candidate item code is included in brackets for reference to earlier chapters regarding their analysis.

The mental health recovery module section first discusses each module item theme in general, then examined in quotes, illustrating how participants described an item as having a dissatisfactory influence on their QoL, followed by first-person narratives about how the same item theme was also a source of life satisfaction and improved QoL. This way of presenting the quotes can parallel the continuum people identify when they place low QoL to high QoL ratings on each module item during recovery planning or evaluation. Chapter 8 provides further discussion about the module items concerning the literature.

Module item 1 – Acceptance (MH 11)

Participants described the need to adjust their lives, perspectives, and approaches to life to get to a place where they could accept what was happening as a critical aspect of recovering their QoL. Difficult experiences within the adjustment and acceptance theme involved an inability to accept the changes that mental health problems brought or the requirement to readjust their goals or aspirations as an early response to their diagnosis or mental health crisis. The more satisfying end of the continuum of the module item theme involved accepting a new reality and adjusting to the mental health crisis in adaptive ways. This type of acceptance helped resolve earlier experiences in ways that facilitated moving forward and led to a greater sense of inner well-being and peace.

Difficulties Adjusting and Adapting to Mental Health Problems

Participants spoke about the less helpful expression of this theme in various ways. Participants discussed times of adopting a passive resignation as a form of passive acceptance, surrendering to the limitations of or changes to life that the initial mental health crisis had brought in ways that led to feeling stuck, no longer striving to change their lives for the better. At other times, participants spoke about how this increased their dependence on services or upon others to resolve a sense of being overwhelmed by the difficulties they were experiencing subjectively and objectively at these times. The participants also discussed that

this maladaptive form of acceptance was problematic when those supporting them passively accepted their diagnosis, as people stopped challenging them to move forward. A passive resignation form of acceptance facilitated maladjustment as it stopped them from moving forward with life or from integrating the experience's existential dimension in ways that allowed them to move forward.

> CC4: "I think it takes at least three to four years from when you are first diagnosed, to even, especially if you're a teenager, accept that there is something wrong with you. Like for me, my diagnosis was 35 years ago, and mental health then, was crazy, I use the word crazy, it is probably not the right word, it was so different from how it is now, there just was no support, you just saw a psychiatrist, got your medication, and were sent home, and hope to hell that you'd come right. And that Carrington experience I had, was just hideous."
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> PCL4: "The irony for me is that they're encouraging people to change and adapt and be more flexible with a mental health diagnosis, you know, to try and help them adapt to changes in their life. But when this has all changed, and it's required, they don't want to move, because they've got to this point in their life. This is what I did. I studied that... I don't want to restudy, at my own expense. So, they're now being challenged with, you know, readjustment…of the possibility of their life. So, …they're fighting the change. But at the heart of it is, you know, we've got vulnerable people who have the possibly of having fantastic lives, but they've been delayed because, you know, you're not willing to retrain, or accept."
>
> CM8: "I found that my family got in the way of my recovery. They were really supportive. They were really so ok, with me being not ok. If that makes sense. They didn't push me to go out and do things that would boost my confidence. They just sort of allowed me stay at home, sit on the sickness benefit, and feel sorry for myself…. It

> is hard to say what they should have done. They did what they felt was right to be doing. It was right to begin with, because it was nice, to just be able to, just take a breath, but after three years, to say it was ok, was just not ok."
>
> KILGBT: "I think one of the things that people receiving services tend to become, is reliant on services. They tend to expect services and become less self-reliant. … A lot of people will see their life as, 'this is the way it's been this is the way it's always going to be'".

Adaptive Adjustment to the Changes Mental Health Problems Brought

Participants more often talked about QoL improving from accepting their mental health diagnosis and the need for rehabilitation. Participants spoke about how their ability to accept and adjust to the changes mental health problems brought was part of a turning point in their recovery. Acceptance helped them to move forward and take action to improve their QoL. Once they had come to terms with it, accepted it, and adjusted their lives to accommodate all the changes that the mental health diagnosis brought, they spoke about being at peace with having had this existential crisis within their personal life experience. The need to go through a process of acceptance and adjustment to be able to accept the life changes that have occurred through the onset and course of mental health problems may be indirectly reflected by other existing WHOQOL-BREF items changing, from patterns of dissatisfaction to satisfaction over time, as life is perceived in new ways, regardless of anything objectively changing in those life areas.

> CC9: "What was important for me, in terms of recovering, well in terms of the process of recovering, was knowing, or just accepting that my life was not going to be the same, so I didn't have to, as much as I wanted to go back to work, and wanted the things I had before and that sort of thing, just accepting that things have now changed and I am going to have to, maybe start again, maybe look at the sorts of things that I

like, that make up me, and kind of put that into a type of job or career that I want to pursue. I had to kind of look at a lot of things that were non-medication based."

WT6: "I actually found a couple of years ago, I actually accepted what I had. They had misdiagnosed me so many times [*laughs*]. And then I've got post-traumatic, and then I actually accepted that my past was not my fault. It was everyone else that was doing it, to me, so I was not to blame for what happened to me. … And I think my big thing was that I don't like the word "illness." I don't have a mental illness, I have a mental injury, because I've got post-traumatic. It's an injury, to the mind. That's my way of understanding it, that it's something that happened, rather than something that I was born with."

WT4: "Initially, I sort of blamed myself for getting ill. I went through all those questions of: why have I got this? And what did I do to get this? And eventually, over time, I've been educated by the doctors and the nurses, psychologists, and on my own. I've done a lot of reading, looking at research papers, and book materials ... to educate myself, and I think I've probably finally, in the last sort of year, accepted the diagnosis that I've got, and that it's not my fault. It's mainly biological, basically, and it just got triggered, from a bad event with my first job, basically. Bullying, that led me into the first episode. So, I have been trying to forgive myself, as others have been saying. So, because I was told I was being too hard on myself. So, that didn't help my recovery, blaming myself, and feeling guilty. So, now that I've sort of accepted my diagnosis and educated myself, I can let that guilt and blame go now, and just focus on the management of my mental illness."

Participants also spoke of the importance of acceptance in a different way and coded differently. Participants spoke at times of acceptance involving an identity adjustment, a process of constructively integrating this new existential experience into their self-concept.

This adjustment in self-concept was part of being able to face others and begin to participate in services or society again. This way of discussing acceptance overlapped with the existing WHOQOL item *satisfaction with oneself* (self-esteem) when spoken about as a process of self-acceptance. The examples below illustrate how a constructive process of integrating the changes to identity brought about by mental health problems led to a deeper level of self-acceptance in the context of mental health issues that, although not necessarily resolved, were acceptable, a part of who they were, and being okay.

> PCL4: "So the things I've seen for people coming to wellness is connecting and starting to try on their own, to be okay, with being different, you know, realising that everyone is actually different. You know, hey, I have some funny thoughts. I say some sentences sometimes, that are a bit weird, but you know, a lot of the time I am on the same page as people, you know, that's okay."
>
> KILGBT: "My self-acceptance in the beginning was horrendous. My belief in myself, in the early days of my, reincarnation, was abysmal. And it was really, really scary. But with acceptance from other people, comes self-acceptance, and self-belief and the knowledge that, hey, I might be different but I'm not a bad person. Cause it is very, very easy, well for me, it is very easy to have negative feelings about myself personally and my value and worth."

Module item 2 – Understanding (MH 18)

Participants explained that understanding and empathy from others was a significant factor involved with their ability to socially reconnect, feel better about themselves, become less isolated, be more able to engage with services, obtain help, and move forward in ways that restored their QoL. Participants described a sense of more profound wounding when feeling vulnerable, seeking help, and being misunderstood or related to with an attitude of judgment or condemnation. The positive expression of this module item involved the healing

and corrective experience offered by those who responded with empathy and genuinely tried to understand the person and the difficulties they were experiencing in their lives in the context of their mental health problems and all the challenges that th***ose problems*** brought**.** Expressed empathy and understanding appeared to operate as an antidote to or buffered the effect of social stereotypes and ignorance inherent to maintaining a stigmatising attitude towards people with mental health problems in society.

Feeling Dissatisfied – The Experience of Not Being Understood

Participants who expressed dissatisfaction with this module item theme described a lack of understanding and empathy from families, their relationships, friendships, and work situations, and a lack of social support within wider society once diagnosed with a mental health issue. Low ratings people are giving to existing WHOQOL-BREF items that speak to the social domain facets or of importance to the individual may occur for many reasons. However, exploring these ratings may reveal where a lack of understanding and empathy from others results in dissatisfaction within this domain or other facet areas.

Participants also discussed a lack of understanding and empathy when discussing other candidate items, such as stigma, as if the two went together. The experience of discrimination and stigma provided clear evidence to participants of not being understood or people not having empathy. Participants experienced a lack of understanding or empathy from others as personal and social rejection. It felt marginalising and intensified their difficulties connecting to others socially or managing the distress experienced in their subjective world. Therefore, this item may cover the emotional impact of stigma and discrimination without requiring an additional specific question about the overt experience of discrimination within one’s life.

CM5: “Sympathy is one of the worst things that a person going through a crisis of mental well-being can ever receive, empathy is what they need, not sympathy. Sympathy takes control away from one’s process of recovery.”

CM1: “…with the meltdowns that I had, my family, and friends, my partner’s family, they all think that I am just lulu, they just don’t understand, that inside, you are just normal, you just have triggers that just flip you out, that you can’t help, that you just can’t manage about life.”

WT4: “People’s perception of what it is. Because they can’t see it, in your head. Like they could if they keep getting told you had a broken leg, in that situation, people can see it. Breaking your leg, because you’ve got on a cast, or whatever, and then the cast comes off, okay, you’re better now. I don’t know, some people probably think that, with mental illness, as well, you know, take your pills, and get over it, type thing, but they can’t see the pain that you’ve gone through, experienced, and what’s led up to that. So that’s um, yeah, if people aren’t educated about it, that makes it really hard. That’s been a big part of my, QoL thing as well, people trying to understand, that it’s not like a broken leg, basically. It’s going to be something that’s lifelong, managing it, and you can’t just get over it. It’s not like that.”

TC3: “My father-in-law said that to me, I don’t know, this was about six months after I found out. I was in hell. I was maybe sleeping about an hour and a half a night. I was having anxiety attacks constantly, along with this huge despair and different colours. Like really psychedelic stuff. And he said, “If you were my wife, I’d just tell you to pull your socks up and get over it.” I remember sitting there breastfeeding my son, thinking, “God, do you think I want to be like this? To feel like this? I would do anything, anything to be better.” Because I was being cheated out of my kids, my

husband. That's what it felt like. So yeah, but I do remember that. And he was a very kind man. But that's ...yeah."

Participants also talked about their experiences in services, where they or their children's needs required understanding and empathy that they felt the young person did not receive; additionally, where they had observed personnel in services not demonstrating understanding and empathy and how that resulted in the service not being able to meet that person's recovery needs.

CC10: "Your circumstances, like with your family, and in my case, [*daughter's name*], but she was very young and didn't know what to do or stuff, and no one would help her deal with what I was going through. So, the support for her was not there at all. I'd say that would be number one. And I think with the mental health people, where I was, talking to me and telling me what was happening to me, because I wasn't being spoken to. When the voices and everything came so real, I was scared, and it made it really hard to know what to do and with the physical pain. When I said that I had physical pain there, they wouldn't listen to me and get a doctor, which I requested. They said no and yeah, that made it very hard because I had to stay in pain until the following day."

PCL4: "The understanding, is a big thing, you know, like you might see people and they go, Oh, you're transgender. Oh my God, your life must have been horrible. And for some people who are transgender, it's like actually finding that they had the abilities to have an operation to change this, or take chemicals to change, was really wonderful. I've always had the same friends. I still do. There's an assumption that there's an amount of doom associated with severe mental illness, you know? "

Participants also described the paradoxical complexity when receiving understanding and empathy from others. Participants spoke of being worried that they were a social burden or uncomfortably socially exposed at times of high vulnerability when people expressed care.

> TC2: "There was a whole lot of people I did not let in the front door, quite on purpose. And I felt slightly guilty about that. But I thought I just can't have too many. There was a handful of people, literally a handful, I'd let in the front door. Not only because of, "How are you," but because I was in pieces. So, who am I going to allow? And I'm in fragments. So, whoever is exposed to that has got to be careful with that. Because you're incredibly vulnerable and you're not only vulnerable at that time, but you're probably vulnerable for all time, because they've seen you in pieces ... I called them the 'gold standard' and they were the ones who could carry the weight. …And the other thing I did, with that was, I would limit the amount of time that I leaned on them too. Because I was terrified everybody would get sick of it. And they'd all get compassion fatigue."

Feeling Satisfied – The Experience of Being Understood

When participants discussed the positive and satisfactory experiences with the module item "understanding and empathy," they spoke about an emotional depth and quality to the experience they received from others. Participants' discourse emphasised a compassionate understanding of the impact of mental health problems on their lives and their inner being more than an intellectual understanding of these issues. This more compassionate type of understanding made the experience of understanding akin to a feeling of being empathically understood on a deeply personal level. This deeper emotional level differed from providing an understanding via information, as depicted by the existing WHOQOL facet "access to information" about one's health condition.

The participants talked about these experiences of being empathically understood, reaching them on a level that made them feel personally understood, and through that, feeling normal, acceptable, or cared about emotionally when they needed that understanding the most in their lives. This experience helped them start to care about themselves and feel that they were okay, not different "in a bad way", which also helped them feel reconnected socially.

This module item theme of experiencing understanding and empathy from others could be fundamental to what is intrinsically helpful for people to experience from others when recovering from mental health problems. Participants often spoke about this as central to restoring QoL personally and socially, as if it were a core need. They highlighted empathic understanding as part of the value of peer support, i.e., meeting people who truly understood their experience due to their own experience of mental health problems.

> WTS: "I think people in recovery need a lot of support. They need compassion and people who, at those times, are aware, they need to realise, that anybody could have a mental illness. Even the prime minister, the bank manager, the psychiatrist himself could have a mental illness. Yeah, with that understanding, compassion is what should flow out and not being judgemental. That's why, it's like that for you, that kind of a thing."
>
> CC1: "Support from family and friends. A doctor that understands mental illness, not just the medication side of things, the emotional and physical side of things and the communication side of things."
>
> WT8: "It was like connecting up with other people who had a similar experience to me. I found that really, really helpful, and being part of the *Young Voices Network* and things like that. I think that was really quite helpful for me when I was much younger, because I felt really isolated in my experience. So, I think some of it was meeting up

with other people who had similar experiences and being able to talk about things together, with people who understood."

PCL4: "The most effective worker I've ever had …was a worker at Framework when I stayed there for eight months, he just made me feel, like I was actually a decent human being, and I was normal. He, yeah, he brought me back into the fold of the human race again, in a sense; he was a doorway for me coming back to being connected."

As peer support workers, participants in the field spoke of how their experience of mental health problems led to greater understanding, empathy, and compassion for others. Through their own experiences of mental health problems, they felt an increased ability to engage with and support others in ways that either mirrored helpful responses they had received from others at times or were motivated by not having had those experiences from others when needed. This empathic ability to identify in part with the service user and their world, although more familiar and consistent among peer support workers, was not absent from other staff working in mental health services nor from being experienced within people's personal or social relationships and networks.

TC3: "One of the things I found, from my experience, and I know other people have as well, but not everybody, that I think is important. I think it might be similar, with physical health, when I think about it. But I am much more compassionate than I was before this. And that happened almost immediately. One of the reasons I started working in mental health was that I couldn't bear to think of people going through that type of pain and not getting what they needed. I just couldn't bear it. It's just like, "I have to make this work better. I have to make this easier for people. I have too … because it was just such a hard thing to survive and still is at times."

PCL4: “Sometimes it’s a person they feel as genuinely warm, that they have a connection with. So, someone who’s often, it’s a connection. It’s often a connection with a support worker. So, you allow someone in, to influence you, often because that person has, they’ve been genuine, they’ve been warm, they’ve shared a little bit of information about their own lives. That they they’ve deliberately chosen a job to shine a light for you, to show you the way.”

TC2: “I know what it is to be a disenfranchised part of the population. I have an affinity. I get, I understand it, at a deep core level. I get it, am I more compassionate? I would hope so. It’s an understanding, I think. I can’t actually even put that into words because I’ve lived my life. Came out when I was 21. I gave up drinking. Other things have happened. It marks you, in some way, it marks you at a psychic level in some way. I think you try, and I’ve tried, to put the silver lining on that. Otherwise, it eats your alive. So those things that don’t kill you make you stronger?”

Module item 3 – Belief in Recovery (MH 4)

This item emerged from the recovery theme “hope” during question writing; it was spoken about in varying ways during discussion sessions. The candidate item that asked about hope in one way, perceiving one had a positive future, correlated highly with several existing WHOQOL-BREF and MHRQoL candidate items. The two other items generated to assess the nuances of this theme operated as better measures of this aspect of MHRQOL, so they were included in the final module item selection during examination with Rasch analysis. The Hope facet descriptor was: “*Able to believe solutions or positive changes will happen in the future. Having an optimistic view of my future, believing recovery is possible.”*

Participants explained that a personal belief that recovery was possible for them was fundamental to their drive to seek recovery. Participants emphasised belief in recovery as also

necessary for recovery supporters to demonstrate to provide the type of support that better enabled their recovery.

Dissatisfying Experiences Associated with the Module Item: Belief in Recovery:

When speaking about the negative side of this module item theme, people spoke to the messaging they received at times, which made them feel that recovery was not possible, where a diagnosis had led to being told they had to accept a lower set of expectations in life. Discussions about the dissatisfying experiences associated with this theme included critiques of a service's orientation at times, not believing a person could fully recover. This mentality affected whether the person perceived it was possible to live life to its full potential.

Some participants discussed this theme as creating frustration and tension between how a person in recovery sees their capability and how a recovery-orientated service is contracted to deliver that service. Participants spoke about a longstanding lack of belief in themselves that had intensified during mental health problems; this reduced people's opportunities for recovery until resolved.

> AE: "I think it's a whole vicious cycle. For example, ...I was diagnosed when I was 17 and committed, and after six months, I was discharged into the care of my family with advice that a return to university would not be wise and independent living would not be an option going forward." …. "The other thing is, people say to me, "So and so's aspirations are to do, whatever, well, that's just completely unrealistic". But I think, when you look back at me, I was doing one paper per semester, you know so, if I had said "I want to do a PhD one day", I would never have said that, because I never wanted to do one. But anyway, people would have said, "There's no way", I was very, I don't think there was ever, any, belief that I, you know, would even complete a degree. "

TC3: “In the early days I believed in recovery. But I also believed medication works, completely. That was what I was told. “Take these you’ll be right.” And when that didn’t quite happen, I don’t know whether I assumed that, because I was certainly programmed that way. Or whether it’s kind of the innate message. But that it was my fault that the medication didn’t work, was really mine. It did work to a degree. But I guess it’s probably a bigger question, and this probably fits with the WHOQOL stuff, what is important enough in your life that makes it makes life worth living?”

KILGBT: “People having no, or very very little ambition, or belief that they can actually achieve things. I think it’s a personal, people put up personal shutters in front of themselves, which stop them going any further. “I can’t do this because I got a mental illness”. People being the mental illness, rather than being a person with a condition, so, people stopping themselves. And the real barriers now are there, but they put up their own barriers before they actually go anywhere. I think that is a very broad brushstroke, but I think that would apply to the majority of, or many of, the people that we work with, with a mental illness.”

The consequences of believing one frame of reference for mental health problems or recovery versus another can affect what people do to recover and can impact a person’s ability to recover their life following mental health problems. One participant discussed the confusion that can come about from exposure to a range of beliefs about mental health diagnoses and what helps recovery. Mental health problems were recognised as a social construct that does not exist, highlighting that it was not so disruptive to the lives of high-status people with mental health diagnoses. Another described it as akin to a medical illness requiring medical treatment, others as a healing experience from personal trauma or a spiritual crisis requiring a change of consciousness.

RCG4: “Sometimes I am thinking do I accept that I have mental illness, or do I just ignore it and say that there is no such thing as mental illness? You know? Stupefying medication, soul destroying medication, psychiatry, anti-psychiatry, who’s advice do you take on, what belief do you adopt? What belief do you want to have on life, yourself, other people, you know, things like philosophical groups, acting groups, you know, GROW, things like GROW, anxiety workshops, hearing voices workshops, you know? That kind of stuff you know?... If you want to recover, you can start with this idea there is no such thing as mental illness, and I am not mentally unwell. And if there is anyone, a suggestion from the outside that I am mentally unwell, that I am mentally ill, then you can internalise this idea. You can say to yourself, there is no such thing as mental illness, and I am 100% well. And you have that belief, and your behaviour is that your behaviour is like that, and your attitude is like that, and you surround yourself with people who are also healthy, smart and wise, or whatever, so then, you use the healthy and normal kind of doctor. You watch the movie *Beautiful Mind*, with Russell Crowe, and you see that other people who have this, they hear voices, in the past, have identified issues. You know presidents, and the artists, and the scientists, and the religious leaders, or whatever, and you can say well, you know, this is a bad scene uncovered, and you can basically *get* other people that way.”

Satisfying Experiences Associated with the Module Item ‘Belief in Recovery’

Participants also discussed the positive and satisfying aspects of this module item theme as closely tied at times to believing in oneself; without self-belief, it was harder to believe that recovery from a specific diagnosis was possible. Participants also discussed how other people believing that recovery was possible for them resulted in starting to believe that recovery was possible for themselves. Participants spoke about recovering their lives, and QoL was only possible once they had restored their belief in themselves.

Participants spoke of this module item theme in ways that described it as a predecessor to being able to take recovery steps, a springboard for the action phase of QoL change. Participants at other times referred to other candidate items as being linked to a belief in recovery, such as the determination to recover, personal growth and transformation, reducing the fear of relapse, and another module item recognising one has the strengths required to make the steps to recover. These were all associated with restoring QoL by working actively on their recovery.

> RCG3: "Knowing that I could, you might be familiar with the term, in my 'wise-mind' I knew that I could do it, and that I was, what do you call it, I was stubborn, that I was going to work on myself and make changes in my life that were important."
>
> KILGBT: "I think other people believing in them helps. I think if you have other people that believe that things could be different for their friends, their son or daughter, whatever, their family member, then that is a great help. Recognising there is a problem that needs to be changed, rather than, oh, this is just the way it is."
>
> PCL4: "So that trust, that somebody, allowing somebody else to believe in you; you start seeing people believing in you and being optimistic about your recovery. You start to take little steps for yourself, you'd try something ...push the envelope a bit."

Module item 4 – Self-Awareness (MH 9)

Developing insight or increased self-awareness was often discussed as critical to making recovery-orientated decisions or realising what actions one needed to take to improve one's QoL. Participants spoke about the need to understand themselves, make sense of their experiences, recognise where they may be holding themselves back, and realise what aspects of their stories and lives in the past led to the mental health or addiction problems they had been experiencing. Participants explained that these insights and awareness helped people to

reorientate towards moving forward, more confident that they had resolved the past conditions leading to their mental health crisis.

Participants also discussed other candidate items when speaking to this module item theme, such as fear of relapse, prompting more internal searching to prevent the patterns underlying their past relapses, and more insight into what was helping them to cope with symptoms and feel equipped to face the challenge of recovering their lives.

Dissatisfying Experiences Associated with the Module Item Self-Awareness

Those speaking about the negative dissatisfying aspects of this candidate item spoke about the times they had less insight about what was happening, had difficulties working things out, or did not know what to do about their distress during the acute phases of being unwell. Others spoke about it being a progressive process, evolving through therapeutic intervention or as a flash of insight when recognising something specific had helped them make necessary changes to recover their lives.

> AE: "I might be giving you the wrong impression because I don't, for me personally, I don't know if I have that awareness, when I'm unwell, it's only once I have the opportunity to reflect back, that I'm able to think, "Oh, that's what was going on". But at the time, I think, not."
>
> RC1: "It's hard to tell because I don't know whether it's, my experience of mental illness, that I notice, that causes that, or whether people's treatment of me, causes that. Do you know what I mean? I'm not able to step out of it, to be able to gauge that, but it definitely feels like people. Oh, it's hard to say, because I really withdraw when I start to have real difficulties. I withdraw from everyone and start to get a bit suspicious, and angry, and confused, and upset."

CM9: “At that time, I did not know why I was going through what I was experiencing, and it dragged on for so long. I don’t think I would have been much, in any kind of state, to give any kind of really good feedback.”

CM3: “Up north I had a manic episode in February. I had been very depressed for a long time, and I was in the wrong job, in the wrong relationship, in the wrong place, and disconnected from my family and from a sense of a real home. All of that (you unconsciously know what is going on) but it needed to be addressed and I was going crazy. I needed to leave that environment, go through that, suffer the anxiety, because I did not know where I was going. In hindsight, things had to be restructured.”

PC2: (*Context: parenting*) “That would be the knock-on result of my unsurety about going this way, and it was totally the wrong way. Or I’d go another way and that was another wrong way. Cause you know I’m lost on my own, trying to…you do what you can, but you can’t really look after anybody when you’re not well …but you struggle on because there is nobody. So, you know, lucky they made it, they are all alive, but you know…. they did, yeah, but we learned to cope with that. You can’t change those things, you know, just like old memories, you go back and relive them. But that’s past, knowledge is power I suppose.”

Another participant talked about how a perceived lack of insight was used within the service environment, at times, to explain a person’s lack of engagement in recovery-orientated interventions. Paradoxically, participants discussed a lack of insight as being helpful when pointed out by others if a person was operating in ways that were not beneficial to their recovery. Some participants described self-awareness as a gradual emerging process that could be gently recognised and worked with to help a person get more insight over time. Participants speaking about recovery supporters facilitating insight described the process as

compassionate with an unpressured understanding of the organic, emergent nature of insight and self-awareness, not one forced into being.

> PCL4: "Yep. That's, that's the: "you've got a lack of insight and I don't really think you have the ability to make these decisions". It's not with every psychiatrist. Some of them are very good. But yeah, people are alienated very often, more often than not, from the process. And they get confused when they're asked about medication, because it's like, well, that's what I come to you for, so you, *you*, sort that out. It's not a mutual process, you know?"
>
> PCL4: "Because, I think to myself, with psychologists, clinical psychologists, and psychiatrists, they should know more about the really bad pathology, you know, and [*name of support worker*] can help me with the social side of things. So, I kind of needed both those skills; someone to go, [*participant's own name*], "you can't quite see this yet. You don't have insight into these times when you become, "fuck everyone, I'm going to be fine", and throwing in the towel." So, it doesn't matter what they're called in some manual or anything, but, you know, its strong emotion, a strong reaction, and it has a strong effect on my life."
>
> PCL4: "And, it's yeah, just that some of the things we, you know, as he has really funny thoughts, what do we do? And I said, well, he does have some unusual thoughts and he does believe some of what we would call conspiracy theories, but he's functioning really well. He's actually quite happy. And he knows to stop after a while talking to certain people, because they'll look at him sideways. But, you know, it was: "is this an early warning sign of becoming really, really unwell?" No, because he's having these thoughts and he's actually sitting with them quite comfortably and he's tailoring who he's telling them to, and they're watering down. And so, he was actually becoming, he was actually seeing these things, and becoming open to other

people, talking about them. It was almost like it was considering the possibility that he might be wrong."

Satisfying Experiences Associated with the Module Item Self-Awareness

When speaking to the positive dimension of this module item, participants spoke about how gaining insight increased their motivation, engagement, and confidence to recover. Participants spoke, at times, about developing insight and greater self-awareness after trying many other things that did not help them to recover. Others described an insight that allowed them to work out what they needed to do to solve their problems in ways that enabled them to move forward in their lives differently.

Participants also discussed insight and self-awareness as being linked to an emerging realisation about how their mental health issues were the direct consequences of their historical life experiences. Making sense of the connection between past experiences and present distress helped them to feel more able to recover their lives or look after themselves to reduce relapse or patterns that led to their initial breakdown, allowing them to stabilise and improve their QoL.

CC3: "At a certain stage there I realised that there was nothing I could do, meditation or, there was nothing I could do, to get me well. I just had to take the pills, I knew I had to take it, because there was nothing, I could do to get myself well. So, I am about seven years of recovery now. So, I make sure I take my medicine every night. I do that and the next day it is ok, it was probably about seven and a half years ago that I knew I had to start taking the medication."

CC4: "You really, really need to be aware of yourself, to be aware, of what's acceptable in your life that's going to help you, and what's not anymore, and sometimes, just knowing your limitations, other people might be able to go on empty, for a long, long, time, to get things done, but, there's got to be a stop point, where you

stop and rest. And not feeling judged because you are in a situation where you're not able to do what you'd do normally if things are going fine. Its ok to say no, if you can't keep the pace with how other people live, and not feel bad if you have a day where you are just squashing around at home, doing your own thing, it is ok to have time out if that is what your body and your mind is telling you."

PC1: "And I didn't know that until now. That's why I had my breakdown. I thought I was all good. I was alright. I thought it was all normal. The era I was brought up in, that was normal, so everyone was doing it. Now that I reflect, I know that I grew up too fast. I was doing things way ahead of time, that I shouldn't have been doing. Because of my moko's and kids. Now I see that, man, I would not want them to be doing what I was doing. I want to be a good example for them. Someone to look up to. Especially after the breakdown. You don't want to be the person who broke down and went back to drugs. I want to be the one that is still trying hard."

Some participants felt that they gained self-awareness and insight from specific interventions. Other participants described obtaining insight from being given information about their mental health problems that helped them realise they had a name and a treatment to resolve them. Other participants talked about experiencing greater self-awareness and insight from observing the behavioural responses of others towards them.

KILGBT: "Well you are going back before then; it was actually putting a name to what it was. And it was, it wasn't actually, even though I didn't have the energy to get out of bed in the morning, I wasn't functioning in my family at all well. But until someone chucked a book at me and said, I think it might be a good idea for you to have a look at that. On the inside cover, it said there were 13 pointers toward depression, and I identified strongly with 12 of them. After that I realised that I actually had depression. It wasn't until I was able to put a name to what I thought I

had, that I could go to the GP and say, this is what is going on for me. So, it is actually really identifying that there is an issue first. Not just I'm feeling all this and not having a name for it. So, I had to, I couldn't be told. I had to discover for myself that this was the issue. So yeah, I imagine that is the first part of it. You need to know what the problem is before you can start resolving it."

RCG4: "Yes, internet also, *YouTube*, you can watch all these different diagnoses from DSM, Diagnostic Statistics Manual, you can watch all these things on the different diagnoses, that doctors give, you know. It's just like, I feel like it helped, from being heard. It is like, an information therapy, and basically when you read that, you say ok, so, I am just normal. I am experiencing some symptoms, they have a name for it, different symptoms, different names. I just feel normal, you know, within myself I feel like I am just normal. Because it is all written in there, so it is not my fault, you know."

RC1: "I certainly know that I'm coming to understand when I'm beginning to get stressed. And I don't notice myself. But I notice other people's reactions towards me changes. And that's when I think, "Oh my goodness, what's happening?" So, it's there, they start treating me differently, and that's when .... but that's at quite a late stage. Do you know what I mean?"

WT2: "I had to become ill to get the counselling that I needed, that showed me that it was that abuse that had either made me who I was, who had the breakdown … you look at that in hindsight, as an older person, through counselling. Because it's not going to come to you naturally. So, I definitely found that. And just speaking to friends of mine who said you know they are mentally ill, you start talking to them, and it is stuff that happened to you, when you were a child, that's coming out. It is that childhood trauma of some kind".

Other participants spoke to specific insights about things to watch out for in their internal world to ensure they did not go down a psychological path leading to a reoccurrence of mental health symptoms or had learned to name it for what it was.

> RCG6: "My inner relation … People talking and saying this about one another, experiencing that, but it doesn't exist anyway. Because when you get into your psychotic attack, paranoia sets in, and it is just paranoia."
>
> RCG2: "One thing that I have found is, I have to be careful about my thoughts. Because I do avoid any thought that would lead to a conclusion of paranoia. There are certain things that I have to avoid that are what I call the poisons of the soul: rage, hatred, bitterness, jealousy, envy, self-pity, and glory. So, I avoid any thoughts that lead there."

Module item 5 – Recognising Strengths (MH 5)

The strengths model is widely used in mental health services (Rapp & Goscha, 2006; Xie, 2013). When discussing this module item, participants stated it took time to recognise their strengths. Recognising their abilities and strengths helped them develop renewed confidence that they could set goals and take action to restore their QoL during their recovery from mental health problems. Participants spoke about needing to recognise that they had the capability, self-worth, and social value and that they could do something with their lives despite the changes that mental health problems had brought.

This recognition occurred in several ways: (1) others recognising and reflecting their strengths or capabilities, (2) encouragement to do the things they wanted to do, and (3) from achieving goals they had set. These experiences signalled to them that they could move forward in other's eyes; they still had innate capabilities to do something meaningful or purposeful with their lives. At other times, people spoke to the importance of recognising

these strengths within themselves, fully owning them, as integral to using them to move forward independently.

Dissatisfying Experiences Associated with the Module Item – Recognising Strengths

Participants who spoke to the dissatisfying aspects of the underlying theme of this item discussed what it was like before recognising they had any capability or strengths. Some spoke about the natural consequence of having a mental health diagnosis as incompatible with feeling resilient, energised, or in touch with having strengths. Participants described the state people can be in where resilience is very low, and the capacity to feel able to do anything could be non-existent or require minimal and simple activities at best. Discussion of this brought up the theme of another module item, the need for others to demonstrate empathy and compassion because of this, as well as the impact of setbacks. Participants also discussed this module item theme as a resolution to themes within other candidate items: fear of relapse or an uncertain future. Other participants spoke about how recognising their strengths was connected to relational processes reflected in module items such as understanding, empathy, people skills, and the capacity to relate.

> CM5: “Those personal attributes, like confidence that you mention, you know those are the things that go out the window when you have mental illness, confidence, self-esteem, the ability to walk out the front door and not think you’ve got horns out of the top of your head, everyone is going to see you. The ability to go to the supermarket. The negative thinking, because I mean, to me, depression is a very deceptive illness, because it tricks you into all sorts of states of negative thinking. Which are, that I find anyway, incredibly difficult to manage. So, all those personal strengths are just about gone, and then that has a knock-on effect, in terms of my physical wellness.”

KILGBT: “It would be something that happens along the way. It would be a belief that they can’t do it, and it would be having a few knockbacks and not having the resilience to go forward.”

PCL4: “But a lot of people, you see, they just don’t believe what they have to say is valid. And they’re not, this is not a process. Some people with really severe schizophrenia are not even in the room sometimes. The ones who are, tend to steer away from things they like, because the feeling of the people who’ve said they’ve had all these suicidal thoughts, severe schizophrenia, and command voices, and of reference and things of that nature, they are really struggling with that. They just want to connect with a couple of people, that they like, and that like them, and have something to occupy their time during the day, maybe a bit of gardening. Somewhere they can go that they’re safe, you know; their resilience isn’t great at the time. So that’s why they want to be around people who are kind and compassionate.”

Satisfying Experiences Associated with the Module Item – Recognising Strengths

Participants who spoke to the more positive and satisfying parts of this module item spoke about their experiences of suddenly recognising they had strengths. They spoke to the excitement and renewed energy this gave them to do things that inspired renewed hope and a positive outlook for their future. Participants described realising they had the power to change their circumstances for the better and could see that there were personally achievable ways to improve their QoL. Some participants described this as “getting themselves back” as if mental health problems took away their ability to recognise they had any strengths, skills, or capabilities.

Other participants experienced recognising strengths as a new type of self-discovery that opened a new pathway forward, one they had never tried before. Some participants recognised that public health promotions reflected this reality, that people with mental health

problems were not devoid of strengths and talents. These promotions helped them feel better about themselves or helped them feel that society recognised their capability and social value.

> RCG3: "It is like having your eyes opened for the first time. And you can think.'"
>
> PC1: "But now that I'm healing, I'm getting back to my old self as well, remembering who I was. I had strengths then as well, that wasn't the drugs. I look back on my life and I have heaps of skills, I just didn't use them in the right way. We've all got talents, and we all just don't talk about it together."
>
> PCL4: "I've seen people just get this, it's like a waking up of, I can do this. I think I can actually do this. And I like this. So, it's actually quite exciting, you know, yet for someone else, it has no meaning."
>
> PC3: "I found we have talents, and we are valued for these talents. It is just over the last…Sir John Kirwan and things like that. Talents, and we are not looked down upon so much."

Participants spoke about an initial recognition of personal strengths when discussing another candidate item, others reflecting their strengths. Participants explained the value of having someone who reflected strengths they saw in them and then encouraged and supported them to use those strengths. After this, they were able to see these strengths in themselves. Yet it was the latter module item theme that was recognised by Rasch analysis to be the better measure of HRQoL in the context of mental health recovery.

> TC3: "It is saying the right things at the right times that gives people strength and allows them to see themselves differently, that is what makes the difference. Where you go from being a victim, to being a hero in lots of ways. That you're not a broken person that needs to be fixed. You're actually a really brave soul that keeps getting up and trying. It's a completely different way of looking at yourself. I think having those messages and people around at those times, especially in early recovery, is one of the

most important things you can have. When people were saying things to you, like, "You're so strong. Wow. Not you're such a loser, you keep falling over. But wow, look at you. You keep getting up."

TC2: "And that's why you need that feedback from someone you trust to go, "Hold on a minute. Actually, you've done this, this, and this." And you go, "Oh yeah, that's right." "I've made kind of huge gains". It's actually good to remember that."

PCL4: "… connecting that person back to the skills they have internally, to awaken those up, get them believing that they're okay. Understanding that they're okay. And it's okay to have the …desire to grow a garden, or … be a good dad ... but not necessarily, work."

A participant also spoke to strengths modelling within a peer-to-peer relationship when mental health issues stemming from a physical injury led to a sense of conveyed resilience and support. The modelling of another person's resilience to a similar problem helped them cope better with what they were going through.

TC2: "…It also made me look at her differently, because she had a bunch of strengths that were just not even in the friendship that we had had, up until that point. So that's resilience. It's how she gets by and lives the life that she lives. So, she had a whole store of things, of experience, and knowledge, and wisdom, that she could give down the phone. Because she can't get out much either, for the same reason. She would communicate to me, that was of huge comfort. I knew she knew exactly what was going on for me. So, it was totally awesome."

Participants also discussed recovery as a process of harnessing the innate inner strength and resilience recognised as core to human survival. The ability to "bounce back" after a crisis. A capability that can sometimes be masked or lost by the idea that one is now different due to having had a mental health problem. Participants reflected on being able to

use positive identifying characteristics when speaking about themselves or defining themselves instead of using pathologizing labels or symptoms to define them after they were more aware of, or in touch with, their strengths. Participants also discussed recovering the quality of their lives by harnessing their strengths.

> TC2: "I like resilience because I think that's what you need to get through life. If you have learnt resilience, if you can learn to be resilient, that means that no matter what happens to you, no matter where you are on that, whatever it is, that you know that you're going to be all right and you know, change is constant. You might be shit today, but eventually, you'll be something else."
>
> PC 7: "You start to get your life back. I just said that word earlier, resilience. Bouncing back from it, bouncing back from a set-back, because we have all probably had setbacks. When I had a set-back, I have been called the black sheep of the family, yeah, or even in school, being in the special needs unit. I was even given labels. I was diagnosed with ADHD. I can be friendly, sociable, outgoing."

Module item 6 – People Skills (MH 12)

Participants described the ability to connect with others, communicate with, or relate to others as a significant issue they faced when recovering their QoL from the impact of mental health problems. Participants spoke about their ability to relate to others changing for the worse due to the impact of mental health issues. Other participants talked about how their mental health problems resulted in long periods of inner preoccupation, distanced them from their relationships with others for various reasons, and impaired their capacity to maintain valued social roles.

Participants who spoke about the positive aspect of this facet area described how developing interpersonal skills, rebuilding relationships, and experiencing social connection were integral to recovering their QoL. Restoring a sense of social connection from their side

of the interpersonal dynamic was a buffer to the isolating social consequence of stigma or lowered self-esteem from being perceived as different, as one participant described, “in not in a good way”.

Dissatisfying Experiences with the Module Item – People Skills

Participants speaking about the dissatisfying aspects of this module item theme described noticing their ability to relate to others had changed due to the specific nature of their mental health issues. Some people spoke about specific issues that resulted in a deterioration of their relationships or how their diagnosis or experience of being unwell led to new relational dynamics that affected how they could relate to others.

> AE: “I think, the main thing that’s effected is, how you relate to people. So, my personal belief is that regardless of symptoms of diagnosis, essentially, mental illness is where your ability to control how you think, and or how you feel, is compromised in some way. If you think about that ability to control how we think and how we feel, is absolutely essential to who we are, and to how we relate in the world. And how we relate in the world is essential to everything else. So then what happens, what you see essentially is, that your relationships break down in all the various areas of your life. And then the consequential impact of that is you have trouble in your relationships, you have trouble with looking after your children, you have trouble with work, and that kind of thing. But ultimately, it’s about those relationships breaking down because you’re not able to relate to people.”
>
> RC1: “When I’ve been in relationships and I’ve felt expectations from that relationship, I get anxious. And when I get anxious, I start to hear voices, and the voices can be quite detrimental about other people. So, every time that I’ve been in a relationship, I’ve ended up becoming unwell and it’s ended the relationship.” It’s

pretty hard to try and maintain a relationship when you're dealing with that kind of thing at the same time."

TC2: (*Context – addiction*) "So, you take yourself out of your life and your head is literally somewhere else. So, your body kind of walks around and engages. Meanwhile things fall around you and it's kind of harsh. Until you have something to value. For me, it was my physical health, but it was also relationships."

CM1: "The reason why I do have to break up with my partner is that it just gets too overwhelming to deal with. So, I have to send him away and he just has to stay in the background until I come right again, and we get back together again. We can't do anything, we can't watch a lot of things, we can't go out socially. If we go to a friend's house we have to make sure there is no women there that I am going to freak out about. Because if I do, I have been known to go off and try suiciding because the pain. It is so tremendous. And I don't understand, and I don't know how to control it."

Participants attributed their difficulties with relating to others as not only being due to how mental health issues were triggered within relationships or the impact of their issues upon their emotional state and capacity to relate. Participants also talked about the problems arising from concerns about how their diagnosis changed them in the eyes of others. The consequences of others knowing about their mental health difficulties led to changes in the relational dynamic with others, making interpersonal dynamics more complex for various reasons.

CC3: "I think I found it hard for the first four or five years, from 18–21, of being schizophrenic. When I first had schizophrenia I found it hard when other people knew I had schizophrenia. Earlier on, it was hard, to let them know. Initially in flatting situations, in the first four years, the stigma, was hard. Both getting it from people and feeling it inside myself."

RCG2: “Yes, years ago, I remember that the only friend I had in place, was an au pair. I felt I was totally terrified of anyone finding out that I had a mental illness”.

KILGBT: (*in relation to coming out)* “Most of us belong to a family of some sort. We’ve got mums and dads, children, parents, husbands, wives …being disconnected from those people is tragic, it really is. I suppose…if you have never had much family, then you possibly won’t miss it so much. But when you’ve been part of a wider family, and then you are rejected from it, that is horrendously painful. You pay a massive price for your honesty and integrity, by doing that. I don’t know that people realise the damage that parents, the rejectors, realise how much damage they do.”

PCL4: “I know for me, sometimes I haven’t had a rant at my parents. But now, you know, many years down the track, we’re talking, you know. It was 20 odd years down the track, since I was, just so difficult, self-destructive. I still don’t have the ability to have a bad day, around my mum or my dad. My mum freaks out, like, I’ll go home afterwards. She hadn’t said anything while I’m there. But she’d ring me up afterwards, and go, “what’s going on? Let me know. I want to help. I’m really worried”. And I’m just like, Oh Mum, “I’m just really tired”. So, when I mention something it’s “is he okay? Is he well? What’s going on?” So, you just don’t know who to trust, and you don’t trust yourself sometimes, and you sit back thinking is this the way it was always, you know. Can I get upset, about things? So yeah”

At times, participants discussed that their way of relating to people prior to the onset of mental health problems was, in retrospect, also part of their problem with relating to others after developing mental health problems:

PC1: “I didn’t care what people say about me, never. I don’t know why. I was just an arrogant person I suppose. I never cared until now. Now that I had a breakdown, all of a sudden, nobody was there. I had too much expectation. I thought they would hug

me, save me, and cuddle me all the way. It's a massive, unique quality of life thing for me, meeting people like this, because I don't talk to no-one. I don't have friends. I have massive barriers because I was losing people. But now I'm like, ok, I've been through that… and I can say it. I can see it now. Before, I just lived my life. I didn't care who was around me. Didn't look at anyone, it was just my life. Now it's like, oh, it's not just about me. So yeah, I'm thankful to be here as well".

WT3: "I used to get people really shocked to know that I had a mental illness, because I had this persona that I put out there. And I always came across as being capable and together. And they were astounded to find out that I had mental illness. They couldn't believe it. And I think part of what kept me separate from other people, was this persona, not being real with other people."

Participants sometimes discussed interpersonal dynamics as the source of their mental health issues. It could trigger setbacks or relapses if people related to them in ways that felt invalidating, disempowering, or unsupportive when they felt most vulnerable. Difficulties navigating interpersonal dynamics could compound problems relating to others or trigger a further escalation of their symptoms, creating maladaptive spirals that are difficult to resolve alone.

RCG3: "I was in, I have been in, relationships where I have felt totally isolated, even though I have, was, with someone else…I still felt that isolation. Where the other person was determined to say that "there was nothing wrong with me", that I was "just being silly" and "Pull your socks up", or "get yourself together", you know. I couldn't get out of that relationship because I felt totally controlled and it was life destroying. I spent most of my time in my bedroom, and I had children at the time too".

CM5: “I think relationships are the parts of my life that have been seriously damaged and have been very affected by depression and anxiety. It could have come from being in a marriage that may have not been the right partnership, because there was a lot of control and overbearingness. I don’t know, we achieved having three children, and two of those children have left. They have abandoned me because of my mental illness.”

CM3: “Relationships which were not really fitting had to change. Support relationships were crucial, and I had to get into the right centred relationships. And that is still ongoing, I know that there are still gaps there, but I am working on it.”

RC1: “My parents, I haven’t contacted them for the last two years. Because the last time I was put in hospital, my mother was just overly involved. When I didn’t want her to be involved. And it really hurt me that the mental health services kept involving her, when I said, “No, I didn’t want her involved.” And they, ignored my wishes, and it really damaged the relationship. So, I haven’t contacted them for two years.”

Participants also discussed the need to proactively change how they related to people close to them during their recovery from mental health problems. Recognising it was vital that they had authentic relationships with clinical and support staff.

PC1: “Because they wanted the unwell me, because I was providing them everything. I was supporting them. I was hindering them. And now that I’m recovering and slowing down, I’m like, no, no, you can take care of your own responsibilities. You are 25, stuff like that, you are moving out. They don’t like that one. And it hurts for me to have to do it. Feels really strange to have to, for me, it’s like kicking them out, like I’m treating them wrong. And I understand that point of view. Before this, I was like, what the hell, why are they judging me like this? It’s because they only knew me

with that, and then I came back different. And they like, who are you? So now I am starting to understand other people's point of view, instead of just mine."

KILGBT: "It's part of being, you know, we want to work, as support workers we need to be authentic, and our clients need to be authentic with us. But if there is a great big gap in the knowledge of a person, then they're not being authentic and so, they're not. But that's not comfortable for some people. Some people it is. So, it all comes down to that … being honest and open with your clinicians, or the people working with you, support workers, about who you are. So, that it's not a hidden issue, even a gender that you've got, that they don't know about. That is probably the main thing."

Satisfying Experiences Associated with the Module Item – People Skills

Participants speaking about the positive aspects of this module item discussed how learning how to relate differently and learning relationship and communication skills was crucial for rebuilding relationships, improving the quality of their relationships, and increasing their sense of social connection with others. Improving their interpersonal relationship skills helped them restore the social domain and relational aspects of QoL in other QoL facet areas, which aided their recovery. In this sense, this module item theme may highlight a way for people in recovery to build bridges to improve levels of social connection from their side.

As discussed in earlier sections of this thesis, this does not lessen the continued public health advocacy required in society to reduce the barriers of stigma, discrimination, and prejudice towards people with mental health issues. Social attitudes also need to change as they can maintain conditions for social isolation after the acute phases of mental health problems are resolved (Bigelow et al., 1991; Gordon et al., 2017; Onken et al., 2007, 2002). However, the theme discussed in this module item also supports service users to manage

interpersonal dynamics in the context of their presenting issues in ways that empower them personally when navigating the restoration of their QoL.

> CC6: "On my journey of recovery, I think one of the best things I have learned is communication, like carrying through the same kind of communication, and keeping that level, is very important, because there is so much disturbance in an illness, like schizophrenia, which I have just been diagnosed with."
>
> CC1: "Once you are on the road to recovery you sort of start to develop a respect for other people, so there is a less self-centred approach, and you start sort of showing respect and communication to others, feelings towards others, wanting to interact, and get out in the community, and do things".
>
> PC1: "Mine's different … It's *my* stuff that I have been hiding away. I don't talk to people. I don't get personal. I don't share all my feelings and that. So, in my recovery, those are coming out. Those special qualities and that. And people are telling me that and I'm like. Because for me it is touching, emotions are real, I don't really deal with them myself. But when I share with people, they tell me that it's real. OK this touchy stuff is not too bad, not too bad, (*laughs*). I will try it, it helps me. Because it releases some pain for me. Instead of taking a drug, I've noticed. Because I'm very selective, nobody gets close to me. Because for me, the barriers are to keep from being hurt. Yes, and it's good because it is with other people that don't know me. They can't come back into my life and my family life. So that's what I was thinking."
>
> T3: "I became a lot more accepting of people and all their eccentricity, and dark and light. And I think part of that was because, if I could accept that, then I could learn to accept it in me. And they could accept it in me."

The personal accounts of this module item theme show how profoundly mental health issues affect people's ability to relate, sustain, or maintain relationships. The issues

participants highlighted discussed how the capacity to relate to people can precede the mental health crisis or emerge as a product of it. When trying to cope and work out what is happening within, people can withdraw into their internal world and, as a result, experience a disconnection with others that can exacerbate feelings of not being understood, not belonging, or being accepted by others.

How others relate to people can change due to mental health issues, mainly if new ways of perceiving others and maladaptive ways of coping with internal distress have emerged during acute phases of distress. Participants spoke about how ways of relating to others and the felt sense of connection with people were a manifestation of, as well as a consequence of, mental health problems. The capacity to relate was spoken about nuancedly in Phase 1, beyond the facet item descriptors in the WHOQOL-BREF that ask about satisfaction with support from others. Participants spoke about this issue in more self-agency-oriented ways, referring to the ability to connect and communicate in an inter-relating way that felt satisfying from their side of the relational dynamic, irrespective of having sufficient social support from others.

Module item 7 – Making Progress in Recovery (MH 19)

This candidate item came from the recovery determinant hope. Hope was spoken about in nuanced ways during discussions so three items were generated to evaluate which was more aligned with the construct of HRQoL restoration and would measure MHRQoL better. Participants discussed this module item theme as both negatively and positively impacting their QoL. Participants discussed the dissatisfying aspects when describing the experiences of feeling stuck, not making progress, or making very slow progress. Participants also discussed what helped them to progress, what they recognised as signs of progress, and what they needed from others, services, and from within themselves to progress in their recovery.

Dissatisfying Experiences Associated with the Module Item – Recovery Progress

Participants discussed difficulties progressing in their recovery impacting their QoL in dissatisfying ways when they experienced the pace of recovery being slow, uncertainty about the recovery process, when negatively affected by those supporting them, when not offered the needed interventions to recover, and how the changing and evolving nature of recovery goals and needs also affected their QoL.

> TC3: "The early process of recovery is the worst by far. It's worse than almost being in the pit. Because you start feeling in, and you have glimpses of what it can be like. Like a sun lit meadow ... in the distance.... And then it goes away again. And that hurts worse than when you're just constantly in pain. I don't know if it hurts worse, you're just aware of how painful it is more. So that's the hardest bit."
>
> CM1: "My recovery is very, very slow in five years. What I do, it has come to the fact that what has happened to me as a child, I have remembered, when I was in my fifties. So, I did not remember anything before that, so everything started to come back when I went to counselling. It just seems to fly out of you, the memories. And from there I became a victim. I really, I didn't start out in a victim attitude. I found that you can very easily get into being a victim and to stay in that. But you have to move on from there, and try to figure out how to move on, and put that all behind you. It is a process; it is very hard. Up and down, every day you go through a roller coaster from suicidal, to being on top of the world, and then back down to settling down for a few days, it's just all over the place."
>
> WT8: "I think perhaps, then, in terms of what stuck my recovery process was perhaps people who were supporting me around me. My family and stuff, not willing to take chances, or perhaps try different things, to see if this was going to be helpful or not. It was very much like a process of restricting what I would like to be doing. Whether

you should've been doing it, because maybe it would be too much pressure for you. I would get that going to university for a period of time. Because professionals thought it was too much for me to handle those sorts of things. And people not willing to give me a chance to try and learn from things. You know, it was like a very protected place where things were coming from, I think. I think that environment, for me, kept me in a stuck position for a while."

PCL4: "When I was a kid, when I was about 15, I was prescribed my first antidepressant for six months... I was lucky. It was great. ... I dealt with a psychiatrist at that time. And he said, "look, you know, these behaviours have been really hard for you. What's been happening in your life and that's been happening since you were about six or seven years old, from what I can gather from your parents. So, for me you would have been in intervention at a much earlier stage." Because then they would have possibly asked me questions around abuse, try to find out about that. So, for me, it would have been, you know, about child services getting involved. Like child and family becoming involved at a much earlier stage. So, I think it definitely would have helped; because as soon as I started to get help, I've changed drastically, because I was open to it. I'd just been through so much suffering, you know, that I was ready for it. So, from a sort of retrospective view, earlier intervention for me may well have helped. If someone had been really skilful, shown care, been warm and genuinely interested in me, I think they could have sped the process up for me."

Participants spoke about how a recovery-orientated system was sometimes a barrier to people's recovery because it felt over-controlling or as if it was dominating a person's recovery process. The system was described as a barrier to recovery progress if staff-imposed limitations on people or had low expectations of what they could achieve once they had experienced a mental health crisis. Peer support participants also highlighted the complexity

involved when attempting to fully support a person's recovery within a system with limited resources and contractual frameworks that can be proscriptive or limited in how they can collaborate with a person during their recovery.

> RCG4: "It is a kind of the 'sickness industry', mental health, mental health centres, like here you know we have these houses, *names them*. It's all like a kind of sickness area. Sometimes I think like, first, they have to make it real, so they can focus on the issues, and you can come out healthy in the end. Like first when you have a psychotic episode, or nervous breakdown, and actually then, they help you, if you want to learn something, you have to fail at it first, so that you can learn from the mistake."
>
> AE: "Personally, I think we have very low expectations. And I kind of see this continuum, if we talk about the process of recovery what are we going from and to? We're going from being clinically managed essentially, most of the time, to being self-managing, but that will be the ultimate, but we don't do that. We support people to get maybe to the middle and then we think that's recovery. So, where, you know, a person is in a flat by themselves with no job, under a community mental health order, compulsory treatment order, and that's recovery, and we think that's good, and we'll just leave people like that. And then we'll ask them, "What do you think about it?" Because they have the same low expectations as everyone else, they'll say, "This is fantastic" and then we go, "Yay, we're brilliant." I'm highly critical of supported employment services because I think you go there and get a job at *Pack'nSave* and why do we think that's a success? You know, I'm sure a lot of people worked in *Pack'nSave,* and that might be very good for them, but if you're a person with an experience of mental illness, still, in this day and age, your life is very limited, because of the expectations of everyone really."

KILGBT: “I think, in services, we have, in the past, had an open-ended expectation. There is no closed end, no end date. I think nowadays we are telling people, hey, we want to be with you for a year or 2 years, and then we want to get out of your life. We don’t want to be here forever. I think that is a really important message we need to get over; we are not here for the rest of your life. And some people are really shocked, some people who have been told, hey, you’re not here for life, your CSW [community support worker] is not going to be coming around for the rest of your life, you know, it’s time-framed.”

PCL4: “So the way services are delivered are almost delivered with a different value base or a different objective. It’s not to actually resolve all the issues for the person. That’s just to sort of get them into a place where they can get them out of hospital. So, to get some kind of stability going, but not to resolve the actual issue? It doesn’t, it doesn’t fix the underlying issue. So, the person is not treated as a whole, you know, it’s expensive, it costs too much. It takes too much time. Yeah. And that’s what, what people are saying. It’s just, it’s a scarcity of resources and, you know, the inability to attract those funds.”

Satisfying Experiences Associated with the Module Item – Recovery Progress

Participants who spoke about the positive aspects of making progress in their recovery spoke about identifying times of being well compared to times when they had relapsed, describing recovery progress as not being steadily progressive. Once they recognised that relapse or setbacks were part of having their mental health issue, participants changed how they managed their lives to better fit with the changeable features of their diagnosis and their personal limits; this helped to restore their QoL.

Participants spoke about achieving milestones and seeing that they had made recognisable progress gave them hope that further progress was possible. Participants talked

about resolving prior barriers to recovery assisted recovery to progress, as it enabled them to restore meaningful aspects of their lives, improve their functioning, and regain a sense of purpose. All of which improved their QoL.

Some participants spoke about recovery progress in terms of moving forward and making changes. Others equated progress with times of stability where there was no change; the turbulent effects of mental health issues on QoL had ended. In essence, Participants discussed making progress in recovery as restoring their lives in ways that were satisfying to them, at times better than they had been before, at others, better than when they were unwell.

> AE: "Yes, but my illness is very episodic, so I get on well, I recover, I get unwell, I recover, I get unwell, I recover. So, it's not a constant thing, and as I say, my life is very controlled and very managed in order to be well. Predictable in the sense of, when I lapse in terms of being as controlled and managed as I should be, that's when I get on well. I could probably be well 100% of the time if I was consistently 100% controlled and managed, but I'm not".
>
> CM9: "I don't know, I think it was just the little milestones, just little milestones that kind of got knocked off, you know, one at a time, and just got back some kind of normalcy, in grades, I guess."
>
> RC1: "Recovery is being able to do what everybody else does: to work, to earn a decent income, to have fun, to be healthy, to have beliefs, my own beliefs, be respected for my own beliefs, be part of the community. So, like, not to be afraid to just live, because with things like, having a bout of mental illness, your neighbours notice, the kids on the street notice, and you get teased and shunned, and it takes quite a long time, to build up those relationships again.
>
> "What have I recovered? … I think I've gained some valuable knowledge and experience about the mental health sector. Growing up, I never had a sense of things

that things were going well, ever. So, it's not something that I've returned to, do you know what I mean? Which is why it's quite exciting now because I'm finding things that help me and support my recovery. Whereas for many years I didn't have that. And now, I'm more hopeful about my recovery. But it's taken many, many years. Which I think is quite parallel to what people would normally experience without mental illness, you know, for my age and stage, I think. Yeah. I feel like I'm catching up now. Yep. Definitely. It's a more of an equal playing field."

CM3: "My life has been re-engineered, and I think that is the reason it has subsided, I got a sense of meaning back in my life, a new direction, towards mental health and support, and away from making money for shareholders, (*laughing*). You know, that's the change that has taken place, mostly in the last two years, while I was going through this so-called mental illness. The healing that needs to be done. When the healing is done, then what? So, for me, it is support, its challenge, and its creation, at the end of the day, of something meaningful."

Some participants highlighted that recovery progress was stimulated by specific interventions or support from social services, returning to work, secure housing, or making more progress once underlying trauma that predisposed them to their problems was resolved.

CM3: "I got a lot of support from the mental health system. Medical side, the counselling side of it, and the peer support side of it, family. I would not be here without family and without the system".

RC1: "I did EMDR, [eye movement desensitization and reprocessing] which is a type of talking therapy. I had a few sessions of that, and that really helped. The mental health service would say that I've been taking regular medication, for a couple of years now, and that would have helped. I've had work. That helps as well. Yeah. Definitely the accommodation one, stability of accommodation has really helped".

KILGBT: “I think that the chemical fix has sort of held me in good stead ever since. I did a six-month course at AUT [Auckland University of Technology], then I was able to get gainful employment as a support worker, or work with IHC [Intellectually Handicapped Children’s Society]. When I moved on from there, I got work in mental health, as a mental health worker. With all of these jobs came self-belief. And working as a CSW, I was exposed to a whole wealth of therapies, CBT [Cognitive Behavioural Therapy], DBT [Dialectical Behaviour Therapy]. I think I have been in a therapeutic environment for such a long time that I have absorbed some of those good ideas ...they’ve been undoubtedly massively important in my recovery.”

PCL4: “Housing and connection to the community. I think connecting them to the community is hugely important, through support workers, consistent work on evidence-based talking therapies, given by someone they have a connection with … or whether that be a group, getting more talking therapies, and dealing with trauma”.

Conclusion

This chapter reviewed predominant themes from Phase 1 reflected in the module items identified in Phase 2 as suitable measures of HRQoL in the context of mental health recovery. The first-person accounts highlighted how these items work well together in the module and may be expressed in unique and varied ways when processing results with people in recovery. Participants discussed how existing generic QoL facets assessed in the WHOQOL were involved with restoring QoL during their recovery and how these more specific MHRQoL items themes were central to recovering their lives from the impact of mental health problems. The following chapter discusses the overall results of the current research and how these results compare to findings in other MHRQoL PROM development research and conceptual models of personal recovery.

Chapter 8

General Discussion

and

Conclusions

General Discussion

The current research aimed to identify personal recovery items that could operate as an adjunct mental health module for the WHOQOL-BREF to improve its precision as a mental health recovery-orientated PROM. This chapter reviews the results of the qualitative and quantitative phases of the current research that led to the achievement of that aim. The chapter then explores the final results against seminal research findings about MHRQoL and personal recovery constructs. The general discussion section ends by examining the utility of using the WHOQOL-BREF with the adjunct MHRQoL module as a PROM in mental health services. The chapter culminates with a discussion of the limitations of the current research, recommendations for further research, and concludes with a final overview of the research through to the final results.

An Exploration of Phase 1 Results

Phase 1 used qualitative methods to identify personal recovery determinants that effect the QoL of people recovering from mental health problems. Coders identified MHRQoL themes within 23 semi-structured discussion meetings with key stakeholders. The Phase 1 method then invited participants to complete two importance rating exercises that provided an opportunity to gather individualised MHRQoL data from all 88 participants.

Content and summative frequency analysis of discussion data and triangulation of this data with importance rating data highlighted the more frequently mentioned personal recovery experiences that affected the QoL of people with lived experience (LE) of mental health issues. The results from Phase 1 identified 24 personal recovery themes frequently identified within the international personal recovery literature as relevant to include in PROMs for people recovering from mental health issues.

Connell et al. (2012, 2014) used a similar methodology, where potential MHRQoL themes sourced from the personal recovery literature were verified by participants with lived

experience of mental health issues in non-cued interviews to identify potential domains for a later developed MHRQoL measure, the ReQoL (Keetharuth et al., 2018). Mental health service users advised adding physical health to the previously identified six MHRQoL domains sourced from the literature (Connell et al., 2018). The MHRQoL findings from the current research compared with Connell et al.'s (2014) MHRQoL findings and the content of the ReQoL measure (Keetharuth et al., 2018) are discussed later in this chapter.

Phase 1 participants confirmed the relevance of the generic WHOQOL-BREF items by completing an importance rating exercise. Participants rated the WHOQOL-BREF facets on average between 3.23 and 4.21 on a 5-point Likert scale of relevance to their recovery, where 3 represented moderate, and 5 represented extremely important to their personal recovery experiences. LE participants and recovery supporters differed on average in their rating of only one item. LE participants ranked the relevance of bodily appearance higher than recovery supporters. Although this exercise was not a validation study, it indicated that the WHOQOL-BREF had sufficient face validity to be used within Phase 2 with New Zealanders with lived experience of mental health issues. The results of this exercise aligned with previously summarised international research findings, identifying the WHOQOL-BREF as having suitable generic HRQoL item content for mental health populations.

The effect of mental health issues on QoL was discussed in 91% of the total sample and 100% of LE discussions. The first-person accounts outlined in Chapter 7 highlight how the onset, treatment, and course of mental health problems severely impacted QoL in multifaceted and individualised ways. Symptoms and the consequences of mental health problems profoundly impact many facets of QoL, such as subjective well-being, personal identity, relationships, the capacity to work, study, accommodation, and social engagement within the community. The issues participants discussed in Phase 1 were not different to the findings of researchers who have examined how mental health problems affect QoL, as cited

in the literature review, for example, Bigelow et al. (1991); Connell et al. (2012, 2014, 2018); Chiu et al. (2010); Keetharuth et al. (2018).

The percentage of LE participants who chose each of the seven Phase 2 module items in the Phase 1 importance rating exercise were: (1) belief in recovery (78.2%), (2) understanding (76.4%), (3) acceptance and adjustment (69.1%), (4) self-awareness (70.9%), (5) recovery progress (67.3%), (6) identifying personal strengths (61.8%), and (7) people skills (52.7%). The percentage of Phase 1 discussion meetings that included mention of the final seven module items identified by Phase 2 analyses were: (1) acceptance and adjustment (100%), (2) understanding (100%), (3) self-awareness (100%), (4) recovery progress (100%), (5) belief in recovery (81.8%), (6) identifying personal strengths (63.6%), and (7) people skills (63.6%). Therefore, more than 50%–100% of Phase 1 discussion sessions and individual participants in the importance rating exercise identified the themes underlying the seven module items in Phase 2 as being central to the restoration of their QoL during their recovery. This indicates reasonable concordance between Phase 1 and Phase 2 results.

Discussions with LE participants provided a context for why the hope questions within the final module, “belief in recovery” and “recovery progress”, were essential to MHRQoL. When other people believed in their capacity to recover and when they themselves believed they could recover, they felt more hopeful about their future. Participants explained that after losing significant parts of their life and well-being from mental health problems, a belief that recovery was possible restored their faith by reframing the QoL disruption brought about by mental health issues as a temporary change, not a permanent one. Identifying clear markers of progress reinforced this faith that things could get and were getting better, thereby increasing their confidence and self-efficacy that they could recover.

Holding hope for people, helping people to believe recovery is possible, and a regular reflection on progress are parts of a recovery-orientated approach that can be fostered within

service environments to improve recovery outcomes (Deegan, 1988; Deegan, 1996; Deegan et al., 2008; Farkas, 2007; O'Hagan, 2001, 2002). Targeting improvements to quality of life is recommended for people with mental health issues including those with chronic functional disability and residual symptoms (Defar et al., 2023; Mayer et al., 2021). The literature review highlighted that the value of focussing service delivery on QoL improvement can avert recovery from being defined in ways that people with more chronic symptoms may not fully achieve, whilst retaining the capacity for recovery goals to be individualised and driven by service users.

Connell et al. (2012) discussed the loss of hope brought about by a mental health crisis is akin to a feeling of profound demoralisation. Connell et al. (2012) described how a person feeling this level of hopelessness starts to present in services: "The demoralised person clings to a small number of habitual activities, avoids novelty and challenge, and fears making long-term plans. This feeling of demoralisation further impacts upon ill-being and, if untreated, leads to chronic distress and possible suicide" (Connell et al., 2012, p.14). Using the WHOQOL-BREF and MHRQoL module during recovery assessment and planning can facilitate a process that keeps hope alive by identifying those with lower QoL, investigating and resolving underlying reasons for lower QoL, and finding ways to reinvigorate hope.

Participants outlined that mental health problems can result in social disconnection, difficulties performing social roles, and disrupted relationships. Participants discussed the importance of social connection being reciprocal; wanting understanding, compassion, and empathy from others, as well as the ability to relate to others in ways that restored social connection. Disruptions to subjective well-being brought about by mental health issues, along with people relating to them and perceiving them differently as a social consequence of these problems, contributed to a more profound existential disruption to their sense of self and social identity. Participants described this profound disruption as surreal, an existential crisis,

"almost spiritual," requiring a deeper level of relational support and compassionate understanding from others. The relational items in the MHRQoL module (MH9) understanding from others and (MH12) people skills were discussed by participants in Phase 1 as helping to rebuild lost confidence, restore a sense of being socially valued and a positive personal and social identity, once they had reconnected with others in satisfying ways.

Systematic and narrative reviews of mental health recovery reported that disrupted well-being, changes to one's sense of self, interruptions to relationships, role functioning, one's orientation to the future, and disconnection with the broader community, were among the commonly cited issues important to resolve during mental health recovery (Andresen et al., 2003; Bonney & Stickley, 2008; Collier & Grant, 2018; Connell et al., 2012; Jacobson, 2001; Leamy et al., 2011; New South Wales Community Advisory Group, 2009; Onken et al., 2002, 2007; Ralph & Muskie, 2000). The WHOQOL-BREF with the MHRQoL items could support the identification of and the ability to target these issues for resolution when it is used as a PROM in mental health services.

An Exploration of Phase 2 Results

Phase 2 used quantitative methods to collect and analyse MHRQoL data from a 55-item HRQoL survey within a larger sample of 389 LE participants and a comparison group (278 participants). The individual performance of each of the 24 candidate MHRQoL items generated from Phase 1 themes was analysed using both CTT and Rash analysis methods. The specific CTT criteria and Rasch methods used in Phase 2 were proven effective for identifying module items in previous NZ WHOQOL research when developing the NZ national items (Krägeloh et al., 2015, 2016). CTT analysis removed items that did not differentiate between the comparison group and those with mental health problems or were redundant in the presence of existing WHOQOL or other candidate items. The following items: MH13 (work confidence), MH8 (coping), MH15 (hope), MH10 (alternative health

care), and MH21 (social networks) were found to correlate too highly with existing WHOQOL-BREF items. The item MH6 (spirituality) did not discriminate between those with and without mental health problems. MH1 (Mental Health G-item) served as a construct variable.

After CTT analysis, 17 out of 24 candidate items from Phase 1 showed signs of being MHRQoL items as they did not duplicate any existing items in the WHOQOL-BREF or other candidate items. Final module items that correlated more highly (over the cut-off of >.30 at >.50) with the research construct variable of MHRQoL during CTT analysis were MH4 (recovery beliefs), MH5 (strengths); MH11 (acceptance and adjustment); MH18 (understanding), and MH19 (recovery progress) – all of which also met internal consistency criteria to show alignment with the MHRQoL construct in later Rasch analysis.

The 17 items that met CTT criteria were subjected to further item analysis within 12 iterative Rasch analysis steps that progressively assessed each item's measurement properties. Phase 2 criteria eliminated items with residual correlation and problematic measurement irregularities. Phase 2 Rasch analysis identified the cluster of items that had the best measurement capabilities individually and as a functioning module. These seven items best measured the core construct of MHRQoL, with no evidence of problematic functioning with demographic variables, or measurement problems, and demonstrated evidence of being suitable for use when analysing outcomes within individual and large aggregated datasets.

Seven of the 17 candidate items retained after CTT analysis met established Rasch criteria. The items enquire about: (1) acceptance and adjustment, (2) feeling empathically understood, (3) self-awareness and insight, (4) belief in recovery, (5) identifying personal strengths, (6) the capacity to relate to others, and (7) making recovery progress. The result of Phase 2 found that these seven items were best suited for an MHRQoL module for the WHOQOL-BREF.

The elimination of 10 items through Rasch analysis does not reduce the importance of the issues underlying those items. The eliminated items asked about the Phase 1 themes of MH2 (loneliness), MH3 (personal growth), MH7 (determination), MH14 (fear of relapse), MH16 (peer support), MH17 (goals), MH20 (others recognising your strengths), MH22 (discrimination), MH23 (boredom) and MH24 (exercise). These personal recovery factors were identified as determinants of personal recovery in the international mental health literature and were often chosen and discussed as effecting MHRQoL by Phase 1 participants. Phase 2 Rasch analysis investigated the candidate items that assessed these issues to examine their measurement properties as potential questions for inclusion in a mental health module for the WHOQOL-BREF. These items did not meet Rasch analysis criteria for inclusion.

The current research approached the question of what is important to HRQoL and the question of what items to include in an HRQoL measure as two separate issues. Phase 1 identified 24 themes essential to include in a MHRQoL module by using qualitative methods, i.e., frequent endorsement in the literature, frequency of mention in discussion, frequent selection in importance rating activities, and through triangulation analysis during Phase 1.

Phase 2 used a robust quantitative approach, i.e., well-established CTT and IRT item analysis methods, to investigate the measurement capabilities of the 24 candidate items to consider which items to include in the MHRQoL module. Rasch analysis investigated each item individually and the performance of the items together as a group. The Rasch model fit statistic evaluates item selections to ensure a good spread of difficult and easy-to-answer items within a measure designed to assess a latent trait. This results in retaining some items and eliminating others due to how well they met IRT measurement criteria. The relevance of the underlying themes of the eliminated items to people's MHRQoL or personal recovery process remains, irrespective of the items' less suitable measurement properties.

An example of how a recovery theme can be essential to include in a recovery measure, yet an item to measure it discarded, was highlighted in the current research. The personal recovery determinant *hope* has been identified as essential to mental health recovery in the literature (Bonney & Stickley, 2008; Connell et al., 2012; Ellison et al., 2016; Liu et al., 2015; Mousa, 2011; Resnick et al., 2005; Siggins Miller Consultants, 2003). SAMHSA's 10 recovery principles contain hope, as do local mental health measures in NZ (Gordon & Ellis, 2013; Gordon et al., 2004; Lapsley et al., 2002). Hope was talked about in 81.8% of LE discussion groups and chosen by 78.2% of LE participants in the Phase 1 importance rating exercise of the current research. The current research asked about the hope theme in three different ways to best represent how LE participants discussed how hope affected MHRQoL.

The hope card sort definition was: "Able to believe that solutions or positive changes will happen in the future. Having an optimistic view of my future, believing recovery is possible." The question-writing team phrased the three items to assess hope to evaluate how best to measure this theme. The items were MH4: "To what extent do you believe you can recover from illness?" MH15: "To what extent do you feel positive about your future?" MH19: "How satisfied are you with your recovery?" MH4 and MH19 met Rasch criteria for inclusion in the module, yet MH15 did not. Not because the hope theme or feeling positive about one's future was not necessary to recovery. MH15 item was identified as redundant in CTT analysis as it correlated with three existing WHOQOL items (one also exampling the positive feeling of hope in the facet descriptor), one NZ national item, and two existing candidate items. The items evaluating the themes of believing in recovery and making recovery progress were identified as better measures of the personal recovery determinant hope within the research sample during IRT analysis. That MH15 correlated highly with Q.6 in the WHOQOL-BREF, incidentally, maintains three ways to assess hope when using the WHOQOL-BREF with the MHRQoL module as a PROM. Conceptually, the future may feel

more positive if you believe you can recover and see that you are progressing, making MH15 redundant to include as an additional module item when covered by the existing WHOQOL-BREF and other module items.

Loneliness, despite being cited in the mental health literature as negatively impacting mental health outcomes (Ebesutani et al., 2015; Wang et al., 2020), can also have a variety of causes. The WHOQOL-BREF and MHRQoL module items can assess the underlying issue of social disconnection within different items. Loneliness can affect many people at episodic times (Hawkley & Cacioppo, 2010). Even though social connection is vital to health and emotional well-being, loneliness cannot be assumed solely by social isolation or demographic characteristics alone (Ortis-Ospina, 2019; Yanguas et al., 2018). Other items that could potentially resolve the type of loneliness for people in recovery that negatively impacts QoL could have operated better within the sample, such as the relational questions that help to rebuild social connection, i.e., being able to relate to others, satisfaction with personal and family relationships, and being empathically and compassionately understood.

That the stigma and discrimination item did not meet Rasch criteria does not mean that this issue is not crucial to identify and address within mental health recovery. Many researchers have identified this in the literature (Clark et al., 2018; Collins et al., 2012; Davidson et al., 2001; Rabkin, 1972, 1974; Rössler, 2016; Stuart, 2006, 2016; Wrigley & Dawson, 2016), hence its inclusion as a Phase 1 importance rating and as a discussion code. Stigma and discrimination also affect the well-being of other populations (Chambers et al., 2015; Matheson et al., 2019; Pascoe & Smart Richman, 2009; Pelleboer-Gunnink et al., 2019; Stangl et al., 2019; Van Brakel, 2006; World Health Organisation Quality of Life Instrument HIV Group, 2003). However, in the current research sample, the item was more relevant to the mental health subsample than to the comparison group. Conceptually, the module item targeting the theme of *understanding and empathy*, a relational acceptance item, may have

performed better in the sample by asking a well-being orientated question that had a broader application and could address the resolution of social marginalisation and disconnection in a more solution-focussed than a problem-focussed way.

In conclusion, CTT and Rasch analysis identified the final seven items as ones that can measure the construct of MHRQoL within a sample of people recovering from mental health issues. This result does not signify that these seven items are the only issues that can impact HRQoL during mental health recovery. The interface between the restoration of mental health and subjectively assessed QoL is dynamic. All items within the existing WHOQOL-BREF can be linked to the MHRQoL of people in recovery when used as a PROM for this population, as identified by the reliability and validity of the WHOQOL items for people recovering from mental health issues previously cited in the literature review.

Phase 2 methods eliminated items that highly correlated with items already contained in the WHOQOL-BREF or existing module or were unreliable for use in larger aggregated data sets. It is critical to emphasise that eliminating items through CTT and Rasch analysis is not an indicator of the importance of the underlying issues that these items represent during a person's recovery. These items can still be used as individual MHRQoL items if people want to track progress or work on those issues during their recovery.

Personal Recovery Research

Connell et al. (2014) stressed the importance of including items about ill-being within QoL measures for this population to validate the negative experiences brought about by mental health issues. The WHOQOL tools are positively framed well-being measures; however, they include items that measure ill-being and the negative consequences of health problems on QoL (Skevington et al., 2004b). The current research included ill-being code book themes in Phase 1 and candidate items for the MHRQoL module that assessed ill-being in the Phase 2 survey (mental health problems, stigma, boredom, and loneliness) along with

existing WHOQOL-BREF illbeing items (mood disturbance, pain, needs for treatment) and ill-being can be assessed when evaluating participants' low results on QoL facets relevant to their recovery (such as work, finances, health service access, social support, safety, energy, functioning, concentration, sleep, self-esteem, or any QoL facets they identify as relevant).

Several researchers have validated the WHOQOL-BREF as a reliable generic QoL measure for use with people with mental health issues in different countries and across different types of mental health issues (Akvardar et al.,2006; Berlim et al., 2005; Garcia-Rea & Page, 2010; Ohaeri et al., 2007; Skevington & McCrate, 2011). The WHOQOL contains items that can measure ill-being directly when asking about the extent of adverse experiences such as negative moods (depression, anxiety, despair, blue mood), pain, and the need for medical treatments. Ill-being, including risk of suicide, can also be explored by examining patterns of low QoL ratings within the WHOQOL (Alves et al., 2006; De Abreu et al., 2007; De Freitas Melo et al., 2022), as each item contains a Likert continuum of response options from low to high QoL (Skevington et al., 2004b). Discussions between service providers and service users about their QoL ratings can improve psychological well-being and the monitoring of issues that impact upon an individual's QoL (Llewellyn & Skevington, 2015).

Routine use of QoL measures can monitor changes in well-being and can offer opportunities for intervention (Alves et al., 2016). A QoL assessment can function as a recovery needs assessment; lower QoL ratings can identify issues for redress within recovery goals and intervention plans (Andrews & Rowthorn, 2013; Awad, 2016). People's low responses to items within the WHOQOL-BREF can provide evidence of the consequences of ill-being on QoL, which is lower for people with mental health issues compared to those with other health conditions (Böckerman et al., 2011; Mayer et al., 2021; Skevington & McCrate, 2011). Low QoL and the severity of unmet needs in mental health service user populations

are inter-related; addressing unmet needs can improve subjective well-being and QoL (Fahy et al., 1999; Fleury et al., 2013), which can also support recovery (Keetharuth et al., 2018).

Connell and colleagues published several articles identifying personal recovery determinants affecting QoL (Connell et al., 2012, 2014, 2018). The themes discovered from their investigation of the personal recovery literature were verified by mental health service users and informed the content of a MHRQoL measure, the ReQoL (Keetharuth et al., 2018). Connell et al. (2012) reviewed the personal recovery literature and identified central themes within personal recovery narratives. They found six core domains of QoL relevant to mental health recovery: (1) activity; (2) belonging and relationships; (3) choice, control, and autonomy; (4) hope; (5) self-perception; (6) well-being; and (7) a seventh issue of physical health identified from later interviews. These seven domains were identified as relevant for inclusion in a QoL measure for the mental health population (Connell et al., 2014, 2018).

The WHQOOL-BREF with the adjunct MHRQoL module can operate as a personal-recovery-sensitive PROM during mental health service evaluation, research, and individual recovery planning and reviews. The following paragraphs will explore whether items in the WHOQOL-BREF and adjunct MHRQoL module can assess the seven domains of MHRQoL that Connell et al. (2012, 2014, 2018) recommend including in an HRQoL measure for this population.

Connell et al.'s (2014) first domain (activities*)* includes leisure activities, everyday activities of life, work activities, and meaningful activities that relieve boredom, provide distraction, and improve QoL. The WHOQOL-BREF contains items that ask about activities of daily living (Q17), work (Q18), leisure activities (Q14), as well as life enjoyment(Q5) and the meaningfulness of life (Q6). The MHRQoL module does not ask about activities directly, however, Phase 1 participants explained how recognising skills and strengths (MH5) helped them to become more engaged in recovering their lives, which could invite new activity.

Connell et al.'s (2014) second domain (relationships and belonging) included social belonging, the quality of personal relationships, and acceptance and understanding from wider society, as opposed to disconnection, stigma, and critical judgemental relationships that lead to loneliness and isolation. These areas can be assessed by (MH12) relating, (MH18) feeling understood, along with the social domain items (Q20) and (Q22) asking about the quality of personal relationships and support from friends within the WHOQOL-BREF.

The third domain (autonomy, control, choice) included balancing dependence (when support is needed) with independence, using coping strategies to maintain control, choice, and opportunity through the availability of financial resources and employment opportunities. Two WHOQOL-BREF items ask about the choice dimension of this domain: whether a person has enough money to meet their needs (Q12) and their capacity to work (Q18). WHOQOL questions about independence include asking about overall mobility (Q15) and the consequence of poor health that can reduce independence, such as access to health services (Q24), requiring medical treatment to function (Q4), physical pain (Q3), mental health, (Q26), energy levels (Q10), and cognitive functioning (Q7). MHRQoL module items asking about the extent of adjustment to mental health issues (MH11) may assess autonomy if poor adjustment is related at times to higher levels of dependence on the health system or problematic levels of social withdrawal. Control could be indirectly assessed through the strengths (MH5) and insight (MH9) items, or higher QoL ratings on WHOQOL items, as people may feel more in control of their lives when they see themselves as capable and able to manage their lives and have the self-awareness to solve problems. For New Zealanders autonomy can be assessed by NZ national items asking about control over life (N31), meeting social expectations (N27), and managing personal difficulties (N29).

The fourth domain (hope) includes a positive view of the future, goals, aspirations, fulfilling activities, meaning and purpose. The WHOQOL-BREF has two questions relevant

to this domain: life enjoyment (Q5), meaningfulness of life (Q6), as well as three questions about leisure activities (Q14), satisfaction with daily living activities (Q17) and work (Q18). The MHRQoL items (MH4) belief in recovery and (MH19) recovery progress were questions related to the theme of hope in the current research. The range of facets a person is satisfied with across all 33 questions of the personal-recovery-sensitive PROM (26 WHOQOL-BREF and seven module items) could indicate a person's engagement with their life and how fulfilling it is for them. However, it is best to discuss QoL ratings with people directly to understand their individualised meaning during service delivery (Andrews & Rowthorn, 2013) as recovery goals, aspirations, and life fulfilment are individually determined.

The fifth domain, (self-perception) was multifaceted and included self-efficacy (having belief and confidence in your abilities), self-identity, self-esteem, and self-stigma. The WHOQOL-BREF items about self-esteem (Q19) and satisfaction with capabilities to perform daily living activities (Q17) and work (Q18). The module item (MH5) recognising one has strengths and skills could assess self-efficacy.

The sixth domain (well-being, ill-being) included an absence of ill-being (distress from symptoms, depression, problems with energy and motivation, fear, anxiety, anger, frustration), relief of symptoms through medication or holistic therapies, use of adaptive or maladaptive coping strategies such as alcohol or substance use. Well-being included: "Feeling healthy, peaceful, calm, relaxed, stable, free from worry." (Connell et al., 2014, p. 15). The WHOQOL-BREF items ask about enjoyment of life (Q5) and ill-being as negative feelings (listed as depression, anxiety, fear, anger) (Q26), or low ratings on items such as energy (Q10), safety (Q8), and items that indicate ill-being through the presence of pain (Q3), reliance on medical treatment (Q4), cognitive problems (Q7), and sleep problems (Q16).

All of the MHRQoL module items can identify well-being when rated at the top end of the Likert scale: making progress in recovery (MH19), belief in recovery (MH4), being

aware of strengths (MH5), having sufficient insight to resolve problems (MH9), being able to relate to others (MH12), feeling understood by others (MH18), and adaptive adjustment (MH11) or can identify ill-being if lowly rated by respondents. As is the case for all of the WHOQOL-BREF items, particularly if they are of vital importance to an individual's QoL.

The seventh domain of physical health included problems with sleep, eating, side effects of medications, somatised aches and pains, and the interaction between physical and mental health. The WHOQOL-BREF physical health domain includes a general question about physical health (Q2) as well as items mentioned previously: energy (Q10), sleep problems (Q16), pain (Q3), medication use (Q4), and cognitive problems (Q7).

The current research aimed to find recovery determinants not covered by the WHOQOL, to improve the precision of the WHOQOL-BREF to measure both generic and personal-recovery-specific QoL issues when used as a mental health PROM. Phase 1 methods therefore coded out themes identified by Connell et al. (2012, 2014) that were covered by existing WHOQOL-BREF items. The number of items in the WHOQOL-BREF compared to the module, along with the known relevance of the generic items to mental health recovery, naturally results in more WHOQOL-BREF items than MHRQoL module items aligning with the conceptual framework of personal recovery and the domains identified by Connell et al. (2012, 2014). However, the MHRQoL items were able to map onto these domains to greater and lesser extents, indicating reasonable alignment with their model.

Bigelow et al. (1991), Chou & Chronister (2011), and Onken et al. (2002) point out that mental health recovery involves more than improved subjective well-being (SWB) assessed in the psychological domain of a HRQoL measure. They highlight that the reclamation of role functioning and equal citizenship in the social world requires the world to open doors and be more accepting of people with mental health issues. Connell et al. (2014)

also discussed the stigma and discrimination that people can receive during social recovery, commenting, “Our interviewees felt that it was not only about how they fit with society but also about how society fits with them” (Connell et al., 2014, p.15). Participants in Phase 1 explained that all areas of life are affected by mental health problems and rated all of the WHOQOL-BREF facets as relevant to their recovery. That stigma and discrimination is a barrier to recovery is added reason to discuss QoL ratings with people to examine the reasons for low scores. Some of the social and environmental facets of the WHOQOL can require advocacy, mediation, and public health promotion efforts to support people to feel connected to and to stay well in the community, achieve their goals, and to achieve their equal citizenship right to strive for as good a QoL as any other person in society.

MHRQoL and its Measurement – ReQoL-20

The previous section reviewed seven conceptual domains developed by Connell et al. (2012) obtained from a review of the personal recovery literature verified by service user interviews (Connell et al., 2014) against items within the WHOQOL-BREF and adjunct MHRQoL module. The below section discusses similarities and differences between issues identified as necessary to include in an MHRQoL measure developed in the United Kingdom compared to those the current NZ sample prioritised for inclusion in a MHRQoL measure.

The ReQoL-20 measure (Keetharuth et al., 2018) is an MHRQoL measure founded on themes identified after reviewing personal recovery literature conducted by Connell et al. (2012, 2014, 2018). The themes were evaluated in non-cued interviews with people who had mild to severe psychiatric issues to verify the potential content for a QoL measure for people recovering from mental health problems. The ReQoL stands for *recovering quality of life* and focuses on ill-being issues that lower QoL as well as well-being issues that improve QoL. ReQoL items ask about experiences that negatively affect the QoL of people with mild to

severe mental health problems. The ReQoL has 20 items and five response options to assess how often a person experiences the issues asked about in the measure.

The sections below explore the results of the current research against the items in the ReQoL measure. The ReQoL questions are listed below with the Phase 1 theme from the current research in brackets to indicate concordance between research findings:

- (ReQoL Q3): “I felt unable to cope” (Coping)
- (ReQoL Q5): “I felt hopeful about my future” (Hope)
- (ReQoL Q9): “I felt lonely” (Loneliness)

Hope was the only ReQoL theme included in the MHRQoL module. The candidate items assessing loneliness and coping can be used in situations where these issues are prominent, or people want to include these in individualised PROMs. The hope items were:

- (MH4) To what extent do you believe you can recover from illness?
- (MH19) How satisfied are you with your recovery?

Candidate items for loneliness and coping were:

- (MH2) To what extent do you feel lonely?
- (MH 8) To what extent do you feel you are able to cope with daily life?

The MHRQoL module is an adjunct health module for the WHOQOL-BREF. The WHOQOL-BREF asks about some of the ReQoL item themes. Where the WHOQOL-BREF items assess the issues asked about in the ReQoL is explored below. The WHOQOL-BREF facet item in the measure is listed first, with the ReQoL question underneath it.

1. WHOQOL-BREF (Q17): How satisfied are you with your ability to perform your daily living activities?

   ReQoL: (1) I found it difficult to get started with everyday tasks, (4) I could do the things I wanted to do, and (12) I avoided things I needed to do.
2. WHOQOL-BREF (Q5): How much do you enjoy life?

ReQoL: (5) I felt happy, (7) I enjoyed what I did, (8) I felt hopeful about my future, (19) I felt calm.

3. WHOQOL-BREF (Q19): How satisfied are you with yourself?

   ReQoL: (10) I felt confident in myself.

4. WHOQOL-BREF (Q26) How often do you have negative feelings such as blue mood, despair, anxiety, or depression?

   ReQoL: (6) I thought my life was not worth living, (13) I felt irritated, (14) I felt like a failure, (16) I felt terrified, (17) I felt anxious.

5. WHOQOL-BREF (Q16): How satisfied are you with your sleep?

   ReQoL: (18) I had problems with my sleep.

6. WHOQOL-BREF (Q7): How well can you concentrate?

   ReQoL: (20) I found it hard to concentrate.

7. WHOQOL-BREF (17): How satisfied are you with your ability to perform your daily living activities?

   ReQoL: (3) I felt unable to cope.

8. WHOQOL-BREF (Q6) To what extent do you feel your life to be meaningful?

   ReQoL: (11) I did things I found rewarding.

9. WHOQOL-BREF (Q5) How much do you enjoy life?

   ReQoL: (Q5) I felt happy. (19) I felt calm.

10. WHOQOL-BREF (Q26): How often do you have negative feelings such as blue mood, despair, anxiety, or depression? Or (Q8) “How safe do you feel?” although initially intended to assess environmental safety, it could function differently in this population to refer to psychological safety.

    ReQoL: (2) I felt able to trust others. (9) I felt lonely. (13) I felt irritated. (14) I felt like a failure. (16) I felt terrified. (17) I felt anxious. (3) I felt unable to cope.

11. NZ WHOQOL-BREF national item (Q31): To what extent do you feel you have control over your life?

    ReQoL: (15) I felt in control of my life.

The WHOQOL-BREF with adjunct MHRQoL module when used as a mental health PROM can, in principle, cover all of the assessment areas asked about in the ReQoL measure. The ways these two PROMs ask about these issues are based on different approaches to measuring HRQoL. The WHOQOL-BREF asks predominantly generic well-being focussed questions with five response options to identify low to high QoL from 1-5 with negatively worded items reverse scored. The ReQoL asks predominantly ill-being focussed questions that emphasise specific issues that lower the QoL of people with mental health problems. It also has five response options from none of the time, to sometimes, or all of the time, scored from 0-4 with positively worded items reverse scored.

The current research did not allow time and resources required to meet all of the PROM development standards recommended such as test-retest reliability or convergent validity with another MHRQoL PROM (Reeve et al., 2013; Regnault et al., 2017). The previous sections of this chapter explored the face validity of the seven MHRQoL domains recommended for a mental health QoL measure (Connell et al., 2012) and the proposed PROM from the current research against the content of a recently developed MHRQoL measure, the ReQoL (Keetharuth et al., 2018). The similarities and differences of findings from the current research against the findings of these other MHRQoL and PROM development research studies were examined. The WHOQOL-BREF with adjunct MHRQoL measure appears able to assess the seven domains of MHRQoL identified by Connell et al. (2012,2014) and the issues asked about in the ReQoL (Keetharuth et al., 2018). The ReQoL item *control over life* could hypothetically be assessed indirectly by patterns of higher QoL ratings, or directly when the NZ WHOQOL-BREF national item is used in NZ populations.

Keetharuth et al. (2018) compared the content of the ReQoL against a well-respected conceptual framework for personal recovery (CHIME) (Leamy et al., 2011) to examine the construct validity of the items within the ReQoL measure against this definition of the personal recovery construct. The content of the ReQoL assessed all CHIME domains. The current research findings are similarly explored in the next section by comparing the seven module themes with the conceptual domains of the CHIME model (Leamy et al., 2011).

Recovery Theory and Conceptual Frameworks

Chapter 3 provided an overview of the CHIME conceptual model. This section begins with a brief reminder of the background to the development of that model. The section will then compare the current research findings with the domains of that model to examine whether the items of the WHOQOL-BREF with adjunct MHRQoL module can assess these theorised factors of personal recovery.

A systematic review of 97 out of 5,208 research papers by Leamy et al. (2011) identified a conceptual framework for the critical determinants of personal recovery. This framework was summarised in an acronym CHIME, standing for: (1) connectedness, (2) hope, (3) identity, (4) meaning in life, and (5) empowerment. (Leamy et al., 2011). The following section names each domain then explores the seven module items and content of the WHOQOL-BREF or MHRQoL module against the named domain.

1. The domain of *connectedness* was captured by the themes underlying module items (MH12) relating to others and (MH18) feeling understood. The WHOQOL-BREF assesses how satisfied people are with their personal relationships (Q20) and support from friends (Q22) in the social domain.
2. The domain of *hope and optimism* was captured by the themes underlying the module items (MH4) belief in recovery, (MH19) making recovery progress. The WHOQOL-BREF assesses hope by asking people how much they enjoy life (Q5).

3. The domain of *identity* was discussed by participants in the themes underlying the module items: self-awareness and insight (MH9), acceptance and adjustment (MH11) and recognising strengths and capabilities (MH20). The WHOQOL-BREF assesses identity by asking a person how satisfied they are with themselves (Q19).
4. Leamy et al. (2011) describe the domain of *meaning in life* as including: spirituality, QoL, a meaningful life, restored social roles, and rebuilding life. The meaning in life domain can be captured by themes underlying the module item: how satisfied are you with your recovery (MH19) asking about rebuilding life through recovery progress. Phase 1 discussions identified that reclaiming one's QoL and achieving milestones can be meaningful for people who have previously felt that limitations were placed on what they could expect from life. Relationship skills (MH12) may support the reclamation of social roles. The WHOQOL-BREF assess these areas by directly asking about meaning in life (the WHOQOL-BREF's spirituality question) (Q6) and about QoL in (Q1). Restoration of social roles may be inferred by improved QoL ratings in areas where the person has lost and then regained social roles, such as work (Q18), satisfaction with personal relationships (Q20) and social support from friends (Q22) or being able to better perform activities of daily living (Q17).
5. The domain of *empowerment* was discussed by participants when talking about drivers of personal agency in the themes underlying the module items: recognising one has strengths and capabilities (MH5) and believing recovery was possible for them (MH4). The WHOQOL-BREF does not assess empowerment directly. It may be investigated or inferred from the question asking: how dependent a person is on medical treatment to function in daily life (Q4). Or by a pattern of low versus high QoL ratings within a measure. The ways services use PROMs can empower a service user to have a more central role in directing their recovery within services. The New

Zealand national item that asks: “To what extent do you feel you have control over your life” (N31) can function as a more direct assessment of personal agency.

The research completed by Leamy et al. (2011), Connell et al. (2012) of which founds the ReQoL (Keetharuth et al., 2018), and the current research all conducted literature reviews before 2018. All three studies used the same historic personal recovery literature to identify the themes they used in their research. Studies drawing from the same literature are likely to identify common themes between studies. The WHOQOL-BREF was developed differently for a different purpose, yet it could still assess for some crucial personal recovery issues, highlighting the value of the generic content of the WHOQOL-BREF for this population.

The WHOQOL-BREF with the MHRQoL module has content that aligns with the CHIME personal recovery framework (Leamy et al., 2011) and the seven domains of MHRQoL developed into a conceptual framework by Connell et al. (2012, 2014). The content of the proposed PROM from the current research considered against the CHIME model shows in principle the items can assess the well-being factors that drive personal recovery outlined in the CHIME model (Leamy et al., 2011). The WHOQOL-BREF with adjunct MHRQoL, when compared to the content of the ReQoL, although framing questions differently, appears able to assess for states of ill-being that can lower QoL for people with mental health problems. The next section considers how the content of the proposed personal-recovery-sensitive PROM (WHOQOL-BREF with the adjunct MHRQoL module) aligns with the content of well-accepted standards for recovery-orientated services for it to operate as a service evaluation measure for services wanting to maintain or improve their personal recovery orientation.

The WHOQOL-BREF with adjunct module as a PROM

The NZ WHOQOL-BREF used to collect data in this research refers to the WHOQOL-BREF validated for assessing generic HRQoL within NZ samples (Hsu, 2009;

Krägeloh et al., 2013). It has the same item content as the original WHOQOL-BREF. The current research methods added NZ national items to the NZ WHOQOL-BREF to include culturally relevant items for NZ participants. This facilitated a data analysis opportunity to differentiate between culturally relevant QoL issues to New Zealanders, which naturally influence well-being, from MHRQoL issues within the data analysis of a New Zealand sample participating in the current research.

The MHRQoL module is not a standalone measure. The MHRQoL module aims to improve the precision of the WHOQOL-BREF as a personal-recovery-sensitive PROM. Phase 1 participants discussed many facet areas of the WHOQOL-BREF that were set aside because the 26 WHOQOL-BREF facet areas form the foundation of the proposed PROM. If the MHRQoL module was to be a standalone measure, many of these WHOQOL-BREF facets (if not all) would need to be re-coded back into the measure, due to their high relevance to people's personal recovery goals. All Phase 1 participants rated the content of the WHOQOL-BREF as relevant to their recovery within the Phase 1 importance exercise. These central HRQoL items can only be assessed by the use of the generic WHOQOL-BREF measure not the adjunct module alone. The proposed recovery-sensitive PROM therefore contains the items of both of these measures when used as a mental health recovery PROM.

The NZ national items within the NZ context can be relevant to service users in NZ. International users may want to add their own country's national items to the WHOQOL-BREF and MHRQoL items to include culturally relevant QoL issues in their service evaluation and outcome measurement suites. Alternatively, they can use the MHRQoL module with the original WHOQOL-BREF freely obtainable from the WHO Geneva website.

Until people have used the module in other countries, the cross-cultural relevance of the MHRQoL module items has yet to be explored. Rasch analysis, used in Phase 2 to identify the seven module items, has a criterion called DIF (differential item functioning) that

checks whether an item performs differently in relation to demographic data. An item would be eliminated if it showed evidence of working better or worse for people of different cultures, diagnoses, or any other demographic factor. Despite including internationally recognised themes relevant to mental health recovery, suppositionally, Phase 1 participants may have prioritised the specific determents they did, or Phase 2 responded to the research survey items as they did, due to how mental health recovery is promoted, conceptualised, or influences people's QoL in NZ. It must be acknowledged that some cultures may orientate to mental health problems and their resolution differently than Western industrialised nations. The cross-cultural relevance of personal recovery determinants that best measure MHRQoL may require further cross-cultural research to investigate.

Research indicates that the WHOQOL-BREF can be used as a valid, reliable PROM for mental health service evaluation, individual recovery planning, or outcome evaluation purposes (Skevington & McCrate, 2011). International studies have identified the items within the WHOQOL tools as valid, reliable assessments of generic HRQoL for people affected by mental health problems (De Vries & Van Heck, 1994; Mas-Expósito et al., 2011; Masthoff et al., 2005; Oliveira et al., 2016; Rocha & Fleck, 2009; Rocha et al., 2011; Trompenaars et al., 2006b). The WHOQOL items show sensitivity to change over a two-week time frame in several research studies with mixed samples of psychiatric patients (Berlim et al., 2005; Garcia-Rea & LePage, 2010; Skevington & McCrate, 2011) and the QoL impacts of service delivery (Picardi et al., 2006; Wu et al., 2006).

Slade (2002) evaluated 6,400 articles about mental health recovery PROMs. Slade found 16 outcome domains, synthesised into seven categories, that were recommended for mental health PROMs. These categories were: (1) well-being, (2) cognition and emotion, (3) physical health, (4) interpersonal functioning, (5) society, (6) behaviour, and (7) services. The

following section reviews the content of the WHOQOL-BREF with the adjunct MHRQoL module against these seven recommended domains.

The WHOQOL-BREF and MHRQoL module directly ask service users about five of these seven domains: 1 (well-being), 2 (cognition and emotion), 4 (physical health), 5 (interpersonal functioning) and 7 (services) illustrated briefly below:

1. **Well-being**: All items within the WHOQOL-BREF and MHRQoL module are essentially an assessment of well-being individually and in their entirety. The WHOQOL-BREF directly askes about well-being in (Q1) life satisfaction, (Q5) life enjoyment, and by assessing its antithesis in (Q26) negative feelings.
2. **Cognition**: is directly assessed in the WHOQOL-BREF in the item how well are you able to concentrate (Q7) (which refers in the facet descriptor to thinking, learning, memory, decision making capability, and concentration).

   Emotion: is investigated in items asking about enjoying life (Q5) (described in the facet descriptor as the presence of positive feelings such as contentment, balance, peace, happiness, hopefulness, joy and enjoying the good things of life), and negative feelings (Q26) (described in the facet descriptor as despondency, guilt, sadness, tearfulness, despair, nervousness, anxiety and a lack of pleasure in life; inclusive of severe depression, mania, and panic attacks), as well as the word “feel” being used in the wording of three other items (Q3, Q6, Q8) and the assessments of subjective satisfaction in 11 items, if one considers satisfaction to be a feeling and an appraisal.
3. **Physical health**: is assessed in the WHOQOL-BREF in items asking about satisfaction with physical health (Q2) and in the physical health domain items that ask about activities of daily living (Q17), dependence on medicinal substances or medical aids (Q4), energy and fatigue (Q10), mobility (Q15), pain and discomfort (Q3), sleep and rest (Q16), and work capacity (Q18).

4. **Interpersonal functioning:** may be explored in items asking about satisfaction with personal relationships (Q20) and support from friends (Q22). The MHRQoL item, how well you feel you can relate to others (MH12), assesses the theme of interpersonal functioning. The MHRQoL item asking if a person feels that people really understand them (MH18) may also allow for an exploration of this domain.
5. **Service use**: is asked about in (Q24) satisfaction with access to health services.
6. **Behaviour:** this domain could be examined in items that ask the person to evaluate their capacities to achieve activities of daily living (Q17), functional mobility (Q15), work capacity (Q18), and participation in leisure activities (Q14). The module item recognising one has skills and strengths (MH5) may also be relevant, as recognising capability can be a precursor to using strengths and skills more proactively. Behavioural problems may emerge for redress when exploring mental health difficulties services users are experiencing or the ways they are coping when discussing WHOQOL-BREF or MHRQoL items with lower QoL ratings.
7. **Society**: The proposed PROM does not ask about this domain directly. Nevertheless, the proposed PROM can be used to explore this domain with service users when exploring reasons for low QoL ratings if they involve factors outside the individual's control and highlight social advocacy needs. The MHRQoL module item asking about the experience of people really understanding you (MH18) could assess this domain, or identify social advocacy or public health promotion needs outside of a PROM's scope. Highlighting again the value of exploring QoL results with service users.

Andrews and Rowthorn (2013) reported that using the WHOQOL-BREF as a recovery needs assessment and discussion tool can integrate a service user driven QoL orientation into routine service delivery. Using the WHOQOL-BREF in this way (to assess, develop, and review recovery goals and their progress) not only enables a PROM to be used

to collect quantitative PROM data for aggregated data analysis. Providers also hear the narrative context for changes in people's QoL scores and can identify opportunities for early intervention, address patterns of deterioration that can predict risk for suicide (Alves et al., 2016; De Freitas Melo et al., 2022), and identify barriers to QoL for redress within certain subpopulations within a service environment (Mayer et al., 2021).

Identifying unmet rehabilitation needs through ratings of life dissatisfaction can increase the opportunity for intervention to further encourage positive recovery outcomes (Fahy et al., 1999; Fleury et al., 2013). Using the proposed PROM from the current research in this way increases the opportunity for providers within a service to better understand how to support people to improve their lives in an individualised way when QoL objectives are individually determined and driven by service users. Working on client-centred QoL interventions can be optimally reflected in improved service-wide aggregated QoL facet scores within a service population over time (Andrews & Rowthorn, 2013). QoL assessment and intervention are less impeded by chronicity and cofactors that result in poorer QoL or recovery outcomes, compared to symptom relief or functional targets during service delivery.

The literature highlighted that routine QoL measurement and aggregated data analysis could potentially identify those at risk of suicide, as identified by progressive dissatisfaction with QoL ratings over time (Alves et al., 2016; De Abreu et al., 2012; De Freitas Melo et al., 2022; Ponizovsky et al., 2003). Unmet rehabilitation needs contribute to lower QoL; identifying and meeting these needs can improve service objectives to improve both mental health and QoL (Fahy et al., 1999; Fleury et al., 2013). Addressing QoL and unmet recovery needs becomes more straightforward when routinely including QoL measures within service delivery processes (Awad, 2016) and discussing the results with service users (Andrews & Rowthorn, 2013; Llewellyn & Skevington, 2015). Integrating the WHOQOL-BREF with an adjunct MHRQoL module within service delivery assessment and review processes,

accompanied by a procedure of discussing rating changes with service users, could provide an opportunity for services to implement a response to the WHO (2013) call to target suicide and reduce the mental health statistic in their *Mental Health Action Plan (2013-2030)* if they monitor progressive QoL deterioration among their service user populations.

The existing evidence to support the use of the WHOQOL-BREF as a PROM in mental health services, locally in New Zealand (Andrews & Rowthorn, 2013) and internationally (Skevington & McCrate, 2011) has been discussed often in this thesis. The proposed PROM with additional recovery-sensitive items may serve as a helpful personal-recovery-orientated service user measure within an outcome suite with several potential purposes: (1) service evaluation, (2) recovery planning and review, or (3) continuous quality improvement for services wanting to maintain or strengthen their recovery orientation.

Limitations

Phase 1 participants were in mid-to-late phases of recovery, with the majority of participants receiving secondary mental health services who ranged in age from 18–71, with 64.7% aged between 31–60 years old. Phase 2 participants recruited from secondary mental health NGO or DHB services would have met the criteria of having a psychiatric diagnosis to be receiving those services. The “About You” demographic questions in the research surveys asked people to identify their diagnosis within broad diagnostic categories; 62%–66% of participants in Phase 1 and 2, respectively, named a mood disorder. In Phase 2, 30% named past or present substance use problems, 17% named symptoms of psychosis, and 7% named a personality disorder, with 26% of Phase 2 participants reporting coexisting physical health and 28% coexisting disability problems. Further use of the module within mixed and specific diagnostic samples could evaluate the performance of the module items with people with psychiatric diagnoses unexamined within the Rasch DIF analysis in the current research.

Phase 1 or 2 participants were not a representative sample of the primary, secondary, or tertiary mental health consumer population. Convenience and purposeful sampling aimed at improving Māori representation. During Phase 2 Rasch analysis, there were no significant DIF findings to indicate that any module items operated differently for any members of the cultures who participated in Phase 2. NZ Census and PRIMHD statistics identified Pasifika and Asian cultures as underrepresented in the current research sample. The cross-cultural significance of the module content is unable to be assessed at this stage of the PROM's development beyond Rasch DIF analysis. Although the seven module items are frequently named in the international literature as central to personal recovery, hypothetically the ways NZ mental health services are delivered, or that mental health promotion occurs within NZ, could have influenced what New Zealand participants perceived as relevant to their personal recovery and the final content of the module.

Subpopulations of people receiving specialist or tertiary mental health services, such as members of the deaf mental health and dual disability communities, people within acute mental health or forensic settings, or people with neurological issues, were not specifically targeted during the recruitment strategy. It is unknown whether any members of these groups responded to the broadly advertised approach used during recruitment.

The focus of this study was to identify generic MHRQoL items more than to identify items of explicit relevance to particular diagnostic subsamples. The utility of various MHRQoL modules, one for every possible disorder, was considered less helpful to a field more commonly working with diverse case mix populations. A generic MHRQoL module with content that measures personal recovery issues common to mental health and addiction problems was considered more helpful. The module may need further evaluation to establish the relevance of the measure's content for subgroups within the mental health population who did not participate in this research.

After question writing, a small pilot group reviewed the item wording at the end of Phase 1. The pilot group gave feedback on item relevance and comprehensibility. If there had been more time and staffing resources, this could have changed the current research design to involve a more extensive pilot study. The question writing group could have involved service users and a review of question-wording before finalising items for the research survey. The current research prioritised the experiences of LE participants by referencing the LE discussions when considering how to phrase and ask the questions developed for the Phase 2 survey and by consultation with LE volunteers who offered feedback on the survey during the piloting phase.

Data collection using survey methods can result in people responding to invitations to participate being those with reasonable literacy and English as a first language. Interviewer-assisted methods ask WHOQOL-BREF and the MHRQoL module questions vocally with the aid of a person who is bilingual or literate without vision impairment or other barriers that can limit people using PROM surveys. Person assisted PROM completion could be a more values-centric approach for some cultural groups or subpopulations within mental health who cannot use self-report paper or electronic survey methods. There were opportunities for recovery supporters to support people without adequate literacy or who preferred oral delivery of questions. It is unknown how often that occurred in the current research.

Items that did not meet the measurement criteria for inclusion in the module are still MHRQoL issues that could be important for some individuals. As such, these can be included within individualised recovery planning and outcome measurement processes when relevant to specific individuals. These items could be included in item banks or be ones that some people may want to track during service provision, or in response to interventions that aim to target the themes underlying those items. However, only the final 7-item module can be used for organisational outcome evaluation purposes. Rasch analysis established that the items

within the final 7-item module had the most appropriate measurement properties to assess MHRQoL in larger aggregated datasets. The 7-item module can therefore be used for both types of PROM situation: individual and service wide outcome evaluation.

The MHRQoL module is an adjunct mental health module for the WHOQOL-BREF. Although theoretically the MHRQoL module can be used as a standalone measure for service evaluation and could be used to research the impact of specific interventions on MHRQoL, it is not designed to be a standalone measure. The content of the WHOQOL-BREF is highly relevant to the HRQoL assessment of people with mental health problems. CTT analysis eliminated candidate items due to item redundancy criteria. If the current research aimed to create a standalone MHRQoL measure those items and WHOQOL-BREF items would have been included in the Rasch analysis step and the resultant module content would be different.

Recommendations for Further Research

The set of seven MHRQoL items showed evidence of unidimensionality and internal consistency through Rasch analysis. Psychometric evaluation of the module's test-retest reliability and convergent validity against other MHRQoL measures still needs to occur. Further use of the tool in services and research applications is needed to establish its value and utility to support QoL improvement and recovery for people with mental health issues.

Using the 33-item measure (WHOQOL-BREF with adjunct MHRQoL items) as a recovery assessment, review, and planning tool to encourage QoL discussions with service users could help service providers to identify specific issues that affect the SWB and QoL of individuals within their services. Service policy and procedures that accurately monitor service-wide PROM data patterns could help services to visibly identify whom in their service population require targeted HRQoL interventions, are at risk due to progressive deterioration of QoL scores over time, and to consider what types of staff training or service improvement initiatives could occur to better meet the QoL improvement needs of service

users. Methods of assisting services to evaluate aggregated QoL scores over time so that they can identify and further examine differences between subsamples, across services, or intervention types could help service providers to identify where MHRQoL is improving or deteriorating for some service users. User-friendly data analysis methods and follow-up signalling within data bases when action is required that is suitable for community agencies and health services who may not have data analysis skills, knowledge, or resources available to make sense of the data they are collecting could support the routine use of QoL measures within health services. Response Shift Theory (Sprangers & Schwartz, 1999) presents one way to assess improvements in QoL over time. Further exploration of how QoL reviews could incorporate the methods outlined by Response Shift Theory may offer services a way to identify where and when QoL has changed over time or in response to services delivered.

The current research included the five NZ national items (Krägeloh et al., 2016) in both phases of this research due to the socio-cultural context of NZ participants and the need to differentiate between culturally relevant HRQoL issues and MHRQoL issues. The NZ items had high relevance to people recovering from mental health issues in NZ. National items as measures of well-being will naturally affect people's mental health within a culture. Further research may consider items from the WHOQOL-BREF, NZ national items, and MHRQoL module to see if a new conceptual domain within the WHOQOL-BREF could emerge for NZ services that identifies personal-recovery-sensitive facets using Rasch analysis. Eliminating items previously identified internationally as relevant, valid, and reliable for this population could unintentionally remove valuable content for some people in recovery. Research exploring how to use item banks to create individualised QoL measures to track individual recovery whilst using briefer measures for aggregated data analysis and service evaluation purposes may resolve the tension between these issues.

Use of the WHOQOL-BREF with the MHRQoL adjunct module in other countries or subpopulations that were not included in this research could explore the reliability and validity of the MHRQoL items in other socio-cultural settings, non-Western cultures, or specialist mental health contexts. There are 76 language versions of the WHOQOL-BREF, yet these do not currently include Te Reo Māori or Pacific language versions. Developing Te Reo Māori and Pasifika language versions, using standardised WHOQOL back translation methods, could improve the WHOQOL-BREF's accessibility for these cultures in NZ.

Conclusions

The WHOQOL-100 and its short form, the WHOQOL-BREF, are multifaceted, patient-reported, health-related QoL questionnaires developed by the WHO. The WHOQOL tools are used as PROMs to assess the QoL of people with health problems. The literature identified that the WHOQOL tools are reliable and valid generic HRQoL measures for people recovering from various mental health problems. Researchers have developed adjunct health and population specific modules to improve the WHOQOL-BREF's sensitivity as a PROM for specific populations since its development in 1996. Before the current research, there had been no investigation into whether a condition-specific module could add further precision to the QoL assessment of people recovering from mental health issues.

A review of the personal recovery literature identified that determinants frequently cited as essential to recovering from mental health problems were not always included within the WHOQOL-BREF. The missing personal-recovery-sensitive content suggested that a condition-specific mental health module for use with the WHOQOL-BREF may be of value to increase its precision as an HRQoL PROM or research tool for this population.

The current research aimed to identify relevant items for an adjunct mental health recovery module for the WHOQOL-BREF. The content of the 7-item module resulting from the current research was informed by the lived experiences of end users in alignment with

mental health recovery principles and the WHOQOL person-centred methods of PROM development outlined in the study guide for developing WHOQOL modules. Established statistical methods were replicated from a previously published research study that described CTT and Rasch methods used when developing NZ national items for use with the WHOQOL-BREF. Established ISOQOL criteria and standards for developing PROM and HRQoL measures also informed the module development, research process, and design.

The current research used a two-phased exploratory sequential mixed-methods design to investigate relevant candidate items for a proposed adjunct MHRQoL module for the WHOQOL-BREF. Phase 1 identified 24 personal recovery themes through the content analysis of 23 group and individual discussions with 55 people recovering from mental health problems and 33 recovery supporters. These themes were used for candidate item writing in preparation for further item evaluation in Phase 2 within a larger NZ-wide sample.

Phase 2 invited participants to complete a 55-item HRQoL survey comprising 26 WHOQOL-BREF questions, five NZ national items, and 24 MHRQoL candidate items. After data cleaning, Phase 2 methods involved analysing the responses to 667 research surveys (389 LE participants and 278 as a comparison group). CTT analysis of the 24 Phase 1 MHRQoL candidate items found that 23 of the 24 candidate items differentiated between those with and without mental health issues. Seventeen of the candidate items did not correlate with existing WHOQOL-BREF facets, NZ national items, or existing candidate items. Rasch analysis further identified which of these 17 candidate items worked well together as reliable and valid questions for measuring MHRQoL changes during someone's recovery from mental health issues. Iterative steps, using Rasch model criteria, resulted in the progressive removal of 10 misfitting items to arrive at a 7-item solution for the proposed content of an MHRQoL module for the WHOQOL-BREF.

The items within the MHRQoL module ask about people's experience of: (1) empathy and understanding from others; (2) their capacity to relate to others; (3) their experience of self-awareness and insight; (4) their ability to accept how life has altered and to make meaningful adaptation to these changes; (5) their belief that recovery is possible for them; (6) their capacity to recognise that they have the self-efficacy and resilience to manage life going forward; and (7) whether they feel their recovery is progressing. The module has been satisfactorily validated using both CTT and IRT analysis. The 7-item selection showed evidence of unidimensionality and a strict-fit with the Rasch model, providing statistical evidence of this selection's internal consistency, construct validity, and reliability to assess MHRQoL. The research provided ordinal-to-interval conversion tables to optimise MHRQoL measurement precision for module users.

The WHOQOL-BREF with adjunct MHRQoL module is a 33-item personal-recovery-sensitive PROM that can be used in mental health services for recovery planning, review and service evaluation purposes. This personal-recovery-sensitive PROM could be used to strengthen service responsiveness to relevant issues affecting the HRQoL of people in recovery and reinforce the service user voice within outcome measurement suites. The WHOQOL-BREF with adjunct MHRQoL module provides a viable method of supporting people to recover their QoL from the negative impact of mental health problems.

The literature identified that routine use of the WHOQOL-BREF within mental health services can provide early intervention opportunities to address unmet rehabilitation or treatment needs and detect patterns of life dissatisfaction that can identify suicide and self-harm risks among vulnerable people within mental health populations. Routine use of QoL measures in services can explore the reasons for any subpopulations showing lower HRQoL scores within the mental health population. These investigations could inspire ways to improve risk management policies and improve QoL interventions during mental health

service delivery. Using MHRQoL module items as discussion topics with service users could enhance their engagement in recovery planning and aid in the development of individualised personal-recovery and QoL interventions during mental health service delivery.

The objectives of improving mental health service responsiveness, reducing suicide, and helping people to recover their mental health and lives from the effects of mental health problems are called for in the WHO *2013–2030 Mental Health Action Plan*, NZ *Mental Health Foundation principles for recovery-orientated services*, and WHO *Live Life* campaign objectives. The WHOQOL-BREF and MHRQoL modules could be used within CQI investigation to explore what interventions and experiences affect people's ability to recover their QoL during mental health service delivery. This information could help to refine service delivery policy to train staff to collaborate with people in ways that foster MHRQoL to strengthen a service's efforts to meet these broader international and national objectives.

The aim of this research, to identify MHRQoL items that can be used in conjunction with the WHOQOL-BREF to improve its precision for use as a PROM or research tool within mental health populations was achieved. The potential value of the measure developed from this research includes the opportunity to strengthen the service user voice, QoL and recovery orientation of service delivery during recovery planning and evaluation processes. Secondly collecting aggregated data could provide a visible method of identifying those at risk of suicide through observed patterns of progressive deterioration of QoL over more facets across time within data sets. Thirdly, the value of using an HRQoL PROM within service delivery and evaluation purposes is that it provides a mechanism to focus service delivery on improving the quality of service users' lives, individually and collectively, that can be driven by service users and is unimpeded by chronicity or disability. Fourthly, the MHRQoL module provides a more sensitive and precise way to collect and analyse MHRQoL data when using the WHOQOL-BREF for evaluation or research purposes.

References

Aaronson, N., Alonso, J., Burnam, A., Lohr, K. N., Patrick, D. L., Perrin, E., & Stein, R. E. (2002). Assessing health status and quality-of-life instruments: Attributes and review criteria. *Quality of Life Research*, *11*, 193–205. https://doi.org/10.1023/a:1015291021312

Accident Compensation Corporation. (2023). *Integrated services for sensitive claims (ISSC) operational guidelines*. https://www.acc.co.nz/assets/contracts/issc-operational-guidelines-december-2022.pdf

Akvardar, Y., Akdede, B. B., Özerdem, A., Eser, E., Topyaka, Ş., & Alptekin, K. (2006). Assessment of quality of life with the WHOQOL-BREF in a group of Turkish psychiatric patients compared with diabetic and healthy subjects. *Psychiatry Clinical Neuroscience*, *60*(6), 693–699. https://doi.org/10.1111/j.1440-1819.2006.01584.x

Alarcón, R. D. (2009). Culture, cultural factors, and psychiatric diagnosis: Review and projections. *World Psychiatry*, *8*(3), 131–139. https://doi.org/10.1002/j.2051-5545.2009.tb00233.x

Allot, P., & Loganathan, L. (2002). Discovering hope for recovery. *Canadian Journal of Community Mental Health*, *21*(2), 13–33. https://doi.org/10.7870/cjcmh-2002-0014

Alves, V., Francisco, L. C., Belo, F. M., de-Melo-Neto, V. L., Barros, V. G., & Nardi, A. E. (2016). Evaluation of the quality of life and risk of suicide. *Clinics*, *71*(3), 135–139. https://doi.org/10.6061/clinics/2016(03)03

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

Andersen, E. B. (1977). Sufficient statistics and latent trait models. *Psychometrika*, *42*, 69–81. https://doi.org/10.1007/BF02293746

Andresen, R., Caputi, P., & Oades, L. (2006). Stages of recovery instrument: Development of a measure of recovery from serious mental illness. *Australian & New Zealand Journal of Psychiatry*, *40*(11–12), 972–980. https://doi.org/10.1080/j.1440-1614.2006.01921.x

Andresen, R., Oades, L., & Caputi, P. (2003). The experience of recovery from schizophrenia: Towards an empirically validated stage model. *Australian and New Zealand Journal of Psychiatry*, *37*(5), 586–594. https://doi.org/10.1046/j.1440-1614.2003.01234.x

Andrews, S., & Rowthorn, M. J. (2013, June 8–9). *Monitoring changes to quality of life during recovery – An NGO exploration into the use of the WHOQOL BREF as an outcome measure* [Paper presentation]. 2nd New Zealand Association of Positive Psychology Conference 2013: Towards a Flourishing New Zealand. Auckland, New Zealand.

Andrich, D. (1978). A rating formulation for ordered response categories. *Psychometrika*, *43*, 561–573. https://doi.org/10.1007/BF02293814

Andrich, D. (2016). Rasch rating-scale model. In W. J. van der Linden (Ed.), *Handbook of item response theory, volume one: Models* (pp. 75–94). Chapman & Hall/CRC. https://doi.org/10.1201/9781315374512

Andrich, D., Sheridan, B., & Luo, G. (2009). *RUMM 2030+*. https://www.rummlab.com.au/

Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, *16*(4), 11–23. https://doi.org/10.1037/h0095655

Anthony, W. A., & Farkas, M. D. (2009). *A primer on the psychiatric rehabilitation process*. Boston University. https://cpr.bu.edu/wp-content/uploads/2011/11/Primer-on-the-Psychiatric-Rehabilitation-Process.pdf

Apezetxea, A., Carrillo, L., Casanueva, F., de la Cuerda, C., Cuesta, F., Irles, J. A., Virgili, M. N., Layola, M., & Lizán, L. (2018). Rasch analysis in the development of the NutriQoL® questionnaire, a specific health-related quality of life instrument for home enteral nutrition. *Journal of Patient Reported Outcomes, 2*(25), 1–11. https://doi.org/10.1186/s41687-018-0050-9

Apon, I., van Leeuwen, N., Allori, A. C., Rogers-Vizena, C. R., Koudstaal, M. J., Wolvius, E. B., Cano, S. J., Klassen, A. F., & Versnel, S. L. (2021). Rasch analysis of patient- and parent-reported outcome measures in the International Consortium for Health Outcomes Measurement Standard Set for Cleft Lip and Palate. *Value in Health*, *24*(3), 404–412. https://doi.org/10.1016/j.jval.2020.10.019

Atkinson, M., Zibin, S., & Chuang, H. (1997). Characterizing quality of life among patients with chronic mental illness: A critical examination of the self-report methodology. *American Journal of Psychiatry*, *154*(1), 99–105. https://doi.org/10.1176/ajp.154.1.99

Atkinson, M. J., & Zibin, S. (1996). *Quality of life measurement among persons with chronic mental illness: A critique of measures and methods*. Canadian Minister of Supply and Services.

Awad, A. G. (2016). The concept of quality of life in schizophrenia: From "an ethereal entity" to a valued health outcome. *Journal of Psychosocial Rehabilitation and Mental Health*, *3*(2), 51–52. https://doi.org/10.1007/s40737-016-0062-9

Baethge, C., Goldbeck-Wood, S., & Mertens, S. (2019). SANRA – A scale for the quality assessment of narrative review articles. *Research Integrity and Peer Review*, *4*(1), 1–7. https://doi.org/10.1186/s41073-019-0064-8

Bakas, T., McLennon, S. M., Carpenter, J. S., Buelow, J. M., Otte, J. L., Hanna, K. M., Ellett, M. L., Hadler, K. A., & Welch, J. L. (2012). Systematic review of health-related quality of life models. *Health and Quality of Life Outcomes*, *10*(134), 1–12. https://doi.org/10.1186/1477-7525-10-134

Balalla, S. K., Medvedev, O. N., Siegert, R. J., & Krägeloh, C. U. (2019). Validation of the WHOQOL-BREF and shorter versions using Rasch analysis in traumatic brain injury and orthopaedic populations. *Archives of Physical Medicine and Rehabilitation*, *100*(10), 1853–1862. https://doi.org/10.1016/j.apmr.2019.05.029

Ballesteros-Urpi, A., Slade, M., Manley, D., & Pardo-Hernandez, H. (2019). Conceptual framework for personal recovery in mental health among children and adolescents: A systematic review and narrative synthesis protocol. *British Medical Journal Open*, *9*(8), Article e029300. https://doi:10.1136/ bmjopen-2019-029300

Barry, M. M., & Zissi, A. (1997). Quality of life as an outcome measure in evaluating mental health services: A review of the empirical evidence. *Social Psychiatry and Psychiatric Epidemiology*, *32*(1), 38–47. https://doi.org/10.1007/bf00800666

Basu, D. (2004). Quality-of-life issues in mental health care: Past, present, and future. *German Journal of Psychiatry*, *7*(3), 35–43. https://psycnet.apa.org/record/2004-17721-003

Bayliss, M., Rendas-Baum, R., White, M. K., Maruish, M., Bjorner, J., & Tunis, S. L. (2012). Health-related quality of life (HRQL) for individuals with self-reported chronic physical and/or mental health conditions: Panel survey of an adult sample in the United States. *Health and Quality of Life Outcomes*, *10*, Article 154. https://doi.org/10.1186/1477-7525-10-154

Beattie, N., Shannon, C., Kavanagh, M., & Mulholland, C. (2009). Predictors of PTSD symptoms in response to psychosis and psychiatric admission. *The Journal of*

Nervous and Mental Disease, *197*(1), 56–60. https://doi.org/10.1097/NMD.0b013e31819273a8

Bebbington, P. E., Bhugra, D., Brugha, T., Singleton, N., Farrell, M., Jenkins, R., Lewis, G., & Meltzer, H. (2004). Psychosis, victimisation and childhood disadvantage: Evidence from the second British National Survey of Psychiatric Morbidity. *The British Journal of Psychiatry*, *185*, 220–226. https://doi.org/10.1192/bjp.185.3.220

Bergström, T., Seikkula, J., Alakare, B., Mäki, P., Köngäs-Saviaro, P., Taskila, J. J., Tolvanen, A., & Aaltonen, J. (2018). The family-oriented open dialogue approach in the treatment of first-episode psychosis: Nineteen–year outcomes. *Psychiatry Research*, *270*, 168–175. https://doi.org/10.1016/j.psychres.2018.09.039

Berlim, M. T., Pavanello, D. P., Caldieraro, M. A., & Fleck, M. P. (2005). Reliability and validity of the WHOQOL-BREF in a sample of Brazilian outpatients with major depression. *Quality of Life Research*, *14*(2), 561–564. https://doi.org/10.1007/s11136-004-4694-y

Bigelow, D. A., McFarland, B. H., & Olson, M. M. (1991). Quality of life of community mental health programme clients: Validating a measure. *Community Mental Health Journal*, *27*(1), 1–11. https://doi.org/10.1007/bf00752714

Biglan, A., Flay, B. R., Embry, D. D., & Sandler, I. N. (2012). The critical role of nurturing environments for promoting human well-being. *The American Psychologist*, *67*(4), 257–271. https://doi.org/10.1037/a0026796

Billington, R., Landon, J., Krägeloh, C., & Shepherd, D. (2010). The New Zealand World Health Organization Quality of Life (WHOQOL) group. *New Zealand Medical Journal*, *123*(1315), 65–70. https://europepmc.org/article/med/20581932

Birnbaum, A. (1968). Some latent trait models and their use in inferring an examinee's ability. In F. M. Lord & M. R. Novick (Eds.), *Statistical theories of mental test scores* (pp. 392–479). Addison Wesley.

Blake, M. (2020). *Mental health and addiction non-government organisations (NGO) sector: Policy briefing 2020–2023*. Atamira Platform. https://www.platform.org.nz/assets/Briefing-to-incoming-Parliamentarians-FINAL.pdf

Bleuler, M. (1968). A 23-year longitudinal study of 208 schizophrenics and impressions in regard to the nature of schizophrenia. *Journal of Psychiatric Research*, *6*(Suppl. 1), 3–12. https://doi.org/10.1016/0022-3956(68)90004-6

Böckerman, P., Johansson, E., & Saarni, S. I. (2011). Do established health-related quality-of-life measures adequately capture the impact of chronic conditions on subjective well-being? *Health Policy*, *100*(1), 91–95. https://doi.org/10.1016/j.healthpol.2010.10.008

Bonicatto, S. C., Dew, M. A., Zaratiegui, R., Lorenzo, L., & Pecina, P. (2001). Adult outpatients with depression: Worse quality of life than in other chronic medical diseases in Argentina. *Social Science & Medicine*, *52*(6), 911–919. https://doi.org/10.1016/s0277-9536(00)00192-1

Bonney, S., & Stickley, T. (2008). Recovery and mental health: A review of the British literature. *Journal of Psychiatric and Mental Health Nursing*, *15*(2), 140–153. https://doi.org/10.1111/j.1365-2850.2007.01185.x

Boone, W. J. (2016). Rasch analysis for instrument development: Why, when, and how? *CBE Life Sciences Education*, *15*(4), 1–7. https://doi.org/10.1187/cbe.16-04-0148

Borkin, J. R., Steffen, J. J., Ensfield, L. B., Krzton, K., Wishnick, H., Wilder, K., & Yangarber, N. (2000). Recovery attitudes questionnaire: Development and evaluation. *Psychiatric Rehabilitation Journal*, *24*(2), 95–102. https://doi.org/10.1037/h0095112

Bowling, A. (2001). *Measuring disease: A review of disease specific quality of life measurement scales* (2nd ed.). Open University Press.

Bowling, A. (2004). *Measuring health: A review of quality-of-life measurement scales* (3rd ed). McGraw-Hill Education.

Bredewold, F., Hermus, M., & Trappenburg, M. (2018). "Living in the community" the pros and cons: A systematic literature review of the impact of deinstitutionalisation on people with intellectual and psychiatric disabilities. *Journal of Social Work*, *20*(1), 83–116. https://doi.org/10.1177/1468017318793620

Brewerton, T. D. (2007). Eating disorders, trauma, and comorbidity: Focus on PTSD. *Eating Disorders*, *15*(4), 285–304. https://doi.org/10.1080/10640260701454311

Bronfenbrenner, U. (2009). *The ecology of human development: Experiments by nature and design*. Harvard University Press.

Brosnan, L. (2018). Who's talking about us without us? A survivor research interjection into an academic psychiatry debate on compulsory community treatment orders in Ireland. *Laws*, *7*(4), Article 33. https://doi.org/10.3390/laws7040033

Brown, L. D., & Wituk, S. (2010). Introduction to mental health self-help. In L. D. Brown & S. Wituk (Eds.), *Mental health self-help* (pp. 1–15). Springer. https://doi.org/10.1007/978-1-4419-6253-9_1

Brunton, W. (2003). The origins of deinstitutionalisation in New Zealand. *Health and History*, *5*(2), 75–103. https://doi.org/10.2307/40111454

Burgess, P., Coombs, T., Clarke, A., Dickson, R., & Pirkis, J. (2012). Achievements in mental health outcome measurement in Australia: Reflections on progress made by the Australian Mental Health Outcomes and Classification Network (AMHOCN). *International Journal of Mental Health Systems*, *6*(1), Article 4. https://doi.org/10.1186/1752-4458-6-4

Burgess, P., Pirkis, J., Coombs, T., & Rosen, A. (2011). Assessing the value of existing recovery measures for routine use in Australian mental health services. *Australian & New Zealand Journal of Psychiatry*, *45*(4), 267–280. https://doi.org/10.3109/00048674.2010.549996

Butorin, N., Mihailova, J., & Petkov, V. (1997, September 26–28). *Preliminary pilot study data from the cultural adaptation of WHOQOL-100* [Paper presentation]. Meeting of the Annual Conference of the Bulgarian Psychiatric Association, Sofia, Bulgaria.

Byrner, L. M. T., & Skevington, S. (1999). Creating disease modules for the WHOQOL: An assessment for cancer. *Quality of Life Research*, *8*(7), 628–628. http://www.jstor.org/stable/4037303

Caballero, F. F., Miret, M., Power, M., Chatterji, S., Tobiasz-Adamczyk, B., Koskinen, S., Leonardi, M., Olaya, B., Haro, J. M., & Ayuso-Mateos, J. L. (2013). Validation of an instrument to evaluate quality of life in the aging population: WHOQOL-AGE. *Health and Quality of Life Outcomes*, *11*(1), Article 177. https://doi.org/10.1186/1477-7525-11-177

Camfield, L., & Skevington, S. M. (2008). On subjective well-being and quality of life. *Journal of Health Psychology*, *13*(6), 764–775. https://doi.org/10.1177/1359105308093860

Campbell, J. (1989). *The well-being project: Mental health clients speak for themselves: A report of a survey conducted for the California Department of Mental Health, Office of Prevention.* California Department of Mental Health.

Campbell, J. (1997). How consumers/survivors are evaluating the quality of psychiatric care. *Evaluation Review*, *21*(3), 357–363. https://doi.org/10.1177/0193841X9702100310

Cari, M., Blake, L., Lynn, A., Greylord, T., & Benning, S. (2022). *Mental health and well-being ecological model*. University of Minnesota. https://mch.umn.edu/resources/mhecomodel/

Carlton, J., Peasgood, T., Mukuria, C., Johnson, J., Ogden, M., & Tovey, W. (2022). The role of patient and public involvement and engagement (PPIE) within the development of the EQ Health and Well-being (EQ-HWB). *Journal of Patient-Reported Outcomes*, *6*(1), 1–8. https://doi.org/10.1186/s41687-022-00437-y

Carr, A. J., & Higginson, I. J. (2001). Measuring quality of life: Are quality of life measures patient centred? *British Medical Journal*, *322*(7298), 1357–1360. https://doi.org/10.1136/bmj.322.7298.1357

Chambers, L. A., Rueda, S., Baker, D. N., Wilson, M. G., Deutsch, R., Raeifar, E., Rourke, S. B., & The Stigma Review Team. (2015). Stigma, HIV and health: A qualitative synthesis. *BMC Public Health*, *15*(1), Article 848. https://doi.org/10.1186/s12889-015-2197-0

Chang, Y., Ailey, S. H., Heller, T., & Chen, M. (2013). Rasch analysis of the mental health recovery measure. *The American Journal of Occupational Therapy*, *67*(4), 469–477. https://doi.org/10.5014/ajot.2013.007492

Chen, H., Zhu, L., Zhou, R., Liu, P., Lu, X., Patrick, D. L., Edwards, T. C., & Wang, H. (2021). Detecting response shift in health-related quality of life measurement among patients with hypertension using structural equation modelling. *Health and Quality of Life Outcomes 19*(88), 1–10. https://doi.org/10.1186/s12955-021-01732-w

Chiu, M. Y., Ho, W. W., Lo, W. T., & Yiu, M. G. (2010). Operationalization of the SAMHSA model of recovery: A quality of life perspective. *Quality of Life Research*, *19*(1), 1–13. https://doi.org/10.1007/s11136-009-9555-2

Chou, C., & Chronister, J. A. (2011). Social tie characteristics and psychiatric rehabilitation outcomes among adults with serious mental illness. *Rehabilitation Counselling Bulletin*, *55*(2), 92–102. https://doi.org/10.1177/0034355211413139

Cieza, A., & Stucki, G. (2005). Content comparison of health-related quality of life (HRQOL) instruments based on the International Classification of Functioning, Disability and Health (ICF). *Quality of Life Research*, *14*(5), 1225–1237. http://www.jstor.org/stable/4039927

Clark, U. S., Miller, E. R., & Hegde, R. R. (2018). Experiences of discrimination are associated with greater resting amygdala activity and functional connectivity. *Biological Psychiatry: Cognitive Neuroscience and Neuroimaging*, *3*(4), 367–378. https://doi.org/10.1016/j.bpsc.2017.11.011

Coffey, M., Hannigan, B., Meudell, A., Hunt, J., & Fitzsimmons, D. (2016). Study protocol: A mixed methods study to assess mental health recovery, shared decision-making, and quality of life (Plan4Recovery). *BMC Health Services Research, 16,* Article 392. https://doi.org/10.1186/s12913-016-1640-y

Cohen, A. S., & Davis, T. E. (2009). Quality of life across the sociotype spectrum: Findings from a large nonclinical adult sample. *Comprehensive Psychiatry*, *50*(5), 408–414. https://doi.org/10.1016/j.comppsych.2008.11.002

Collier, E., & Grant, M. J. (2018). A literature review on the experience of long-term mental illness. *Issues in Mental Health Nursing*, *39*(6), 506–513. https://doi.org/10.1080/01612840.2017.1404169

Collins, R., Wong, E., Cerully, J., Schultz, D., & Eberhart, N. (2012). Interventions to reduce mental health stigma and discrimination: A literature review to guide evaluation of California's mental health prevention and early intervention initiative. *RAND Health Quarterly*, *2*(4), 1–47. https://doi.org/10.7249/tr1318

Compton, M. T., & Shim, R. S. (2015). The social determinants of mental health. *FOCUS*, *13*(4), 419–425. https://doi.org/10.1176/appi.focus.20150017

Connell, J., Brazier, J., O'Cathain, A., Lloyd-Jones, M., & Paisley, S. (2012). Quality of life of people with mental health problems: A synthesis of qualitative research. *Health and Quality of Life Outcomes*, *10*(1), Article 138. https://doi.org/10.1186/1477-7525-10-138

Connell, J., Carlton, J., Grundy, A., Taylor Buck, E., Keetharuth, A. D., Ricketts, T., Barkham, M., Robotham, D., Rose, D., & Brazier, J. (2018). The importance of content and face validity in instrument development: Lessons learnt from service users when developing the recovering quality of life measure (ReQoL). *Quality of Life Research*, *27*(7), 1893–1902. https://doi.org/10.1007/s11136-018-1847-y

Connell, J., O'Cathain, A., & Brazier, J. (2014). Measuring quality of life in mental health: Are we asking the right questions? *Social Science & Medicine*, *120*, 12–20. https://doi.org/10.1016/j.socscimed.2014.08.026

Cook, J. A., & Jonikas, J. A. (2002). Self-determination among mental health consumers/survivors: Using lessons from the past to guide the future. *Journal of Disability Policy Studies*, *13*(2), 88–96. https://doi.org/10.1177/10442073020130020401

Coons, S. J., Rao, S., Keininger, D. L., & Hays, R. D. (2000). A comparative review of generic quality-of-life instruments. *PharmacoEconomics*, *17*(1), 13–35. https://doi.org/10.2165/00019053-200017010-00002

Copeland, M. E. (2002). Wellness recovery action plan. *Occupational Therapy in Mental Health*, *17*(3–4), 127–150. https://doi.org/10.1300/J004v17n03_09

Corrigan, P. W., Giffort, D., Rashid, F., Leary, M., & Okeke, I. (1999). Recovery as a psychological construct. *Community Mental Health Journal*, *35*(3), 231–239. https://doi.org/10.1023/a:1018741302682

Corrigan, P. W., Salzer, M., Ralph, R. O., Sangster, Y., & Keck, L. (2004). Examining the factor structure of the Recovery Assessment Scale. *Schizophrenia Bulletin*, *30*(4), 1035–1041. https://doi.org/10.1093/oxfordjournals.schbul.a007118

Crawford, M. J., Robotham, D., Thana, L., Patterson, S., Weaver, T., Barber, R., Wykes, T., & Rose, D. (2011). Selecting outcome measures in mental health: The views of service users. *Journal of Mental Health*, *20*(4), 336–346. https://doi.org/10.3109/09638237.2011.577114

Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). SAGE.

Damsgaard, J. B., & Angel, S. (2021). Living a meaningful life while struggling with mental health: Challenging aspects regarding personal recovery encountered in the mental health system. *International Journal of Environmental Research and Public Health*, *18*(5), Article 2708. https://doi.org/10.3390/ijerph18052708

Danaher, M., Cook, J., Danaher, G., Coombes, P., & Danaher, P. A. (2013). Designing and conducting research with marginalized communities. In M. Danaher, J. Cook, G. Danaher, P. Coombes, & P. A. Danaher (Eds.), *Researching education with marginalized communities* (pp. 51–73). https://doi.org/10.1057/9781137012685_4

Davidson, L. (2016). The recovery movement: Implications for mental health care and enabling people to participate fully in life. *Health Affairs*, *35*(6), 1091–1097. https://doi.org/10.1377/hlthaff.2016.0153

Davidson, L., Lawless, M. S., & Leary, F. (2005). Concepts of recovery: Competing or complementary? *Current Opinion in Psychiatry*, *18*(6), 664–667. https://doi.org/10.1097/01.yco.0000184418.29082.0e

Davidson, L., & Roe, D. (2007). Recovery from versus recovery in serious mental illness: One strategy for lessening confusion plaguing recovery. *Journal of Mental Health*, *16*(4), 459–470. https://doi.org/10.1080/09638230701482394

Davidson, L., Roe, D., Andres-Hyman, R., & Ridgway, P. (2010). Applying stages of change models to recovery from serious mental illness: Contributions and limitations. *Israel Journal of Psychiatry and Related Sciences*, *47*(3), 213–221. https://www.proquest.com/docview/818561808

Davidson, L., Stayner, D. A., Nickou, C., Styron, T. H., Rowe, M., & Chinman, M. L. (2001). "Simply to be let in": Inclusion as a basis for recovery. *Psychiatric Rehabilitation Journal*, *24*(4), 375–388. https://doi.org/10.1037/h0095067

De Abreu, L. N., Nery, F. G., Harkavy-Friedman, J. M., De Almeida, K. M., Gomes, B. C., Oquendo, M. A., & Lafer, B. (2012). Suicide attempts are associated with worse quality of life in patients with bipolar disorder type I. *Comprehensive Psychiatry*, *53*(2), 125–129. https://doi.org/10.1016/j.comppsych.2011.03.003

Deb, P., Holmes, A. M., & Deliberty, R. N. (2004). Adjusting for patient characteristics and selection effects in assessment of community mental health centres. *Medical Care*, *42*(3), 251–258. https://doi.org/10.1097/01.mlr.0000114913.12520.6b

Deegan, P. (1996). Recovery as a journey of the heart. *Psychiatric Rehabilitation Journal*, *19*(3), 91–97. https://doi.org/10.1037/h0101301

Deegan, P. E. (1988). Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal*, *11*(4), 11–19. https://doi.org/10.1037/h0099565

Deegan, P. E. (2002). Recovery as a self-directed process of healing and transformation. *Occupational Therapy in Mental Health*, *17*(3–4), 5–21. https://doi.org/10.1300/j004v17n03_02

Deegan, P. E., Rapp, C., Holter, M., & Riefer, M. (2008). Best practices: A program to support shared decision making in an outpatient psychiatric medication clinic. *Psychiatric Services*, *59*(6), 603–605. https://doi.org/10.1176/ps.2008.59.6.603

Deering, D., Robinson, G., Wheeler, A., Pulford, J., Frampton, C., Dunbar, L., & Black, S. (2009). *Preliminary work towards validating a draft outcome measure for use in the alcohol and drug sector*. Te Pou. https://www.tepou.co.nz/resources/preliminary-work-towards-validating-a-draft-outcome-measure-for-use-in-the-alcohol-and-drug-sector

Defar, S., Abraham, Y., Reta, Y., Deribe, B., Jisso, M., Yeheyis, T., Kebede, K. M., Beyene, B., & Ayalew, M. (2023). Health related quality of life among people with mental illness: The role of socio-clinical characteristics and level of functional disability. *Frontiers in Public Health*, *11*, 1134032. https://doi.org/10.3389/fpubh.2023.1134032

De Freitas Melo, C., De Vasconcelos Filho, J. E., Costa, I. M., Sousa Cavalcante, A. K., Martins da Silva, S. M., & De Freitas Filho, R. A. (2022). Assessment and associations between quality of life and risk of suicide. *Psico-USF*, *27*(1), 61–72. https://doi.org/10.1590/1413-82712022270105

De Silva, M. J., Breuer, E., Lee, L., Asher, L., Chowdhary, N., Lund, C., & Patel, V. (2014). Theory of change: A theory-driven approach to enhance the Medical Research Council's framework for complex interventions. *Trials*, *15*, Article 267. https://doi.org/10.1186/1745-6215-15-267

De Sisto, M. J., Harding, C. M., McCormick, R. V., Ashikaga, T., & Brooks, G. W. (1995). The Maine and Vermont three-decade studies of serious mental illness. *British Journal of Psychiatry*, *167*(3), 331–338. https://doi.org/10.1192/bjp.167.3.331

De Vries, J., & Van Heck, G. L. (1994). Quality of life and refugees. *International Journal of Mental Health*, *23*(3), 57–75. https://doi.org/10.1080/00207411.1994.11449287

DiClemente, C. C., Schlundt, D., & Gemmell, L. (2004). Readiness and stages of change in addiction treatment, *American Journal on Addictions*, *13*(2), 103–119. https://doi.org/10.1080/10550490490435777

Diener, E. (2006). Guidelines for national indicators of subjective well-being and ill-being. *Journal of Happiness Studies*, *7*(4), 397–404. https://doi.org/10.1007/s10902-006-9000-y

Donnelly, M., Scott, D., McGilloway, S., O'Neill, T., Williams, J., & Slade, M. (2011). *Patient outcomes: What are the best methods for measuring recovery from mental illness and capturing feedback from patients in order to inform service improvement?* Public Health Agency. https://www.publichealth.hscni.net/sites/default/files/Patient Outcomes.pdf

Dorrer, N. (2006). *Evidence of recovery: The 'ups' and 'downs' of longitudinal outcome studies* (SRN Discussion Paper Series, Report No. 4). Glasgow Scottish Recovery Network. https://lx.iriss.org.uk/sites/default/files/resources/Evidence of Recovery The 'Ups' and 'Downs' of Longitudinal Outcome Studies.pdf

Double, D. (2002). The limits of psychiatry. *British Medical Journal*, *324*(7342), 900–904. https://doi.org/10.1136/bmj.324.7342.900

DuBrul, S. A. (2014). The Icarus project: A counter narrative for psychic diversity. *Journal of Medical Humanities*, *35*(3), 257–271. https://doi.org/10.1007/s10912-014-9293-5

Durie, M. H. (1994). *Waiora: Māori health development.* Oxford University Press.

Ebesutani, C., Fierstein, M., Viana, A. G., Trent, L., Young, J., & Sprung, M. (2015). The role of loneliness in the relationship between anxiety and depression in clinical and school-based youth. *Psychology in the Schools*, *52*(3), 223–234. https://doi.org/10.1002/pits.21818

Elliott, M., & Cloet, A. (2017). *People's mental health report: A crowdfunded, crowdsourced story-based report*. Action Station Aotearoa 2017. https://apo.org.au/node/75964

Ellison, M. L., Belanger, L. K., Niles, B. L., Evans, L. C., & Bauer, M. S. (2016). Explication and definition of mental health recovery: A systematic review. *Administration and Policy in Mental Health and Mental Health Services Research*, *45*(1), 91–102. https://doi.org/10.1007/s10488-016-0767-9

Engel, G. L. (1980). The clinical application of the biopsychosocial model. *The American Journal of Psychiatry*, *137*(5), 535–544. https://doi.org/10.1176/ajp.137.5.535

Ensfield, L. B. (1998). *The personal vision of recovery questionnaire (PVRQ): The development of a consumer-derived scale* [Doctoral thesis, University of Cincinnati]. http://uclid.uc.edu/search/o39802897

Evans, S., Banerjee, S., Leese, M., & Huxley, P. (2007). The impact of mental illness on quality of life: A comparison of severe mental illness, common mental disorder, and healthy population samples. *Quality of Life Research*, *16*(1), 17–29. https://doi.org/10.1007/s11136-006-9002-6

Fahy, T., Kent, A., Tattan, T., Van Horn, E., & White, I. (1999). Predictors of quality of life in people with severe mental illness. *British Journal of Psychiatry*, *175*(5), 426–432. https://doi.org/10.1192/bjp.175.5.426

Farkas, M. (2007). The vision of recovery today: What it is and what it means for services. *World Psychiatry*, *6*(2), 68–74. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2219905/

Farkas, M. (2013). Introduction to psychiatric/psychosocial rehabilitation (PSR): History and foundations. *Current Psychiatry Reviews*, *9*(3), 177–187. https://doi.org/10.2174/1573400511309030003

Farkas, M., Anthony, W., Montenegro, R., & Gayvoronskaya, E. (2016). Person-centred psychiatric rehabilitation. In J. Mezzich, M. Botbol, G. Christodoulou, C. Cloninger, & I. Salloum (Eds.), *Person centred psychiatry* (pp. 277–289). https://doi.org/10.1007/978-3-319-39724-5_21

Farley, M. Golding, J. M., Young, G., Mulligan, M., & Minkoff, J. R. (2004). Trauma history and relapse probability among patients seeking substance abuse treatment. *Journal of Substance Abuse Treatment, 27,* 161–167. https://doi.org/10.1016/j.jsat.2004.06.006

Feng, X. (2011). *Selection of national items for the New Zealand WHO Quality of Life Questionnaire* [Unpublished honour's thesis]. Auckland University of Technology.

Ferguson, G. A. (1943). Item selection by the constant process. *Psychometrika*, *7*, 19–29. https://doi.org/10.1007/BF02288601

Fisher, D. B. (1994). Health care reform based on an empowerment model of recovery by people with psychiatric disabilities. *Psychiatric Services*, *45*(9), 913–915. https://doi.org/10.1176/ps.45.9.913

Fisher, D. B. (2017). *What are the characteristics of a person who has recovered from mental illness?* National Empowerment Centre. https://power2u.org/what-are-the-characteristics-of-a-person-who-has-recovered-from-mental-illness/

Fleck, M. P. (2013, June 8–9). *Possible uses of WHOQOL in mental health: International and Brazilian perspectives* [Keynote presentation]. 2nd New Zealand Association of Positive Psychology Conference: Towards a Flourishing New Zealand. Auckland, New Zealand.

Fleury, M. J., Grenier, G., Bamvita, J. M., Tremblay, J., Schmitz, N., & Caron, J. (2013). Predictors of quality of life in a longitudinal study of users with severe mental disorders. *Health and Quality of Life Outcomes*, *11*, Article 92. https://doi.org/10.1186/1477-7525-11-92

Floen, S. K., & Elklit, A. (2007). Psychiatric diagnoses, trauma, and suicidality. *Annals of General Psychiatry*, *6*(12), 1–8. https://doi.org/10.1186/1744-859x-6-12

Franz, M., Fritz, M., & Meyer, T. (2012). Discriminant and convergent validity of a subjective quality-of-life instrument aimed at high content validity for schizophrenic persons. *Quality of Life Research*, *22*(5), 1113–1122. https://doi.org/10.1007/s11136-012-0221-8

Frese, F. J., Knight, E. L., & Saks, E. (2009). Recovery from schizophrenia with views of psychiatrists, psychologists, and others diagnosed with this disorder. *Schizophrenia Bulletin*, *35*(2), 370–380. https://doi.org/10.1093/schbul/sbn175

Frisch, M. B., Cornell, J., Villanueva, M., & Retzlaff, P. J. (1992). Clinical validation of the Quality-of-Life Inventory. A measure of life satisfaction for use in treatment planning and outcome assessment. *Psychological Assessment*, *4*(1), 92–101. https://doi.org/10.1037/1040-3590.4.1.92

Garcia-Rea, E. A., & LePage, J. P. (2010). Reliability and validity of the World Health Organization quality of life: Brief version (WHOQOL-BREF) in a homeless substance dependent veteran population. *Social Indicators Research*, *99*(2), 333–340. https://doi.org/10.1007/s11205-010-9583-x

Garno, J. L., Goldberg, J. F., Ramirez, P. M., & Ritzler, B. A. (2005). Impact of childhood abuse on the clinical course of bipolar disorder. *The British Journal of Psychiatry, 186*, 121–125. https://doi.org/10.1192/bjp.186.2.121

GBD 2019 Mental Disorders Collaborators. (2022). Global, regional, and national burden of 12 mental disorders in 204 countries and territories, 1990–2019: A systematic analysis for the global burden of disease study 2019. *The Lancet Psychiatry*, *9*(2), 137–150. https://doi.org/10.1016/s2215-0366(21)00395-3

Giffort, D., Schmook, A., Woody, C., Vollendorf, C., & Gervain, M. (1995). *Recovery Assessment Scale* [Database record]. APAPsycTests. https://doi.org/10.1037/t12324-000

Ginieri-Coccossis, M., Triantafillou, E., Tomaras, V., Liappas, I. A., Christodoulou, G. N., & Papadimitriou, G. N. (2009). Quality of life in mentally ill, physically ill, and healthy individuals: The validation of the Greek version of the World Health Organization quality of life (WHOQOL-100) questionnaire. *Annals of General Psychiatry*, *8*, Article 23. https://doi.org/10.1186/1744-859x-8-23

Gordon, S., Davey, S., Waa, A., Tiatia, R., & Waaka, T. (2017). *Social inclusion and exclusion, stigma and discrimination, and the experience of mental distress.* Mental Health Foundation. https://mentalhealth.org.nz/resources/download/169/l8dbqz1fuozzouix

Gordon, S., & Ellis, P. (2013). My voice, my life: A measure based on the consumer model of recovery. *World Psychiatry*, *12*(3), 277–277. https://doi.org/10.1002/wps.20055

Gordon, S., Ellis, P., Haggerty, C., Rangitane, L. P., Platz, G., & McLaren, K. (2004). *Tāku reo, tāku mauri ora, my voice, my life.* Te Pou. https://www.tepou.co.nz/resources/taku-reo-taku-mauri-ora-tool

Gordon, S. E. (2013). Recovery constructs and the continued debate that limits consumer recovery. *Psychiatric Services*, *64*(3), 270–271. https://doi.org/10.1176/appi.ps.001612012

Gordon, S. E., Ellis, P. M., Siegert, R. J., & Walkey, F. H. (2012). Development of a self-assessed consumer recovery outcome measure: My voice, my life. *Administration and Policy in Mental Health and Mental Health Services Research*, *40*(3), 199–210. https://doi.org/10.1007/s10488-012-0417-9

Green, C. A. (2004). Fostering recovery from life-transforming mental health disorders: A synthesis and model. *Social Theory & Health*, *2*(4), 293–314. https://doi.org/10.1057/palgrave.sth.8700036

Guilford, J. P. (1936). *Psychometric methods*. McGraw-Hill. https://doi.org/10.1007/BF02287877

Guo, Y., Qu, S., & Qin, H. (2018). Study of the relationship between self-stigma and subjective quality of life for individuals with chronic schizophrenia in the community. *General Psychiatry*, *31*(3), Article e100037. https://doi.org/10.1136/gpsych-2018-100037

Guyatt, G. H., Feeny, D. H., & Patrick, D. L. (1993). Measuring health-related quality of life. *Annals of Internal Medicine*, *118*(8), 622–629. https://doi.org/10.7326/0003-4819-118-8-199304150-00009

Hansson, L., & Björkman, T. (2006). Are factors associated with subjective quality of life in people with severe mental illness consistent over time? A 6-year follow-up study. *Quality of Life Research*, *16*(1), 9–16. https://doi.org/10.1007/s11136-006-9119-7

Happell, B., & Roper, C. (2007). Consumer participation in mental health research: Articulating a model to guide practice. *Australasian Psychiatry*, *15*(3), 237–241. https://doi.org/10.1080/10398560701320113

Haraldstad, K., Wahl, A., Andenæs, R., Andersen, J. R., Andersen, M. H., Beisland, E., Borge, C. R., Engebretsen, E., Eisemann, M., Halvorsrud, L., Hanssen, T. A., Haugstvedt, A., Haugland, T., Johansen, V. A., Larsen, M. H., Løvereide, L., Løyland, B., Kvarme, L. G., & Helseth, S. (2019). A systematic review of quality-of-life research in medicine and health sciences. *Quality of Life Research*, *28*(10), 2641–2650. https://doi.org/10.1007/s11136-019-02214-9

Harding, C. M., Brooks, G. W., Ashikaga, T., Strauss, J. S., & Breier, A. (1987). The Vermont longitudinal study of persons with severe mental illness, II: Long-term outcome of subjects who retrospectively met DSM-III criteria for schizophrenia. *American Journal of Psychiatry*, *144*(6), 727–735. https://doi.org/10.1176/ajp.144.6.727

Harrison, G., & Mason, P. (1993). Schizophrenia – Falling incidence and better outcome? *British Journal of Psychiatry*, *163*(4), 535–541. https://doi.org/10.1192/bjp.163.4.535

Hartley, S., McArthur, M., Coenen, M., Cabello, M., Covelli, V., Roszczynska-Michta, J., Pitkänen, T., Bickenbach, J., & Cieza, A. (2014). Narratives reflecting the lived experiences of people with brain disorders: Common psychosocial difficulties and determinants. *PLoS ONE*, *9*(5), Article e96890. https://doi.org/10.1371/journal.pone.0096890

Hawkley, L. C., & Cacioppo, J. T. (2010). Loneliness matters: A theoretical and empirical review of consequences and mechanisms. *Annals of Behavioural Medicine*, *40*(2), 218–227. https://doi.org/10.1007/s12160-010-9210-8

Hawthorne, G., Herrman, H., & Murphy, B. (2006). Interpreting the WHOQOL-BREF: Preliminary population norms and effect sizes. *Social Indicators Research*, *77*(1), 37–59. http://www.jstor.org/stable/27522572

Herrman, H., Hawthorne, G., & Thomas, R. (2002). Quality of life assessment in people living with psychosis. *Social Psychiatry and Psychiatric Epidemiology*, *37*(11), 510–518. https://doi.org/10.1007/s00127-002-0587-y

Hesse-Biber, S. (2010). Qualitative approaches to mixed methods practice. *Qualitative Inquiry*, *16*(6), 455–468. https://doi.org/10.1177/1077800410364611

Ho, L. (2011). *Schizophrenia, acculturation, and Chinese American families: A review and clinical recommendations for treatment* [Doctoral thesis, Pepperdine University]. https://digitalcommons.pepperdine.edu/cgi/viewcontent.cgi?article=1209&context=etd

Ho, W. W., Chiu, M. Y., Lo, W. T., & Yiu, M. G. (2010). Recovery components as determinants of the health-related quality of life among patients with schizophrenia: Structural equation modelling analysis. *Australian & New Zealand Journal of Psychiatry*, *44*(1), 71–84. https://doi.org/10.3109/00048670903393654

Hobart, J. C., Cano, S. J., & Thompson, A. J. (2010). Effect sizes can be misleading: Is it time to change the way we measure change? *Journal of Neurological & Neurosurgical Psychiatry*, *81*(9), 1044–1048. https://doi.org/10.1136/jnnp.2009.201392

Houghton, J. F. (1982). First person account: Maintaining mental health in a turbulent world. *Schizophrenia Bulletin*, *8*(3), 548–553. https://doi.org/10.1093/schbul/8.3.548

Hsu, P. (2009). *Development of a New Zealand version of the World Health Organisation quality of life survey instrument (WHOQOL)* [Master's thesis, Auckland University of Technology]. Tuwhera. https://orapp.aut.ac.nz/bitstream/handle/10292/978/HsuP.pdf?sequence=3&isAllowed=y

Ilic, I., Sipetic-Grujicic, S., Grujicic, J., Zivanovic Macuzic, I., Kocic, S. & Ilic, M. (2019). Psychometric properties of the World Health Organization's Quality of Life (WHOQOL-BREF) questionnaire in medical students. *Medicina (Kaunas, Lithuania)*, *55*(12), 772. https://doi.org/10.3390/medicina55120772

Ioane, J., & Tudor, K. (2017). The fa'asamoa, person-centred theory and cross-cultural practice. *Person-Centred & Experiential Psychotherapies*, *16*(4), 287–302. https://doi.org/10.1080/14779757.2017.1361467

Jacob, K. S. (2015). Recovery model of mental illness: A complementary approach to psychiatric care. *Indian Journal of Psychological Medicine*, *37*(2), 117–119. https://doi.org/10.4103/0253-7176.155605

Jacobson, N. (2001). Experiencing recovery: A dimensional analysis of recovery narratives. *Psychiatric Rehabilitation Journal*, *24*(3), 248–256. https://doi.org/10.1037/h0095087

Jacobson, N., & Curtis, L. (2000). Recovery as policy in mental health services: Strategies emerging from the states. *Psychiatric Rehabilitation Journal*, *23*(4), 333–341. https://doi.org/10.1037/h0095146

Jencks, S. F. (1987). Case-mix measurement and assessing quality of hospital care. *Health Care Financing Review*, *1987*(Suppl.), 39–48. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4195096/

Jenkinson, C., & McGee, H. M. (1998). *Health status measurement: A brief but critical introduction*. Radcliffe Publishing.

Jeong-gyu, B., Myeong-ja, S., & Jong-goo, L. (2009). Development of the recovery attitudes scale for persons with psychiatric disabilities. *Korean Journal of Clinical Psychology*, *28*(2), 605–627. https://doi.org/10.15842/kjcp.2009.28.2.016

Jerrell, J. M., Cousins, V. C., & Roberts, K. M. (2006). Psychometrics of the recovery process inventory. *The Journal of Behavioural Health Services & Research*, *33*(4), 464–473. https://doi.org/10.1007/s11414-006-9031-5

Karimi, M., & Brazier, J. (2016). Health, health-related quality of life, and quality of life: What is the difference? *PharmacoEconomics*, *34*(7), 645–649. https://doi.org/10.1007/s40273-016-0389-9

Katschnig, H. (2006). Quality of life in mental disorders: Challenges for research and clinical practice. *World Psychiatry*, *5*(3), 139–145.

Keene, M. (2013). *Mad house: The hidden history of insane asylums in 19th century New York* (2nd ed.). Willow Manor Publishing.

Keetharuth, A. D., Brazier, J., Connell, J., Bjorner, J. B., Carlton, J., Taylor Buck, E., Ricketts, T., McKendrick, K., Browne, J., Croudace, T., & Barkham, M. (2018). Recovering quality of life (ReQoL): A new generic self-reported outcome measure for use with people experiencing mental health difficulties. *The British Journal of Psychiatry*, *212*(1), 42–49. https://doi.org/10.1192/bjp.2017.10

Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry*, *62*(6), 593–602. https://doi.org/10.1001/archpsyc.62.6.593

Kessler, R. C., Sonnega, A., Bromet, E., Hughes, M., & Nelson, C. B. (1995). Posttraumatic stress disorder in the National Comorbidity Survey. *Archives of General Psychiatry, 52*(12), 1048–1060. https://doi.org/10.1001/archpsyc.1995.03950240066012

Khan, A., Chien, C., & Brauer, S. G. (2013). Rasch-based scoring offered more precision in differentiating patient groups in measuring upper limb function. *Journal of Clinical Epidemiology*, *66*(6), 681-687. https://doi.org/10.1016/j.jclinepi.2012.12.014

Kingi, T., & Durie, M. (2000). "*Hua oranga": A Māori measure of mental health outcome* (Research Report TPH 00/01). Ministry of Health. https://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/2E3845581DC2CF9DCC257F070007CD17/$file/Hua Oranga Kingi & Durie 2000.pdf

Kleinman, A. (2009). Global mental health: A failure of humanity. *The Lancet*, *374*(9690), 603–604. https://doi.org/10.1016/s0140-6736(09)61510-5

Koenen, K. C., Moffitt, T. E., Caspi, A., Gregory, A., Harrington, H., & Poulton, R. (2008). The developmental mental-disorder histories of adults with posttraumatic stress disorder: A prospective longitudinal birth cohort study. *Journal of Abnormal Psychology*, *117*(2), 460–466. https://doi.org/10.1037/0021-843X.117.2.460

Krägeloh, C. U., Billington, D. R., Hsu, P. H., Feng, X. J., Medvedev, O. N., Kersten, P., Landon, J., & Siegert, R. J. (2016). Ordinal-to-interval scale conversion tables and national items for the New Zealand version of the WHOQOL-BREF. *PLOS ONE*, *11*(11), Article e0166065. https://doi.org/10.1371/journal.pone.0166065

Krägeloh, C. U., Billington, D. R., Hsu, P. H., & Landon, J. (2015). What New Zealanders find important to their quality of life: Comparisons with international WHOQOL data from 14 other countries. *Australian and New Zealand Journal of Public Health*, *39*(4), 384–388. https://doi.org/10.1111/1753-6405.12350

Krägeloh, C. U., Kersten, P., Billington, D. R., Hsu, P. H., Shepherd, D., Landon, J., & Feng, X. J. (2013). Validation of the WHOQOL-BREF quality of life questionnaire for general use in New Zealand: Confirmatory factor analysis and Rasch analysis. *Quality of Life Research*, *22*(6), 1451–1457. https://doi.org/10.1007/s11136-012-0265-9

Kvalsvig, A. (2018). *Well-being and mental distress in Aotearoa New Zealand: Snapshot 2016.* Health Promotion Agency. https://www.hpa.org.nz/sites/default/files/Well-being-And-Mental-Distress-Snapshot-2016-Final-FEB2018.PDF

Lamb, H. R., & Bachrach, L. L. (2001). Some perspectives on deinstitutionalization. *Psychiatric Services*, *52*(8), 1039–1045. https://doi.org/10.1176/appi.ps.52.8.1039

Lapsley, H., Waimarie Nikora, L., & Black, R. (2002). *"Kia mauri tau!" Narratives of recovery from disabling mental health problems*. Mental Health Commission of New Zealand. https://researchcommons.waikato.ac.nz/handle/10289/1666

Lawley, D. N. (1943). On problems connected with item selection and test construction. *Proceedings of the Royal Society of Edinburgh*, *61*(3), 273–287. https://doi.org/10.1017/S0080454100006282

Lazarsfeld, P. F. (1950). The logical and mathematical foundation of latent structure analysis. In S. A. Stouffer, L. Guttman, E. A. Suchman, P. F. Lazarsfeld, S. A. Star & J. A. Clausen (Eds.), *Measurement and prediction* (pp. 362–412). Wiley.

Leamy, M., Bird, V., Boutillier, C. L., Williams, J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: Systematic review and narrative synthesis. *British Journal of Psychiatry*, *199*(6), 445–452. https://doi.org/10.1192/bjp.bp.110.083733

Lehman, A. F., Lieberman, J. A., Dixon, L. B., McGlashan Miller, A. L., Perkins, D. O., Kreyenbuhl, J. T. H., Miller, A. L., Perkins, D. O., Kreyenbuhl, J., & Working Group on Schizophrenia. (2004). Practice guideline for the treatment of patients with schizophrenia. American Psychiatric Association. *American Journal of Psychiatry*, *161*(2), 1–56. https://doi.org/10.1176/ajp.154.4.1

Leung, Y. Y., Png, M. E., Conaghan, P., & Tennant, A. (2014). A systematic literature review on the application of Rasch analysis in musculoskeletal disease -- A special interest group report of OMERACT 11. *The Journal of Rheumatology*, *41*(1), 159–164. https://doi.org/10.3899/jrheum.130814

Likert, R. (1932). A technique for the measurement of attitudes. *Archives of Psychology*, *140*, 4-55.

Lin, C., Lee, T., Sun, Z., Yang, Y., Wu, J., & Ou, H. (2017). Development of diabetes-specific quality of life module to be in conjunction with the World Health Organization quality of life scale brief version (WHOQOL-BREF). *Health and Quality of Life Outcomes*, *15*(167), 1–10. https://doi.org/10.1186/s12955-017-0744-3

Lin, X., Lin, I., & Fan, S. (2013). Methodological issues in measuring health-related quality of life. *Tzu Chi Medical Journal*, *25*(1), 8–12. https://doi.org/10.1016/j.tcmj.2012.09.002

Liu, R. T., Kleiman, E. M., Nestor, B. A., & Cheek, S. M. (2015). The hopelessness theory of depression: A quarter century in review. *Clinical Psychology*, *22*(4), 345–365. https://doi.org/10.1111/cpsp.12125

Llewellyn, A. M., & Skevington, S. M. (2015). Using guided individualised feedback to review self-reported quality of life in health and its importance. *Psychology & Health*, *30*(3), 301–317. https://doi.org/10.1080/08870446.2014.972396

Lohr, K. N. (2002). Assessing health status and quality-of-life instruments: Attributes and review criteria. *Quality of Life Research, 11*, 193–205. https://doi.org/10.1023/A:1015291021312

Longden, E. (2013). *The voices in my head* [Video]. Ted Conferences. https://www.ted.com/talks/eleanor_longden_the_voices_in_my_head

Lord, F. M. (1952). A theory of test scores. *Psychometric Monographs, 7*.

Lord, F. M., & Novick, M. R. (1968). *Statistical theories of mental test scores*. Addison-Wesley. https://psycnet.apa.org/record/1968-35040-000

Lourenco, C. A. (2007). *Examining the relationship between stigma and subjective quality of life in persons with schizophrenia* [Doctoral thesis, University of Hartford]. ProQuest Dissertations Publishing. https://www.proquest.com/openview/3f24e3745fd7a020a140fefe11858b66/1?pq-origsite=gscholar&cbl=18750

Lucchetti, G., Koenig, H. G., & Lucchetti, A. (2021). Spirituality, religiousness, and mental health: A review of the current scientific evidence. *World Journal of Clinical Cases*, *9*(26), 7620–7631. https://doi.org/10.12998/wjcc.v9.i26.7620

Lundgren-Nilsson, Å., Jonsdottir, I. H., Ahlborg, G., & Tennant, A. (2013). Construct validity of the psychological general well-being index (PGWBI) in a sample of patients undergoing treatment for stress-related exhaustion: A Rasch analysis. *Health and Quality of Life Outcomes 11*(2), 1–9. https://doi.org/10.1186/1477-7525-11-2

Luo, W., Harvey, R., Tran, T., Phung, D., Venkatesh, S., & Connor, J. P. (2016). Consistency of the health of the nation outcome scales (HoNOS) at inpatient-to-community transition. *BMJ Open*, *6*(4), Article e010732. https://doi.org/10.1136/bmjopen-2015-010732

MacCallum, R. C., Browne, M. W., & Sugawara, H. M. (1996). Power analysis and determination of sample size for covariance structural modelling. *Psychological Methods, 1*, 130–149. https://doi.org/10.1037/1082-989X.1.2.130

MacKeith, J., Burns, S., Facey, E., & Johnson, J. (2008). *Mental health recovery star: User-guide*. Mental Health Providers Forum. https://mnpmind.org.uk/wp-content/uploads/2021/09/Recovery-STAR-User-Guide.pdf

Macpherson, R., Pesola, F., Leamy, M., Bird, V., Le Boutillier, C., Williams, J., & Slade, M. (2016). The relationship between clinical and recovery dimensions of outcome in mental health. *Schizophrenia Research, 175*(1-3), 142–147. https://doi.org/10.1016/j.schres.2015.10.031

Malla, A., Joober, R., & Garcia, A. (2015). "Mental illness is like any other medical illness": A critical examination of the statement and its impact on patient care and society. *Journal of Psychiatry and Neuroscience, 40*(3), 147–150. https://doi.org/10.1503/jpn.150099

Mansfield, R., Patalay, P., & Humphrey, N. (2020). A systematic literature review of existing conceptualisation and measurement of mental health literacy in adolescent research: Current challenges and inconsistencies. *BMC Public Health, 20*, Article 607. https://doi.org/10.1186/s12889-020-08734-1

Maris, M. A., Podea, D. M., & Rotund, C. D. (2012). Well-being as a component of quality of life in schizophrenia. *Journal of Psychological and Educational Research, 20*(2), 31–43. https://www.researchgate.net/publication/287298391_Well-being_as_a_component_of_life_quality_in_schizophrenia

Mas-Expósito, L., Amador-Campos, J. A., Gómez-Benito, J., & Lalucat-Jo, L. (2011). The World Health Organization Quality of Life Scale brief version: A validation study in patients with schizophrenia. *Quality of Life Research*, *20*(7), 1079–1089. https://doi.org/10.1007/s11136-011-9847-1

Maslow, A. (1954). *Motivation and personality*. Harper & Row.

Mason, V. L., Skevington, S. M., & Osborn, M. (2004). Development of a pain and discomfort module for use with the WHOQOL-100. *Quality of Life Research*, *13*(6), 1139–1152. https://doi.org/10.1023/b:qure.0000031344.53009.eb

Masters, G. N. (1982). A Rasch model for partial credit scoring. *Psychometrika*, *47*(2), 149–174. https://doi.org/10.1007/bf02296272

Masters, G. N. (2016). Partial credit model. In W. J. van der Linden (Ed.), *Handbook of item response theory, volume one: Models* (pp. 109–126). Boca Raton, FL: Chapman & Hall/CRC. https://doi.org/10.1201/9781315374512

Masthoff, E. D., Trompenaars, F. J., Van Heck, G. L., De Vries, J., & Hodiamont, P. P. (2006). The relationship between stress and quality of life in psychiatric outpatients. *Stress and Health*, *22*(4), 249–255. https://doi.org/10.1002/smi.1105

Masthoff, E. D., Trompenaars, F. J., Van Heck, G. L., Hodiamont, P. P., & De Vries, J. (2005). Validation of the WHO quality of life assessment instrument (WHOQOL-100) in a population of Dutch adult psychiatric outpatients. *European Psychiatry*, *20*(7), 465–473. https://doi.org/10.1016/j.eurpsy.2004.09.012

Masthoff, E. D., Trompenaars, F. J., Van Heck, G. L., Hodiamont, P. P., & De Vries, J. (2006). Quality of life and psychopathology: Investigations into their relationship. *Australian & New Zealand Journal of Psychiatry*, *40*(4), 333–340. https://doi.org/10.1080/j.1440-1614.2006.01799.x

Masuda, A., Hayes, S. C., Lillis, J., Bunting, K., Herbst, S. A., & Fletcher, L. B. (2009). The relation between psychological flexibility and mental health stigma in acceptance and commitment therapy: A preliminary process investigation. *Behaviour and Social Issues*, *18*, 25–40. https://doi.org/10.5210/bsi.v18i1.2525

Matheson, K., Foster, M. D., Bombay, A., McQuaid, R. J., & Anisman, H. (2019). Traumatic experiences, perceived discrimination, and psychological distress among members of various socially marginalized groups. *Frontiers in Psychology*, *10*(416), 1–16. https://doi.org/10.3389/fpsyg.2019.00416

Mayer, R. C. F., Alves, M. R., Yamauti, S. M., Silva, M. T., & Lopes, L. C. (2021). Quality of Life and Functioning of People With Mental Disorders Who Underwent Deinstitutionalization Using Assisted Living Facilities: A Cross-Sectional Study. *Frontiers in Psychology*, *12*, 622973. https://doi.org/10.3389/fpsyg.2021.622973

Mayo, N. E. (2015). *ISOQOL dictionary of quality of life and health outcomes measurement*. ISOQOL. https://www.isoqol.org/dictionary/

McClintock, K. K., Mellsop, G. W., & Kingi, T. K. (2011). Development of a culturally attuned psychiatric outcome measure for an Indigenous population. *International Journal of Culture and Mental Health*, *4*(2), 128–143. https://doi.org/10.1080/17542863.2010.537484

McDowell, I. (2006). *Measuring health: A guide to rating scales and questionnaires* (3rd ed.). Oxford University Press. https://doi.org/10.1093/acprof:oso/9780195165678.001.0001

Medici, C. R., Vestergaard, C. H., Hjorth, P., Hansen, M. V., Shanmuganathan, J. W., Viuff, A. G., & Munk-Jørgensen, P. (2015). Quality of life and clinical characteristics in a non-selected sample of patients with schizophrenia. *International Journal of Social Psychiatry*, *62*(1), 12–20. https://doi.org/10.1177/0020764015585330

Medvedev, O. N., & Krägeloh, C. U. (2022). Rasch measurement model. In O. N. Medvedev, C. U. Krägeloh, R, J., Siegert, & N. N. Singh (Eds.), *Handbook of assessment in mindfulness research* (pp. 1–18). Springer. https://doi.org/10.1007/978-3-030-77644-2_4-1

Medvedev, O. N., & Landhuis, C. E. (2018). Exploring constructs of well-being, happiness, and quality of life. *PeerJ*, *6*, Article e4903. https://doi.org/10.7717/peerj.4903

Medvedev, O. N., Siegert, R. J., Kersten, P., & Krägeloh, C. U. (2017). Improving the precision of the five-facet mindfulness questionnaire using a Rasch approach. *Mindfulness*, *8*(4), 995–1008. https://doi.org/10.1007/s12671-016-0676-8

Medvedev, O. N., Turner-Stokes, L., Ashford, S., & Siegert, R. J. (2018). Rasch analysis of the UK Functional Assessment Measure in patients with complex disability after stroke. *Journal of Rehabilitation Medicine*, *50*(5), 420–428. https://doi.org/10.2340/16501977-2324

Meeberg, G. A. (1993). Quality of life: A concept analysis. *Journal of Advanced Nursing*, *18*(1), 32–38. https://doi.org/10.1046/j.1365-2648.1993.18010032.x

Melle, I., Friis, S., Haahr, U., Johannesen, J., Larsen, T., Opjordsmoen, S., Roessberg, J., Rund, B., Simonsen, E., Vaglum, P., & McGlashan, T. (2005). Measuring quality of life in first-episode psychosis. *European Psychiatry*, *20*(7), 474–483. https://doi.org/10.1016/j.eurpsy.2005.03.002

Mellsop, G., Dutu, G., & Robinson, G. (2007). New Zealand psychiatrists views on global features of ICD-10 and DSM-IV. *Australian and New Zealand Journal of Psychiatry*, *41*(2), 157–165. https://doi.org/10.1080/00048670601109931

Mental Health Foundation. (2006). *The impact of spirituality: A literature review.* https://www.elament.org.uk/self-help-resources/the-mental-health-foundation-the-impact-of-spirituality-a-literature-review/

Mental Health Foundation. (2018, February 28). *Commissioner's report shows scale of mental health challenge* [Press release]. https://www.mentalhealth.org.nz/home/news/article/202/commissioners-report-shows-scale-of-mental-health-challenge

Merriam-Webster. (n.d.). Stigma. In *Merriam-Webster.com dictionary.* Retrieved September 3, 2023, from https://www.merriam-webster.com/dictionary/stigma

Michaels, C., Blake, L., Lynn, A., Greylord, T., & Benning, S. (2022, April 18). *Mental health and well-being ecological model*. University of Minnesota. https://mch.umn.edu/resources/mhecomodel/

Michalos, A. C. (2008). Satisfaction and happiness. *Social Indicators Research*, *8*, 385–422. https://doi.org/10.1007/978-94-007-0753-5_2379

Millum, J., Campbell, M., Luna, F., Malekzadeh, A., & Karim, Q. A. (2019). Ethical challenges in global health-related stigma research. *BMC Medicine*, *17*, Article 84. https://doi.org/10.1186/s12916-019-1317-6

Ministry of Health. (2016a). *Commissioning framework for mental health and addiction: A New Zealand guide* (HP 6438). https://www.health.govt.nz/system/files/documents/publications/commissioning-framework-mental-health-addiction-nz-guide-aug16.pdf

Ministry of Health. (2016b). *Mental health and addiction: Service use 2014/15*. https://www.health.govt.nz/publication/mental-health-and-addiction-service-use-2014-15

Ministry of Health. (2018). *Mental health and addiction: Service use 2015/16*. https://www.health.govt.nz/publication/mental-health-and-addiction-service-use-2015-16

Mizock, L., & Carr, E. (2021). History of the mistreatment of women with serious mental illness. In L. Mizock & E. Carr (Eds.), *Women with serious mental illness: Gender-sensitive and recovery-oriented care* (pp. 6–23). https://doi.org/10.1093/med-psych/9780190922351.003.0002

Moncrieff, J. (2010). Psychiatric diagnosis as a political device. *Social Theory & Health*, *8*(4), 370–382. https://doi.org/10.1057/sth.2009.11

Monk, G., & Hancock, S. (2015). Recovering a life with severe mental illness: Psychologists and peer support specialists working together. *Psychology Aotearoa*, *7*(2), 112–118. https://www.psychology.org.nz/journal-archive/PsychAo-November-2015-for-email.pdf

Mousa, M. (2011). *The development of a mental health recovery module for the World Health Organization's Quality of Life Assessment* [Unpublished paper submitted for partial course completion]. School of Psychology, Auckland University of Technology.

Mueser, K. T., Bond, G. R., Drake, R. E., & Resnick, S. G. (1998). Models of community care for severe mental illness: A review of research on case management. *Schizophrenia Bulletin*, *24*(1), 37–74. https://doi.org/10.1093/oxfordjournals.schbul.a033314

Mueser, K. T., Gingerich, S., Salyers, M. P., McGuire, A. B., Reyes, R. U., & Cunningham, H. (2005). Illness Management and Recovery (IMR) Scales. In T. Campbell-Orde, J. Chamberlin, H. Carpenter & S. Leff (Eds.), *Measuring the promise: A compendium of recovery measures* (Vol. II, pp. 32–35). Human Services Research Institute. https://www.hsri.org/publication/measuring-the-promise-a-compendium-of-recovery-measures-volume-ii

Narvaez, J. M., Twamley, E. W., McKibbin, C. L., Heaton, R. K., & Patterson, T. L. (2008). Subjective and objective quality of life in schizophrenia. *Schizophrenia Research*, *98*(1–3), 201–208. https://doi.org/10.1016/j.schres.2007.09.001

New South Wales Community Advisory Group. (2009). *Literature review on recovery: Developing a recovery-oriented service provider resource for community mental health organisations*. Mental Health Coordinating Council.

New Zealand Mental Health Commission. (2012). *Blueprint II: How things need to be.* https://www.hdc.org.nz/media/1075/blueprint-ii-how-things-need-to-be.pdf

New Zealand Psychological Society. (n.d.). *Counselling psychology*. https://www.psychology.org.nz/journal-archive/Careers_Counselling.pdf

New Zealand World Health Organization Quality of Life Group. (2014). *NZ WHOQOL-BREF user manual* (2nd ed.). Auckland University of Technology.

Oades, L. (2012). Responding to the challenge of mental health recovery policy. In L. L'Abate (Ed.), *Mental illnesses: Evaluation, treatments, and implications* (pp. 391–406). Intech. http://doi.org/10.5772/30061

O'Connell, K. A., & Skevington, S. M. (2010). An international quality of life instrument to assess well-being in adults who are HIV-positive: A short form of the WHOQOL-HIV (31 items). *AIDS and Behaviour*, *16*(2), 452–460. https://doi.org/10.1007/s10461-010-9863-0

Ohaeri, J. U., Awadalla, A. W., El-Abassi, A. M., & Jacob, A. (2007). Confirmatory factor analytical study of the WHOQOL-BREF: Experience with Sudanese general population and psychiatric samples. *BMC Medical Research Methodology, 7*, Article 37. https://doi.org/10.1186/1471-2288-7-37

O'Hagan, M. (2001). *Recovery competencies for New Zealand mental health workers*. http://www.maryohagan.com/resources/Text_Files/Recovery%20Cometencies%20O'Hagan.pdf

O'Hagan, M. (2002, November). Living well: Mary O'Hagan describes how recovery has been redefined in New Zealand. *Openmind*, *118*, 16–17. http://www.maryohagan.com/resources/Text_Files/Recovery%20Openmind%20Magazine.pdf

O'Hagan, M., Divis, M., & Long, J. (2008). *Best practice in the reduction and elimination of seclusion and restraint: Seclusion: Time for change*. https://www.maryohagan.com/resources/FINAL-SECLUSION-REDUCTION-BEST-PRACTICE-Research-Report.pdf

Oliveira, S. E., Carvalho, H., & Esteves, F. (2016). Toward an understanding of the quality-of-life construct: Validity and reliability of the WHOQOL-BREF in a psychiatric sample. *Psychiatry Research*, *244*, 37–44. https://doi.org/10.1016/j.psychres.2016.07.007

Oliver, J., Huxley, D. P., Bridges, K., & Mohamad, H. (1996). Definitions and conceptual issues concerning quality of life. In K. Bridges, D. P. Huxley, H. Mohamad & J. Oliver (Eds.), *Quality of life and mental health services* (pp. 15–47). Routledge. https://doi.org/10.4324/9780203977460

Onken, S. J., Craig, C. M., Ridgway, P., Ralph, R. O., & Cook, J. A. (2007). An analysis of the definitions and elements of recovery: A review of the literature. *Psychiatric Rehabilitation Journal*, *31*(1), 9–22. https://doi.org/10.2975/31.1.2007.9.22

Onken, S. J., Dumont, J. M., Ridgway, P., Dornan, D. H., & Ralph, R. O. (2002). *Mental health recovery: What helps and what hinders? A national research project for the development of recovery facilitating system performance indicators*. National Association of State Mental Health Program Directors (NASMHPD) & National Technical Assistance Centre (NTAC). https://www.nasmhpd.org/sites/default/files/MHSIPReport%281%29.pdf

Orley, J., Saxena, S., & Herrman, H. (1998). Quality of life and mental illness. *British Journal of Psychiatry*, *172*(4), 291–293. https://doi.org/10.1192/bjp.172.4.291

Ortis-Ospina, E. (2019, December 11). The media claims we are experiencing a 'loneliness epidemic'. What is the evidence for this? *Our World in Data*. https://ourworldindata.org/loneliness-epidemic

Osborn, D. P., Lloyd-Evans, B., Johnson, S., Gilburt, H., Byford, S., Leese, M., & Slade, M. (2010). Residential alternatives to acute in-patient care in England: Satisfaction, ward atmosphere and service user experiences. *British Journal of Psychiatry*, *197*(S53), s41–s45. https://doi.org/10.1192/bjp.bp.110.081109

Padilla, G. V., Grant, M. M., & Ferrell, B. (1992). Nursing research into quality of life. *Quality of Life Research*, *1*(5), 341–348. https://doi.org/10.1007/bf00434948

Panesar, N., & Valachova, I. (2011). Whose choice is mental health rehabilitation? *Australian & New Zealand Journal of Psychiatry*, *45*(10), 899–899. https://doi.org/10.3109/00048674.2011.588171

Papadimitriou, G. (2017). The “biopsychosocial model”: 40 years of application in psychiatry. *Psychiatriki*, *28*(2), 107–110. https://doi.org/10.22365/jpsych.2017.282.107

Parcesepe, A. M., & Cabassa, L. J. (2012). Public stigma of mental illness in the United States: A systematic literature review. *Administration and Policy in Mental Health and Mental Health Services Research*, *40*(5), 384–399. https://doi.org/10.1007/s10488-012-0430-z

Parry, M. S. (2006). Dorothea Dix (1802–1887). *American Journal of Public Health*, *96*(4), 624–625. https://doi.org/10.2105/ajph.2005.079152

Pascoe, E. A., & Smart Richman, L. (2009). Perceived discrimination and health: A meta-analytic review. *Psychological Bulletin*, *135*(4), 531–554. https://doi.org/10.1037/a0016059

Patterson, R., Durie, M., Disley, B., Rangihuna, D., Tiatia-Seath, J., & Tualamali’I, J. (2018). *He ara oranga: Report of the government inquiry into mental health and addiction*. New Zealand Government of Enquiry into Mental Health and Addiction. https://mentalhealth.inquiry.govt.nz/assets/Summary-reports/He-Ara-Oranga.pdf

Payton, A. R. (2009). Mental health, mental illness, and psychological distress: Same continuum or distinct phenomena? *Journal of Health and Social Behaviour*, *50*(2), 213–227. https://doi.org/10.1177/002214650905000207

Pelleboer-Gunnink, H. A., Van Oorsouw, W. M., Van Weeghel, J., & Embregts, P. J. (2019). Stigma research in the field of intellectual disabilities: A scoping review on the perspective of care providers. *International Journal of Developmental Disabilities*, *67*(3), 168–187. https://doi.org/10.1080/20473869.2019.1616990

Petkov, V. (1998, November 15–17). *Measuring quality of life in people suffering from schizophrenia or depression* [Paper presentation]. Annual Conference of the International Society for Quality-of-Life Research, Baltimore, Maryland.

Philips, R. (2006). Consumer participation in mental health research. *Social Policy Journal of New Zealand*, *27*(3), 171–182. https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/journals-and-magazines/social-policy-journal/spj27/27-pages171-182.pdf

Phillips, S. D., Kramer, T. L., Compton, S. N., Burns, B. J., & Robbins, J. M. (2003). Case-mix adjustment of adolescent mental health treatment outcomes. *The Journal of Behavioural Health Services & Research*, *30*(1), 125–136. https://doi.org/10.1007/bf02287818

Picardi, A., Rucci, P., De Girolamo, G., Santone, G., Borsetti, G., & Morosini, P. (2006). The quality of life of the mentally ill living in residential facilities. *European Archives of Psychiatry and Clinical Neuroscience*, *256*(6), 372–381. https://doi.org/10.1007/s00406-006-0647-5

Pietrzak, R. H., Goldstein, R. B., Southwick, S. M., & Grant, B. F. (2011). Personality disorders associated with full and partial posttraumatic stress disorder in the U.S. population: Results from Wave 2 of the National Epidemiologic Survey on Alcohol and Related Conditions. *Journal of Psychiatric Research*, *45*(5), 678–686. https://doi.org/10.1016/j.jpsychires.2010.09.013

Pirkis, J., John, A., Shin, S., DelPozo-Banos, M., Arya, V., Analuisa-Aguilar, P., Appleby, L., Arensman, E., Bantjes, J., Baran, A., Bertolote, J. M., Borges, G., Brečić, P., Caine, E., Castelpietra, G., Chang, S. S., Colchester, D., Crompton, D., Curkovic, M., … Spittal, M. J. (2021). Suicide trends in the early months of the COVID-19 pandemic: An interrupted time-series analysis of preliminary data from 21 countries. *Lancet Psychiatry*, *8*(7), 579–588. https://doi.org/10.1016/S22150366(21)00091-2

Platform Trust. (n.d.). *Our work*. https://www.platform.org.nz/what-we-do/work/

Ponizovsky, A. M., Grinshpoon, A., Levav, I., & Ritsner, M. S. (2003). Life satisfaction and suicidal attempts among persons with schizophrenia. *Comprehensive Psychiatry*, *44*(6), 442–447. https://doi.org/10.1016/s0010-440x(03)00146-9

Power, M., Quinn, K., & Schmidt, S. (2005). Development of the WHOQOL-old module. *Quality of Life Research*, *14*(10), 2197–2214. https://doi.org/10.1007/s11136-005-7380-9

Power, M. J., & Green, A. M. (2010). Development of the WHOQOL disabilities module. *Quality of Life Research*, *19*(4), 571–584. https://doi.org/10.1007/s11136-010-9616-6

Priebe, S., McCabe, R., Junghan, U., Kallert, T., Ruggeri, M., Slade, M., & Reininghaus, U. (2011). Association between symptoms and quality of life in patients with schizophrenia: A pooled analysis of changes over time. *Schizophrenia Research*, *133*(1–3), 17–21. https://doi.org/10.1016/j.schres.2011.09.021

Priebe, S., Reininghaus, U., McCabe, R., Burns, T., Eklund, M., Hansson, L., Junghan, U., Kallert, T., Van Nieuwenhuizen, C., Ruggeri, M., Slade, M., & Wang, D. (2010). Factors influencing subjective quality of life in patients with schizophrenia and other mental disorders: A pooled analysis. *Schizophrenia Research*, *121*(1–3), 251–258. https://doi.org/10.1016/j.schres.2009.12.020

Prieto, L., Alonso, J., & Lamarca, R. (2003). Classical test theory versus Rasch analysis for quality-of-life questionnaire reduction. *Health & Quality of Life Outcomes, 1*, Article 27. https://doi.org/10.1186/1477-7525-1-27

Prince, P. N., & Prince, C. R. (2001). Subjective quality of life in the evaluation of programs for people with serious and persistent mental illness. *Clinical Psychology Review*, *21*(7), 1005–1036. https://doi.org/10.1016/s0272-7358(00)00079-9

Rabkin, J. (1974). Public attitudes toward mental illness: A review of the literature. *Schizophrenia Bulletin, 1*(10), 9–33. https://doi.org/10.1093/schbul/1.10.9

Rabkin, J. G. (1972). Opinions about mental illness: A review of the literature. *Psychological Bulletin*, *77*(3), 153–171. https://doi.org/10.1037/h0032341

Ralph, R. O. (2005). Verbal definitions and visual models of recovery: Focus on the recovery model. In R. O. Ralph & P. W. Corrigan (Eds.), *Recovery in mental illness: Broadening our understanding of wellness* (pp. 134–145). American Psychological Association. https://doi.org/10.1037/10848-006

Ralph, R. O., Kidder, K., & Phillips, D. (2000). *Can we measure recovery? A compendium of recovery and recovery-related instruments*. Human Services Research Institute. https://www.hsri.org/publication/Can_We_Measure_Recovery_A_Compendium_of_Recovery_and_Recovery-Related_

Ralph, R. O., & Muskie, E. S. (2000). *A synthesis of a sample of recovery literature 2000 review of recovery literature*. National Association of State Mental Health Program Directors (NASMHPD) & National Technical Assistance Center for State Mental Health Planning (NTAC). https://www.nasmhpd.org/sites/default/files/MHSIPReport%281%29.pdf

Randal, P., Stewart, M. W., Proverbs, D., Lampshire, D., Symes, J., & Hamer, H. (2009). "The re-covery model" – An integrative developmental stress-vulnerability-strengths approach to mental health. *Psychosis, 1*(2), 122–133. https://doi.org/10.1080/17522430902948167

Rapp, C. A., & Goscha, R. J. (2006). The strengths model: Case management with people with psychiatric disabilities. In M. Harris & H. C. Bergman (Eds.), *Case management for mentally ill patients: Theory and practice* (pp. 143–164). Harwood Academic Publishers. https://psycnet.apa.org/record/2006-03969-000

Rasch, G. (1960). *Probabilistic models for some intelligence and attainment tests*. Danish Institute for Educational Research.

Read, J., Fink, P., Rudegeair, T., Felitti, V., & Whitfield, C. (2008). Child maltreatment and psychosis: A return to a genuinely integrated bio-psycho-social model. *Clinical Schizophrenia & Related Psychoses*, *2*(3), 235–254. https://doi.org/10.3371/csrp.2.3.5

Reeve, B. B., Wyrwich, K. W., Wu, A. W., Velikova, G., Terwee, C. B., Snyder, C. F., Schwartz, C., Revicki, D. A., Moinpour, C. M., McLeod, L. D., Lyons, J. C., Lenderking, W. R., Hinds, P. S., Hays, R. D., Greenhalgh, J., Gershon, R., Feeny, D., Fayers, P. M., Cella, D., … Butt, Z. (2013). ISOQOL recommends minimum standards for patient-reported outcome measures used in patient-centred outcomes and comparative effectiveness research. *Quality of Life Research*, *22*(8), 1889–1905. https://doi.org/10.1007/s11136-012-0344-y

Regnault, A., Willgoss, T., Barbic, S., & International Society for Quality-of-Life Research (ISOQOL) Mixed Methods Special Interest Group. (2017). Towards the use of mixed methods inquiry as best practice in health outcomes research. *Journal of Patient-Reported Outcomes*, *2*(19), 1–4. https://doi.org/10.1186/s41687-018-0043-8

Renwick, L., Jackson, D., Foley, S., Owens, E., Ramperti, N., Behan, C., Anwar, M., Kinsella, A., Turner, N., Clarke, M., & O'Callaghan, E. (2012). Depression and quality of life in first-episode psychosis. *Comprehensive Psychiatry*, *53*(5), 451–455. https://doi.org/10.1016/j.comppsych.2011.07.003

Resnick, S. G., Fontana, A., Lehman, A. F., & Rosenheck, R. A. (2005). An empirical conceptualization of the recovery orientation. *Schizophrenia Research*, *75*(1), 119–128. https://doi.org/10.1016/j.schres.2004.05.009

Revicki, D. A., Kleinman, L., & Cella, D. (2014). A history of health-related quality of life outcomes in psychiatry. *Dialogues in Clinical Neuroscience*, *16*(2), 127–135. https://doi.org/10.31887/dcns.2014.16.2/drevicki

Reynolds, M., Mezey, G., Chapman, M., Wheeler, M., Drummond, C., & Baldacchino, A. (2005). Comorbid post-traumatic stress disorder in a substance misusing clinical population. Drug and Alcohol Dependence, *77*(3), 251–258. https://doi.org/10.1016/j.drugalcdep.2004.08.017

Richardson, M. W. (1936). The relationship between the difficulty and the differential validity of a test. *Psychometrika*,*1*, 33–49. https://doi.org/10.1007/BF02288003

Ridgway, P. (2001). ReStorying psychiatric disability: Learning from first person recovery narratives. *Psychiatric Rehabilitation Journal*, *24*(4), 335–343. https://doi.org/10.1037/h0095071

Ristau, A. (2020). *Benefits of exercise on mental health: Literature review* [Master's thesis, Minnesota State University]. Cornerstone. https://cornerstone.lib.mnsu.edu/etds/983/

Roberts, G., & Wolfson, P. (2004). The rediscovery of recovery: Open to all. *Advances in Psychiatric Treatment*, *10*(1), 37–48. https://doi.org/10.1192/apt.10.1.37

Rocca, P., Castagna, F., Mongini, T., Montemagni, C., & Bogetto, F. (2010). Relative contributions of psychotic symptoms and insight to quality of life in stable schizophrenia. *Psychiatry Research*, *177*(1–2), 71–76. https://doi.org/10.1016/j.psychres.2009.01.030

Rocca, P., Giugiario, M., Montemagni, C., Rigazzi, C., Rocca, G., & Bogetto, F. (2009). Quality of life and psychopathology during the course of schizophrenia. *Comprehensive Psychiatry*, *50*(6), 542–548. https://doi.org/10.1016/j.comppsych.2008.12.002

Rocha, N. S., & Fleck, M. P. (2009). Validity of the Brazilian version of WHOQOL-BREF in depressed patients using Rasch modelling. *Revista de Saúde Pública*, *43*(1), 147–153. https://doi.org/10.1590/s0034-89102009000100019

Rocha, N. S., Power, M. J., Bushnell, D. M., & Fleck, M. P. (2011). Cross-cultural evaluation of the WHOQOL-BREF domains in primary care depressed patients using Rasch analysis. *Medical Decision Making*, *32*(1), 41–55. https://doi.org/10.1177/0272989x11415112

Rochester Recovery Inventory. (n.d.). *Quality of life matters for everyone*. Rehabilitation Research and Training Centre on HCBS Outcome Measurement. https://rtcom.umn.edu/database/instruments/rri#ici-rtcom-instrument-domains

Rochford, T. (2004). Te whare tapa whā: A Māori model of a unified theory of health. *The Journal of Primary Prevention*, *25*(1), 41–57. https://doi.org/10.1023/b:jopp.0000039938.39574.9e

Rose, D., Evans, J., Sweeney, A., & Wykes, T. A. (2011). A model for developing outcomes measures from the perspectives of mental health service users. *International Review of Psychiatry*, *23*(1), 41–46. https://doi.org/10.3109/09540261.2010.545990

Rose, G., & Smith, L. (2018). Mental health recovery, goal setting and working alliance in an Australian community-managed organisation. *Health Psychology Open*, *5*(1). https://doi.org/10.1177/2055102918774674

Rössler, W. (2016). The stigma of mental disorders. *EMBO Reports*, *17*(9), 1250–1253. https://doi.org/10.15252/embr.201643041

Rothman, J., Smith, W., Nakashima, J., Paterson, M. A., & Mustin, J. (1996). Client self-determination and professional intervention: Striking a balance. *Social Work*, *41*(4), 396–405. https://psycnet.apa.org/record/1996-04973-006

Rowthorn, M. J., Billington, D. R., Krägeloh, C. U., Landon, J., & Medvedev, O. N. (2019). Development of a mental health recovery module for the WHOQOL. *Quality of Life Research*, *28*, 3363–3374. https://doi.org/10.1007/s11136-019-02265-y

Saarni, S. I., Viertiö, S., Perälä, J., Koskinen, S., Lönnqvist, J., & Suvisaari, J. (2010). Quality of life of people with schizophrenia, bipolar disorder, and other psychotic disorders. *British Journal of Psychiatry*, *197*(5), 386–394. https://doi.org/10.1192/bjp.bp.109.076489

Saeri, A. K., Cruwys, T., Barlow, F. K., Stronge, S., & Sibley, C. G. (2018). Social connectedness improves public mental health: Investigating bidirectional relationships in the New Zealand attitudes and values survey. *Australian & New Zealand Journal of Psychiatry*, *52*(4), 365–374. https://doi.org/10.1177/0004867417723990

SAMHSA. (2012). *SAMHSA's working definition of recovery: 10 guiding principles of recovery*. https://store.samhsa.gov/sites/default/files/d7/priv/pep12-recdef.pdf

SAMHSA. (2014). *Trauma-informed care in behavioural health services.* https://www.ncbi.nlm.nih.gov/books/NBK207192/

Sarbin, T., & Allen, V. (1968). Role theory. In G. Lindzey & E. Aronson (Eds.), *The handbook of social psychology* (Vol. 1, 2nd ed., pp. 488–567). Addison Wesley.

Sartorius, N., & Henderson, A. S. (1992). The neglect of prevention in psychiatry. *Australian and New Zealand Journal of Psychiatry*, *26*(4), 550–553. https://doi.org/10.3109/00048679209072087

Schwatz, C. E., & Sprangers, M. A. G. (2000). *Adaption to changing health: Response shift in quality-of-life research.* American Psychological Association. https://doi.org/10.1037/10382-000

Scott, D. (2007). Resolving the quantitative–qualitative dilemma: A critical realist approach. *International Journal of Research & Method in Education*, *30*(1), 3–17. https://doi.org/10.1080/17437270701207694

Segal, S. P., Silverman, C. J., & Temkin, T. L. (2011). Outcomes from consumer-operated and community mental health services: A randomized controlled trial. *Psychiatric Services*, *62*(8), 915–921. https://doi.org/10.1176/ps.62.8.pss6208_0915

Shalaby, R. A., & Agyapong, V. I. (2020). Peer support in mental health: Literature review. *JMIR Mental Health*, *7*(6), Article e15572. https://doi.org/10.2196/15572

Shen, G. C., Eaton, J., & Snowden, L. R. (2017). Mainstreaming mental health care in 42 countries. *Health Systems & Reform*, *3*(4), 313–324. https://doi.org/10.1080/23288604.2017.1356424

Shepherd, G., Boardman, J., & Slade, M. (2008). Putting recovery into mental health practice. *Mental Health Today*, 28–31.

Sherrer, M. V. (2011). The role of cognitive appraisal in adaptation to traumatic stress in adults with serious mental illness: A critical review. *Trauma, Violence, and Abuse*, *12*(3), 151–167. https://doi.org/10.1177/1524838011404254

Siegert, R. J., Tennant, A., & Turner-Stokes, L. (2010). Rasch analysis of the Beck Depression Inventory-II in a neurological rehabilitation sample. *Disability and Rehabilitation*, *32*(1), 8–17. https://doi.org/10.3109/09638280902971398

Siggins Miller Consultants. (2003). *Consumer self-rated outcome measures in mental health*. https://www.vgls.vic.gov.au/client/en_AU/search/asset/1160693/0

Silverstein, S. M., & Bellack, A. S. (2008). A scientific agenda for the concept of recovery as it applies to schizophrenia. *Clinical Psychology Review*, *28*(7), 1108–1124. https://doi.org/10.1016/j.cpr.2008.03.004

Sirgy, M. J. (2021). *The psychology of quality of life: Well-being and positive mental health*. Springer. https://doi.org/10.1007/978-3-030-71888-6

Skevington, S. M. (1999). Measuring quality of life in Britain: Introducing the WHOQOL-100. *Journal of Psychosomatic Research*, *47*(5), 449–459. https://doi.org/10.1016/S0022-3999(99)00051-3

Skevington, S. M., Gunson, K. S., & O'Connell, K. A. (2012). Introducing the WHOQOL-SRPB BREF: Developing a short-form instrument for assessing spiritual, religious, and personal beliefs within quality of life. *Quality of Life Research*, *22*(5), 1073–1083. https://doi.org/10.1007/s11136-012-0237-0

Skevington, S. M., & McCrate, F. M. (2011). Expecting a good quality of life in health: Assessing people with diverse diseases and conditions using the WHOQOL-BREF. *Health Expectations*, *15*(1), 49–62. https://doi.org/10.1111/j.1369-7625.2010.00650.x

Skevington, S. M., Lotfy, M., O'Connell, K. A., & WHOQOL Group (2004a). The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. A report from the WHOQOL group. *Quality of life research*, *13*(2), 299–310. https://doi.org/10.1023/B:QURE.0000018486.91360.00

Skevington, S. M., Sartorius, N., & Amir, M. (2004). Developing methods for assessing quality of life in different cultural settings. *Social Psychiatry and Psychiatric Epidemiology*, *39*(1), 1–8. https://doi.org/10.1007/s00127-004-0700-5

Slade, M. (2002). What outcomes to measure in routine mental health services, and how to assess them: A systematic review. *Australian & New Zealand Journal of Psychiatry*, *36*(6), 743–753. https://doi.org/10.1046/j.1440-1614.2002.01099.x

Slade, M. (2010). Mental illness and well-being: The central importance of positive psychology and recovery approaches. *BMC Health Services Research*, *10*, Article 26. https://doi.org/10.1186/1472-6963-10-26

Slade, M. (2013). *100 ways to support recovery: A guide for mental health professionals* (2nd ed.). Rethink. https://www.rethink.org/media/704895/100_ways_to_support_recovery_2nd_edition.pdf

Slade, M., Bird, V., Le Boutillier, C., Williams, J., Mc Crone, P., & Leamy, M. (2011). Refocus trial: Protocol for a cluster randomised controlled trial of a pro-recovery intervention within community based mental health teams. *BMC Psychiatry*, *11*, Article 185. https://doi.org/10.1186/1471-244x-11-185

Smith, E. V. (2002). Detecting and evaluation the impact of multidimensionality using item fit statistics and principal component analysis of residuals. *Journal of Applied Measurement*, *3*(2), 205–231. https://europepmc.org/article/med/12011501

Smith, J. C., Hyman, S. M., Andres-Hyman, R. C., Ruiz, J. J., & Davidson, L. (2016). Applying recovery principles to the treatment of trauma. *Professional Psychology: Research and Practice*, *47*(5), 347–355. https://doi.org/10.1037/pro0000105

Spaniol, L., Koehler, M., & Hutchinson, D. (1994). *The recovery workbook: Practical coping and empowerment strategies for people with psychiatric disability*. Centre for Psychiatric Rehabilitation. https://cpr.bu.edu/wp-content/uploads/2011/11/Preview-The-Recovery-Workbook-Practical-Coping-and-Empowerment-Strategies-for-People-with-Psychiatric-Disabilities-Revised-edition.pdf

Spilker, B., & Revicki, D. (1996). Taxonomy of quality of life. In B. Spilker (Ed.), *Quality of life and pharmacoeconomics in clinical trials* (pp. 25–31). Lippincott-Raven Publishers.

Spittel, S., Maier, A., & Kraus, E. (2019). Awareness challenges of mental health disorder and dementia facing stigmatisation and discrimination: A systematic literature review from Sub-Sahara Africa. *Journal of Global Health*, *9*(2), Article 020419. https://doi.org/10.7189/jogh.09.020419

Sprangers, M. A., & Schwartz, C. E. (1999). Integrating response shift into health-related quality of life research: A theoretical model. *Social Science & Medicine*, *48*(11), 1507–1515. https://doi.org/10.1016/s0277-9536(99)00045-3

Stangl, A. L., Earnshaw, V. A., Logie, C. H., Van Brakel, W. C., Simbayi, L., Barré, I., & Dovidio, J. F. (2019). The health stigma and discrimination framework: A global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Medicine*, *17*, Article 31. https://doi.org/10.1186/s12916-019-1271-3

Stedman, T. (1996). Approaches to measuring quality of life and their relevance to mental health. *Australian & New Zealand Journal of Psychiatry*, *30*(6), 731–740. https://doi.org/10.3109/00048679609065039

Stedman, T., Yellowlees, P., Mellsop, G., Clarke, R., & Drake, S. (1997a). *Measuring consumer outcomes in mental health: Field testing of selected measures of consumer outcome in mental health* [Data set]. PsycExtra. https://doi.org/10.1037/e676532010-001

Stedman, T., Yellowlees, P., Mellsop, G., Clarke, R., & Drake, S. (1997b). *Measuring consumer outcomes – A Report to the Australian Health Ministers' Advisory Council National Mental Health Working Group Mental Health Branch*. Department of Health and Family Services. University of Queensland. https://www.amhocn.org/sites/default/files/publication_files/measuring_consumer_outcomes_stedman_etal.pdf

Stewart, M. (2009). Service user and significant other versions of the health of the nation outcome scales. *Australasian Psychiatry*, *17*(2), 156–163. https://doi.org/10.1080/10398560802596116

St George, L. C., O'Hagan, M., Bradstreet, S., & Burge, M. (2017). The emerging field of peer support within mental health services. *Advances in Psychology, Mental Health, and Behavioural Studies*, 222–250. https://doi.org/10.4018/978-1-5225-1874-7.ch011

Stuart, H. (2006). Media portrayal of mental illness and its treatments. *CNS Drugs*, *20*(2), 99–106. https://doi.org/10.2165/00023210-200620020-00002

Stuart, H. (2016). Reducing the stigma of mental illness. *Global Mental Health*, *3*(17), 1–14. https://doi.org/10.1017/gmh.2016.11

Stuhler, L. S. (n.d.). The inmates of Willard 1870 to 1900 / A genealogy resource. *The Inmates of Willard*. https://inmatesofwillard.com/new-york-state-county-poor-houses/

Sumner, L. W. (1996). *Welfare, happiness, and ethics*. Oxford University Press.

Sutton, D. (2008). *Recovery as the re-fabrication of everyday life: Exploring the meaning of doing for people recovering from mental illness* [Doctoral thesis, Auckland University of Technology]. Tuwhera. http://hdl.handle.net/10292/662

Swinbourne, J. M., & Touyz, S. W. (2007). The co-morbidity of eating disorders and anxiety disorders: A review. *The Journal of the Eating Disorders Association*, *15*(4), 253–274. https://doi.org/10.1002/erv.784

Symonds, P. M. (1929). Choice of items for a test on the basis of difficulty. *Journal of Educational Psychology*, *20*, 481–493. https://doi.org/10.1037/h0075650

Tabak, N. T., Link, P. C., Holden, J., & Granholm, E. (2015). Goal attainment scaling: Tracking goal achievement in consumers with serious mental illness. *American Journal of Psychiatric Rehabilitation*, *181*(2), 173–186. https://www.tandfonline.com/doi/abs/10.1080/15487768.2014.954159

Taillefer, M., Dupuis, G., Roberge, M., & LeMay, S. (2003). Health-related quality of life models: Systematic review of the literature. *Social Indicators Research*, *64*(2), 293–323. https://doi.org/10.1023/a:1024740307643

Taminiau-Bloem, E. F., Visser, M. R. M., Tishelman, C., Koeneman, M. A., Van Zuuren, F. J., & Sprangers, M. A. G. (2010). Somatically ill persons' self-nominated quality of life domains: Review of the literature and guidelines for future studies. *Quality of Life Research*, *19*(2), 253–229. https://doi:10.1007/s11136-009-9569-9

Tasca, C., Rapetti, M., Carta, M. G., & Fadda, B. (2012). Women and hysteria in the history of mental health. *Clinical Practice & Epidemiology in Mental Health*, *8*(1), 110–119. https://doi.org/10.2174/1745017901208010110

Tennant, A., & Conaghan, P. G. (2007). The Rasch measurement model in rheumatology: What is it and why use it? When should it be applied, and what should one look for in a Rasch paper? *Arthritis & Rheumatism*, *57*(8), 1358–1362. https://doi.org/10.1002/art.23108

Te Pou. (2015). *Measuring recovery in adult community addiction services: The testing and validation of ADOM Section 3 recovery questions*. https://www.tepou.co.nz/uploads/files/resources/measuring-recovery-in-adult-community-addiction-services.pdf

Te Pou. (2021). *Least restrictive practice.* https://www.tepou.co.nz/initiatives/least-restrictive-practice

Te Whatu Ora. (2023). *Introduction to classification.* https://www.tewhatuora.govt.nz/our-health-system/data-and-statistics/classification-information-2/introduction

Thissen, D., & Steinberg, L. (2020). An intellectual history of parametric item response theory models in the twentieth century. *Chinese English Journal of Educational Measurement and Evaluation, 1*(1), Article 5. https://doi.org/10.59863/GPML7603

Thornicroft, G., Brohan, E., Rose, D., Sartorius, N., & Leese, M. (2009). INDIGO Study Group: Global pattern of experienced and anticipated discrimination against people with schizophrenia: A cross sectional survey. *The Lancet*, *373*, 408–415. https://doi.org/10.1016/S0140-6736(08)61817-6

Thornicroft, G., Mehta, N., Clement, S., Evans-Lacko, S., Doherty, M., Rose, D., Koschorke, M., Shidhaye, R., O'Reilly, C., & Henderson, C. (2016). Evidence for effective interventions to reduce mental-health-related stigma and discrimination. *The Lancet*, *387*(10023), 1123–1132. https://doi.org/10.1016/s0140-6736(15)00298-6

Thurstone, L. L. (1925). A method of scaling psychological and educational tests. *Journal of Educational Psychology,16*, 433–449. https://doi.org/10.1037/ h0073357

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349–357. https://doi.org/10.1093/intqhc/mzm042

Tran, N., Poss, J. W., Perlman, C., & Hirdes, J. P. (2019). Case-mix classification for mental health care in community settings: A scoping review. *Health Services Insights*, *12*, https://doi.org/10.1177/1178632919862248

Trauer, T. (2010). Outcome measurement in chronic mental illness. *International Review of Psychiatry*, *22*(2), 99–113. https://doi.org/10.3109/09540261003667525

Trauer, T., Eagar, K., Gaines, P., & Bower, A. (2004). *New Zealand mental health consumers and their outcomes*. Health Research Council of New Zealand. https://www.lattice.co.nz/documents/nz-mental-health-consumers-and-their-outcomes-june-2004.pdf

Tripathi, A., Das, A., & Kar, S. K. (2019). Biopsychosocial model in contemporary psychiatry: Current validity and future prospects. *Indian Journal of Psychological Medicine*, *41*(6), 582–585. https://doi.org/10.4103/IJPSYM.IJPSYM_314_19

Trompenaars, F. J., Masthoff, E. D., Van Heck, G. L., De Vries, J., & Hodiamont, P. P. (2007). Relationships between social functioning and quality of life in a population of Dutch adult psychiatric outpatients. *International Journal of Social Psychiatry*, *53*(1), 36–47. https://doi.org/10.1177/0020764006074281

Trompenaars, F. J., Masthoff, E. D., Van Heck, G. L., Hodiamont, P. P., & De Vries, J. (2006a). Relationship between mood related disorders and quality of life in a population of Dutch adult psychiatric outpatients. *Depression and Anxiety*, *23*(6), 353–363. https://doi.org/10.1002/da.20180

Trompenaars, F. J., Masthoff, E. D., Van Heck, G. L., Hodiamont, P. P., & De Vries, J. (2006b). The WHO Quality of Life Assessment Instrument (WHOQOL-100): Investigating its discriminant ability for psychiatric outpatients. *European Journal of Psychological Assessment*, *22*(3), 207–215. https://doi.org/10.1027/1015-5759.22.3.207

Tsuang, M. T., Woolson, R., & Fleming, J. A. (1979). Long-term outcome of major psychoses: I. Schizophrenia and affective disorders compared with psychiatrically symptom-free surgical conditions. *Archives of General Psychiatry*, *36*(12), 1295–1301. https://doi.org/10.1001/archpsyc.1979.01780120025002

Tucker, L. R. (1946). Maximum validity of a test with equivalent items. *Psychometrika*, *11*, 1–13. https:// doi.org/10.1007/BF02288894

Tudor Hart, J. (2010). Mental health in a sick society: What are people for? *Socialist Register*, *46*, 315–325. https://socialistregister.com/index.php/srv/article/view/6777/3930

UNICEF. (2020, September 3). *New report card shows that New Zealand is failing its children* [Press release]. https://www.unicef.org.nz/media-releases/new-report-card-shows-that-new-zealand-is-failing-its-children

Üstün, T. B., Kostanjesek, N., Chatterji, S., & Rehm, J. (Eds.). (2010). *Measuring health and disability: Manual for WHO Disability Assessment Schedule WHODAS 2.0*. World Health Organization. https://apps.who.int/iris/handle/10665/43974

Vaganian, L., Bussmann, S., Boecker, M., Kusch, M., Labouvie, H., Gerlach, A. L., & Cwik, J. C. (2021). An item analysis according to the Rasch model of the German 12-item WHO Disability Assessment Schedule (WHODAS 2.0). *Quality of Life Research*, *30*(10), 2929–2938. https://doi.org/10.1007/s11136-021-02872-8

Van Brakel, W. H. (2006). Measuring health-related stigma--A literature review. *Psychology, Health & Medicine*, *11*(3), 307–334. https://doi.org/10.1080/13548500600595160

Ventegodt, S., Merrick, J., & Andersen, N. J. (2003). Quality of life theory I. The IQOL theory: An integrative theory of the global quality of life concept. *The Scientific World Journal*, *3*, 1030–1040. https://doi.org/10.1100/tsw.2003.82

Vita, A., & Barlati, S. (2019). The implementation of evidence-based psychiatric rehabilitation: Challenges and opportunities for mental health services. *Frontiers in Psychiatry, 10,* Article 147. https://doi.org/10.3389/fpsyt.2019.00147

Waks, S., Scanlan, J. N., Berry, B., Schweizer, R., Hancock, N., & Honey, A. (2017). Outcomes identified and prioritised by consumers of partners in recovery: A consumer-led study. *BMC Psychiatry*, *17,* Article 338. https://doi.org/10.1186/s12888-017-1498-5

Waller, R. J., & Thyer, B. A. (1997). [Review of the book *Outcomes assessment in clinical practice*, by L. I. Sederer & B. Dickey]. *Research on Social Work Practice, 7*(2), 280–282. https://doi.org/10.1177/104973159700700210

Wang, J., Lloyd-Evans, B., Marston, L., Mann, F., Ma, R., & Johnson, S. (2020). Loneliness as a predictor of outcomes in mental disorders among people who have experienced a mental health crisis: A 4-month prospective study. *BMC Psychiatry 20,* Article 249. https://doi.org/10.1186/s12888-020-02665-2

Ware, J. E., & Sherbourne, C. D. (1992). The MOS 36-Item Short-Form Health Survey (SF-36) conceptual framework and item selection. *Medical Care*, *30*(6), 473–483. https://doi.org/10.1097/00005650-199206000-00002

Warner, R. (2004). *Recovery from schizophrenia: Psychiatry and political economy* (2nd ed.). Routledge. https://doi.org/10.4324/9780203420874

Weeks, G., Slade, M., & Hayward, M. (2010). A UK validation of the stages of recovery instrument. *International Journal of Social Psychiatry*, *57*(5), 446–454. https://doi.org/10.1177/0020764010365414

Whitaker, R. (2010a). *Anatomy of an epidemic: Magic bullets, psychiatric drugs, and the astonishing rise of mental illness in America*. Random House Digital.

Whitaker, R. (2010b). *Mad in America*. Ingram Publisher Services. https://www.madinamerica.com/mad-america-book/

The WHOQOL Group. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine*, *28*(3), 551–558. https://doi.org/10.1017/s0033291798006667

Wiering, B., De Boer, D., & Delnoij, D. (2016). Patient involvement in the development of patient-reported outcome measures: A scoping review. *Health Expectations*, *20*(1), 11–23. https://doi.org/10.1111/hex.12442

Weiring, B., De Boer, D., & Delnoij, D. (2017). Patient involvement in the development of patient-reported outcome measures: The developers perspective. *BMC Health Services Research*, *17*(1), Article 635. https://doi.org/10.1186/s12913-017-2582-8

Willard, S. D. (1865). *Documents of the Assembly of the State of New York, Eighty-Eight Session, 6,* 199-112. C Wendell Legislative Printer (pp. 169–178). https://inmatesofwillard.com/new-york-state-county-poor-houses/

Williams, K., Sansoni, J., Morris, D., Grootemaat, P., & Thompson, C. (2016). *Patient-reported outcome measures: Literature review*. Australian Commission on Safety and Quality in Health Care. https://www.safetyandquality.gov.au/wp-content/uploads/2017/01/PROMs-Literature-Review-December-2016.pdf

Wilson, I. B., & Cleary, P. D. (1995). Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *JAMA*, *273*(1), 59–65. https://doi.org/10.1001/jama.273.1.59

Wing, J. K., Beevor, A. S., Curtis, R. H., Park, S. G., Hadden, J., & Burns, A. (1998). Health of the nation outcome scales (HoNOS), research and development. *British Journal of Psychiatry*, *172*(1), 11–18. https://doi.org/10.1192/bjp.172.1.11

World Health Organization. (1993). Study protocol for the World Health Organization project to develop a quality-of-life assessment instrument (WHOQOL). *Quality of Life Research, 2*(2), 153–159. https://doi.org/10.1007/bf00435734

World Health Organization. (1997). *WHOQOL: Measuring quality of life.* https://apps.who.int/iris/handle/10665/63482

World Health Organization. (1999). *ICDIDH-2: International Classification of Functioning and Disability.* https://apps.who.int/iris/handle/10665/63832

World Health Organization. (2002). *Towards a common language for functioning, disability, and health ICF*. (WHO/EIP/GPE/CAS/01.3). https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health

World Health Organization. (2012). *Agenda item 13.2 WHA65.4: The global burden of mental disorders and the need for a comprehensive, coordinated response from health and social sectors at country level* (A65/VR/9). https://apps.who.int/gb/ebwha/pdf_files/WHA65/A65_R4-en.pdf

World Health Organization. (2013). *Mental health action plan 2013–2020*. https://apps.who.int/iris/bitstream/handle/10665/89966/9789241506021_eng.pdf

World Health Organization. (2015). *Comprehensive mental health action plan 2013–2020*. https://www.who.int/publications/i/item/9789240031029

World Health Organization. (2017). *Preventing suicide: A global imperative*. http://apps.who.int/iris/bitstream/handle/10665/131056/9789241564779_eng.pdf?sequence=1

World Health Organization. (2018, October 10). *World mental health day 2018 – Young people and mental health in a changing world.* https://www.who.int/news-room/events/detail/2018/10/10/default-calendar/world-mental-health-day-2018

World Health Organization. (2019a). *Global health estimates: Life expectancy and leading causes of death and disability*. https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates

World Health Organization. (2019b). *Mental disorders fact sheet*. https://www.who.int/news-room/fact-sheets/detail/mental-disorders

World Health Organization. (2021a). *Comprehensive mental health action plan 2013–2030*. https://www.who.int/publications/i/item/9789240031029

World Health Organization. (2021b). *ICD-11 for mortality and morbidity statistics.* https://icd.who.int/browse11

World Health Organization. (2021c). *LIVE LIFE: An implementation guide for suicide prevention in countries*. https://www.who.int/publications/i/item/9789240026629

World Health Organization. (2021d, June 17). *One in 100 deaths is by suicide: WHO guidance to help the world reach the target of reducing suicide rate by 1/3 by 2030* [Press release]. https://www.who.int/news/item/17-06-2021-one-in-100-deaths-is-by-suicide

World Health Organization. (2021e). *WHO fact sheet: Suicide worldwide in 2019, global health estimates*. https://www.who.int/publications/i/item/9789240026643

World Health Organization. (2022a). *WHOQOL: Measuring quality of life*. https://www.who.int/tools/whoqol/whoqol-bref

World Health Organization. (2022b). *World mental health report: Transforming mental health for all.* https://www.who.int/publications/i/item/9789240049338

World Health Organization Division of Mental Health. (1996). *WHOQOL-BREF, Introduction, administration, scoring and generic version of the assessment: Field trial version, December 1996*. World Health Organization. https://apps.who.int/iris/handle/10665/63529

World Health Organization Quality of Life Group. (1998). The World Health Organization Quality of Life Assessment (WHOQOL): Development and general psychometric properties. *Social Science & Medicine, 46*(12), 1569–1585. https://doi.org/10.1016/s0277-9536(98)00009-4

World Health Organization Quality of Life Instrument HIV Group. (2003). Initial steps to developing the World Health Organization's Quality of Life Instrument (WHOQOL) module for international assessment in HIV/AIDS. *AIDS Care, 15*(3), 347–357. https://doi.org/10.1080/0954012031000105405

Wright, B. (1967, October 28). *Sample-free test calibration and person measurement* [Paper presentation]. ETS Invitational Conference on Testing Problems. University of Chicago, IL. https://www.rasch.org/memo1.htm

Wright, N., Bartlett, P., & Callaghan, P. (2008). A review of the literature on the historical development of community mental health services in the United Kingdom. *Journal of Psychiatric and Mental Health Nursing*, *15*(3), 229–237. https://doi.org/10.1111/j.1365-2850.2007.01218.x

Wrigley, A., & Dawson, A. (2016). Vulnerability and marginalised populations. In D. H. Barrett, L. W. Ortmann, A. Dawson, C. Saenz, A. Reis & G. Bolan (Eds.), *Public health ethics analysis* (Vol 3., pp. 203–240). Springer. https://doi.org/10.1007/978-3-319-23847-0_7

Wu, C. F., Mak, W. W., & Wan, D. L. (2006). Quality of life of mental health consumers in Hong Kong: Analysis of service perceptions. *Quality of Life Research, 16*(1), 31–40. https://doi.org/10.1007/s11136-006-9104-1

Xie, H. (2013). Strengths-based approach for mental health recovery. *Iranian Journal of Psychiatry and Behavioural Sciences*, *7*(2), 5–10. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3939995/

Yang, S., Kuo, P., Su, S., Wang, J., & Lin, M. (2006). Development and psychometric properties of the dialysis module of the WHOQOL-BREF Taiwan version. *Journal of the Formosan Medical Association*, *105*(4), 299–309. https://doi.org/10.1016/s0929-6646(09)60121-2

Yanguas, J., Pinazo-Henandis, S., & Tarazona-Santabalbina, F. J. (2018). The complexity of loneliness. *Acta Biomedica*, *89*(2), 302–314. https://doi.org/10.23750/abm.v89i2.7404

Yohanna, D. (2013). Deinstitutionalization of people with mental illness: Causes and consequences. *AMA Journal of Ethics*, *15*(10), 886–891. https://doi.org/10.1001/virtualmentor.2013.15.10.mhst1-1310

Zikmund, V. (2001). Health--Mental health--Quality of life. *Bratislavske Lekarske Listy*, *102*(11), 527–529.

Appendices

Appendix A Ethics Approval

25 September 2014

Chris Krageloh
Faculty of Health and Environmental Sciences

Dear Chris

Re Ethics Application: **14/227 Developing a mental health recovery module for the WHOQOL _BREF**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 25 September 2017.

As part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through http://www.aut.ac.nz/researchethics. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 25 September 2017;
- A brief report on the status of the project using form EA3, which is available online through http://www.aut.ac.nz/researchethics. This report is to be submitted either when the approval expires on 25 September 2017 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,

Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Melissa Rowthorn melissa.rowthorn@gmail.com

Appendix B

WHOQOL Study Guidelines.

Table B1 presents each step of the standardised WHO research study protocol steps for collecting and analysing data when developing a new module for the WHOQOL tools. The left of Table B1 overviews the main steps from the WHOOQL study guide and the right shows how these were followed in this research.

Table B1

WHO Study Protocol Guidelines Implemented in this Research.

Step	**WHO Study Protocol**	**How this was replicated in the current research where adaptations were required**
1.	A thorough review of existing WHOQOL core questions and published quality of life questions to establish the need for a new module.	A review of the literature identified the potential need for a module based on personal recovery conceptual frameworks containing items not covered by the existing WHOQOL-BREF.
2.	Review by professionals / researchers working in the target population field.	Discussion groups and data analysis included mental health professionals, researchers, and experts in mental health outcomes and QoL.
3.	Conduct discussion groups with members of the target population.	Discussion groups included mental health consumers.
4.	Conduct discussion groups with health care providers.	Discussion groups included mental health staff - clinical and non-clinical, peer support workers, and family members.
5.	Development of the pilot instrument (1) Facet Structure (2) Question Pool (3) Derivation of Response Scales	Methodology used in the development of the NZ WHOQOL research to develop national items for the WHOQOL-BREF (Krägeloh, et al., 2016) was used; further detailed on Table B3.
7.	Administration of pilot questionnaires	A research survey piloted MHRQoL questions and pilot review of the research survey occurred before inviting participants into Phase 2.
8.	Development of the final module	The module was developed using CTT and Rasch analysis with criteria for item inclusion and elimination previously used in the published research that developed New Zealand national items for the WHOQOL-BREF (Krägeloh, et al., 2016).

Table B2 identifies the WHOQOL study protocol recommendations for conducting discussion groups when developing WHOQOL modules. The left column contains study protocol wording, as directly quoted, or slightly paraphrased at times, for brevity. The right column explains how these were replicated along with any departures to fit with this research's aims.

Table B2

WHO Study Protocol Guidelines for Conducting Discussion Groups adapted for the current study.

Methodology cited in the WHO study protocol for the Discussion Group Question Generation phases of WHOQOL module development MNH/PSF/93.9 (pp13-15).	**How the methodology was replicated in the current research where adaptations were required:**
Characteristics of the discussion group setting: • Natural setting • Flexible • Semi-structured • Minimum of 2 discussion groups for each population group. • "Where data from these 2 groups was dissimilar additional discussion groups were conducted until the data showed a marked pattern and further discussion groups added nothing new" to "provide an important methodological safeguard against idiosyncratic data." (MNH/PSF/93.9, p.13)	**Characteristics of the discussion group setting:** • Discussion groups were held in sites of participating organisations, where participants were used to visiting where possible, or AUT. • Time and day were flexible for people attending and the organizations participating. • 22 discussion groups were held in total (88 participants). A minimum of 2 for each group: • Clients of mental health NGO services • Community NGO support workers • Family members of mental health clients • Mental health clinicians **Only one group occurred for the below population**: • Experts in mental health outcomes / recovery **Key informant interviews occurred for the below populations less represented in the above groups:** • Māori • Asian • LGBTI • Younger people (18-30)
Aims of the Discussion Groups: • To generate potential questions for each facet • To provide preliminary importance ratings for each facet • To assess further the validity and comprehensiveness of the existing facet list (MNH/PSF/93.9, p.13)	**Aims of the Discussion Groups:** • To generate MHRQoL candidate items for further evaluation in Phase 2 • To identify if any existing personal recovery determinants commonly cited in recovery literature or personal recovery conceptual models were relevant to MHRQoL. • To identify any additional MHRQoL candidate items not identified in the literature. **Aims of importance exercises after discussion groups:** • To examine each existing core WHOQOL-

	BREF facet for its importance to the personal recovery process / lived personal experiences. • To examine each new potential mental health module candidate item for its relevance and importance to the QoL of someone recovering from mental health and addiction issues.
Procedure within Discussion Groups: • Detailed orientation and instructions • Facet by facet discussion – participants asked how each facet affects their QoL and how one might best ask about that facet. • Importance weightings of facets and demographic data collected at the end of the discussion groups via questionnaire. (Pp14 MNH/PSF/93.9)	**Procedure within Discussion Groups:** • Three explorative questions were asked to examine how mental health and addiction problems negatively impacted QoL, what personal recovery processes improved QoL and what QoL issues are unique to recovering from mental health and addiction issues. • Additional questions identified if the person was in early, mid, or late stages of recovery at the time of participation. • Importance rating was separately assessed through analysing the frequency of issues mentioned in the discussion groups or chosen within the importance rating exercises.
Training / Support for Discussion Group Moderators: • Central training at WHO Geneva • "Visit by a member of the central group to most field centres ensured standardization and assists principal investigators to resolve local issues arising in the application of the protocol. • Separate and detailed protocol for running the groups made available to moderators." (MNH/PSF/93.9, p.14)	**Training / Support for Discussion Group Moderation:** • Rex Billington was trained by the WHO as a facilitator – he provided facilitator training and orientation material. • Rex Billington functioned as the quality control person ensuring WHO standards and procedures were adhered to within the discussion groups. • The researcher was the primary moderator and attending supervisors were moderation supports within the discussion groups.
Participants 1. 6-8 individuals who are representative of the target population in the following demographics: • Gender • Age • Ethnic group • Educational background • Socioeconomic status • Marital status 2. Recruited from: inpatient and outpatient health settings. 3. With both acute and chronic disorders 4. People from the general population 5. Informal caregivers, 6. Health personnel." (MNH/PSF/93.9, p.14)	**Participants** 1. Participants were recruited from outpatient mental health service settings and wider community settings. Discussion groups ranged from three, on one occasion, to 10 as the largest group. Investigation of how many participants of each demographic listed occurred post and during recruitment. A prior objective of recruiting 1% of the sub-populations listed in available mental health population statistics at the time of the research planning stage (2009-10) was calculated as 120 people. The following mental health service user population statistics were initially used as a recruitment aim for the number of participants to invite into the research: • Males (54%) Females (46%) • Ethnic groups – Māori: 22% – Pacific Island: 6% – Asian: 3% – European/Other: 69% • Ages of people receiving MH services according to 2010-11 MOH statistics were: - 15-19 = 12% - 20-24 = 9.8%

	- 25-29 = 8.5% - 30-34 = 8.7% - 35-39 = 9.8% - 40-44 = 8.7% - 45-49 = 7.8% - 50-54 = 5.7% - 55-59 = 3.8% - 60-64 = 2.8% - 65-69 = 2.1% 2. Participants were recruited in settings where chronicity characteristics were the highest. Some participants were in the mild to moderate group living independently in the community post recovery. Some participants were working as peer support workers after a prior history of recovering from mental health issues. 3. Acuity and chronicity characteristics were: • Acuity (if currently in acute clinical services) • Chronicity (NGO's residential / DHB CMHC) • Mild to moderate symptoms of mental illness (GP managed mental health care, PHO psychological services, and those receiving CSW services available to non-secondary mental health clients - between 1-2 hours of community support or home help). 4. Diversity of diagnostic groups were identified as: Mental Health Diagnoses (Mixture of Axis 1: Mood (Anxiety/Depression), Psychotic, Substance use Disorders, Personality Disorder). Phases 1 and 2 participants – respectively -62-66% had self-reported mood disorders, 23-30% addiction or substance use issues, 31-17% - psychosis, 4-7% - personality disorder and 2-2% self-identified - 'other'. MOH MH statistics named 23 services attending to clients with MH issues across five broad service types (Community (38.5%), Kaupapa Māori (5.8%), AoD (19.8%), Residential (20.8%), Other (25.6%). Phase 1 & 2 recruitment invited service-users from all five types of services to participate. 5-6. People invited to participate from the general population involved: • Field experts (one group only). • Family members of people who are recovering from mental illness (Two groups). • Support workers and clinical staff who work with people in recovery from the impact of mental illness (Two groups). In Phase 2 invited people from the general population to participate as a comparison group; some of whom were staff members of participating health services.
Question generation work • Transcripts of the discussion groups and notes made during the group are prepared. • A question-writing panel was assembled: Principal investigator, main discussion	**Question generation work** • Audio recordings of the discussion groups were made at the time of the meetings. • A question writing panel was formed – the principal investigator and 3 QoL researchers. • Importance ratings were collated after

group moderator, and two individuals involved in the project make up this panel – one of these members being a person with good interviewing skills and another being a lay person who has participated in a discussion group. • Panel make use of the information from the discussion groups to assess the comprehensiveness of the existing facet list, comprehensibility, and completeness of facet definitions. Specific suggestions for changes to facets and facet definitions and rationale for such changes included as part of the report to Geneva. • Question writing panel frame questions for each facet for each level of questioning: ▪ Perceived objective ▪ Self-report subjective • Criteria were used by the panel when writing the questions: Questions should: ▪ Give rise to answers that are illuminating about a person's QOL. ▪ Be amenable to a rating scale. ▪ Reflect the meaning conveyed in the facet definition. ▪ Avoid any explicit reference point of time or comparison points. ▪ Be applicable to people with a range of impairment. ▪ Framed as questions not statements. ▪ Reflect the discussion held in the discussion groups. ▪ Make use of questions posed by discussion group participants. ▪ Clearly reflect the typology of questions – subjective and objective. • A report is written & submitted to WHO that includes questions & preliminary importance ratings for each facet, commentary on the validity and comprehensiveness of the provisional facet list, in the standardized format of the data record form provided by WHO (MNH/PSF/93.9, pp.14-15)	discussion group participation and identified as frequency of mention in most discussion groups. • The principal investigator and primary supervisor listened to all discussion group tapes prior to participating in the question writing. Secondary supervisor attended some discussion groups prior to participating in discussion groups. • A discussion group listening panel coded all discussion groups – 5 people coded all LE groups. • The question writing panel met and considered different ways to word MHRQoL candidate items suitable for testing with people without mental health problems as well as those with these problems. • The WHO criteria for questions were referred to during question writing to conform to how QoL is asked about within the WHOQOL-BREF. • Perceived objective and perceived subjective questions were asked as well as negatively worded items to be reverse scored along with positively worded items. • Questions were then piloted within a draft research survey with a sample of service users for feedback on the time taken to complete the survey, comprehensibility, and relevance of the questions to their mental health recovery context. • Transcripts of the lived experience groups were prepared to obtain quotes relevant to the final results.

Table B3 identifies the WHOQOL study protocol recommendations for instrument development. The left column contains direct quotes from the study protocol or slightly paraphrased versions of this at times, for brevity, to ensure adherence to the original intent and meaning. The right column explains the specific elements replicated in this research and the departures from them that needed to occur to suit the purposes of this study.

Table B3

WHO Study Protocol Guidelines for Instrument Development Implemented in this Research.

Methodology cited in the WHO study protocol for the Development of a Pilot Instrument MNH/PSF/93.9 (pp 15-27)	**How this methodology was replicated in the current research where adaptations were required:**
The following data was collated from the discussion group phase: 1. Demographic data of discussion group members 2. Proposed questions for the instrument 3. Preliminary importance weightings of facets (MNH/PSF/93.9, p.15)	Demographic data was collected in both phases with an adapted "About You" section. Phase 1 collected importance data. Phase 2 did not collect importance data.
Facet structure – instrument structure and facet definitions were evaluated from reports and recommendations of the field centres. Any structural changes, rewording to ensure cross cultural relevance, or facets that require deletion were done. (MNH/PSF/93.9, p.15)	A question-writing panel worked on how questions would be asked, in consideration of the participants who would be end users of the survey. Consultation with Māori Kaumatua, Asian clinical and support staff, and Pacific service staff occurred to obtain feedback on item wording during the instrument piloting stage.
Question pool – Revised facet definitions, proposed national questions with rating scales and anchor points and proposals for standardized importance questions were sent back to field centres with the request that the same question writing panels write questions for any facets that had undergone considerable change or were additional than those provided. (MNH/PSF/93.9, p.16)	Importance was assessed in Phase 1 by the frequency of its mention within and across discussion groups and by how often recovery determinants were chosen by participants. Any facets that were not related to mental health or addiction recovery were not included for analysis. Existing WHOQOL-BREF discussion group themes were coded out of the list of potential candidate items.
Question writing panels completed the following activities, ensuring question: • Rating scales are optimally matched. • Genuinely ask about respondents QOL as defined by this project. • Are amenable to respondents with a wide range of impairment. • Only refers to a single issue, which reflects the	Wording of candidate MHRQoL items sought to conform with the ways QoL is asked about in the WHOQOL-BREF with additional consideration to: • Likert ratings scales from the standard WHOQOL instrument were replicated for new MHRQoL items.

facet to which it was intended. • Were edited or rewritten if the facet structure or definition had changed considerably. • 3 global questions were written. • Returning revised questions to WHO (MNH/PSF/93.9, p.16)	• Definitions provided by WHO and personal recovery literature were used as reference points when considering candidate items that were indicative of MHRQoL. • Questions needed to reflect the ways the QoL items were discussed as affecting people's lives within the LE discussion groups. • Consideration was given to whether the questions could be answered by people with more severe mental health problems as well as mild mental health problems. Feedback was sought; members of the small pilot group included people with chronic and severe mental health problems, as well as mild and moderate problems. • Attempts to discussion on a single issue and match rating scales relevant to that issue were made during the question writing phase.
WHO pooled all revised questions and decided on an optimum number of questions for the instrument. The following steps were used to select questions for the pilot instrument: 1. Duplicate questions and redundant questions removed. 2. Similar questions that were semantically equivalent were treated as one question. 3. Questions were examined to assess the extent to which they met the criteria for WHOQOL questions (defined in table 2 of the study protocol). Any that did not were deleted. 4. Questions that could be usefully elaborated on with examples were edited so consistent examples were used throughout the facet. 5. Questions in the global pool were edited to maximise their match to the standardised rating scales. Where-ever possible the same beginning stem was used to homogenise the questions "How much… How satisfied/happy … To what extent …" (MNH/PSF/93.9, p.17)	Cut off criteria was established to reduce the initial greater pool of potential candidate items to include the most important and frequently cited items for question writing. The cut off criteria was established as the candidate items discussed in above 50% of the lived experience (LE) discussion groups when items were triangulated with the results of LE importance data from Phase 1. The candidate items from the discussion groups were examined in light of their relevance to MHRQoL. The definitions of HRQoL, as measured by the WHOQOL tools, and the definition of personal recovery were used as reference criteria for identifying potential MHRQoL items and where to place candidate items within the existing WHOQOL-BREF survey structure. The same range of beginning stems used in the WHOQOL BREF were considered when forming the candidate MHRQoL items. The most appropriate prefix for each candidate item was selected. A review of existing modules that asked about any same facet areas was done to consider avoiding duplication of process. It was decided to not use any existing WHOQOL-BREF health or disability items when the theme was the same as that identified within other health populations.
Conceptual clustering of questions within facets and within levels of questioning (perceived objective and self-report	MHRQoL items were clustered with like-stemmed questions within the existing

subjective) was then conducted via the following: 1. A facet comprises several aspects addressed by separate questions - these were all clustered to the central theme – i.e., if all relating to pain = question on pain. 2. Where questions were related to two ends of a continuum, they were clustered to the continuum category e.g., Vitality & Fatigue = energy levels. 3. When a question does not have a clear dimension, it can be addressed with positively framed questions or negatively framed questions to ensure both types of question are included in the pilot. 4. Conceptually simple facets were not clustered. 5. When assignment of questions to clusters were considered, the aim was to facilitate the selection of questions. 6. Global pool of questions arranged in conceptual and semantic clusters went to each of the field centres to be ranked – on how important it is to its QOL facet in your culture and how much it tells you about a respondents QOL in your culture. 7. The combined rankings were then used to select the questions for the pilot instrument. More questions were selected from conceptual clusters ranked as more salient to the given facet. (MNH/PSF/93.9, p.18)	WHOQOL-BREF questionnaire when developing the research survey. Proposed questions were evaluated against the existing WHOQOL-BREF items and NZ module items. Any candidate items that appeared to duplicate these were not included in the research survey unless a nuance occurred in the ways the theme was discussed by participants that would warrant further evaluation in Phase 2. Consideration to items that would be negatively worded – such as boredom, stigma, and loneliness - was given; reverse scoring was established for these items. The question writing group used a process of consensus regarding item wording to finalise decisions about retaining items or how to word items.
Derivation of Response Scales: Response scale descriptors derived to ensure their matched equivalence between field centres. Anchor points for each of the response scales (intensity, capacity, frequency, and evaluation) made translatable by following the following guidelines: 1. Language translation to ensure meaning and magnitude remained equivalent. 2. List of 15+ descriptors for each response scale from dictionaries, relevant literature, and other instruments. 3. 20 lay subjects' representative of the health care users in the field center asked to place each descriptor on a 10cm line as to where they thought it lay in relation to the two anchors. Series of descriptors presented in random order and a fresh line for each descriptor. 4. Mean distances were calculated from the 20+ subjects – means falling between 20-30mm {=25%}; 45-55mm {50%}; 70-80mm {75%}. Descriptor with lowest standard deviation chosen for cases of several descriptors falling in the same range. 5. Bilingual review process checked the comparability of descriptors; ordinality was established by a small group of respondents rank ordering descriptors. (MNH/PSF/93.9, p.19)	**Derivation of Response Scales:** Response scale descriptors and anchor points were the same as those developed for use in the existing WHOQOL-BREF, so that the module items fitted within the structure of the existing tool. Response scales were the same as in the existing WHOQOL-BREF – a five-point Likert scale that meant scale descriptors could be transferred to numerical scores for quantitative analysis. Feedback on the comprehensibility of the survey items was part of the pilot step within the survey development phase of the research. Developing bilingual versions of the research survey was beyond the scope of this research.
Pilot instrument Constructed: Each field centre had the following questions in the pilot instrument: 1) Slimmed down version of the global pool of questions 2) Number of questions originating in that particular field centre that meet criteria for WHOQOL questions that do not appear in the global pool (as national items). 3) Questions were grouped by response format and a facet-by-facet basis for more complex facets.	**Research Survey Instrument constructed:** The research survey used in Phase 2 contained: 1) The 26 NZWHOQOL-BREF items 2) The five NZ national items 3) The 24 new proposed MHRQoL candidate items. Pre-testing with a small sample of mental

4) Translation and back translation occurred. 5) Pretested with small sample of health care users in several field centres to provide preliminary feedback on – problems with wording, response scales, instructions, question relevance, overall impression. Important - the respondent was encouraged to comment on the questions in the course of completing the measure. (MNH/PSF/93.9, p.20)	health service users from a range of settings sought to obtain the same preliminary feedback recommended in the WHO study protocol – namely problems with wording, response scales, instructions, question relevance, overall impression. The principal investigator sat with respondents when they were evaluating the measure. Respondents were encouraged to comment on the questions in the course of completing the measure to explain their understanding of, or difficulty understanding, the item.
Administration of Pilot Questionnaire Piloted in each field centre with the aim of: 1. Reducing and refining facet structure 2. Reducing the number of questions in each facet 3. Maintaining core domain and facet structure across all centres 4. Achieve a balance between minimum number of facets / questions and adequate coverage of key areas contributing to people's quality of life. 5. Pilot data to establish national importance weightings for each facet, validity, and reliability figures for the instrument. 6. Pilot instrument has a balance of perceived objective and self-report subjective questions per facet and one importance question for each facet. 7. Facets with multi-dimensional aspects to them (e.g., pain–discomfort, intensity, control, distress, disability) required more questions than unidimensional facets. 8. Piloted on at least 300 people per field centre – required number of subjects per cell needed for the analysis of pilot data. Respondents briefed carefully about the rationale for the length and repetitiveness of the pilot measure to ensure cooperation. 9. All respondents are adult -50% < 45; 50% +/= 45; 50% Male, 50% female; 250 with health impairment; 50 well people. Disease and demographic characteristics gathered. Recruitment to reflect as close to profile of health care users in the region of the field centre. For practical reasons only respondents' fluid in national language used in pilot study where many cultures coexisted all speaking different languages. Good cross section of people with varied levels of quality of life – sampling from cross section of primary care, hospitals, community care settings for people with more chronic disabling, transient acute, mild, and issues not impinging on QoL cases. 10. If required, interviewers can assist respondents to answer the questionnaire – interviewers need to recruit, distribute questionnaires, assist completion, collect questionnaires, engage in data entry. (MNH/PSF/93.9, pp.20-22)	**Administration of Research Questionnaire** The aims were to identify the most robust measures of HRQoL, whilst also aiming to keep the final module as small as possible, to reduce response burden when used with the core measure. Phase 2 invited participants from a range of settings – NGO residential, mobile mental health services, peer support services, AoD/specialty rehabilitation centres, clinical, primary care, and community agencies. 667 participants surveys were used in the data analysis – 389 with lived experience of mental health and addiction problems and 278 without these problems. Recruitment occurred in settings where participants could be assisted to complete surveys if required by mental health support staff. Support from peer support and NGO or DHB service staff occurred to enable the distribution and collection of surveys to occur. Attempts were made to recruit for all ages, cultures, and genders identified in the NZ mental health MOH statistics to recruit for as representative sample of the demographics typically seen within the NZ mental health population. The ratios and proportions of each group recruited relevant to the dominant population were not equivalent, however members of the broad groups named in the MHO mental health statistics participated in both phases of the study.

Development of the core module	**Development of the MHRQoL module**
1. Analyse the data collectively to examine psychometrically the domain and facet structure and potentially reduce the number of facets. 2. Mapping procedure that focuses on representativeness and discriminatory power used where association of domains to global questions about QoL, facets to domains, facets to facets can be examined. 3. Facet structure reduced and refined on the basis of this data and importance ratings. 4. Strategy of 'representativeness' (high correlations with national items) and discriminatory power (low correlation to core facets) used to select national items. 5. Data omitted consecutively to see the effect this has on the refined facet structure. 6. Multi-dimensional scaling and confirmatory factor is analysis conducted to check the instrument structure. 7. Universality of questions within facets and facets across all field centres examined. 8. Data for each centre analysed separately. The best question selected for that centre that defines each facet most effectively within core number of facets decided. 9. After facet structure and questions finalized the psychometric properties of the instrument examined – facet relationship to domains. Reliability assessed by examining internal consistency within each facet and inter-changeability of questions within each facet (split half) except for questions in facets where more than one concept is being addressed – e.g., sensory function. 10. Universality established by: • Common agreed facet definitions. • Common methodology for question development and selection. • Global pool that national items have to compete against. • Limited number of core questions. 11. Normative data from sample populations, in combination with national importance ratings, allows comparison between individuals of different cultures. (MNH/PSF/93.9, pp.22-23)	The CTT and Rasch analysis procedures used in the development of the national items for the NZWHOQOL-BREF were used when developing MHRQoL module (Krägeloh, et al., 2016). Table 10 within the thesis outlined the specific psychometric criteria that were used to obtain the final module items in Phase 2. The construct of mental health recovery related QoL (MHRQoL) was considered as the latent trait being assessed for in this study. Iterative analysis of items meeting CCT and Rasch criteria from the above cited published study was conducted to establish which final item selection would adequately measure the latent trait of HRQoL for this population – as MHRQoL.
Testing Core Module for Reliability, Validity, Responsiveness. 1. Administering the instrument to a large and diverse group of subjects in each centre to examine internal consistency and discriminative validity. 2. Sensitivity to change and validity separately assessed. 3. Smaller study with clear homogenous populations; longitudinal design (including simultaneous / repeated ratings); specific interventions and parallel use of other national and international instruments to assess convergent validity. This can establish test-retest reliability, responsiveness to change, cross validation of the measure, criterion validation with regard to convergent, discriminative, and predictive validity. 4. At the end of the development study the facet descriptions reviewed and changed to overcome any difficulties that became apparent. (MNH/PSF/93.9, p.24)	**Testing Core Module for Reliability, Validity, Responsiveness.** Further testing of the module on large diverse groups described in recommendation one is beyond the scope of this research yet can be done in the future. Rasch analysis allows for each item's construct validity to be ascertained as well as the selection of items to be identified as measuring the latent trait of interest – in this instance MHRQoL. Chapter 7 provided further detail about this recommendation. Further study to refine questions and facets can be done with the MHRQoL module.

Appendix C

ISOQOL Guidelines

Definition of the PRO measurement standard. Source: Reeve et al. (2012).	**How it is identified in the MHRQoL module.**
Conceptual and measurement model – provides a description and framework for the targeted construct included in the PRO measure. The measurement model maps the individual items in a PRO model to the construct.	Construct theory was examined by considering the 33 PROM items against personal recovery determinants cited as belonging to the construct of MHRQoL (Connell et al., 2012, 2014), the CHIME personal recovery framework and ReQoL MHRQoL measure..
Reliability - The degree to which the PRO measure is free from measurement error	Rasch analysis evidenced no DIF, residual correlations, disordered thresholds and identified each item's unidimensionality with MHRQoL.
Internal consistency reliability - The degree of intercorrelations among items in a multi-PRO measure	Residual correlations checked – no >.2. were evident in the final 7-item MHRQoL selection.
Test-retest reliability – The degree of reproducibility of the PRO – ability to produce stable consistent scores over time	Not completed within the scope of this research
Validity - The degree to which the PRO instrument measures the PRO construct it purports to measure	The selection of items within the MHRQoL measure met a strict fit with the Rasch model. CFA found all items loaded onto one factor.
Content Validity – the degree to which the content of the PRO measure includes the most important and relevant aspects of a concept in the context of a given measurement application	Phase 2 final items demonstrated alignment with the most important themes identified\ in the Phase 1 discussion groups. Phase 2 CCT and Rasch analysis obtained items aligned with the determinants of recovery found in the CHIME conceptual module and ReQoL MHRQoL measure indicating face validity for relevant content aligned with the two central constructs.
Construct Validity – the extent to which the PRO measure relates to other measures – (e.g., Patient-reported, or clinical indicators) in a manner that is consistent with theory or a priori hypotheses about the concepts being measured	Convergent validity was not able to be formally researched within the scope of this study. This was however explored in the discussion section of the thesis in relation to the CHIME model - a well-accepted conceptual personal recovery model, Connell et al.'s (2012, 2014) personal recovery conceptual framework and the ReQoL measure, an MHRQoL measure obtained from a review of the personal recovery literature.
Criterion Validity – the extent to which the scores of a PRO are an adequate reflection of a 'gold standard'	Items met criterion set by the NZ National items study and WHOQOL study protocol modified for relevance to the current research.
Responsiveness – the extent to which the PRO measure can detect over time changes in the construct measured.	Test-retest reliability is yet to be completed. The core measure (26/33) items meet this criteria.
Interpretability of scores – the extent to which one can easily assign meaning to a PRO measures scores.	Ordinal to Interval Scale conversion has been provided to increase measurement precision. Ease of interpretation - low scores indicate low MHRQoL, high scores indicate better MHRQoL.
Minimal Important Difference – (MID) – The smallest difference in score in the outcome of interest that an informed patient or informed proxies can use or perceive is important - either beneficial or harmful - that would lead the patient or clinician to decide on a change of management.	The Likert scale identifies items 1-2 as evidencing poorer QoL. Recommendations are to explore these scores with module users and to consider risk in relation to the person having progressively deteriorating QoL over time on the WHOQOL-BREF and MHRQoL measure.
Burden – the time, effort and other demands placed on those to whom the instrument is administered (respondent burden) or on those who administer the instrument (investigator or administrator burden).	The MHRQoL module was developed to be the smallest possible size that could be used with individuals and large groups without losing relevant content to limit end-user burden.

Appendix D

Counselling Psychology Worldview

Counselling Psychology

Counselling psychology as a career path is a relatively new opportunity in Aotearoa New Zealand, although it is well established in other countries, including in Britain, USA, South Africa and Australia. Counselling psychology has been established as a scope of practice by the New Zealand Psychologists Board. To register as a counselling psychologist you require a minimum of a Master's degree in psychology from an accredited educational organisation and an accredited Postgraduate Diploma in Counselling Psychology, or equivalent qualification. Eligibility for the counselling psychologist scope of practice also requires a Psychologists Board approved practicum or internship involving 1500 hours of supervised practice which is normally included in the Postgraduate Diploma.

Training in New Zealand is currently available at Auckland University of Technology (AUT University), which offers an accredited programme comprising a Masters in Health Science and Postgraduate Diploma in Counselling Psychology.

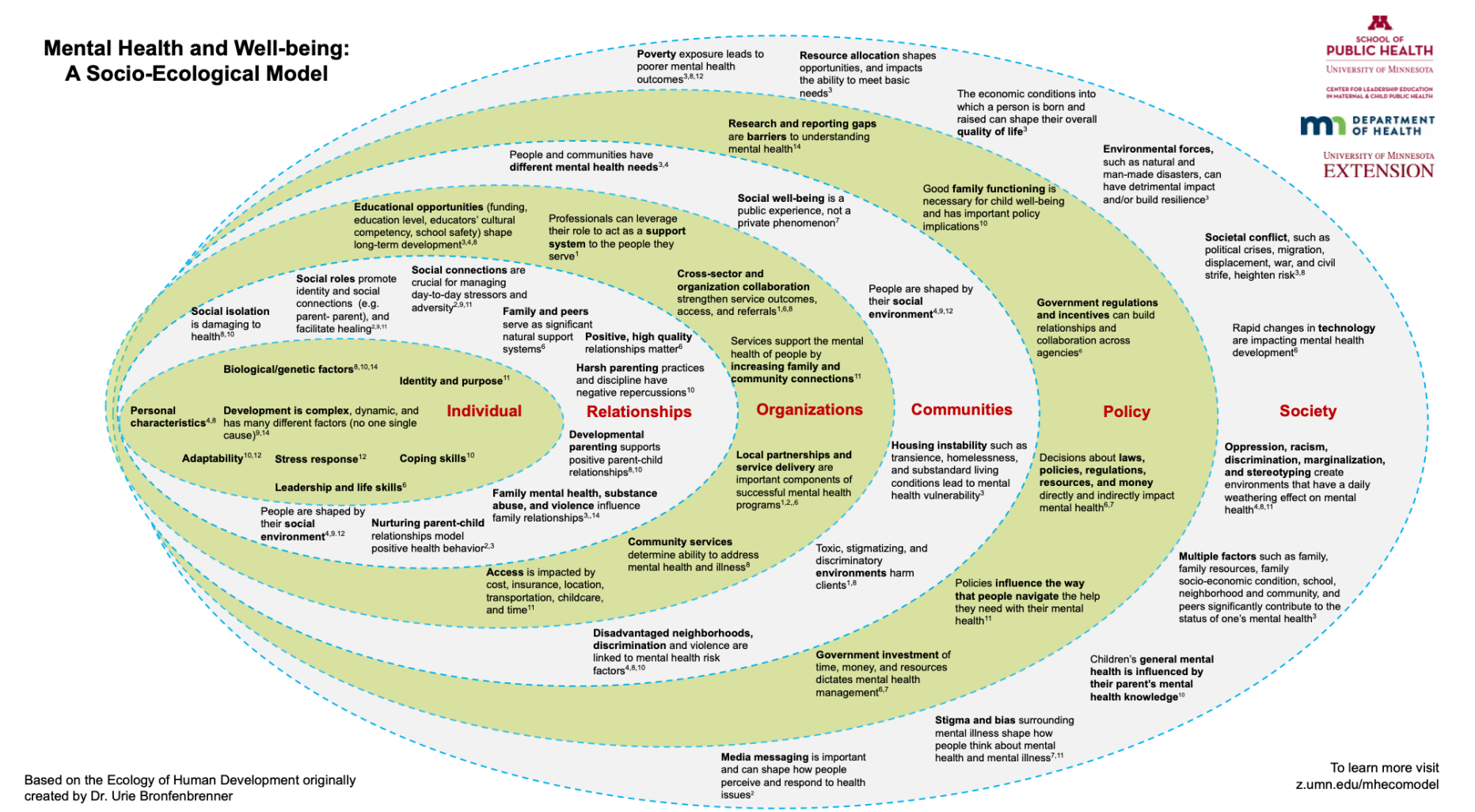
Counselling psychologists are trained in therapeutic relationship skills as well as psychological assessment, diagnosis and intervention. While counselling psychologists class themselves as scientist-practitioners, many prefer the term "practitioner-scholar" as this recognises the importance of practice based evidence as well as evidence based practice. Frameworks for practice include psychodynamic, phenomenological, developmental, systemic, prevention/educational, empowerment, cultural and ethical. A hallmark of counselling psychology is that the discipline takes a contextual approach. This means that counselling psychologists endeavour to take account of the person/whanau/family's whole context, including their world views, cultural identity, social networks, and strengths, in order to collaboratively develop an intervention that will work best to resolve their issues. AUT's counselling psychology programme provides an overview of a range of therapeutic approaches, with foundation training in cognitive behavioural therapy and narrative therapy. In common with other scopes, case formulation is a crucial part of the training and at the heart of the work. A comprehensive assessment leads to an ever-evolving formulation that informs the therapeutic approach and specific interventions, targeted to agreed goals for therapy. For counselling psychologists, the formulation is explicitly multi-perspective, including relevant contextual elements as well as psychological elements.

Counselling psychologists work across the spectrum from everyday adjustment difficulties, to existential crises, through to severe mental health problems. Work settings may include NGOs, community agencies, rehabilitation, health, education, care and protection, youth justice, addiction and mental health services. Interns and graduates from AUT's counselling psychology programme are working with a diversity of presenting issues including eating disorders, drugs and alcohol, gambling, child and adolescent mental health, youth behaviour/family therapy, relationship issues, physical health concerns and palliative care. In summary, counselling psychologists work collaboratively with children and families, adults, groups, organisations and communities to assist people to adjust to life's demands and developmental challenges and to facilitate opportunities for living full and productive lives.

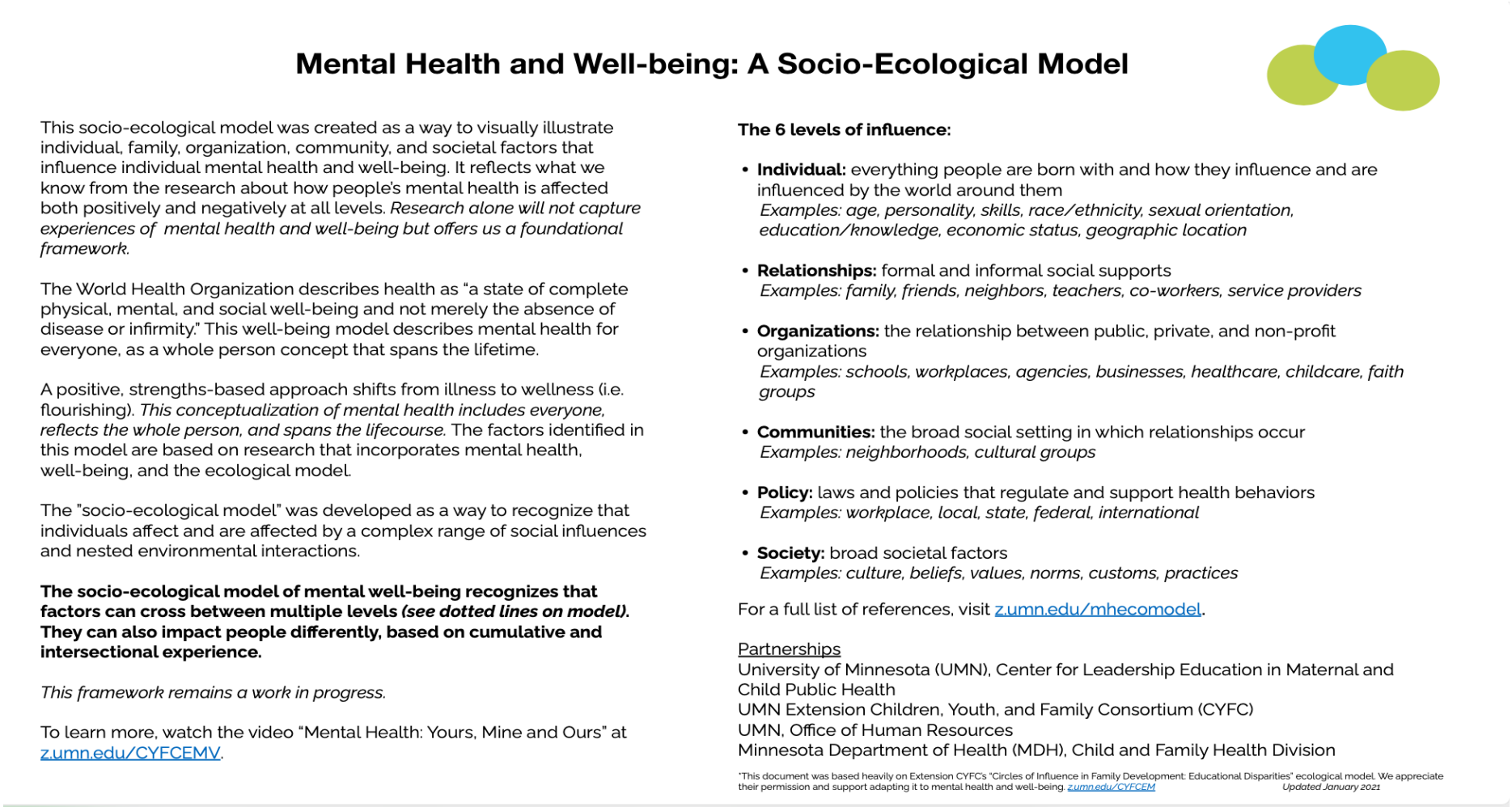
To find out more about training as a counselling psychologist go to
Auckland University of Technology
http://www.aut.ac.nz/study-at-aut/study-areas/health-sciences/postgraduate-study/psychology.

To find out more about registering in the counselling psychology scope of practice go to http://www.psychologistsboard.org.nz/scopes-of-practice2

Source: https://www.psychology.org.nz/journal-archive/Careers_Counselling.pdf



Note. From *Mental Health and Well-being Ecological Model*, by C. Michaels et al. 2022. (https://mch.umn.edu/resources/mhecomodel/). Copyright C. Michaels et al.



Mental Health and Well-being: A Socio-Ecological Model

This socio-ecological model was created as a way to visually illustrate individual, family, organization, community, and societal factors that influence individual mental health and well-being. It reflects what we know from the research about how people's mental health is affected both positively and negatively at all levels. *Research alone will not capture experiences of mental health and well-being but offers us a foundational framework.*

The World Health Organization describes health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity." This well-being model describes mental health for everyone, as a whole person concept that spans the lifetime.

A positive, strengths-based approach shifts from illness to wellness (i.e. flourishing). *This conceptualization of mental health includes everyone, reflects the whole person, and spans the lifecourse.* The factors identified in this model are based on research that incorporates mental health, well-being, and the ecological model.

The "socio-ecological model" was developed as a way to recognize that individuals affect and are affected by a complex range of social influences and nested environmental interactions.

The socio-ecological model of mental well-being recognizes that factors can cross between multiple levels *(see dotted lines on model)*. They can also impact people differently, based on cumulative and intersectional experience.

This framework remains a work in progress.

To learn more, watch the video "Mental Health: Yours, Mine and Ours" at z.umn.edu/CYFCEMV.

The 6 levels of influence:

- **Individual:** everything people are born with and how they influence and are influenced by the world around them
  Examples: age, personality, skills, race/ethnicity, sexual orientation, education/knowledge, economic status, geographic location
- **Relationships:** formal and informal social supports
  Examples: family, friends, neighbors, teachers, co-workers, service providers
- **Organizations:** the relationship between public, private, and non-profit organizations
  Examples: schools, workplaces, agencies, businesses, healthcare, childcare, faith groups
- **Communities:** the broad social setting in which relationships occur
  Examples: neighborhoods, cultural groups
- **Policy:** laws and policies that regulate and support health behaviors
  Examples: workplace, local, state, federal, international
- **Society:** broad societal factors
  Examples: culture, beliefs, values, norms, customs, practices

For a full list of references, visit z.umn.edu/mhecomodel.

Partnerships
University of Minnesota (UMN), Center for Leadership Education in Maternal and Child Public Health
UMN Extension Children, Youth, and Family Consortium (CYFC)
UMN, Office of Human Resources
Minnesota Department of Health (MDH), Child and Family Health Division

This document was based heavily on Extension CYFC's "Circles of Influence in Family Development: Educational Disparities" ecological model. We appreciate their permission and support adapting it to mental health and well-being. z.umn.edu/CYFCEM *Updated January 2021*

Source: Michaels, C., Blake, L., Lynn, A., Greylord, T., & Benning, S. (2022, April 18). *Mental health and well-being ecological model*. Center for Leadership Education in Maternal & Child Public Health, University of Minnesota–Twin Cities. Retrieved 02.08.2022, from https://mch.umn.edu/resources/mhecomodel/

Appendix E1

COREQ Guidelines

Criteria for Reporting Qualitative studies (COREQ): 32-item checklist (Tong, et al., 2007).

COREQ Guideline Number	COREQ guideline information requested	COREQ guideline information provided
Domain 1: Research team and reflexivity. Personal Characteristics 1.	Interviewer, facilitator Primary Supervisor/s	Melissa Rowthorn – primary researcher, PhD candidate Dr Rex Billington, primary supervisor Phase 1 Dr Chris Krägeloh, secondary supervisor Phase 1
2.	Interviewer Credentials	Master's in social science (MSocSci) (Psychology); Post Graduate Diploma Cognitive Behavioural Therapy (PGDipCBT). Registered in the Counselling Psychologist scope of practice with the New Zealand Psychologists Board. Dr Rex Billington – Adjunct Professor Dr Chris Krägeloh – Associate Professor
3.	Occupation	Registered Counselling Psychologist Rex Billington – Health Psychologist Chris Krägeloh – Research Psychologist
4.	Genders	Female (discussion facilitator) Male (attending supervisors)
5.	Experience and training	The PhD candidate had previous focus group facilitation experience within their Master's degree - focus groups were held with staff in nursing homes for the elderly to investigate items for a pain assessment measure to be used with older adults who have varying degrees of aphasia due to dementia. Behavioural observation, psychometric assessment and interviewing of older adults with was involved in that prior research study. Prior to involvement in the current research, the PhD candidate had experience in the social service and mental health sector since 1995; registering as a psychologist in 2006. Initially this involved working

		as a support worker in the NGO sector supporting people to recovery their lives from the negative effects of mental health problems, then to roles that involved training staff, reviewing recovery plans, and providing recovery orientated consultancy services requested by the organisation. Post registration as a psychologist, employment tasks included a therapeutic caseload – providing therapy services to people recovering from mental health problems, project management (inclusive of the outcome measurement project when the organisation decided to use the WHOQOL-BREF as PROM), development of various psychological intervention programmes for a range of populations inclusive of severe mental illness, youth, and the general public, cofacilitating recovery groups and training group sessions, and providing programme development, coaching, and psychological consultancy services for the organisation's social enterprise – a change management consultancy. The researcher also has lived experience of mental health issues within their family and previous personal life experiences. Dr Rex Billington provided guidance and training around implementing the WHOQOL study guide discussion meeting and question writing procedures. Dr Billington has had extensive experience working for the World Health Organization as the Director of Mental Health 1996–2000 and with research related to both mental health and quality of life.

Relationship with participants

6.	Relationship established prior to and within discussion situations. <u>Two discussion circumstances occurred:</u> Group discussions 1:1 Interview discussions	An information sheet was provided to all participants when they first expressed interest in participating. This can be reviewed in Appendix F. An opportunity to ask questions prior to deciding to participate occurred when the participant made contact expressing interest in participating, after reading the information sheet, as well as on the day of the discussion meeting. An initial introduction round of all participating members, with an opportunity for members to add to the group discussion boundaries to ensure conversational and psychological safety, occurred as a warmup activity. A discussion meeting procedure was reviewed and approved

		by the Ethics committee prior to the research beginning and can be reviewed in Appendix G. This protocol was followed to ensure consistency between discussion meetings. An opportunity to build a safe and supportive discussion dynamic was offered to each participant prior to the discussion beginning. This is described in the protocol outlined in Appendix G.
7.	Participant knowledge of the interviewer	The information sheet stated why the research was being done, who the researcher was, that it was part of a PhD research study, and what the goals of the research were. This was articulated again at the discussion meeting. The researcher worked for one organisation who agreed to support recruitment during the research. Therefore a small number of the recovery supporter sample - staff participants (in one recovery supporter group and two key informant interviewees) knew of the interviewer. One key informant interviewee and the outlier interviewee knew of the researcher from a prior professional contact situation in the distant past. Two members of the expert group knew the interviewer from prior collaborative work completed professionally. Two people with lived experience had met the researcher before in a work and community circumstance yet were not well known to the researcher. The attending supervisors who attended discussion group meetings were known of by two expert group members.
8.	Interviewer characteristics	The information sheet outlined the reasons the interviewer was interested in this research topic – see Appendix F. Potential biases as well as understandings that could have supported the research process and decision making could have been present from the following background experiences: (1) previous exposure to the use of the WHOQOL-BREF tool as a PROM; (2) to the field of mental health and recovery since 1995; (3) lived experience with family members who have had mental health and addiction problems and their own personal life experiences; (4) the worldview of counselling psychology, educational training in clinical psychology, community and social psychology, phenomenological and humanistic perspectives. Attempts to reduce the potential for bias were made by the selection of methods by which to interpret data and assign significance to the results of Phase 1 and 2. These involved: (1) using multiple coders to code discussion tapes; (2) the use of data triangulation to identify significant results; (3) using the most frequently cited recovery determinants from the literature as coding criteria rather than researcher generated codes; (4) the data analysis was not primarily

		driven by psychological interpretation in Phase 1, by using quantitative frequency based methods to identify themes. Summative frequency analysis and triangulation of frequency and rank ordered data led to the prioritisation of what items to go forward for question writing; (5) the qualitative interpretation of the quantitatively generated Phase 2 results obtained by people with lived experience was given by illustrative quotes from participants in Phase 1 through their personal accounts and experiences of the themes that the final seven module items assessed for in Phase 2. This balanced the power between researcher interpretations within discussion of these results with the participants lived experience of these seven issues. It is possible that tone of voice or body language could have been read or examined by participants. The interviewer was mindful of this and attempted to adopt an affirming, empowering, supportive, and neutral stance towards participant experiences when they were shared in discussions along with a genuine interest in their answers to the questions asked. Supervisors were present in all lived experience interviews. They did not state that any obvious or overt biases were being demonstrated by the interviewer in the discussion meetings. Although passion and enthusiasm for the topic and past personal and professional experiences may have driven commitment to this research, one integrity check on whether the final items within the module were obtained solely from or considerably affected by researcher bias can be considered. There are items discarded that I would have potentially possibly favoured or thought to include from such biases. I was grateful to the ways the use of scientific methods of gathering and analysing data, use of quantitative methods alongside qualitative methods, and the involvement of objective input from others during consultations and reviews with key and wider stakeholders at all phases of this research, and most importantly the world view and experiences of people recovering from mental health challenges drove the methods of finding answers beyond the limits of my own personal experiences.

Domain 2: study design

Theoretical framework

9.	Methodological orientation and theory	Phase 1 was a qualitative phase of a larger exploratory sequential mixed methods designed study, using a critical realist approach. Analysis methods included – summative content and frequency analysis, data triangulation, code book and thematic coding of discussion data, latent consensus decision making through data triangulation and cross coder ratings occurred to rank order potential candidate items based on convergent data patterns. Data saturation provided an indicator of when to stop collecting data.

Participant selection

10.	Sampling	A combination of purposeful and convenience sampling was used through a variety of recruitment methods: maildrop flyers, forum presentations, noticeboard posters in the community and community based mental health NGO settings, snowball, and word of mouth advertising - letters of introduction and emails to key stakeholders who communicated the research opportunity within their organisations to potential participants. Purposeful targeted sampling involved advertising to known mental health agencies that had relevant participants within them, ensuring services were approached within all of the four major geographical regions of the city that Phase 1 of the research was conducted in. Approaching specific cultural services that could increase the opportunity for minority groups and cultures to participate where possible. Presentations to mental health groups such as early intervention psychosis forums to encourage participation of people who may not participate as often as those with mood disorders in general mental health research studies.
11.	Method of approach	Participants were approached through 1) Their proactive response to advertising and flyers in the community, or to promotions within the agency they worked in, received services in, or visited; 2) Word of mouth discussions by people within the agency who were informing them about the research prompting them to make contact.
12.	Phase 1 sample size	Eight-eight participants agreed to participate in Phase one, 55 were people with lived experience and 33 were key stakeholders in their recovery. Twenty-three discussions were held – in either a semi-structured group or interview format. Eleven discussions were with people with lived experience and 11 discussions were with recovery

		supporters. There was one additional outlier interview with a workforce development training coordinator who provided contextual information about the service environment people received recovery services within during the discussion data gathering exercise in Phase 1. <u>Lived Experience</u> (11 discussions and their codes): Five interviews: CC10; AE1; PS4; RC1; KILGBT Six group discussions: RC; PC; CC; WC; CM; TC <u>Recovery supporters</u> (11 discussions and their codes): Five interviews – NLE = AE8; (WFD), KICF, ACL4; KIM Seven discussions NLE = AE; EF; AF; ACL; RS, CS, PS
13.	Non-participation	No participants dropped out. There were likely to be people who saw adverts or were told about the research by people they knew who decided not to participate. There was an emphasis on choice and there being no consequences for the person or the services they received for saying no to the invitation. There was also a choice to attend a group or a 1:1 interview. Participants who chose a 1:1 interview disclosed their reasons for this being – challenges with being in a group situation or leaving their home - staff at times discussed additional commitments that resulted in being unable to attend set discussion group days and times. Some made a time for a 1:1 interview to offset this barrier. Potential recovery supporter participants that declined participation declined due to workload and perceived service disruption if discussion groups were held in a work setting. In one case an Asian mental health service stated the clients were unlikely to have sufficient English to fully understand and participate in the discussion and staff were unable to provide translation support due to work demands. The time and travel costs were considered as possible reasons for people not participating. A travel voucher was given and holding group meetings in places closer to where participants lived occurred to offset travel barriers.

<u>Setting</u>

14.	Setting of data collection	The lived-experience discussions were conducted within service settings that people received services from, or community house rooms. One family group, an expert group, and three clinician interviews were held in an interview room at AUT. On one occasion an interview occurred within a clinic room of the researcher, another requested as a person with lived experience's home.
15.	Presence of non-	The researcher's supervisors were present in all of the lived

	participants, i.e., not lived-experience or recovery supporter participants.	experience discussions and some of the recovery supporter discussions. The primary supervisor was present in one clinician, two family, and one expert group. All discussions were taped. The lived experience discussion tapes were listened to and coded by five coders. The recovery supporter discussion tapes were listened to and coded by two coders – the researcher and primary supervisor.
16.	Description of sample	Table 4 in the thesis describes the demographics of the Phase 1 sample - pages 144–146 contain this information.

Data collection

17.	Interview guide	A discussion group protocol was developed. This was reviewed by the AUT ethics committee prior to the research beginning. The same materials and method of conducting the group discussions were used and replicated in the semi-structured interviews. This protocol can be reviewed in Appendix G.
18.	Repeat interviews	No repeat interviews were conducted.
19.	Audio visual recording	All discussions and interviews were tape recorded on a small tape recorder placed on the floor central to the group yet was not conspicuous. Participants were aware that the discussion was being recorded and when the recording started and stopped. These tapes were stored in a confidential location, transferred to electronic files for computer storage and used for later transcription. Photos of participant card sorting were taken with an anonymous identifier code to represent the type of group and a number to identify one participant result from another. Photos were stored in a computer folder and the name of the recovery determinant chosen recorded on a spreadsheet with the code to identify each participant record for later between group and whole sample summative frequency analysis.
20.	Field notes	Records were kept of the group location, the group type (lived experience, recovery supporters – family, clinician, expert, or staff), the date of the group and who participated as interviewers. Tape recordings of each interview and discussion were kept and turned into MP3 files for long term storage. Consent forms signed by participants for each group were kept within a research folder with completed surveys. Discussions with supervisors attending, or after group sessions occurred, for learning, feedback on shared perceptions and process issues, and as a way to consider when data saturation had been reached. Communications between the PhD candidate and their supervisors via email and meeting notes were stored as part of the field notes. Process documents that documented steps and decisions made were developed to maintain records of the methods and procedures used to establish the final results.

21.	Duration	The discussion time ranged from 45 mins to 1.5 hours, on average 60 minutes. The discussions were followed by a refreshment break and then two importance rating exercises. Each activity took between five to 15mins; the pen and paper task was quicker than the card sort activity. This resulted in a 2–3-hour commitment from participants. This was shorter in a 1:1 discussion, which averaged from 1-2 hours in total.
22.	Data saturation	Discussions and interviews stopped once data saturation appeared to have occurred. This was established by mutual recognition when the researcher and primary supervisor were participating in, listening to, and coding tapes after each discussion meeting ended. Saturation was identified when the same themes were being repeated, with no new themes being identified.
23.	Transcripts returned	Transcription was not part of the Phase 1 procedure. Transcripts of the LE discussions were later made for data interpretation purposes within the thesis as a way to identify relevant quotes that provided context for the QoL items within the final research result. The purpose of data collection in Phase 1 was not to explore the context or reasons for the QoL issues being identified. Coders identified themes from discussion tapes and summative frequency analysis was used to identify predominant themes.

Domain 3: analysis and findings

<u>Data analysis</u>

24.	Number of data coders	There were five coders coding lived experience discussions. Two coders coded the recovery-supporter discussions.
25.	Description of the coding tree	The code book can be reviewed in Appendix L. The code book included 26 existing WHOQOL-BREF facets, five New Zealand National items, and 48 recovery card themes. When any of these issues were mentioned the coder noted that this theme was discussed in the code book. There was a place for the coder to write any themes or topics that were not included in the code book. This offered the opportunity for any new themes to emerge from the groups that did not fit into any pre-existing code. The code book tallied the number of times each code was noted.
26.	Derivation of themes	N-vivo was used to explore higher order and lower order themes between the recovery determinants listed from the personal recovery literature and record of recovery measure content. It was decided not to overly interpret the existing

		records with higher level themes prior to the research beginning, that this is a later task once participants had reported on each one. The process of selecting the 48 themes from those gathered from the literature was done through removing duplication, summative frequency analysis and rank ordering to choose the most often cited themes as more likely candidates for potential personal recovery themes relevant to the QoL of people with mental health problems. Themes that were already covered by facets within the WHOQOL-BREF were not included. Review of the themes with supervisors occurred to further consider if any were already contained within the WHOQOL-BREF before finalising the 48 themes for use as codes and in the importance rating exercise of Phase 1. Inductive analysis in the form of content analysis using summative frequency analysis of the tallies created within the code book to pre-existing code book themes allowed for rank ordering of codes that were more frequently discussed by participants within and between groups. The codes relating to the existing WHOQOL-BREF and National items were set aside. The new codes not covered by the code book were tallied and those most often mentioned were included for consideration during question writing. Sub themes emerged during question writing when the writing of questions identified a question was being formulated the same way to more than one theme that was closely associated with it. These themes were subsumed under more predominant themes. The assimilation of themes into higher order themes during question writing was displayed on Table 9 – page 176 in the thesis.
27.	Software	A code book designed by a software engineer who was part of the WHOQOL special interest group. The code book enabled the creation of a summative frequency score for each item coded to be generated. An Excel workbook was used for side by side analysis of between group results. The software engineer who designed the code book was Jillian Pemington, who worked for a company (*Wild Bamboo*) that developed *Recordbase*, a client management system that two organisations using the WHOQOL-BREF were using to store and manage WHOQOL data at the time of the research. Wild Bamboo was part of the WHOQOL special interest group..
28.	Participant checking	The discussion group process included clarification and request for affirmation that the understanding of the

		researcher or primary supervisor attending was correct in their understanding of what was said where ambiguity occurred during the discussion meetings. Additional participant feedback was sought through: (1) a small pilot group reviewing the survey questions and survey completion process; (2) consultancy around the Phase 1 themes by a coder with lived experience who had coded all of the lived experience tapes; (3) wider stakeholder feedback at special interest group forum meetings.

Reporting

29.	Quotations presented	Participant quotes from Phase 1 transcripts are provided in Chapter 7 and in Appendix M. The identification of separate participant comments by the use of anonymous codes has been explained prior, in COREQ question 12, 20. When transcribing tapes, the same sample identifier code (i.e., if family was still F or if at a specific location such as R, C, P, or E) was given to a group discussion participant quote, yet the participant numeric code referred instead to speaker 1, speaker 2, and so forth. The transcription code does not align with the card sort results code of each participant. Some people attending a group did not share their thoughts and there was no way to identify participants by voice and link this to importance activity data codes. This protects the anonymity of participants through the meaningless nature of the anonymisation to a future thesis reader. The only place where identity was recorded was in the consent forms. Consent forms were filed separately from importance survey forms without codes attached to them.
30.	Data and findings consistent	The concluding result from Phase 2 was consistent with Phase 1 with respects to six out of seven items in the final module were chosen as relevant to QoL in recovery by over 60 percent of the LE participants in Phase 1. Three of these six were chosen by 70 percent of the LE participants; with one item (people skills) recognised as relevant to HRQoL by 52 percent of LE participants in Phase 1. All phase 2 results were therefore chosen as relevant to the personal recovery of over 50 percent of Phase 1 participants with lived experience. The results were also compared to well respected personal recovery conceptual models and another MHRQoL measure developed for this population with consistent findings about the relevance of the content of the WHOOQL-BREF and MHRQoL module to people recovering from mental health problems being evident from a face validity perspective. The content of this more precise version of the WHOQOL-BREF with the MHRQoL module attached having content also recognised

		by leading mental health outcome researchers and experts as relevant to focus upon to improve recovery outcomes for people. This initial observation is not surprising as the content for the measure came from this literature however it could reinforce that the measure will perform well in the field as recovery orientated PROM for use in situations when assessing and improving people's QoL is of interest.
31.	Clarity of major themes	The major themes from Phase 1 are summarised on Table 9 of the Phase 1 results. Given the themes were established by frequency analysis within the use of a code book this assisted the identification of major themes. New themes were more complex to consider and code, some used different words for existing WHOQOL-BREF facets or recovery determinants already accounted for. Those that did not, were included in the question writing phase, regardless of their frequency of mention, as they were not able to be subjected to the same rigour of triangulation as existing codes were, to consider their level of importance against importance data. Some major themes were already covered by the WHOQOL-BREF so were not focussed upon in this research. The aim of this research was to discover major themes not already covered by the WHOQOL tools.
32.	Clarity of minor themes	Chapter 7 contains examples of personal accounts of sub-themes occurring within the exploration of the final results. The way that mental health or addiction problems impact upon a person's QoL were varied yet clustered into minor theme areas that were also measured by the existing WHOQOL tool. MHRQoL meeting classical test theory criteria as not being included in the existing WHOQOL-BREF, national items, or by existing candidate items have been included in Appendix M.

Appendix E2

Phase 1 Participant Recruitment Methods.

Quality of Life Research Study

An invitation to participate

What do you think is most important to

Quality of Life, during mental health recovery?

We are interested in what people think and feel about this issue.

Answers will help services to identify what is most important to people living with and recovering from mental illness.

If you would like to contribute to this study by

giving your views in a focus group and completing a survey:

Please make contact for more information:

melissa.rowthorn@gmail.com

or text / call:

022 123 6619

We are looking for people recovering from mental illness, people working with these people - in peer, support-worker, or clinical roles, and family members of people recovering from mental illness, to be participants in this study. Feel free to pass this opportunity on to others, who could be interested in participating.

Thank you ☺

Recruitment Plan

1) Quota sampling. Source 10 services from each of the 5 service types:
   a. Community (38.5%),
   b. Kaupapa Māori (5.8%),
   c. AoD (19.8%),
   d. Residential (20.8%),
   e. Other (25.6%) – [Family, Whanau, Specialist, Private, PHO]
2) Choose at least 2 of every service from the following regions to ensure rural and urban spread as well as differences between services and different QOL issues in different regions. One NGO and one clinical service type of the 5 above in each region.
   i. Auckland
   ii. Northland
   iii. Mid North Island
   iv. Wellington
   v. South Island
3) Access the web-health directory to obtain the phone and address details for each service. Choose range of providers small, medium, large, the search engine options will assist with this: e.g. http://www.linkage.co.nz/search?categories=11&sub_categories=88
4) Contact the Platform Trust WHOQOL group of NGO services to see which of these will be willing to participate in the research – some of whom are organisations that cross all of these regions or are situated out of Auckland in these regions. Obtain contact person from each who is willing to be contacted and followed up with.
5) Call these services and ask for the person most relevant to speak to about research that could interest staff, clients, and family members.
6) Send relevant information to this person: Information Sheet, Covering letter, example of consent form and poster for advertising to participants.
7) Offer time to consider and call back in one week to see if they feel comfortable promoting the research.
8) If they agree, arrange where and when it will be promoted, additional materials needed. Agree on a follow up plan and contact arrangements for any potential participants that have questions they would like answered before deciding.
9) When participants make contact, field questions and go over information sheet and informed consent with them. If they are happy to participate ask them to sign the consent form and fax, scan, post back to myself. Collect their contact details to follow up with them and to call back regarding dates and times for focus groups.
10) When 8-10 people in a region have shown interest in participating a focus group venue can be established with the participating organisation – at their site or near by community house. A booking time and day will be set and the participants informed.
11) A check of people responding will be made throughout to ensure a representative mix of cultures, genders, and ages as well as service types and regions are involved in the research. If no participants from a specific group have responded to the invitation further recruitment of other services across the region that offer services to these populations will occur to attempt to recruit a representative sample.

AUT UNIVERSITY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

July 17, 2014

To whom it may concern,

I am writing to you, to let you know about a quality of life research study occurring at the moment. It involves service users, support and clinical workers, peer support services and family members. It is being completed as a PhD research study at AUT, under the guidance of Rex Billington and the NZ WHOQOL group, by Melissa Rowthorn [a psychologist at Connect Supporting Recovery].

The research is looking into whether there are specific and unique quality of life issues that emerge after the onset of mental illness or during the mental health recovery process. If so, whether these issues are all covered by the existing World Health Organisations quality of life survey – the WHOQOL-BREF – or whether there are additional items that need to be added to this survey when it is used as an assessment, clinical aid, or service / intervention outcome tool with mental health service users during their recovery process.

We would like to invite service users, support and clinical workers, peer support workers and family members to attend some focus groups. At these groups we will ask them about this issue and collate their answers. People will also be asked to rate existing WHOQOL-BREF items and potential issues named in the literature in order of their importance to the recovery process.

The results of this will be to see what issues were named most often. A process of factor analysis will occur to select the most robust items of those most frequently mentioned. These will then be turned into questions that will form a module as an appendix to the WHOQOL-BREF. We then aim to test this module to see if it can differentiate between people with and without mental illness.

The utility of this is two-fold. It will help to identify the most important QOL issues for people recovering from mental illness. This can help with identifying these, providing services that target these, and ensure that current outcome analysis with the WHOQOL includes these. It also enables the people receiving and working in services to be the people informing the development and content of an outcome measure used to support their recovery process.

I am writing to ask if you would consider advertising this research study in your service? I enclose a poster and information sheet for you to review along with a copy of the NZWHOQOL-BREF.

This could involve putting the poster up in places service users and workers can see it; emailing the workers about the study attaching the poster to the email, communicating with workers and service users at meeting forums, including an advertisement about it in your organisational newsletters, and letting family members know about it if you have family forums or other routine communications with family members. Any further ideas you have for getting the message out to potential participants would be welcomed.

I would appreciate a response back from you about whether you would agree to promoting this research opportunity within your service within seven days. I will make contact with you again around this time, if I have not heard from you.

If you have any further questions, I am happy to respond to these via email, phone, or in person.

My contact details are as follows:

melissa.rowthorn@gmail.com

Cell: 022 123 6619

The other researchers involved with this project are also available to discuss any issues or questions you have. Their contact details are:

- Rex Billington on 09 921 9999 extension 9466 or by emailing: rex.billington@aut.ac.nz
- Chris Krageloh on 09 921 9999 extension 9466 or by emailing ckragelo@aut.ac.nz>
- Jason Landon on 09 921 9999 extension 9466 or by emailing jlandon@aut.ac.nz

Thank you for considering whether you are happy to advertise this opportunity to your staff and clients.

Yours sincerely,

Melissa Rowthorn

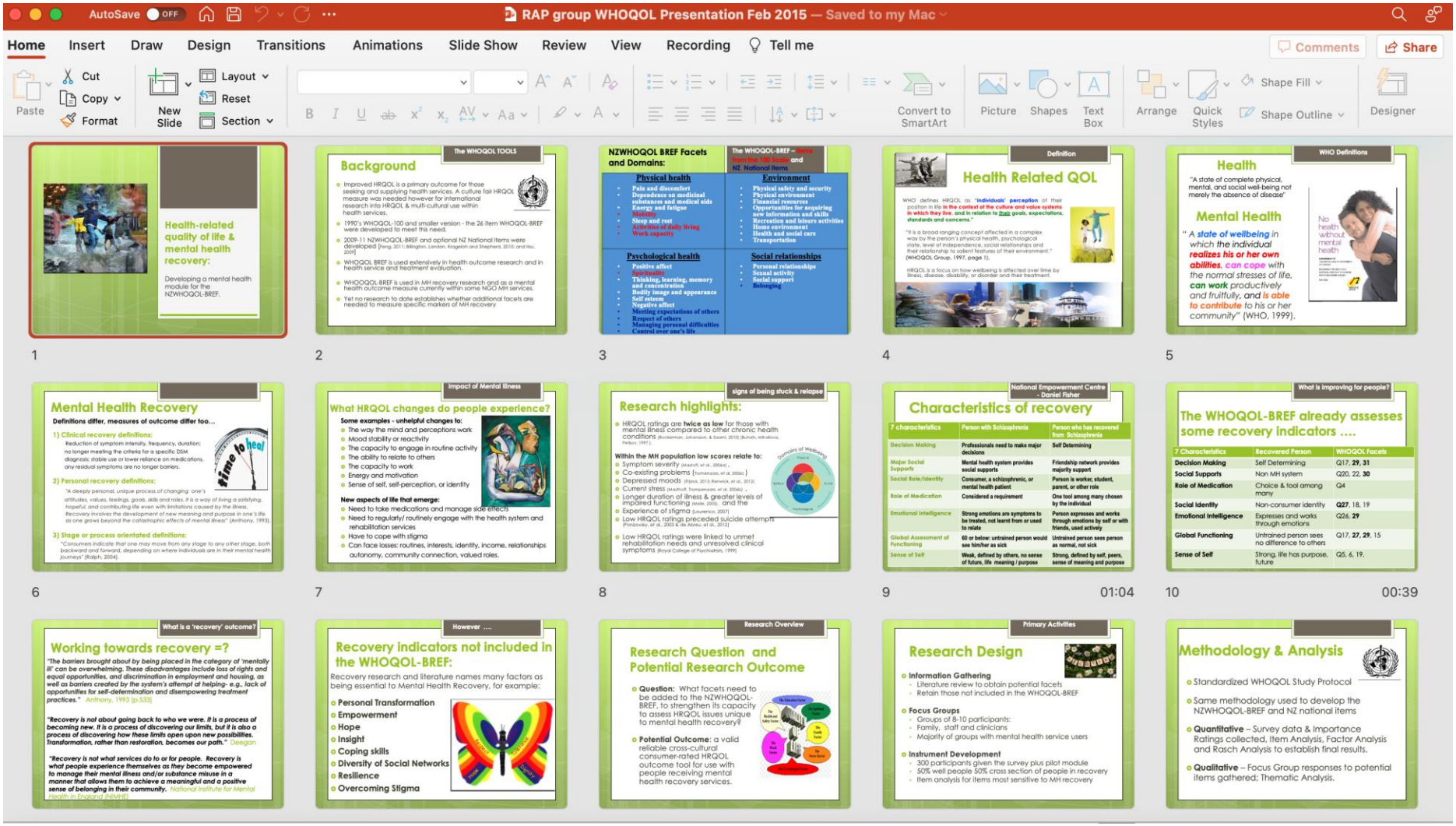
Psychologist

MSocSci, PGDipCBT, MNZPS,

Reg NZPB 90-02716

Approved by the Auckland University of Technology Ethics Committee on: 25th September 2014. AUTEC Reference number 14/227

February 2015, Example of a presentation to psychological treatment of psychosis forum to recruit participants during Phase 1.



Appendix F

Phase 1 Participant Information Sheet and Consent Form

Participant Information Sheet

Who am I?
Melissa Rowthorn – a psychologist at Connect Supporting Recovery who is studying quality of life during mental health recovery. I am enrolled in a degree called a PhD at AUT. The research I am doing is part of the learning requirement of that qualification.

What is the research about?
We want to develop a small set of questions that focus on the most important issues for people recovering from mental illness, and add them to a quality of life survey called the WHOQOL-BREF, to make a mental health recovery module.

What would I be doing?
You are being invited to come and talk with 6-8 of your peers, to complete a 31-item survey and do a card sort exercise. These will help us to find out what you think the most important things are, for people recovering from mental illness. People's answers will help us to find out what to put into the mental health recovery module.

Are there any risks?
No. If you have been in a group before you will know what this experience is like. People will be asked to respect each other and their differences in the group. If you are uncomfortable in groups we can meet for a 1:1 interview instead. If any questions on the survey are upsetting you don't have to answer them. People will be supported.

Is it private?
Yes. Only the researchers will see the forms you fill out. The meeting will be audio taped, however only researchers will listen to them afterwards and everyone in the study signs confidentiality agreements. No names will be on the forms. No one where you work, or receive services from, will know what you've said and nothing will change about your services if you choose to participate or choose not to participate or if you want to pull out later.

What are the benefits?
When services know what the most important issues are for people recovering from mental illness they can focus more on these when delivering services to them. By helping to make this module, people are helping towards improving recovery services for people with mental illness and helping services to recognise the most important areas to focus on to improve people's quality of life during their recovery.

Will it cost me anything?
No. People who choose to participate will get a $20 voucher. It will require 2-3 hours of your time. Refreshments will be provided.

Who do I contact if I have concerns?
Text me and I'll call to arrange a time to discuss things further: 022 123 6619. If you have concerns about the research, call my supervisor Rex Billington on (09) 921 9999 extension 9466. Or Kate O'Connor: *ethics@aut.ac.nz* or ph: 921 9999 ext 6038.

How do I sign up?
Register with me, complete a consent form, and come along to the focus group.

Date Information Sheet Produced: **24 August 2014**
Project Title: **Developing a Mental Health Recovery Module for the WHOQOL-BREF.**
Date approved by AUTEC: 25th September 2014. AUTEC reference number: 14/227

CONSENT FORM

Project Title: **Developing a Mental Health Recovery Module for the WHOQOL-BREF**
Project Supervisor: **Rex Billington**
Researcher: **Melissa Rowthorn**

- ○ I have read and understood the information provided about this research project in the Information Sheet dated 24 August 2014
- ○ I have had an opportunity to ask questions and to have them answered.
- ○ I understand that the identity of my fellow participants and our discussions in the discussion group is to remain confidential to the group. I agree to keep this information confidential.
- ○ I understand that the group meeting will be audio-taped and could be transcribed.
- ○ I understand that I may withdraw myself, or any information that I have provided at any time, without any loss of support, I receive from any services or from the research providers.
- ○ If I withdraw, I understand that while it may not be possible to destroy all the records of the discussion group discussion I took part in, the relevant information about myself including tapes and transcripts, or parts thereof, will not be used in the analysis or write up.
- ○ I agree to take part in this research.
- ○ I wish to receive a copy of the report from the research: Yes ○ No ○
- ○ I would like to be contacted if further research develops out of this study: Yes ○ No ○

Participant signature: .....……

Participant name: .....……

Participant contact details:

Phone: ……

Email **or** postal address ……

Best time and day to contact me: …….

Preferred days and times for attending a discussion group or interview, if the date has not been set:

……

……

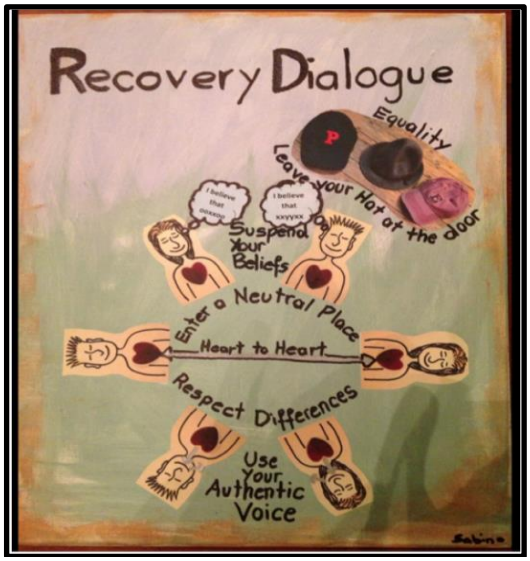
Date: ……

Approved by the Auckland University of Technology Ethics Committee 25th September 2014.
AUTEC Reference number 14/227 *Note: The participant should retain a copy of this form.*

Appendix G

Phase 1 Discussion Group Protocol

The poster used in the discussion meetings when establishing group guidelines and culture. Artwork by lived experience artist - Sabine Tibbett - used with permission Dr Daniel Fisher – National Empowerment Centre for mental health consumer research.



Discussion Group Questions:

1. **What parts of life are most affected by mental illness?**
2. **What parts of life are important to the process of recovering from mental illness?**

Prompts:

   a. What keeps recovery stuck?

   b. Or helps to make progress over time?

3. **What unique quality of life issues emerge during the process of recovering from mental illness?**

Prompts:

   a. What new things are experienced?

   b. What did you need to draw on within yourself?

   c. What did you need from others?

Discussion Group Protocol

1) After eight people indicate that they would like to participate, a discussion group time and venue is set in an area local to the participants.
2) Participants are contacted about the time, date, and place to meet for a discussion group. Information forms are given, questions answered, and consent forms signed prior to participation.
3) If people did not want to attend a group yet did want to participate an individual interview a date, time and place could be arranged with them.
4) The discussion group room is an open space with 10-12 chairs set in a circle prior to people arriving. Water is available and light refreshments are set up for the break.
5) When people arrive, they are welcomed by the facilitator, shown where to sit, given information about where they can access toilets, water, and smoking break policy.
6) The discussion group facilitator can answer any questions about the research, the participant gives a pre-signed, or signs, a consent form for participation.
7) Participants from residential facilities arriving with support staff have access to those staff for support if required at any time throughout the meeting.
8) Prior to the start of the discussion group, the following information is given:
    - People are informed of the fire exits and procedure if an alarm was sounded and where the bathrooms were. Participants are free to go to the bathroom as needed.
    - People are informed the room was a non-smoking facility, where they can go to have a cigarette, and that they are free to take a break when needed.
    - People are informed they will be asked three questions that aim to explore the most important quality of life issues that people recovering from mental illness experience.

- A brief rationale is given about how their answers will help the researchers to ensure the most important quality of life issues are included in a quality-of-life survey to be used to explore changes in quality of life during mental health service delivery. A repeat of the information covered in the Phase 1 information sheet.
- People are informed of the discussion group prospective timeline and that there will be light refreshments following.
- An opportunity for someone to say Karakia is given.
- People are informed when the discussion group is about to start and when the tape has been turned on. This will indicate a start to the discussion group.
- A request for people to consider discussion group principles focused on the group dynamic is made – these were visually present on a poster during the discussion group and covered the following points:
    a. The principles of recovery dialogue poster is referred to and remains visibly present throughout the meeting.
    b. Additionally, a group guidelines poster covered the following:
    c. One person speaks at a time.
    d. We will start with each person giving an answer around the circle.
    e. Respect each other's different views – it is ok to disagree.
    f. There are no right answers, just our own experiences and truth.
    g. Request time-out if you are feeling stressed.
    h. With some space for any additional items people want to add.
- Participants are invited to add any additional things to ensure they feel safe and respected in the group during the meeting. Any things stated are added to the guidelines at each group.

- A welcome and thank you for choosing to participate is communicated. A warmup exercise for participants to introduce themselves and state their interest in participating in the research occurs prior to the tape starting.
- Three large pieces of paper with the 3 research questions written on them are available. The facilitator puts the first question up on the wall, so it is visible throughout the time that question is focussed upon in the discussion. This process is repeated for each question so that only one question can be viewed at a time.
- The tape is turned on just prior to the first question being asked. Participants are invited to comment in a round initially, with one person saying their thoughts, then moving to the next. Participants have the right to pass at any point. Those who had additional things to say discussed these in an open discussion style.
- At times, the researcher repeats the question if people require this, asks for clarification if needed in response to people's comments, or reflects appreciation for people's contributions or answers questions from participants as required. The facilitator checks in with the group before moving on to the next question by saying: "Does anyone else have anything more to add about [question x]." When the answer is no, then that signals time to move to the next question. This process is followed for all three questions to aim for data saturation within each question.
- Two researchers attended each group were possible to ensure that one is available to support people and provide any additional support that any person may require during the discussion group. Residential support staff attended the group with any participant that required more intensive 1:1 support to participate.
- At the end of the discussion group participants were thanked for participating and are offered a break and information that two additional activities are to follow.

- The importance version of the NZWHOQOL-BREF with brief STORI questions at the end of the questionnaire in the “About You” section is given to participants. The instruction for completing the survey is given verbally and is written form on the survey; participants are invited to ask questions as needed.
- Each participant is given a set of laminated cards with a laminated code within the pack to represent individual card sort packs. Participants are asked to choose the cards that affected their quality of life the most during their recovery so far, or that of a specific person they supported if they are a person without lived experience of mental health issues. They are asked to rank order these to show what was most important at the top. They are informed that a photo of their cards will be taken without them being in the picture. The code identifier card is within the photo.
- An invitation for an ending karakia is given.
- Appreciation is given to participants in recovery by means of a recovery resource gift bag and a travel voucher is given to all participants.
- Refreshments are served – a table with fruit, biscuits, snack foods and drinks have a cover over them. This is taken off to represent time to socialise, eat, and drink.
- The researcher places the tapes, importance surveys, cards, into a file box with the date, location, facilitator names, and time of the discussion group written upon it.
- The researcher packs up the discussion group resources, packs up left over refreshments, cleans the room, and returns it to how was found as stipulated by the venue owners.

Appendix H

Phase 1 WHOQOL-BREF Importance Survey

WORLD HEALTH ORGANISATION

QUALITY OF LIFE QUESTIONNAIRE

NEW ZEALAND VERSION

of the NZ-WHOQOL- BREF

Instructions:

This questionnaire asks how important various quality of life issues are to mental health recovery. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can be your first one.

Please keep in mind your own personal standards, hopes, pleasures and concerns. We ask that you think about your own journey of recovery. If you are a staff or family member – think about the recovery journey of the people or family member you support with mental illness and their personal standards, hopes, pleasures and concerns.

For example, thinking about your journey of recovery, a question might be:

How important is satisfaction with your physical health, to your own personal experience of mental health recovery?				
Not at all 1	A little 2	A moderate amount 3	Very 4	An extreme amount 5

You should circle the number that best fits with how important you feel being satisfied with your physical health affects your own journey of mental health recovery. So you would circle the number **4** if you think satisfaction with your physical health is "**very**" important.
Like the below:

How important is satisfaction with your physical health, to your own personal experience of mental health recovery?				
Not at all 1	A little 2	3	Very 4	An extreme amount 5

If you think satisfaction with your physical health is "**Not at all**" important to mental health recovery however you would instead circle the number **1**.

Please read each of the following questions, assess your own journey of recovery, or that of those you support, and circle the number on the scale for each question, that fits best for you.

Please read the question, assess your feelings, and **circle the number** on the scale for each question that gives the best answer, **for you**.

Indicate how important each of the following are to the unique circumstance of living with and recovering from mental illness. **If you are currently recovering from mental illness or have done so in the past,** please think about your own experiences and answer on this basis.

PART A- Generic Questions

	How important is …	Not at all	A little	A moderate amount	Very	An extreme amount
1	Overall quality of life?	1	2	3	4	5

	How important is …	Not at all	A little	A moderate amount	Very	An extreme amount
2	Satisfaction with your overall or general Health?	1	2	3	4	5

The following questions ask about **how much** you experience certain things**. Consider how important it is to experience these things during your journey of mental health recovery**.

	How important, during mental health recovery, is it to …	Not at all	A little	A moderate amount	Very much	An extreme amount
3	Not have physical pain preventing you from doing what you need to do?	1	2	3	4	5
4	Not need any medical treatment to function in your daily life?	1	2	3	4	5
5	Enjoy life?	1	2	3	4	5
6	Feel your life to be meaningful?	1	2	3	4	5
7	Concentrate well?	1	2	3	4	5
8	Feel safe in your daily life?	1	2	3	4	5
9	Have a healthy physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience **or** are able to do certain things.
Consider how important it is to experience these things during your journey of mental health recovery. Circle the number that best fits your experience:

	How important is it to …	Not at all	A little	A moderate amount	Very much	Extremely
10	Have enough energy for everyday life?	1	2	3	4	5

11	Be able to accept your body appearance?	1	2	3	4	5
12	Have enough money to meet your needs?	1	2	3	4	5
13	Have information for your day-to-day life available to you?	1	2	3	4	5
14	Have the opportunity for leisure activities?	1	2	3	4	5
15	Be mobile and get around physically?	1	2	3	4	5
11	Be able to accept your body appearance?	1	2	3	4	5
12	Have enough money to meet your needs?	1	2	3	4	5
13	Have information for your day-to-day life available to you?	1	2	3	4	5
14	Have the opportunity for leisure activities?	1	2	3	4	5
15	Be mobile and get around physically?	1	2	3	4	5

The following questions ask about **how good or satisfied** you feel about aspects of your life.
Consider how important it is to experience these things during your journey of mental health recovery:

	How important is it to …	Not at all	A little	A moderate amount	Very much	Extremely
16	Be satisfied with your sleep?	1	2	3	4	5

17	Be satisfied with your ability to perform your daily living activities?	1	2	3	4	5
18	Be satisfied with your capacity for work	1	2	3	4	5
19	Be satisfied with yourself?	1	2	3	4	5
20	Be satisfied with your personal relationships?	1	2	3	4	5
21	Be satisfied with your sex life?	1	2	3	4	5

	How important is it to …	Not at all	A little	A moderate amount	Very much	Extremely
22	Be satisfied with the support you get from your friends?	1	2	3	4	5
23	Be satisfied with the conditions of your living place?	1	2	3	4	5
24	Be satisfied with your access to health services?	1	2	3	4	5
25	Be satisfied with your transport?	1	2	3	4	5

The following question refers to **how often** you feel or experience certain things. **Consider how important it is to experience these things during your own personal journey of mental health recovery.**

	How important is it to …	Not at all	A little	A moderate amount	Very much	Extremely
27	Be able to meet the expectations placed on you?	1	2	3	4	5

PART B - National Questions

The following question asks about **how good or satisfied** you feel about various aspects of your life. **Consider how important it is to experience these things during your experience of mental health recovery.**

	How important is it to …	Not at all	A little	A moderate amount	Very much	Extremely
28	Feel respected by others?	1	2	3	4	5
29	To be able to manage personal difficulties	1	2	3	4	5

The following questions ask **how much** you experience certain things during your journey of mental health recovery.

	How important is it to …	Not at all	A little	A moderate amount	Very much	Extremely
30	Have feelings of belonging?	1	2	3	4	5
31	To feel you have control over your life?	1	2	3	4	5

Please answer the below questions, by ticking which answer best fits where you are at the moment. Please let us know why this answer fits your situation at the moment.

1. When you think about your future... do you think that recovery or having a better life is **impossible** for you?

Yes ☐ No ☐

Comment: _____

2. Have you ***just started*** thinking about the possibility of recovery?

Yes ☐ No ☐

Comment: _____

3. Would you say that you have **just started working on plans** towards your recovery?

Yes ☐ No ☐

Comment: _____

4. Would you say that even though you are actively pursuing goals, that you ***have a way to go*** before you feel you can say you are recovered?

Yes ☐ No ☐

Comment: _____

5. When you think about your future do you feel a sense of contentment and happiness that **you can continue to achieve the things that you want?**

Yes ☐ No ☐

Comment: _____

THANK YOU FOR YOUR HELP ☺

About You

Please mark or tick the answer that best fits you or fill in the answer in the space provided:

Are you (please tick): □ Male □ Female or □ LGBT / other: _____

□ Person currently in recovery from addiction or mental illness □ Peer Support worker

□ Mental Health Support Worker □ Family Member of someone recovering from mental illness

□ Clinical or DHB staff member □ Other: _____

If staff: what type of service do you work for? If client: who is your main service provider?

□ NGO Type: _____ □ Clinical / DHB □ Peer □ Other _____

Please mark your age group: □ 18-20 □ 21-30 □ 31-40 □ 41-50 □ 51-60 □ 61-70 □ 71 or above

Which ethnic group do you belong to? Tick the option or options that most apply to you.

□ New Zealand European	□ Māori	□ Samoan
□ Cook Island Māori	□ Tongan	□ Niuean
□ Chinese	□ Indian	□ European
□ Korean	□ Other, please state: _____	

What is the highest level of education you have <u>completed</u>?

Primary school □ Secondary school □ Technical College □ University Degree □

Certificate course □ Diploma course □ Other: _____

What is your marital status?

□ Single □ Married □ Separated □ Widowed □ Living as married □ Divorced

What is your current employment status?

□ Full-time work □ Part-time work □ Retired □ Student □ Unemployed

□ On leave /sick leave □ Own household work □ Other: _____

If you are not receiving services have you experienced mental illness in the past? □ Yes □ No

Please answer – if you are currently recovering from mental illness:

What is the mental health diagnosis / diagnoses you have been given: [Tick any or write below]

□ Mood Diagnosis [e.g., Depression / Anxiety / Bipolar Disorder] □ Psychosis (e.g., Schizophrenia)

□ Personality Diagnosis □ Addiction □ Other: _____

Are you also recovering from alcohol or drug addiction: □Yes □ No **or the past?** □Yes □No

Do you also have a GP diagnosed physical health condition/s? □ Yes □ No

If you answered yes, please name: _____

Appendix I

Phase 1 Recovery Determinants and Definitions

Inner strength	[Feeling strong on the inside and being able to draw on this when I need to.]	**Purpose**	[Having a reason for what I am doing in my life that is important to me.]
Culture / Ethnicity	[Connection to my culture or cultural identity.] e.g., through beliefs, interests, cultural services, family, other people of my culture, or community activities.	**Social networks**	[Having different groups of people as friends, contacts or supports.]
Recovery progress	[Being able to look back and see I have made progress.] Recognising how far I have come from the past. Moving forward or closer to where I want to be in my life.	**Collaboration** **Or** **Partnership**	[Working with others to achieve my recovery.] Could be from services working together to help me recover. Services working with my family and me. Or me as part of a team with services.
Personal Worldview	[Having my own way of seeing things that helps my recovery.]	**Self-care / self-nurturing**	[Being able to take good care of myself.] Making sure my health, mind, feelings, body, and wellbeing are cared for.

People skills	[Being able to get along with others.] e.g., could involve - asserting myself, managing relationships at work, home, socially, with friends, work mates, or family.	**Legal issues**	[Dealing with courts, judges, police, lawyers, or being under an act of some sort.] Getting legal support or needing it for safety.
Peace of Mind	[A state of peace inside myself, with myself or my life as it is, or has been.] Not worried about things all the time or focussed on my problems, past experiences, or issues.]	**Understanding**	[The experience of understanding] Understanding my illness, feeling understood by others; or the issues I have being understood.]
Engagement	[Active participation in life.] Using services offered, family support, or getting more involved in other parts of life to achieve recovery goals, connect with my life or improve well-being.	**Role Functioning**	[Able to do what I need to do, to maintain important roles in my life.] e.g., parent, family member, worker, friend, student, church goer, team-player…
Exercise	[Physical activity done to get fit or healthy or help my recovery.]	**Time out**	[Time away from all the responsibilities of my life.] Needing to depend on others, withdrawing from my roles or life activities, stopping my life as it is, respite or hospital time.]

Community integration	[Living in and being part of my local community.]	**Structure**	[Having a regular daily routine or weekly plan that helps me to feel stable.]
Peer support	[Support from people who have experienced mental illness or addiction.]	**Positive experiences**	[Fun, enjoyment, laughter, good times, being able to live my positive values and enjoy my hobbies and interests in life, feel happy.]
Spirituality	A personal belief, set of values or inner experiences, that helps me to see the bigger picture, transcend what is happening, and maintain my recovery.] Could be through religion or other practices, values, or beliefs you call spiritual.	**Hope**	[Able to believe solutions or positive changes will happen in the future.] Having an optimistic view of my future; believing recovery is possible.]
Self Help	[Taking responsibility for my own recovery and helping myself more.] Learning how to rely on myself more independently or use self-help tools.	**Political Activism**	[Taking action in the system to change things for myself or other people recovering from mental illness or addiction.] Advocacy for self/others.

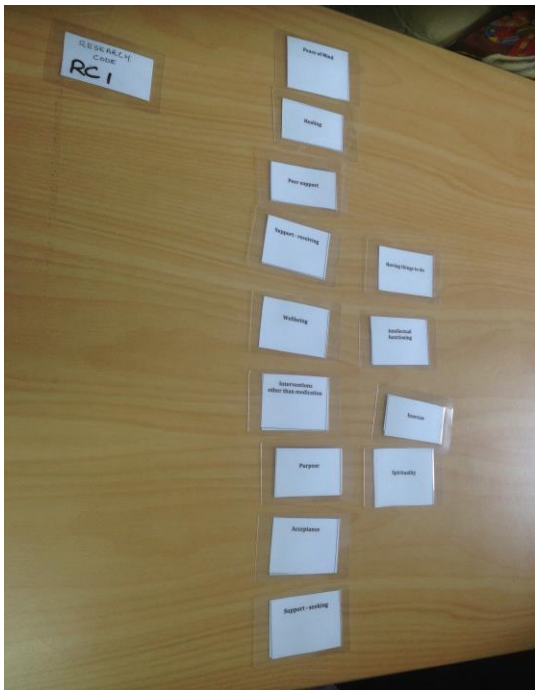
Having things to do	[Activities to keep me busy so I don't get bored and can keep myself active.]	**Recognising Strengths**	[Being able to see strengths that help me move forward or recover]. Other people recognising or showing me my strengths and abilities.
Recovery readiness **or determination**	[Being ready to make changes or work towards my recovery.] Being determined to recover and do whatever it takes.	**Self-Awareness**	[Recognising thoughts, feelings or patterns of coping that are helpful to my recovery or that keep me stuck or create problems for me in life.]
Intellectual functioning	[Concentration, able to use my mind to problem solve, or think through things, when I need to.]	**Interventions other than medication**	[Things that help my recovery that are not related to medication or medical services.] [e.g., therapies, groups, work support, social support, practical help, etc.]
Personal Growth **or Change**	[Feeling I am developing, growing, discovering who I am or changing as a person.] I know myself more, am more able to do things I used to find difficult or have grown out of old ways of feeling or thinking.	**Unmet needs**	Important things necessary for survival are restricted by a certain life situation. [e.g., food & water, shelter, clothing, healthcare, safety, relationships, money, freedom, etc.]

Wellbeing	[A sense of being well within myself.]	**Acceptance**	[Turning point in how I see myself, my illness or my symptoms that helped.] Able to adjust to, accept, or adapt to things I can't change.] Letting go, to move forward.
Stigma / Discrimination	[Feeling people judge me, see me as less able to do things, or are nervous about me, because of my history or current experiences of mental illness.]	**Support - receiving**	[Being able to get support when I need it.] The support I get from others is important to my recovery.
Social acceptance	[People I meet that make me feel like they accept me as I am.] Ways they talk to me or involve me in things, like there is no difference between me and others.	**Illness Symptoms**	[Experiences my illness brings that gets in the way of my recovery.] e.g., voices, mood swings, tiredness, certain beliefs, or thoughts that concern me or others, fears, highs …]
External factors	[Experiences of life not directly related to my illness or health services I receive.]	**Self-Direction or Self-determination**	[My life and my future is my own to make decisions and choices about.] Self Determination.

Support - seeking	[Being able to ask for help and knowing when to get help when I need it.]	**Goals**	[Having plans and things to work towards for the future.] Could also be a vision for the future that I want to achieve or changes I am planning to make.
Access to resources	[Able to find or get what I need to support my recovery.] Could be services, information, ways to change, opportunities to do things, support, ways to meet needs or achieve goals, etc.	**Non-patient identity**	[No longer thinking of myself as someone with a diagnosis or illness. Having a positive sense of self.] Others see me as a person with other roles in life more than a patient or a person with this illness.
Health System issues	[The way the health system is and works.] Being in a health system, being affected by the services or the health system.	**Self-Trust**	[Being able to believe in myself and trust myself at a deeper level.] Knowing I can trust my mind, emotions, or thoughts. I can trust myself to manage my life & future.
Self-Stigma	Seeing myself as less of a person or socially rejectable because I have a mental illness or addiction, even if others don't, or say I am not.	**Healing**	Old hurts, trauma, or relationships are no longer getting in the way of my life or happiness or don't cause the same pain they used to.

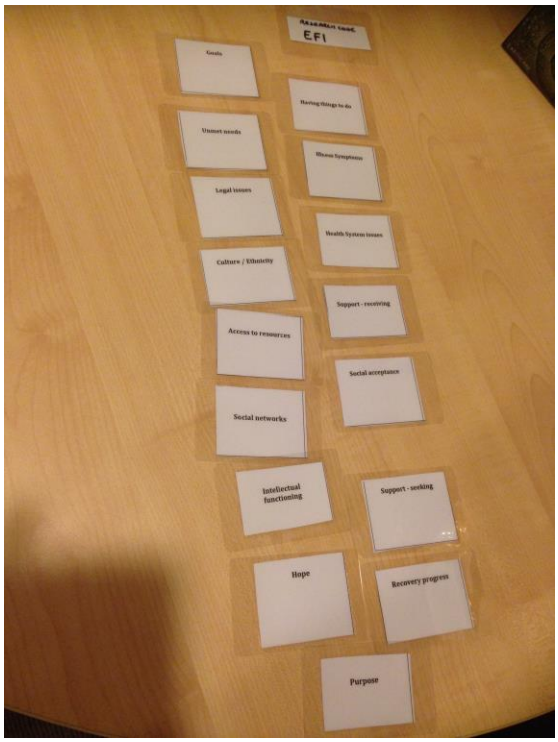
Appendix J

Phase 1 Importance Exercise Examples

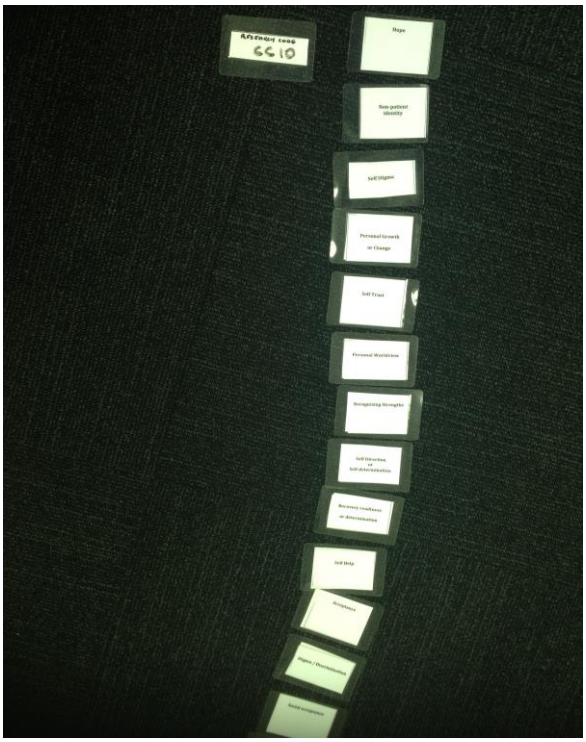


Lived experience (late recovery).

Lived experience (early recovery – residential rehab).



Recovery supporter – family member.



Recovery supporter – staff.

Appendix K

Phase 1 NZ WHOQOL-BREF Facet Descriptors

Question No.	Quality of Life Facet	Facet Descriptor
1	Overall Quality of Life	A person's general perception of their overall quality of life
2	Overall Physical Health	A person's general perception of their overall physical health
3	Pain and Discomfort	Explores unpleasant physical sensations experienced by a person and, the extent to which these sensations are distressing and interfere with life. The assumption is made that the easier the relief from pain, the less the fear of pain and its resulting effect on quality of life. Even when a person is not actually in pain, either through taking drugs or because the pain is by its very nature on and off (e.g., migraine), his/her quality of life may be affected by the constant threat of pain. It is acknowledged that people respond to pain differently, and differing tolerance and acceptance of pain is likely to affect its impact on quality of life. Unpleasant physical sensations such as stiffness, aches, long-term or short-term pain, or itches are included. Pain is judged to be present if a person reports it to be so, even if there is no medical reason to account for it.
4	***Dependence on medication or treatments***	Originally in the Levels of Independence domain. This facet explores a person's dependence on medication or alternative medicines (such as acupuncture and herbal remedies) for supporting his/her physical and psychological well-being. Medications may in some cases affect a person's quality of life in a negative way (e.g., side-effects of chemotherapy) whilst in other cases it may enhance the person's quality of life (e.g., cancer patients using pain killers). Medical interventions that are not pharmacological but on which the person is still dependent, for example a pacemaker, artificial limb or colostomy bag are included.
5	Positive Feelings	Examines how much a person experiences positive feelings of contentment, balance, peace, happiness, hopefulness, joy, and enjoyment of the good things in life. For many respondents, this facet may be regarded as synonymous with quality of life. Negative feelings are not included as these are covered elsewhere.
6	***Spirituality/religiousness and /personal beliefs*** -	This facet was originally a domain by itself. It examines the person's personal beliefs and how this affects quality of life. This might be by helping the person cope with difficulties in his/her life, giving structure to experience, ascribing meaning to spiritual and personal questions, and more generally providing the person with a sense of well-being. For many people religion, personal beliefs and spirituality are a source of comfort, well-being, security, meaning, sense of belonging, purpose, and strength. However, it is acknowledged that some people feel that religion has a negative influence on their life.
7	***Thinking, learning, memory, and concentration***	Explores a person's view of his/her thinking, learning, memory, concentration, and ability to make decisions. It is acknowledged that some people with cognitive difficulties may have no insight into their difficulties, and in these cases proxy evaluations may be a necessary addition to the person's subjective evaluation. A similar problem may be a reluctance to admit to problems in this area among some respondents.
8	Physical Safety and Security	Explores the person's sense of safety and security from physical harm. A threat to safety or security might arise from any source such as other people, political oppression or the availability of "resources"

		which protect or might protect his/her sense of safety and security. As such this facet is likely to bear directly on the person's sense of freedom. This facet is likely to have particular significance for certain groups, such as victims of disasters, the homeless, people in dangerous professions, relations of criminals, and victims of abuse. The discussion is on a person's own perception of how safe or secure they feel in their environment and the effect on their quality of life. The feelings of those who might be seriously mentally ill and perceive that their safety is threatened by "being persecuted by aliens", for example are not included.
9	***Physical environment, pollution, / noise, / traffic/, climate***	Examines the person's view of his/her environment. This includes the noise, pollution, climate, and general aesthetic of the environment and whether this serves to improve or adversely affect quality of life. In some cultures, certain aspects of the environment may have a very particular bearing on quality of life, such as the central nature of the availability of water or air pollution. This facet does not include *home environment* or t*ransport* as these are covered in separate facets.
10	***Energy and fatigue***	Explores the energy, enthusiasm, and endurance that a person has to perform the necessary tasks of daily living, as well as other chosen activities such as recreation. This may extend from reports of disabling tiredness to adequate levels of energy, to feeling really alive. Tiredness may result from any one of a number of causes, for example illness, problems such as depression, or over-exertion. The impact of fatigue on social relationships, the increased dependence on others due to chronic fatigue and the reason for any fatigue are beyond the scope of questioning, although they are implicit to the questions in this facet and facets concerned specifically with daily activities and interpersonal relationships.
11	***Body image and appearance***	Explores the person's view of his/her body. The discussion is on the person's satisfaction with the way he/she looks and the effect it has on his/her self-concept. How others respond to a person's appearance is likely to affect the person's body image very considerably and it is important that respondents to answer how they really feel rather than how they feel they should respond.
12	Financial Resources	Explores the person's view of how his/her financial resources (and other exchangeable resources) and the extent to which these resources meet the needs for a healthy and comfortable lifestyle. What the person can afford or cannot afford and any sense of satisfaction/dissatisfaction with those things that the person's income enables them to obtain will affect quality of life. It is acknowledged that a person's perspective on financial resources as "enough", "meeting my needs", etc. is likely to vary, regardless of the respondent's state of health or whether or not the person is employed.
13	***Opportunities for acquiring new information and skills***	Explores a person's perceived opportunity and desire to learn new skills, acquire new knowledge, and feel in touch with what is going on. The discussion is on a person's perceived ability to fulfil any need for information and knowledge whether this refers to knowledge in an education sense, or to local, national, or international news that has some relevance to that person's quality of life. It is assumed that the question will be interpreted by respondents in ways that are meaningful and relevant to their position in life.
14	***Participation in and opportunities for recreation and leisure***	Explores a person's ability, opportunities, and inclination to participate in leisure, pastimes, and relaxation. This includes all forms of pastimes, relaxation, and recreation; this might range from seeing friends, to sports, to reading, to watching television or spending time with the family, to doing nothing.

15	Mobility	Originally in the Level of Independence domain and explores the person's view of his/her ability to get from one place to another, to move around the home, move around the workplace, or to and from transportation services. The discussion is on the person's general ability to go wherever he/she wants to go without the help of others regardless of the means used to do so. The assumption is made that wherever a person is dependent to a significant extent for his/her mobility on another person this is likely to affect quality of life adversely. A person's impairment does not necessarily affect his/her mobility. So, for example someone using a wheelchair or walking frame may have satisfactory mobility in an adequately adapted home or workplace. Nor does this facet include transportation services (e.g., car, bus) as this is covered in a separate facet (Transport).
16	Sleep and Rest	This is concerned with the effect of sleep and rest, and problems in this area, on the person's quality of life. Sleep problems might include difficulty going to sleep, waking up during the night, waking up early in the morning and being unable to go back to sleep and lack of refreshment from sleep. The facet's discussion is on whether sleep is disturbed or not; this can be for any reason, either to do with the person or to do with the environment. Specific aspects of sleep such as waking up early in the morning or whether or not a person takes sleeping pills are not included. The question of whether a person is dependent on substances (e.g., sleeping pills) to help him/her sleep is covered in a separate facet.
17	Activities of Daily Living	Originally in the Levels of Independence domain and explores a person's ability to perform usual daily living activities. This includes self-care and caring appropriately for property. The discussion is on a person's ability to conduct activities, which he/she is likely to need to perform on a day-to-day basis. The degree to which people are dependent on others to help them in their daily activities is also likely to affect their quality of life. Aspects of daily living are covered in other areas; namely, specific activities affected by fatigue, sleep disturbances, depression, anxiety, mobility, and so on.
18	Capacity to Work	This facet was taken from the facet, originally in the levels of independence domain. This facet examines a person's use of his or her energy for work. "Work" is defined as any major activity in which the person is engaged. Major activities might include paid work, unpaid work, voluntary community work, full-time study, care of children and household duties, focusing on a person's ability to perform work, regardless of the type of work. The questions do not include how people feel about the nature of the work that they do, nor do they include the quality of their work environment.
19	Self Esteem	Explores how people feel about themselves. This might range from feeling positive about themselves to feeling extremely negative about themselves. To some people self-esteem depends largely on how they function, whether at work, at home or how they are perceived and treated by others. In some cultures, self-esteem is the esteem felt within the family rather than individual self-esteem. It is assumed that questions will be interpreted by respondents in ways that are meaningful and relevant to their position in life. Influences of body image and social relationships on self-esteem are covered in different areas. However, the sense of self-worth that comes from these areas is intended to be covered at a more general level. It is acknowledged that some people may find self-esteem difficult to

		talk about, attempts to take this into account.
20	Personal Relationships	Explores the extent to which people feel the companionship, love, and support they desire from the intimate relationship(s) in their life. This includes the ability and opportunity to love, to be loved and to be intimate with others both emotionally and physically. The question includes how much satisfaction a person gets from or has problems managing the burdens of caring for others. The possibility of this being both a positive as well as a negative experience is implicit to the facet. This facet addresses all types of loving relationships, such as close friendships, marriages and both heterosexual and homosexual partnerships.
21	Sexual Activity	Concerns a person's urge and desire for sex, and the extent to which the person is able to express and enjoy his/her sexual desire appropriately. Sexual activity and intimacy are for many people intertwined. In some cultures, fertility is central to this facet, and childbearing is an extremely valued role is likely to be interpreted in these terms in these cultures. Thus, the person's sexual orientation, sexual practices or value judgements towards sex are not seen as important in and of themselves: rather it is the desire for, expression of, opportunity for and fulfilment from sex that is the discussion of this facet. It is acknowledged that sexual activity is difficult to ask about, and it is likely that responses to this question in some cultures may be more guarded. It is further anticipated that people of different ages and different gender may respond differently. Some respondents may report little or no desire for sex without this having any adverse effects on their quality of life.
22	Social Support	Explores how much a person feels the commitment, approval, and availability of practical assistance from family and friends. The discussion is on how much the person feels he/she has the support of family and friends, in particular to what extent he/she might depend on this support in a crisis. The potentially negative role of family and friends in a person's life, such as verbal and physical abuse, may affect responses to this question.
23	***Home environment***	Examines the principal place where a person lives (and, at a minimum, sleeps and keeps most of his/her possessions), and the way that this impacts on the person's life. An individual may assess their home environment both, based on being comfortable and affording the person a safe place to reside and the quality of the immediate neighbourhood around the home. Other areas which are included implicitly are: crowdedness; the amount of space available; cleanliness; opportunities for privacy; facilities available (such as electricity, toilet, running water); and the quality of the construction of the building (such as roof leaking and damp). The question is phrased to include people who do not live in one place with their family, such as refugees, or people living in institutions. It would not usually be possible for homeless people to answer this question meaningfully.
24	Health and Social Care – availability and quality	This facet examines the person's view of the health and social care in the near vicinity. "Near" is the time it takes to get help and ease/difficulty in reaching local health and social services and access for friends and relatives to these facilities. This includes how the person views the availability of health and social services, which may include volunteer community support (religious charities, temples, etc.), which either supplement or may be the only available health care system in the person's environment, as well as the quality and completeness of care that they receive or

		expect to receive should these services be required.
25	Transport	This facet explores the person's view of how available or easy it is to find and use transport services to get around. This may include any mode of transport that might be available to the person (bicycle, car, bus...) and how affects the person performing the necessary tasks of daily life as well as the freedom to perform chosen activities. Means to get around in the home itself are not included or personal mobility of the individual is not included because this is covered elsewhere (*Mobility*).
26	Negative Feelings	Investigates how much a person experiences negative feelings, including despondency, guilt, sadness, tearfulness, despair, nervousness, anxiety, and a lack of pleasure in life. The question is framed to include people with quite disabling psychological difficulties such as severe depression, mania, or panic attacks. The effect of poor concentration and the relationship between negative affect and the person's social relationships are covered elsewhere. Detailed assessment of the severity of the negative feelings is not included.
27	Meeting the expectations of others	Refers to the ability to meet the expectations placed upon a person by family, friends, community, social and workplace contacts with whom the person identifies with and values. They may be physical or mental. The expectations are those perceived by the individual as being ones they should fulfil whether fair or unfair. The expectations need not be explicitly documented or communicated but are also be those that the person feels are expected of them in their various roles and circumstances in their culture.
28	Respected by others	Explores how an individual feels they are seen and valued by others This item resembles the NZ Māori concept of Mana; this concept includes the concepts of prestige, authority, status, and charisma and is connected to how much an individual perceives themselves to be regarded well by others they value.
29	Manage personal difficulties	Explores an individual's ability to manage both day to day problems and wider longer-term challenges. It explores an individual's estimate of their personal resourcefulness and ability of these to meet the difficulties they believe they are facing. These personal difficulties may relate to health directly or be health related issues. The essence of the question is the person's confidence and capability to organise and plan to contain and overcome the problems they face.
30	Feelings of belonging	This facet is correlated with the social domain. It mirrors the NZ Māori concept of Whānau. While this term initially referred to family or those connected to family members, but in the modern context the term also includes friends and groups The perception the person has is one of comfort and security in believing that there is someone or a group who accepts them for who they are, the person believes, identifies, and feels they are a part of that group. Examples include religious groups, clubs, or a team which the person wants to be part of.
31	Control over your life	Explores an individual's perceived ability to take charge of their life and to decide for themselves those objectives and activities that they wish to pursue. Taking a decision for themself does not discount listening to the advice and guidance of others. The mind-set is of a person who believes that what they do in life is up to themself and not dependent on others.

Appendix L

Phase 1 Code Book

Figure L1

Code Book Home Screen that Coders Used to Select a Tape to Code

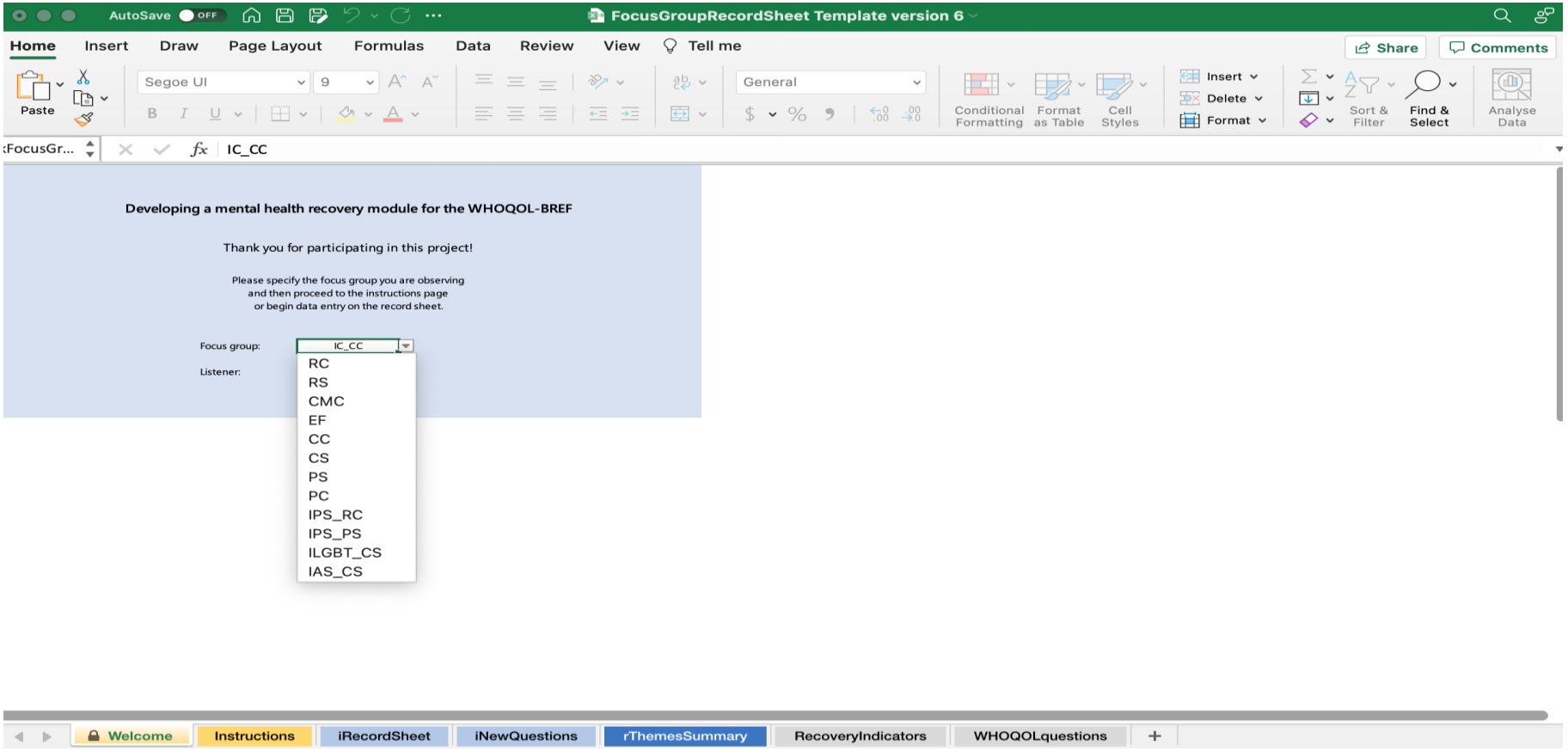


Figure L2

Instructions for Coders

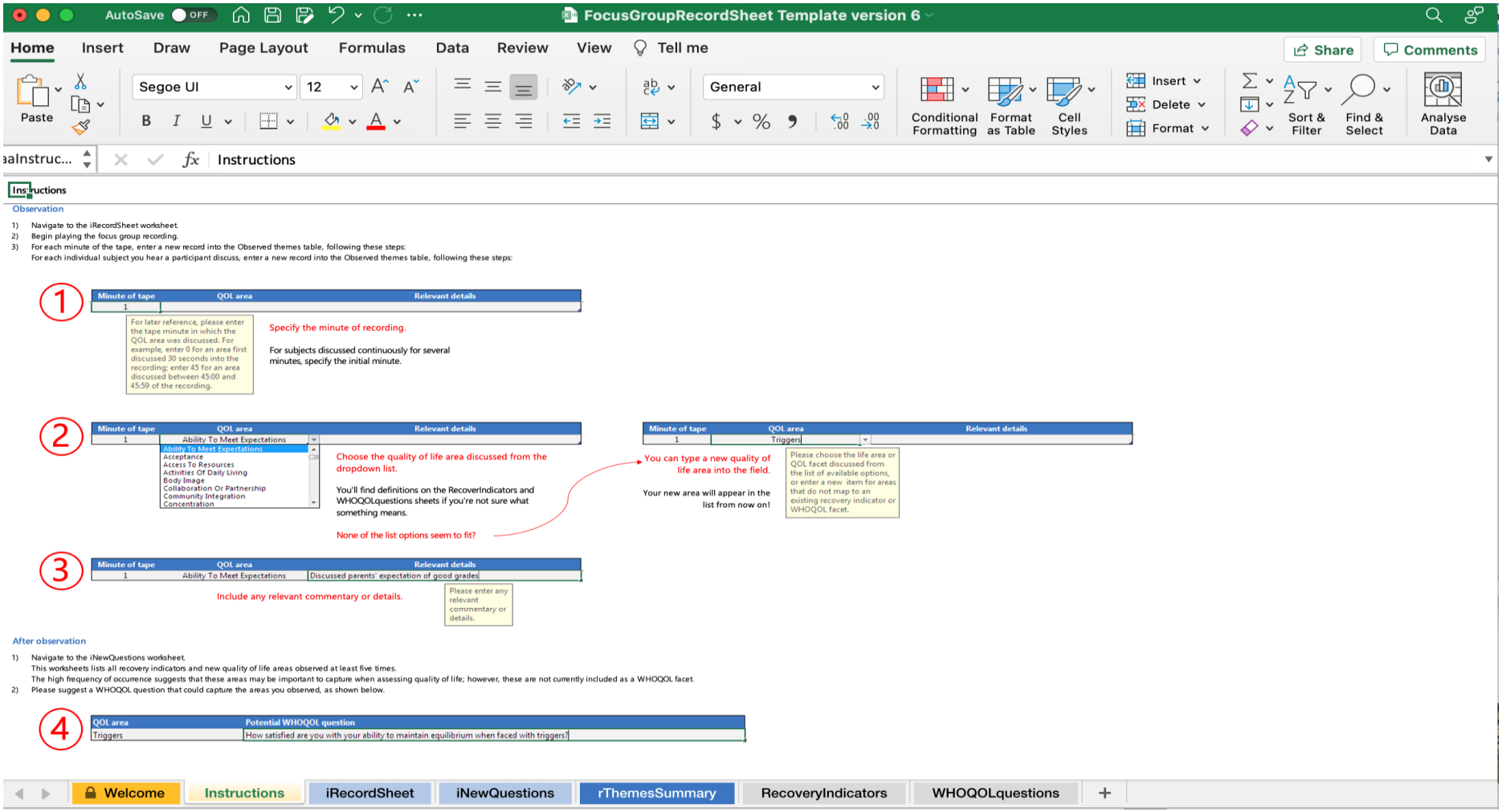


Figure L3

Code Book Record Sheet

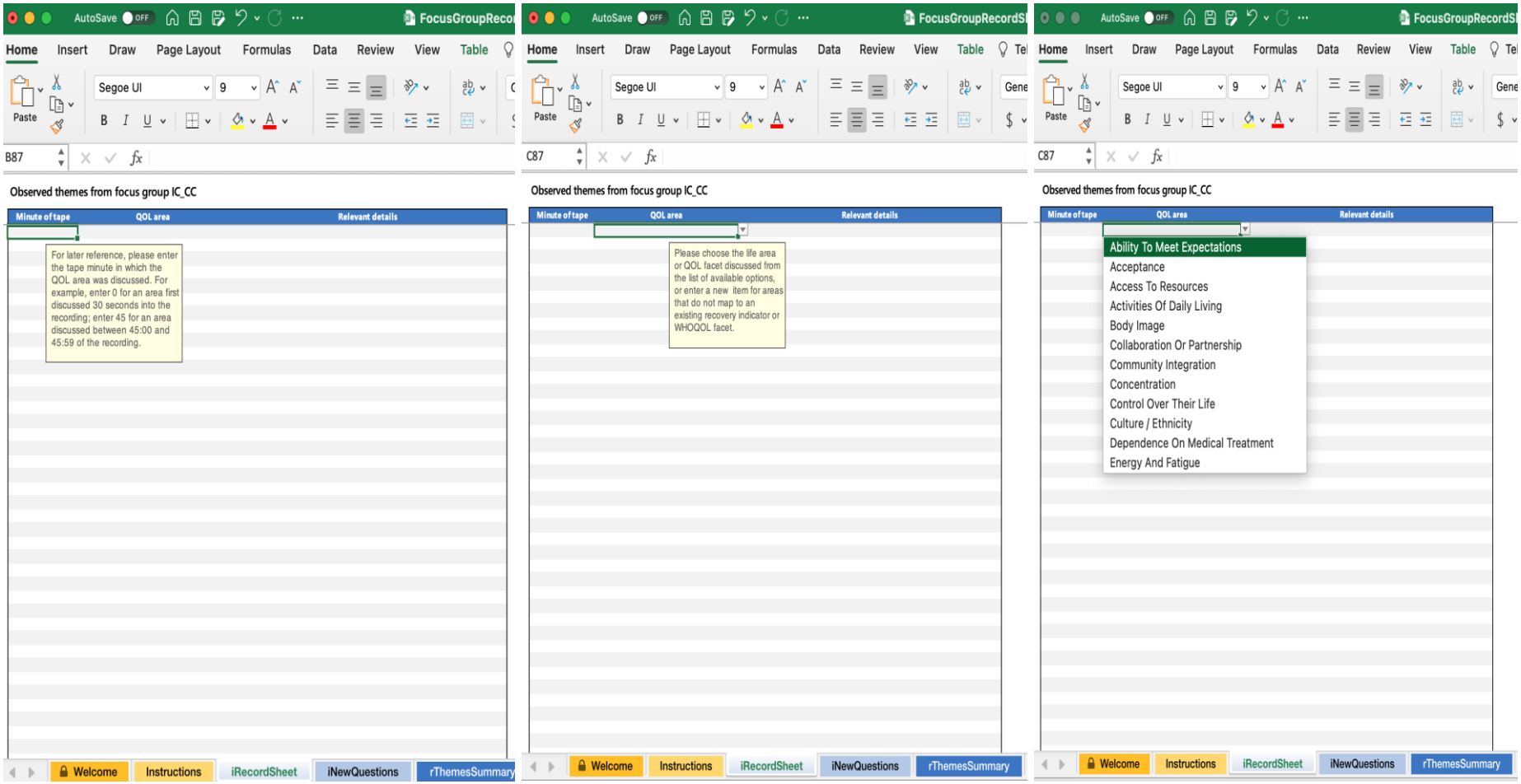
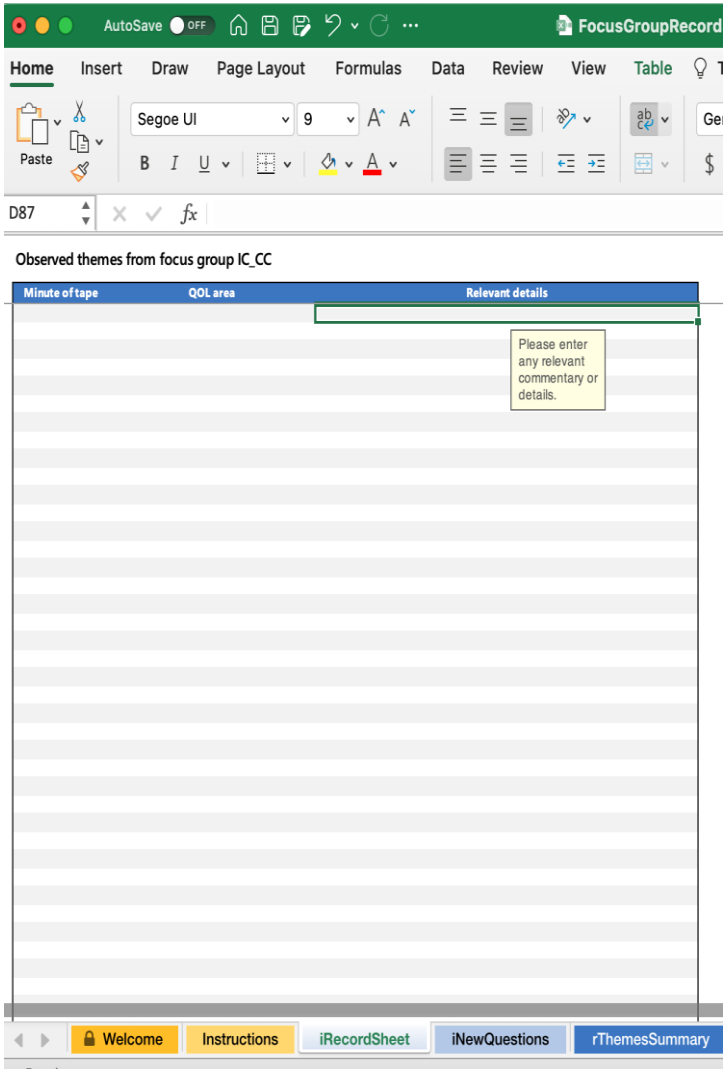
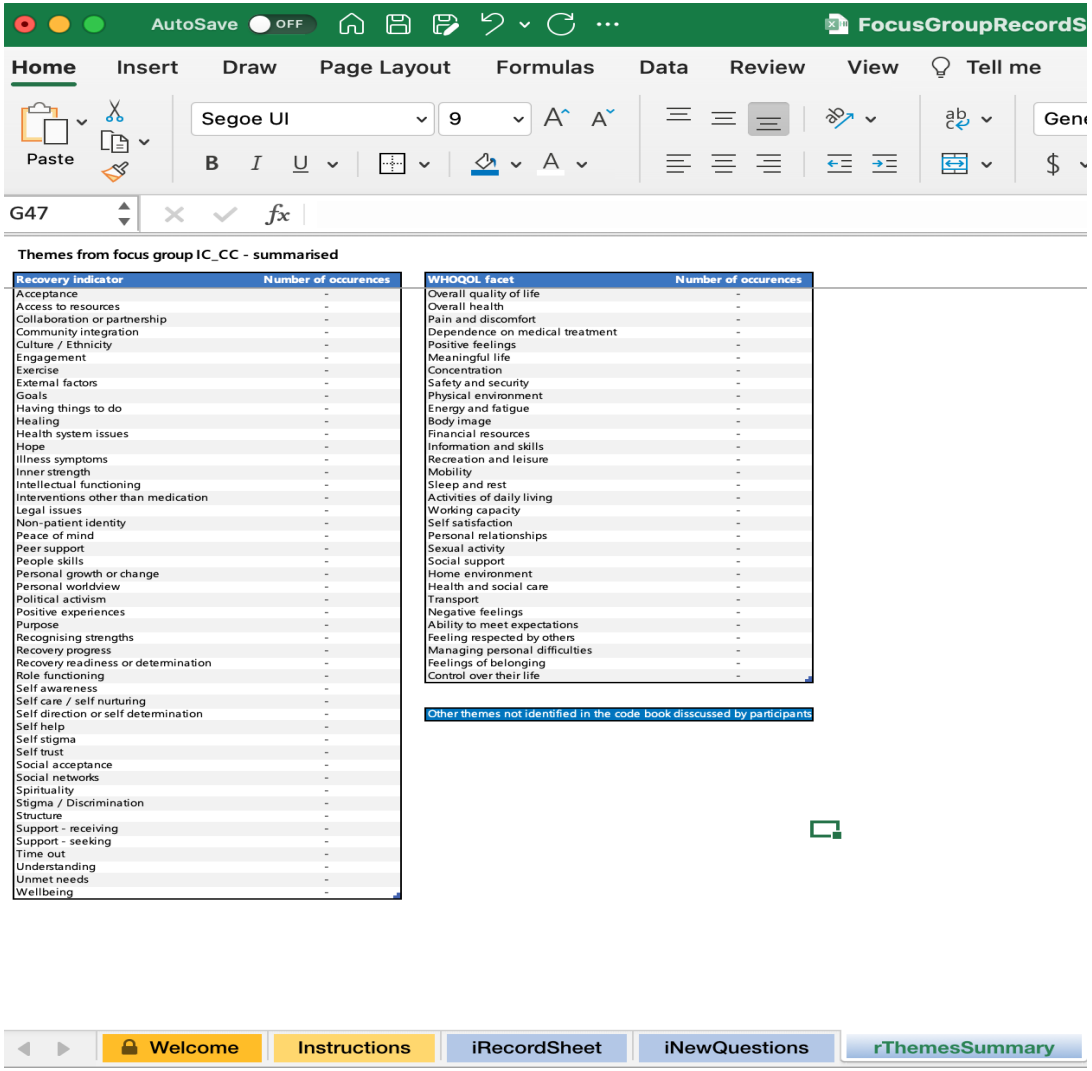


Figure L4

Example of Frequency Calculation of Codes Identified within Each Discussion Group





Appendix M

Participant Quotes for Residual MHRQoL Candidate Items

The residual candidate items identified in the discussion groups that could be considered part of 'mental health quality of life' due to meeting the classical test theory (CTT) criteria in Phase 2 are discussed in this appendix. The dissatisfying aspect of the candidate item is discussed first, followed by quotes exampling these. The satisfying aspects of the candidate item are then given, followed by quotes as examples. This is to provide a sense of the continuum of each MHRQoL item and how it impacted both positively and negatively on people's QoL. The candidate items asking about: (1) goal achievement; (2) one form of the hope question asking about a positive future; and (3) spirituality are also included in this section – despite not meeting either CTT or Rasch criteria due to the relevance of the underlying themes to MHRQoL reported in the literature (hope, spirituality) and individualised recovery planning (goals) that is part of outcome evaluation reported in the literature.

The first candidate item that will be discussed – stigma and discrimination - is an experience that affected many facets and domains asked about in the WHOQOL-BREF. This candidate item is discussed more fully than other candidate items to examine the social consequences of mental health issues; mental health issues do not just affect an individual's QoL on a personal or subjective level. The QoL of people with mental health and addiction problems is also negatively impacted by the socio-cultural context surrounding them during their recovery. This social context can create further barriers to their recovery and make the reclaiming of their lives and quality of their lives more challenging. Participants felt that the stigma they experience is less common for people recovering from other health problems. Stigma has been noted to be present for people recovering from other health issues, such as

HIV (Chambers et al., 2015), dementia (Spittel et al., 2019) and disabling conditions such as intellectual disability (Pelleboer-Gunnink et al., 2019).

M.1 Stigma, Discrimination

The Merriam-Webster dictionary defines stigma as “a mark of shame or discredit” (n.d.). Stigma has been noted to have three ways of being experienced: (1) through prejudice; (2) by stereotypes; and (3) through discrimination (Rössler, 2016). It can have a negative impact upon people’s capacity to find work, access health care, obtain housing, build, and maintain supportive relationships, maintain family relationships and to experience the same civil and legal rights as people without mental health and addiction problems (Collins et al., 2012; Gordon et al., 2017; Parcesepe et al., 2012; Stuart, 2016).

The literature review section described how mental illness became a stigmatised health condition through the ways in which it was initial conceptualised and treated by removing people from society and placing them into lifelong care within institutionalised asylum facilities (Stuart, 2006). Stereotypes have been maintained by portrayals in the media of people with mental health problems being associated with out of control, criminal, dangerous or violent states and behaviours typically modelled by fearful, rejecting, or demoralising responses from others (Stuart, 2006).

Stigmatised attitudes and behaviours can also be demonstrated by healthcare professionals in the mental health system (Rössler, 2016). Internalised stigma refers to when a person looks at themselves with shame, and feels as if they are not the same as other people, or are no longer an acceptable member of society, due to internalising the stigmatised attitudes, prejudicial, and discriminatory behaviour of the society around them towards mental illness or addiction problems (Collins et al., 2012; Rössler, 2016; Stuart, 2016; Thornicroft et al., 2009). Experiences of stigma may therefore be revealed by dissatisfaction with many quality-of-life facets within the WHOQOL-BREF and has been consistently

correlated with reduced QoL for people diagnosed with mental illness (Lourenco, 2007; Parcesepe et al., 2012; Stuart, 2016).

Stigma was more often discussed as a negative experience than having any positive consequences for people within the discussion groups; although positive stigma can exist for people with mental illness (Thornicroft et al., 2016). Within the discussion groups, participants described experiences of stigma and discrimination in different ways. Participants explained that they had noticed different types of stigmas can be experienced, depending upon your mental health diagnosis or addiction issue.

> AE: “My understanding of stigma and discrimination is that they have the same levels but very different types of stigmas and discrimination. So, you know with depression what it's like, you're lazy and your kind of hopeless and you are kind of weak and that kind of thing. Whereas with psychosis, you're kind of violent and that kind of thing. It's different stereotypes really. …. stigma is stereotypes, negative beliefs about people with experience of mental illness / mental distress ... and prejudice, as agreement with the stereotypes, leading to negative emotions. Then discrimination is the unfair treatment.”

> RCI: “I think that people, people worry, especially if you say you're hearing voices or something like that, they worry that there could be the possibility that he could be a danger to someone else, and that kind of thing. But that's not, really a reality. I mean, you're much more likely to be a victim of crime, if you have a mental illness, and hear voices, than you are to be a perpetrator of crime. And I don't think the general public understand that. And I mean, myself, when I see someone down the street who's yelling at voices or something like that, you know, it's kind of like you think, "Whoa. That person's really going through a rough time." Usually, I know them, and I can go and say, "Hi." But, if I didn't know them, I would be scared and I would want to keep my children safe. I'd be the same, you know, so ...”

> PC1: “… people are coming out. I was able to say for myself that I actually identify myself as an AoD user. I didn’t realise there was a difference between AoD and mental health, and I was like, whoa …That’s the stigma they are talking about. We get the same sort of stigma as being an AoD user, like: “why can’t you just stop?”

Participants spoke about feeling the whole of society had stigmatised them because of the type of health issue they had (mental health or addiction problems). This they spoke of as being unjust and being more unique to mental illness, compared to the social responses given to people recovering from other health problems.

PC3: “I think a big one is that; it is a lot better now, but I think it still exists quite a lot is stigma and discrimination. And that we are different. Whereas if you have diabetes, you are type 1 you get insulin, type 2 a diet sort of thing. But if you have a mental illness, you are labelled as an, *other*, and hopefully not, but a lot of us used to be. You are like in a box, you know. I prefer that I am a citizen of society, and as mentioned earlier, that I am already equal.”

CM1: “I don’t use the term mental illness just sexual abuse. That in itself is a stigma, with friends and family, that kind of makes me feel very guilty, for being a victim.”

RCG1: “Why do people get antisocial when you’ve got a mental illness, it is because everything that’s said about them isn’t true…”

CM1: “Stigma attached to mental health; it would be great if they could change those names. If you stay in the room and you watch TV and it comes on that someone with mental health has just murdered somebody, and you think everyone is looking at you because you are mentally incapacitated, they think that you might do something like that, that is what I think when people look at me. I wouldn’t hurt a fly, but they don’t know that. They just thing you are a mental person. So yes, it would really help if that could change.”

KILGBT: “I mean yeah, people, by nature are social animals and being excluded or not included is a big negative for any of us. Whether it is being accepted or included in our family or rejected from our family because we have come out is being something that happens terribly often. We, we have a recent experience a young transgender woman, at the end of last year, who committed suicide. Absolutely tragic, 22 years old, receiving services from mental health. She took her own life and there is so little acceptance within the family, that at the funeral they refused to use female pronouns or the names that this person had chosen for themselves and went back to the male name that had been given at birth, even though this person had been living, had chosen to live…. for 7 years! Now, that level of unacceptance by the family is horrific. It makes my blood boil – makes me shiver to think how cold and callous those people are, that they couldn’t honour their young person that they buried. And, as a parent, I can’t imagine how difficult it is to bury a child. But they couldn’t honour her chosen, not chosen, nobody ever chooses it – but honour the truth of her life. So, that is evidence of non-acceptance being a really negative influence on a person’s ability to continue living. This person had so much to live for, they were bright, they were going to university, and yet they chose not to continue living.”

PCL4: “You are unacceptably different; you've got a black mark against your name. So, if you've got breast cancer, for instance, there's, Australia, they have probably one of the greatest ever cricketers runs promotions for all of that. And they have, they, when they go to play cricket, they'll have a pink handle. Someone will have pink gloves almost. And were there pink pants on, supporting, you know, breast cancer. Not that I would wish breast cancer on anyone. But when it comes to mental illness there's, you're unacceptably different to the citizenship ideals of the general community, you know, you're different and it's not a good, different, your you're not predictable. They don't understand you know.”

RCG3: “The feeling of not being normal. Feeling isolated and looked upon as something lesser than.”

RCG5: “I agree with that. I feel different, and the people, most people are aware of, …some sort of … I suppose ... there is something wrong with me anyway.”

TC2: “It's less stigma” (*referring to the difference between social responses to physical health problems verse mental health problems)*

YC3: “That's true. And sometimes you can see it (*physical illness*). So, people will take more care if they see you with crutches.”

TC3: “Because people would say to me, "Oh, you don't look like you've got a mental illness." Because I'd say somewhere, "Oh, been through this thing and blah, blah." They're like, "Oh wow, you don't look like that." …

T2: “The stereotypical mad person, and you don't fit?”

T3: “Exactly …”

T2: “And that's the difference, isn't it? Because as much as it's an individual problem, it's a societal problem.”

T3: “Yeah, it is a societal problem.”

T2: “And a broken leg is not. Broken legs are an accident.”

T3: “That’s true.”

WTS: “You tend to lose friends, the friends that see you as normal, now they see you as abnormal, and no longer fitting into their own lives. So, you know, they all backtrack from you. And like I said, in my culture, people don't talk about this openly, and when it's done, it's seen as something very bad. You might hear parents making comments like, "Oh, don't go to that house. There's a mad man there." And the parents would be telling their children, "You can't play with, she's not your friend anymore." And the kids will say, "Oh, mom, why?" "His uncle is a mad man. You can't go to that compound to play anymore." It's that kind of attitude.”

Several participants also discussed stigma and discrimination being intensified by co-existing conditions and their membership in other socially marginalised or minority groups.

KILGBT: “… a lot of transgender people have difficulty finding work and sustaining work…. visibly you might not be so obvious. So, then there’s the…. there’s a degree of you don’t have to be ‘out’ at work if you’re a gay man or woman, you can just be yourself. You can just go to work. If you’re transgendered you are going to look different. The chances are that you are going to stand out from your peers. It might not be a lot but, yeah, you are probably going to stand out and be more noticeable. So, it takes a whole level of, probably more strength and perseverance and self-belief, and that, can be easily knocked and eroded …. there is a massive difference between having a same sex attraction to being someone who is transgender, because same sex attraction isn’t going to make you physically look different. Ok, someone who is transgender very often, …well it is not an easy transition…. differences between, male and female. If you are trying to overcome those, you are trying to be accepted as a female and you’re 6 ft 2” and you got great big broad shoulders and size 12 feet, it’s

> not easy. You know, a jaw like a coal shovel, it's not easy, and you are always going to get looked at. You're always going to get noticed, nobody wants to be noticed. What most transgender people want to do is to go in the woodwork. Is not to be noticed, is just to be who they want to be, within society, without it causing a stir."

> TC2: "And I think for the lesbian, gay, bisexual, transgender community, it's a huge issue of addiction. Because that's how we socialized. It's how we probably still do. You're like, "I'm not in that." I don't go and sit in bars anymore, that much. I have no need to. But for our community, mental health and addiction, huge issues…. because of all the stigmas. So, it's a double whammy. And that's partly also why people are using stuff because you're dealing with the stigma of being queer in a straight society. And when I came out, it wasn't halfway as acceptable or mainstream as it is right now. My generation was better off than the generation before me. You hear some horrific tales. So, it was a way of kind of moving through life and coping with prejudice and discrimination. Which still goes on."
>
> TC3:" It's a triple whammy, really, if you look at it. Because there's the gay and lesbian thing, there's the drugs and alcohol stigma, plus, for people with co-existing, there's a mental health thing. That's a lot for one person. And I'll guarantee, a lot of gay and transgender people have all three."
> TC2: "Oh, totally…. but it's different, I think, certainly it's different at least being gay, because of the stigma. And there's still a stigma. And also, within our community, I meet grave mental health and addiction issues and kids still struggling. Kids still killing themselves. But certainly, if you're Māori or Samoan, and you're gay and you've got mental health addiction issues, sitting out there, just asked to be cumulative. I just say to them, "It's going to get better. You find your people and it'll be, get better. And you put your life together in a way that is something that you value. And you treat it as a great adventure."

Participants spoke about stigma and discrimination affecting their ability to get work or their direct experiences within work settings:

> PC7: "Yeah, there is a bit of discrimination out there, even when I have done these courses – oh yeah there's a job and then when I complete it, there is no job."

> KILGBT: "So, I know a lot of people feel discriminated against with housing, with work...my personal, experience – I have experienced rejection once. I went for a job for Framework… I heard back that I was laughed about afterwards. I had someone hear the interviewers talking about their experience interviewing me and they were laughing at it."

Participants spoke about the experience of social stigma and discrimination affecting how they felt about themselves in the social world and discussed recognising self-stigma. People discussed stigma resulted in them perceiving themselves as being less capable, as being less worthy, or who they were in their own eyes changing for the worse, when experiencing mental health and addiction problems.

> KILGBT: “Acceptance in society, self-acceptance, stigma, self-stigma. I think self-stigma is one of the big ones, and people limiting themselves.”
>
> RC1: “I think as some of it's about self-stigma. Because I think that, probably the only kind of person that would be interested in me is someone else who has mental health condition as well, and someone who doesn't have a mental health condition, wouldn't be attracted to someone like me. So, you don't put yourself out there. … I would be concerned that, once they found out, that they would not be interested anymore. … I have to go and have medication given to me once a month. And I have to be observed for several hours afterwards. And so, it's not something you can hide very easily. Because I'm under the Mental Health Act, I have to attend appointments and things. So, it's not something that you can, kind of, overlook, if you know what I mean. You have to be up front with people, if they're going to get to know you in a personal way.”
>
> RCG2: “Not being labelled, you have an illness, do other people get labelled for having an illness like diabetes or heart disease?”
> RCG6: “Diabetic, there is a label there, it is called Diabetic.”
> RCG2. “Yes, but do you get judged by it?”
> RCG6. “No one actually judges anyone. It’s you that judges yourself.”
>
> TC3: “What happens is that somehow your identity changes, not only for yourself, but in the eyes of other people... So, it's something about identity within and without.”
>
> TC3: “A little bit of stigma, although my mother experiences a huge, she had, or she has major depressive disorder.”
>
> RC1: (*referring to being under the compulsory treatment act)*: “That it's ridiculous and it's intrusive. When you don't have any choice about it. It's really awful because once a month, you have to go and report, and receive medication, and nobody else has to do that. And, once a month, it's just another reminder that you've got mental illness, that people want to, treat you for. It's not very nice at all. Certainly, doesn't help with the self-stigma.”.

A participant also explained when unwell it can be hard to address it when it is happening:

> RCG2: “I did feel that, but I didn't know what to do about it, because I was about 19 or 20. And, I really had no skills or knowledge to be able to address it. And I was in a psychiatric hospital, so I wasn't really in a space to be able to address that either. But I definitely felt that there was a reason. I can't remember the words that they used in that letter, but there was, "No". Because, I had achieved 75% pass rate right throughout the course, all I had to do was complete the final exam, and they wouldn't let me complete the final exam. So, I just assumed that that was because I've been put in hospital, and was remained in hospital, yeah.”

Few participants spoke about stigma or discrimination as having a positive impact upon their recovery. This was also observed in the card sort exercise where only 39 percent

of participants chose the stigma card as something that they had personally experienced as affecting their QoL during their recovery. It was rank ordered second to last compared to other recovery determinants that affected QoL. This may be due to it being a politicised issue that is commonly raised in groups, yet as individuals not all people may personally experience it, even when they know it exists. Recovery supporters spoke about and identified stigma and discrimination as an experience they noted as a barrier for people's recovery more often in the discussion groups and card sort exercise. This may have been due to their greater awareness of it and roles as advocates when assisting people to obtain work, housing, and to recover their QoL in other WHOQOL-BREF facet areas.

One participant explained how the anger they felt about the ways they were experiencing sigma motivated affirmative action to improve social awareness within their social group. They found that by normalising mental illness with others, this reduced the social stigma they experienced personally at that time.

> TC3: "I'd say somewhere, "Oh, been through this thing and blah, blah." They're like, "Oh wow, you don't look like that." … And it used to make me angry. Because I thought, "Well, what does that look like then?" So that's how I started. I think I lived as the elephant in the room, at the time, I started going to like, *Rotary* clubs, which were filled of mainly farming men and *Lions*, which had more women and things. But talking about the experience and things because I was so pissed off that they would think…I wasn't mad on my behalf, I was mad on everybody's behalf. So, I just used to start talking about my experience, so that they would know that, that woman who was married with two kids and owned a petrol station with her husband, had been as crazy as you could get; really crazy and still looks like everybody else. That's how I started. That was before I knew about the consumer movement or anything."

Participants who spoke about the positive side of this candidate item spoke about the importance of social acceptance, their experiences of this, and eventually overcoming the feeling of being oppressed by people's rejection or stereotypical judgements:

> KILGBT: (*Speaking to transgender experiences within mental health services*): "I would suggest that the people who have made some sort of transition, would, and I know from the people that, um, I'm aware of, they don't get treated any differently by clinicians. I think the service they receive would be, in my experience, from the people I know, would be the same as anybody else."

KILGBT: “I’ve lived a very easy existence. My acceptance hasn’t been an issue.”

RCG4: “You don’t want the labelling, the stigma, of other people’s, the lack of understanding or whatever, you just don’t want to internalize that negative stuff that is out there in the community, you’ve got to fight for your own sanity or whatever, intelligence, you know, that plays on your soul or whatever you know, and get on with, you need to, it helps to talk to people you know, friends, a few doctors, psychiatrists, social workers, a support worker, talk about it.”

TC3**:** “And that's huge. I think I'm really privileged in lots of ways, because white, middle-class, pretty normal in every other, laughs, although, I don't think anyone's ever called me normal exactly. But at least I didn't have those things on top of everything else. Also, as a shocking drinker, I just never coped with it at all. It used to make me get panic attacks. And drugs and alcohol, dope was great for a while, and then went south. Thank goodness. Because I would've used. I would've done anything to feel better.”

WT3: “In the early days, the stigma actually really affected me, to the point where I tried to take my own life. But these days, I think, well, I've gained so much through my illness. I've learned so much. I'm a better person for it.”

WT2: “I can speak to [*Speaker 9 named*], I was very lucky to become ill in Australia, in a very rural area, really rural, and in the rural territory, right in the bush. And what was happening there, because I lived on a farm, and what was happening then, when I became ill, because I was quite open about becoming ill. In fact, I think the whole of the Northern Territory would've heard me crying or, you know, when I was at my worst. And the people started coming out of the woodwork of saying, you know, "I, too, have had depression, and I, too, have felt in this way." And I was always so surprised, because they started coming out because they needed to talk, so literally, they've been isolated. But because I was so open and making my recovery such, my recovery became my work, and they were, and they began, and I became more, more and more open as I began to see that people, there were some people who ostracized me, yes. I was definitely, "Gosh, don't talk to her." You know, and there were some church people very close by, and it was taboo. "She's definitely got the devil in her," or whatever. So, the ones who came forward, became my support group, and we supported each other, very similar to what [Name of the NGO Rehab] does. We didn't have a [*Name of the NGO Rehab*] there. And yet, the actual mental health working group, they have their own, Team Health Northern Territory, I think it's called. And they would come, and that's how I got my support. And I did find, and I have a very supportive husband, very, very supportive husband. And the people were coming to him, too, at his workplace to say, "Oh, gosh. I see that she's ill. You know, I, too, have had a mental health problem." There's the other side of that as well. It is this awareness, and I think the education around it, I think it is that education around it that need, that we need to work on and make other people more aware of. Yeah, there is help out there for the person who's ill, and for the support people. Look, you're not alone. We can help you get through it, sort of like an AA for mental health, you know? … for the person who's not mentally ill, for the carer. Yeah. So, and for the

> family, because they think, "Oh, if I get away from that, I will then be able to cope with this mentally ill person." But it's not really, that's not what's the best."

The discussions among participants were at times spoken about within a context of their needs for understanding and empathy, to resolve how they felt from being outcasted due to the stigma around mental illness. Existing WHOQOL-BREF items were also referred to, such as the WHOQOL items self-esteem, particularly in reference to self-stigma, as well as problems with housing, work, and satisfaction with personal, health and social care services or family support. The New Zealand items of belonging, meeting people's expectations were also noted to be affected by stigma. This could suggest that dissatisfaction within existing WHOQOL-BREF facets and domains or within other module items could warrant further exploration with people as these low ratings may highlight problems brought about by stigma and self-stigma for people. Without necessarily having to have a question that specifically asks about the experience of stigma and discrimination directly. If people are given understanding and empathy this may offset some of the social disconnection aspects of stigma, yet it will not address issues such as prejudice and discrimination, which still require advocacy and socio-political change (Thornicroft et al., 2016). Participants spoke about these experiences as:

> KILGBT: "Yep, yep, belonging, belonging to a group. Being, feeling love and acceptance from a group of people, um. I know, this is personal experience, a group that I belong to there is a woman within that group that has attempted suicide many times. I know that part of her recovery is when she is actively involved in the group. When she is actively involved in being there with all her associates around her. Participating, so participating and belonging are a real, big, positive factor in people's lives. But that's just an instance I know of. I know of several people that …… have lived with a sort of depression type issue, being part of that group and belonging. You feel that you belong to a group of very accepting, loving people, it feels fabulous. But that's a real, strong motivator."

> KILBT: "My self-acceptance in the beginning was horrendous. My belief in myself, in the early days of my, reincarnation, was abysmal. And it was really, really scary. But with acceptance from other people, comes self-acceptance and self-belief and the knowledge that, hey, I might be different but I'm not a bad person." … "I don't make any pretences of being in the woodwork because it is too difficult, it creates too much

anxiety…..No, nothing can hurt me because everybody is aware of who I am, it is not an issue. It is better that way, but that is my personal choice, a choice I made many years ago."

AE: "He was kind of saying, that, "I can keep this person well if I can keep them under the Mental Health Act", and that to my mind, just like, reflects all these issues coming together, because it's like, because to my mind, you can't call anyone recovered, if they're under the Mental Health Act, to my mind. Some people don't see it as a problem."

RC1: "I think, I've got more coping strategies these days and I'm much better able to cope with any stressors, than I used to be. So, I would like the opportunity to try and reduce and come off medication. Yeah. … I had a mental health act review, last week, and they said, under no circumstances, were they going to take that risk. And they put me under the act for another six months."

PCL4: "A job is a way to, "don't go back to that job you had as a schoolteacher, don't get back. Cause we all know what happened". So, people start looking at very limited amounts of information, you know … It's just, "no, you're a particular person that has a weakness and a susceptibility. So that's always going to be there. So, let's keep everything nice, steady, and just have this low level of stimulation", which for some people creates depression because they feel ineffective, you know, the ability to affect things as you want in their life. …. "We want you to just …", "we want…", these are a lot of things I hear. "Well, why don't you just stay with that job? Okay. Just stay there. Don't move. We'll help you out a bit with your rent. We'll do …" those kinds of things. So, then they're dependent on the parents or whoever was doing that. And yeah … it creates great a new problem, which can often be harder to come out. And then the original one comes on again.

CM5: "Stigma, I have had people, I am a local tennis player and I have been a member of this club for a long, long, time, and on one occasion, I had someone say to me "Go and have another mental breakdown!" … and this was an educated man, who was a teacher at King's College, so you know, the level of judgement … discrimination is the biggest barrier to allowing people to even start recovering. … That to me sums up people's attitude to mental illness, when I had people in my home the other day, I was sure they felt that mental illness is something they could catch…When that attitude still presides in this country, we have a long way to go."

TC2: "So, if society stop pathologizing and making mental health and addiction 'special', it used to be part of a hospital, Carrington, or something. And now she gets the house with four people down the road. If we looked at the population and said, "There's something happening for people in our population, what might we do differently as a society? One, to support those individuals, if that happens. But two, to prevent it, or to mitigate it in the first place? That is a very different paradigm."

Overall, the experiences of the participants matched the findings in the literature by describing the ways in which stigma negatively impacted both their recovery and their quality of life in many different facet areas that pertained to all aspects of their recovery. These ranged from difficulties receiving treatment through to problems re-engaging with the community, rebuilding their lives with family, and developing personal relationships, through to regaining employment, housing, and restoring their self-esteem and self-worth.

Stigma within society makes things more difficult for people recovering from mental health and addiction issues. Onken et al. (2007) discuss the differences between 'first order effects, which are what is involved with recovering from mental illness itself and the 'second order effects' of recovery. The first order effects were exampled in the first section of Chapter 7 - how mental illness impacts upon the subjective world of the individual and their QoL. This section describes the second order effects. The barriers and challenges involved with building one's life after mental illness. This can be influenced by the people surrounding the person, who can help them to feel socially connected, as well as by those they encounter as they go about recovering their lives who can make them feel marginalised and disconnected. People in society can open or close doors to them as they make steps to rebuild their lives; through discriminative attitudes and prejudices or through offering equal opportunities. Yet as participants stated, and the literature asserts, to reduce many of the social barriers and challenges related to the second order effects of mental health problems, it requires advocacy, support, and ecological interventions (Collins et al., 2012; Spittel et al., 2019; Thornicroft et al., 2016). A paradigm shift, a change to the way mental illness and addiction problems are viewed and are responded to, in all of the areas of society that people interact with, to enable people to achieve a satisfying quality of life (Rössler, 2016; Stangl et al., 2019; Stuart, 2006, 2016; Van Brakel, 2006).

M.2 Determination, Recovery Readiness

Most participants spoke about this candidate item in positive ways. Some spoke of it indirectly when speaking about there being a turning point marked by renewed determination with a discussion upon doing whatever was required to recover, regardless of the effort or costs of doing so. This candidate item was closely linked to the module items - belief in recovery and recovery progress. This belief in recovery being a pre-requisite to the determination and willingness to do the work involved with recovering, and to making recovery progress. Participants at times spoke about key relationships impacting upon their determination to recover; sometimes for the worse, yet also that this determination buffered the effect of this on their motivation to remain focussed on change. At other times, determination was discussed in reference to significant relationships that motivated a strong drive to attain recovery outcomes. Participants also discussed a sense of readiness to work on their recovery in a more committed way as being part of a renewed determination to recover, that then led to improved recovery outcomes for them. Their determination to recover was also at times spoken about as a conscious choice for change, requiring discipline, as well as of it being an exercise of determined will power:

> CM8: "So, I found that I had to make the decision to push myself, which was good in a way, yet it was made more difficult by my family."
>
> PC7: "And … people said I can't change, I won't change. And then you know I've proved people wrong. I don't like it, but sometimes you have to prove people wrong. But I'm not giving up, I'm just got to keep knocking on those doors till those doors open, one or two. But yeah, you just got to be willing to change I suppose."
>
> RCG3:" You've got to have a determination, to recover"
> RCG5: "Yes"
> RCG3. "You've got to really want to, do it, otherwise if you go to all these groups and stuff, and not really want to be there, then, it is not going to work, so you have to really put the effort in, it is hard at times…"
> PC7: "People can change, you just got to want it."
>
> WT9: "For me, it was willpower. I mean, the drugs helped, but it was actually my will, because I used to suffer a lot from paranoia, and I used to find it really difficult to go out. I'd have to force myself to go out. But I found, if I forced myself, and I

> went against my feelings, it was like a big part of the recovery process. People actually tend to rely on their drugs, and I find that the very act of using my will, to actually control my feelings and my thoughts and things, is a big part of my recovery …. I actually, I really forced myself to actually go out, and these days, I don't have a problem, but in the early days, it was sort of a major issue. I was sort of in cold sweats and really, really struggling to force myself to do things against my will. You know, yeah. Yeah. I found that willpower was the actual, it was the moving force behind me doing things."

M.3 Fear of Relapse, Setbacks, Loss of Confidence

Participants did not speak about the recovery process as a steadily moving forward experience. It was marked by setbacks, barriers, difficulties sourcing the right treatments, or resolving the issues that needed to be resolved to be able to move forward. This inability to have a clear pathway for steady progression increased their feelings of uncertainty about their future when it was marked by the knowledge that there would be relapses ahead. These types of experiences also severely affected their confidence, to the extent that at times it undermined their ability to believe in their recovery, to have the determination, or resilience to put the work into making the changes required to recover and led to times of increased reliance upon the mental health system, or upon others for support. In this way, this candidate item was closely linked to other candidate items and existing items within the WHOQOL-BREF.

> WT4: "Things that have kept my recovery stuck, in a way, has been hospital admissions. I feel like, when I go back to hospital, I feel like a bit of a failure, and I feel like I've stepped back a bit. And when I get out again, I sort of keep going in and I've been put back in the hospital, and just feels like a bit of a cycle, so I'm trying to stay out, I'm trying to use other ways to stay out, rather than have hospital treatment, at home, in the future, basically. I don't really want to go back to hospital. There's been things that have happened in hospital that have really upset me, and it hasn't helped my recovery, so, I see that as a bad place now, unfortunately, with some negative events that have happened with certain nurses in that. Yeah, that's basically, I think that's going to be a continuing thing for me. I'm still in recovery phase, but I've been told I'm going to be on this medication for my life, basically. So, I have to have it for my mental illness, otherwise I just get really sick."

> CC4: "It is sort of like an ongoing journey, you don't live and breathe it every day as things are getting well and that, but there's always a chance that things are going to fall off again, and you've got to go back to square one, to start building to get back

> where you want to be again, so it is a constant effort, in life you know, to get ahead, sometimes you think when does this ever end, when is this going to be straight forward for a while, and not so complex."

> TC3: "I'm always frightened of having things taken away by becoming unwell again and not being able to do them or not being able to. So, I just don't look too far ahead, ever. And I try not to look back too hard as well."

> CC4: "I got Bipolar at the age of 17 …. I had to rebuild my life again and I have long periods of wellness, 10 years at a time, so every 10 years or so I have to stop, and I have to rebuild my life and relationships and everything and sometimes it just gets a bit weary. I have a family who try to understand, but they go west when I get unwell, they don't want to know, they don't cope. Their way of coping is shutting the door, so therefore I have to rely on the system, and supporters, to help get me on my feet again and get strong again. It takes the confidence out of you each time, you fall down that little bit harder. Takes a bit more, the older you get to come back to normal again."

Participants also spoke about other people's fear of their relapse, prevented them from moving forward at times. When they were feeling better or more able to take further steps forward, others responded that this was too risky - as they may become unwell again.

> RC1: "Yeah. Everyone's fearful that it will happen again. Yeah. And history shows that it could happen again, which is really disheartening and really disappointing …You put a brave face on. Yeah."

> PCL4: "Yeah, you know, and we'll have, we'll have family meetings with, with people at [*Rehabilitation unit*] and they'll be talking about things that their kids have done. And then like, we're so scared to go forward, because you know what, if he goes backwards, so they're not holding, this one particular guy, they're not holding the 20 years before, but he became ill quite quickly. So, 20 years of being a great kid, going to school, working, doing all of that, and then bang, two bad years, self-medicating and in (*Rehab unit*], everything's judged on those two years. What if that, what if this, what if, what if, you know, a lot of anxiety, a lot of fear and looking at circumstances and find all the ones that are in common with the support, the theory that he's becoming unwell again, and a lot of stuff gets discounted. They believe they're seeing early warning signs; you know? …Not that it's quite normal to have pain or upset for everyone, and that there's a possibility you'll get through it."

> WT8: "I think perhaps, then, in terms of what stuck my recovery process was perhaps people who were supporting me around me, and my family and stuff, not willing to take chances or perhaps try different things to see if this was going to be helpful or not. It was very much like a process of restricting what I would like to be doing, whether you should've been doing it, because maybe it would be too much pressure for you. I would get that going to university for a period of time. Professionals thought it was too much for me to handle, those sorts of things, and people not willing

> to give me a chance to try and learn from things. You know, it was like a very protected place where things were coming from, I think. I think that environment, for me, kept me in a stuck position for a while."

Participants who spoke to the positive and satisfying side of this candidate item spoke to how they resolved their own and other's fears of relapse, despite the potential for relapse remaining present. They spoke about this being facilitated by their active use of coping skills, a strong commitment to their recovery, as well as from being confident that they had well-developed support systems for any future times of setback. In this way, this candidate item could be seen to be related to other candidate items such as – coping skills, determination to recover, and WHOQOL-BREF items of social support, access to information, and access to health and social services.

> CC4: "If ever things break down for me like that again I have got people in the right places who can support me to get over the hiccups, but in saying that I am lucky as I can go 10 years without needing support."

> CM5:" I think recovery is quite a tenuous concept, I think if I know that I've got a mental health vulnerability, that means that I have to put extra effort in to preserve my mental wealth or my mental health and I need to do that every day, your wellness recovery plan is called your daily maintenance plan. Things that if I need to do every day I have written down in my black book: 'Wellness Recovery Action Plan' and I would recommend everybody to grab hold of the opportunity to do one of those."

> WTS: "Education is very important in the recovery process, and when people recover, as the word "recovery," they tend to get better. At times, they may relapse, and then keep getting better. So, understanding of that process, even for the person, that what you're going through is normal, and you're heading, you're getting better. It's very important, it cannot be overstated."

M.4 Coping Skills, Vulnerability

This question was not originally a code or card sort item, yet it emerged during question writing from the code themes of self-help and self-care. Participants spoke about this candidate item as feeling vulnerable, not being able to cope, adopting maladaptive coping mechanisms that brought further rehabilitation needs to resolve, having unmet needs that led to adopting maladaptive coping mechanisms, and not coping being associated with not wanting to face feelings that were connected to past trauma, or negative life experiences.

Positive or satisfying comments about this candidate item were made by participants who discussed how learning specific and new coping strategies to face feelings, deal with emotions, memories, thoughts and manage triggers helped them to start to recover. This then enabled them to restore their QoL by improving their ability to function, from being less affected by symptoms. Some discussion examples of the negative or dissatisfying aspects of this candidate item are below:

> CM6: "My experience first started through stress, so, one of the things that I think, in all my years … I have had multiple experiences and that sort of thing … I think a lot of what I have also seen too, recently, is that what is lacking, is for people who break down because of stress, what a lot of organizations think, is that it is just a lack of coping skills, and it is I guess. I would like to see, something, happen I guess, particularly in Auckland, because it is such a highly strung city, and it is such a rat race and if it affects you mentally, then it will affect you, socio-economically."

> RCG3: "Definitely, I think I, basically I had turned off all my emotions, that I did not allow myself to feel emotions, so I was self-harming, and yeah … because …I had no friends, just really, really, lonely."

> WT3: "Yeah. That was the only way I could deal with... You see, he very much mirrored the parent that actually traumatized me when I was a child. And I didn't know, at the time, when I married him, that he was the mirror image of her. He mimicked all the behaviours that she did because she physically, mentally, sexually, and verbally abused me all through my life. I had so much trauma that that's why I kept breaking down, because my subconscious couldn't deal with what was coming up…. I just completely lost it that week. Eventually I got to the stage where I knew that I wasn't coping, and I'd sort of gone into autopilot. And I was aware of what I was doing, but I couldn't stop myself. And within a week, I was arrested by the police and put in jail, and the crisis team came out and saw me and put me straight into hospital. I was there for three months. "

> PC1: "…I's made me go back further into my life. To wonder why, what happened, and it brings up all the memories. Like, all the memories that I was like numb, I realise now, I'm having to deal with. So, I'm like, ugh, I don't like that feeling. To feel feelings, I don't like it, 'because I've been numbing them, straight out yeah."

> RCG3: "…In my experiences, If I was having a really rough time, or stressed, or anxious I was what I would call unwell and was either put in hospital or respite, so eventually it got to the point, where even just, I could just have been having a bad day, I was unwell, and I have had to re-programme myself, through hard work, oh, I am just having a bad day, it is normal, everyone has bad days. You are constantly being told, oh you look unwell, should we put you in respite?... and you know, the

> damage that's caused me, I have had to do lots of hard work to change that thought pattern."

Some participants spoke directly to the use of alcohol and drug use to cope with subjective experiences that they could not cope with at the time. The use of alcohol or drugs as a way of managing distress and the subsequent problem of addiction in this way, was identified as evidence of insufficient coping skills to manage what a person was experiencing within themselves, or within their social or relational world at the time.

> RCG2: "They are wanting to blot out the pain of what's happening, so they turn to binge drinking, I used to do that myself. Now I have cut down to a can of beer a day."

> PCL4: "So, and there's a lot of, I guess, a lot of work. I think that a lot of clinical psychiatrists have to do, because even though, I had this person that plugged me back in, I still had some real trouble with strong emotions. So, when things happened with [*name of colleague*] back at [*NGO name*] I started using drugs, to, to get me through that. And the problem is, of course, once you start using, using these drugs, they create their own mood swings and grandiosity. And I'm like, I don't need this, [*Colleague's name*] is the problem here, it's clearly her, and I left."

> TC2: "And I think for the lesbian, gay, bisexual, transgender community, it's a huge issue of addiction. Because that's how we socialized. It's how we probably still do. You're like, "I'm not into that." I don't go and sit in bars anymore, that much. I have no need to. But for our community, mental health and addiction, huge issues."

When participants discussed more positive examples of this candidate item, they discussed finding or learning more adaptive coping mechanisms that restored a sense of control over their subjective world. This allowed them to move forward with tasks in their objective world. Participants acknowledged the need to learn self-help skills and that coping was not something that could be achieved by a medication or could be provided by a service. It was something they needed to learn how to do for themselves, for their recovery to progress. Participants talked about cognitive changes that were made, emotional coping strategies learned, and specific interventions that helped them to manage their internal worlds more.

AE: “I also think that self-management is huge, because ultimately, no matter how effective the services are, recovery is ultimately going to be about the choices that the individual makes, and we can't do recovery for people.”

CC4: “I’ve been feeling anxiety, and that’s quite foreign to me, so learning to deal with that they best I can, and cope with that is a big thing.”

CM4: “And for me another aspect of recovery is self-management and self-advocacy. The system isn’t perfect, we need to, actually, I learnt this over time, I have been a victim and been stuck, and all the rest of it, as much as anyone, but eventually I learned you have to manage yourself and fight for yourself, and make the most of things, and not take too much crap, if it is not good enough, then speak up, and seek the change.”

RC1: “I think I'm much better these days at dealing with stress and putting things in place to be able to cope better with stress. …I think, I've got more coping strategies these days and I'm much better able to cope with any stressors, than I used to be. So, I would like the opportunity to try and reduce and come off medication. Yeah.”

CM5: “So, you know, it is diet, cooking, its playing tennis, its walking, its drinking water, its taking a very small dose of medication, it is sleeping well it is all of those things.”

KILGBT: “Working as a CSW, I was exposed to a whole wealth of therapies. Learning about CBT, DBT, learning about the strengths model – there were so many, um, therapies or new ideas and ways of being I was exposed to. So that I’ve absorbed so many of these things, become a practitioner in many of these ideas, so. And the idea of self-help and self-belief was, it worked …. they’ve been undoubtedly massively important in my recovery if you like.”

PC6: “…I don’t understand why all the clients don’t start out …don’t start off with a WRAP programme…. That breathing technique, there are times when you can absolutely use them. And you can use that in your little box of wondrous tools that you could use to help soothe yourself before you really can’t find out what it is and lose control.”

RCG2: “Positive thinking, that has made a big difference to me.”

RCG3: “For me, finding out, learning about my emotions, learning to feel them, and accept them for what they are, and to feel human.”

RCG4: “I think sometimes it is just to watch our thoughts, because we are not our thoughts, we are like a spirit, even in a dangerous situation, we are a human being, you are more in your head than in the here and now, and your psyche is here but if your mind it has its own mind and sometimes you can just watch your thoughts but you can just accept yourself and your feelings where you are. Emotion mind and wise mind I have heard that one before, cognitive behavioural therapy. But you also want to, just like, um, you don’t have to think, you know, or … you know, …just you surrender for a little bit….”

> WT4: “Mine's probably, I would say 60% medication, and the rest of it, managing the stresses in my life and pushing myself to do social things as well.”

Coping skills were spoken about as a pre-requisite to managing stresses within a person’s relational world, as well as their capacities to perform tasks of daily living connected to valued roles. In this way coping skills were essential early-stage recovery needs that helped a person to reclaim their quality of life subjectively and objectively. Coping skills were also described as self-soothing skills, ways to take care of oneself when going through a challenging and difficult life experience. These self-care coping skills were ways to reduce patterns of self-neglect, or to address unmet needs that were part of the early experience of having mental health problems, or the impact of early life experiences that did not teach a person how to cope, or what it was like to be cared for during times of distress.

> PC1… “Now I buy some flash moisturiser…. Wardrobes… I was always working all the time, I didn’t spend money on myself, simple things in life….”

> PC1: “Self-care, now I really look after myself really now that I … man… my hair. That’s to say it out loud didn’t bother me. It’s like a real journey because I was a tomboy. I didn’t care, I’d wear jeans and a shirt. And the girls would say…do your nails mum. And I’d say what do I want to do that for? It’s a major. After looking after everyone, except for me.”

Coping skills could be recognised to fit within the existing WHOQOL-BREF item – satisfaction with your ability to perform your daily living activities, management of negative feelings, or the New Zealand national item “To what extent are you able to manage personal difficulties”. The adoption of coping skills could also be part of some of the candidate module items such as developing new strengths, the process of adaption to the changes mental illness brought, and the capacity to relate to others in more satisfying ways once learned.

M.5 Personal Growth, Transformation, Healing

Participants talked about the experience of recovering being akin to a personal growth or healing process. A process that was influenced by module items such as insight and self-awareness, being in touch with their strengths and resiliency or demonstrated through recovery progress, as well as within existing WHOQOL items such as improved satisfaction with themselves, self-esteem, or candidate items such as coping. At times, this candidate item was discussed as being facilitated by specific interventions, or types of social support provided. At other times, it was a deep subjective experience that others may not have been aware of, or involved in, yet altered the consciousness a person had, or the way that they felt within themselves. This then led to looking at their life differently and being able to respond to past problems in new ways, that were more adaptive as they enabled greater functioning.

Participants who spoke about times where they were dissatisfied with this candidate item, spoke about struggling to achieve a sense of growth or healing of past traumas through their recovery journey.

> CC10: “I think because my behaviour was really bad being on drugs and stuff, and I have a lot of issues with the past and I haven't dealt with them, it has made it really hard, but yeah, my key-workers are trying to help me with that, and my psychiatrist is too.”

> TC2: “I think it's a very internal thing. And that's also about role. Because, I think, being most effective, if you've got a huge event in your life, you also fall out of your life. So, your ability to be engaged as a parent, a partner, or a workmate and be involved in employment, all those things that you took for granted, it's formed part of your identity about who you are, also gets thrown to the four winds. So not only having to rebuild yourself on the inside, it's like there's this whole kind of role definition thing that goes on the outside. And in many respects to do that, you've got to put yourself back together, almost at the same time. So, there's this sort of funny kind of cross thing.”

> TC3:” I remember thinking, to picture it, I always think in pictures. The picture I had in my head is of me made of glass and just shattering into a billion pieces. And I had to find all these bits and put them back together. And it wasn't always easy getting the bits back and fitting together right. And you didn't notice some holes sometimes until they sort of bit you in the backside. And then one of the big learnings for me, but for

> the down was, I didn't have to put all of the pieces back. If there were bits that weren't serving me, then I could actually get rid of them. So, it was cool. That was a good bit. But you're exactly right. The other thing that I remember experiencing so deeply, and still do, if I go into a really bad dip. Particularly the dips, was I just wanted me back. I missed me."

Participants also described that they felt their needs for personal growth could conflict with a family system that maintained a historic way of being and older maladaptive strategies. This meant they had to pull away from that family system to grow in ways that supported their recovery. They also discussed how doing this, role modelled that positive change could occur. They hoped that this could potentially also help other family members, to realise that they too can make change, heal past wounds, and restore relationships. The links to the module item self-awareness was demonstrated when discussing a recognition of new insights, as markers of their personal growth and transformation.

> PCI: "My family, my culture – I don't know how to say it. They are like staunch, and that sort of stuff is like, weak. And I went, ugh, man – and they look at me and go whoa, she is actually going to services and things, and it's been hard. And when they say stuff, like 'what is it like?' I say …It gives good results, so they are getting feedback and they are starting to come back with it. Cause I was a real proud woman before that. And then when that happened, I was like, ahh, like, I went from hero to zero, in a matter of 5 minutes. All my family gapped it. And now they go, oh shit, hang on. Yeah, it's …. for me. The …QOL, is for me, everyone is at me because I'm … I've got 2 brothers that committed suicide and I lost my parents……Aunty. So, I'm the oldest one left. And I had everything together. So, when I did break down, I was like, oh fuck. I could have taken drugs; I could have just gone back to the same life. And they would love me again. But I knew I would end up back on the same road. So, I just stepped out and tried it, man, what's the worst that can happen? I can always go back to the drugs if it doesn't work. I don't mean to say it like that, but that's how I look at it, yeah."

> CM4: "For me, everything is about some trauma in the past, a hurt, it is like a boat, you have all this pillage at the bottom of the boat, swishing around, there is all this stuff, it is about cleaning this stuff out,….But the last year I have bene living with her again as part of the family and we have been able to go through all the pain we caused each other in the relationship and come to understand it. It has been painful and quite weird in a way, but it has been massively healing. So, it is not only that I have had the privilege of sorting things out for me, but I have been also able to sort things out between us, and that has been very liberating, that has been a really important part of the process. I suppose it is the same with many relationships, children, I have ended up becoming closer to children, and that has again, been liberating, but it has been the process, and it has taken time. "

Overall, the participants spoke more to the positive sides of this candidate item during discussion group discussions. At times, discussing the changes they had experienced as personal growth experiences. They described the process of recovery as a progressive learning process, a process of self-exploration, self-discovery, and personal development. Some stated that the term recovery was better defined as personal growth. Others saw it as their life changing, or as a process where they started to live truer to themselves, and to their values more consistently, or to live a life with more meaning or purpose. Participants also talked about turning towards relationships in different ways, which resulted in their relationships changing for the better. In this way, the candidate item was showing some connections to other module items, such as relating to others, recovery progress, self-awareness, and insight, and finding new strengths and abilities. Connection to existing WHOQOL-BREF facets could be referenced like a change in self-perception (self-esteem), meaning and purpose in life, positive thoughts, and feelings, that negative thoughts and feelings were less dominant, along with greater satisfaction with personal and family relationships. This again could there is the capacity within QoL measures to observe patterns of change as much as specific fact changes to evidence progress is occurring in recovery or deterioration warranting intervention is occurring. People's ratings on several items may shift and change, to evidence more life satisfaction in specific facet areas as they recover. The process of recovering could be mapped using the WHOQOL-BREF and mental health module as a recovery outcome measure.

> WT8: "That's what I really think. It's like a constant learning process of self-discovery, I think. I'm always learning new things about myself, and I think now, I finally feel like I know my true self, if that makes sense, as opposed to like, the selves that I used to think I might have been at some point, or the self that other people wanted me to be, perhaps. Just like a learning process about, inside me, my spirit…"

> PC3: "For me, what happened to me, a lot of people would call a wilderness experience….so I have taken myself out of circulation and a whole lot of things caused me to do a lot of thinking…. later on. But it's sort of like, the master potter

had a piece of clay on the wheel but just couldn't fashion….and he had to smash it and start all over again. So, I have sort of been built again from the bottom up and become a lot stronger inside. …Because there were lessons…. lessons that I had to learn. One of them was changing from negative to positive, and looking at things that were good and pure, lovely, good report…Think on these things. In fact, my wife had that verse stuck on the back of our bedroom door for ages. But it took a whole long time for my mind shift to change to positive. I used to be a terrible worrier, so yeah. And another thing too that did help me too, a lot, is one of those 5 basic things of, or 2 of them actually…the mental health foundation, is 'giving', and another one is, 'keep learning'. And so, for a number of years I have actually been helping out at different camps."

CC1: "…then the strength comes in sort of growing as a person, as you sort of learn new skills, and on the road to recovery you build on each thing step by step and you find you can do more things that you did when you were unwell and then you sort of start making new friends, connections, maybe get a job or something, get some new friends or something, yeah. I have always sort of been a bit introverted and now I am getting out in the community, meeting other people, and getting to know them, yeah."

PC6: "Oh yeah, having gone through it I wouldn't wish it on anyone, but there is a lot of things I have learned that I probably wouldn't have learned any other way. So um, it's been a blessing in disguise though I hated it at the time, yeah."

RCG4: "You know it can actually be a blessing in disguise, or strong in ways, that mental illness can be a blessing in disguise." … "You can be stronger and wiser, and more serious and smarter, and not just like some people thinking you're dumb or stupid, or something like that, you can kind of like grow too." "So, it is kind of like … kind of like what you call spiritual growing and personal growth, personal development."

CM5: "I think when I achieve those things, I grow from my mental health experience, I have now learned about compassion, and thinking about other people, I do a lot of things in the community now, which take me out of my 'oh woe is me type attitude' to thinking about other people, helping other people in a voluntary role. I think that when we can think of others, we can start to forget about ourselves."

CM3: "The healing that needs to be done, when the healing is done, then what, so to me. So, for me, it is support, its challenge, and its creation at the end of the day, something meaningful." … "My life has been re-engineered, and I think that is the reason why it has subsided. I got a sense of meaning back in my life, a new direction, towards mental health and support, and away from making money for shareholders, you know, that's the change that has taken place, mostly in the last two years, while I was going through this so-called mental illness."

CM1: "I have always laughed at people who turn around and say, 'I just have to go out and find myself', I think how ridiculous, you must know yourself by now, because they are normally in their 40 or 50's. But there is actually truth in that, because when you get all that experience under your belt in life, and you go through all this stuff, and you start to really get to know yourself, and that is what they are talking about.

> Because when you are in a relationship and you are a wife, or a mother, or grandmother or whatever, you are everything but yourself. So when you go off by yourself, and all your children have grown up, and they have all gone off, and you leave your husband or wife or whatever, you really start to find out who you are and what you are about, because you have been all this other person for so long that you lose yourself, and that is something I think you gain when you are in mental recovery, because you find out so much about yourself, what you like, what you really want in life, mental recovery has done that for me, I am not there yet, but I am definitely have learned a lot more about myself."

This candidate item was often discussed in terms of a changed way of seeing or relating to oneself that offered a new consciousness, a changed way of seeing themselves and the problems in their lives that led to the development of mental health or addiction issues. They noted the development of a stronger identity, a more self-compassionate view of themselves, a greater level of self-acceptance, an experience of self-forgiveness, as well as the ability to forgive others. This candidate item with its discussion upon changing for the better, naturally aligns with improved self-esteem that could be reflected in changed scores on the WHOQOL-BREF item - satisfaction with oneself (improved self-esteem).

> PC1: "I feel whakama, shame, because I don't know where I come from. But now I am starting to learn in my recovery, only because I'm recovering, I'm starting to look for that, and they're all proud that I am asking. I am starting to feel grounded, and I feel prouder as a Māori…. I feel like I can understand where you're coming from….. cause I felt this way, I am a Māori aren't I? My own father telling me not to hang with them. That I'm not one, don't bring one home, so yeah.

> RCG3: "Yes, I did, about a year ago, I started intensive … therapy, I started working on the issues that led to my breakdown, and that was a very big turning point for me and also being part of a community group, helped gain confidence in myself, maturity, knowledge, acceptance of myself …I no longer have the diagnoses that I was given, years ago. Just maybe a few traits, (*laughs*)."

> CC4: "I have started to be kinder to myself. Not expecting too much, and just learning … to just take baby steps to get back to wherever I am going to go … I think the big thing is that I do not have to prove anything to anyone else, I am only answerable to myself, as far as my mental and physical health is concerned. I have stopped beating myself up."

> WT8: "What was perhaps really important to my process of recovery was self-compassion. I think you touched on that a little bit earlier, forgiveness for other people. I had a lot of forgiveness to do for myself, kind of as well, and that was part of my healing process I guess, was self-compassion rather than thinking about

> perhaps what people would have told me, like ah, "That's because of your mental illness," thinking about things in different ways that made sense, and that I connected with. Yeah, I think compassion for myself in different ways. …yeah, compassion for myself was really important for my recovery…. because I had a lot of like self-blaming… Or, if I hadn't had been there at this time, or doing this, maybe this might've not happened, or did I do this, that might have led to that? Like all those sorts of things, I think in my mind, and so I really had to let go of that, [laughs], and have kindness towards myself. Yeah."

M.6 Peer Support

Participants speaking about peer support spoke about the specific ways they were helped by peer support workers that were distinct from the support they were receiving from mainstream services. The experiences they had of peer support services made a significant difference to their recovery. On the dissatisfaction side of this candidate item were some experiences that peer support workers themselves had, when working within the system. This was both within their roles, amongst one another, as well as having their own recovery issues to address, whilst performing their roles and supporting others. People spoke about specialist peer support roles that come with a caveat, a glass ceiling, and they go nowhere, so led to limitations for career progression. Limitations were also discussed as experiences of feeling contained, and kept in their place, when working within their roles within the system.

> TC3: "I think there's a hierarchy. Well, there definitely is in the consumer world! (*Laughs*). I'm only halfway up. I've never been in seclusion. So, I didn't make it to the gold standard! (*Laughs*) Yeah, pretty much that's how it was went, when I first started working in mental health, which was about 16 years ago, and we were just starting with consumer advisor roles and things like that. I entered it all bright and bushy tailed, excited about changing the world, slaying stigma, and creating a better world, forever. With my own sort of complete traumatic, and for me, world changing life experiences, And, plus my experiences of recovery. And to my shock, there was, I expected to be welcomed with open arms, people who understood me, would stand together shoulder to shoulder, you know, and fight the good fight. Well, let me tell you, within the first couple of months, people were shooting at me from my own team. It was so bizarre. And I realized there was this hierarchy. And it was, top of the hierarchy was the worst. Psychosis, long-term inpatient, here in seclusion, horrible drugs, which had horrible side effects and sort of losing everything really. And they were the ones, you know, that were at that top of the hierarchy. …It was like, "Wow." It was really weird. It took me a while to get my head around the fact that, being part of that world was part of a social movement. We were all a lot of disenfranchised and

marginalized people, that were fighting for our place and our value and, our futures really. All our manner and self-respect as well. And we were all looking to make our experiences worth something. But sometimes to do that, because of where lots of people had come from, that meant standing on other people who were pushing them out the way or sort of... So that was unexpected. Really unexpected. And so taught me took me a bit to learn to accept that.

TC2: “So it is that thing about, kind of keeping secrets and, who you let in, and how bad does it get for you to kind of then reveal to somebody that your life's coming apart? For what that's worth, that's my own kind of personal take on it. So, working in the mental health and addiction sector, I guess I fall back. I talk about the physical health stuff because it's more recent, everyone knows about it and it's more acceptable. But I also fall back on my own personal experience of being a young woman who was completely off her face with her life going to pieces.”

RC1: “I think that because I'm in one of those positions for consumers, or one of those, specially developed positions for people with experience of mental illness. Because I'm in one of those positions, there aren't that many available across the sector, and there are only a few of us involved. Do you know what I mean? Once you've been in a role that defines you as someone with experience of mental illness, it kind of puts a glass ceiling up for other positions, because you've come out and identified yourself as having mental health issues. And so, applying for other positions because it's such a small sector, people know. And you wonder, if you were applying for a management role, you wonder whether you wouldn't get it because of that reason. Even though now have a post-grad certificate management, and I'm well qualified to run a service, I wonder whether that has had an impact. Yeah.

RC1: And, because there's no real career pathway, for, if you're in a consumer position, not like if you're coming into the organization as a CSW, and then you can get a CSW with higher duties, and then you can be an acting STM and then you can be an ECM. Then you could be acting OEM. You know that your career pathways is laid out for you. But, in my role, there's nothing else. It's just my role. And there's no opportunity for me to step up. …. So, yeah, if you come out as having a mental illness then, you only, there are only certain doors that are open to you. Unless you go to a consumer organization, and I have done that before. And I've been involved in developing two organizations from ground up, and I've been chairperson, or coordinator, in those kinds of roles. So, you can do it within a consumer organization. It's just in a general mental health organization. It's very difficult.

PCL4: So, you know, at the moment I went to, to [*name of an inpatient acute unit*]. And I was asked to work with this lady to help her with her complaint. And I got there, and I was, I was talking with her, and part of my role is we've got a full job description. And part of it is making sure that this person has been made aware of what resources are available out there. So, I'm talking with her, and she's talking about these extreme relations and this trauma, she's had in the background and how it, when she gets upset, it's always, there's a violent act that occurs. And she's been in the psych ward since, since April, when she bought all these things, she bought all these things up with me and you know, her …abuse, …and it is all true, and she's now in

> her fifties and New Zealand housing have rejected that, as so many times she keeps getting booted out of their houses because she brings people over, there's drugs there. And doesn't look after the place, threatens to destroy it. Destroys it nine times out of 10 herself. And so …she's going through all these things that she's been through ... Then I had a meeting with the social worker afterwards and I said what's she using for distress tolerance. And what skills or strategies are there for her to deal with, you know, these very strong reactions that are causing her to lose the things she desires, … And she's like, "Yeah, we're nurses, OTs and social workers in here". Yeah. So, I said, "Oh, we can get her into the 'Balance Program', which is a DBT program that runs for 12 months at [*named CMHC*] she said, "Oh, what program?" so I said, I'll send you an email. And so, I sent the email to [*name of colleague*] who's the head of nursing at [*name of acute unit*], and he's like, "we didn't ask you to go in there to do a therapeutic diagnosis. I obviously don't understand the scope of your job". "We sent you in there, in the hope that you would work with her and have her not manipulate the complaints process."

> RC1: "Well, sometimes we do orientation for new staff, and sometimes, I will decide to tell my recovery story, at the orientation. Because quite a big part of my recovery story is actually a service user of the service of this organization. So, it was quite an interesting... you know, I used to be a client of the service and now I work for the service. So, that's quite a good example of recovery. … There was a service that I went to, which was out of town, and I went to speak to the clients of the service to say to them, how's it going. Talk with them confidentially, how's it going with the service? What are the positives about being here, and what are the negatives about being here? And when I went, the manager got the report. She ...it was a relatively positive report, but because I did the consultation without her involvement, and without staff involvement, she became very, very angry with me. And still to today, still very angry with me. So, it's quite stressful.

These experiences, although specific to working in peer support roles, were also ones that could be potentially captured in the QoL facet within the WHOQOL-BREF that rate a person's satisfaction with their work, the NZ national items - control over life or meeting the expectations of others -, as well as the MHR candidate item - goals.

Receiving peer support itself, was discussed more positively in the context of a qualitatively different relational experience within the system or personally. When speaking to the positive and satisfying aspects of this candidate item, participants spoke about the value of working with someone with similar experiences and problems who could help them to orientate to and navigate the health system better. They spoke about the deeper understanding and empathy they had experienced from these workers. That this had made a

difference to feelings of emotional support and social connectedness during their recovery. They also spoke about the value of role modelling recovery outcomes that increased their belief that recovery was possible for them too. The support discussed was not fully captured all the time by the WHOQOL-BREF facet item social support, as it is defined in the WHOQOL manual. It some ways it could be reflected indirectly within the module items empathy and understanding, as well as by other candidate items that capture the ways that peer support workers perform their roles - with more of a strengths based focus, showing evidence of accepting their diagnosis, and exampling prosocial adjustment, demonstrating recovery progress by their presence as role models, and their role's purpose of helping people believe that recovery was possible for them.

> PC1: "Definitely (*Peer Support Service named*) was the one for me. Was the first place I went to. I couldn't believe I was actually going to ask a service for help. …And they were so beautiful to me and supportive. I just thought, look at your surroundings man, these people are here to help. So I am, yeah, I am…. thanks to (*Peer Support Service named*) If it wasn't for them, I wouldn't have reached out to support meetings. Wouldn't have reached out to (*Peer Consumer Network named),* (*NGO service named)*, yeah, I'm blessed now. And I just keep trying and trying every day."
>
> CC10: (*in reference to peer support workers*) They helped me to understand, to do things. They help me nicely, where they don't demand a great respect. Like they'll suggest something, and I'll say, "yeah, I'll give it a try, but if I can't do it don't force me into doing something".
>
> CC4: "Mixing with people that have issues, I find that easier than mixing with dare I say the word 'normal' people, mixing with people who have suffered too and are coping with mental illness is actually easier than the 'real' world out there at times, there is a connection because they have walked in their own shoes through things like that to, I grow through mixing with people who've had their own issues, you can sort of bounce off each other, yeah."
>
> CC3: "Somewhere where flatmates are not drinking, people share the cleaning, when you are sick you've got nowhere to go, the system gave me somewhere to live that was safe when you had mental illness, which was good. QoL was being able to source a nice place to live. And long-term things I learned from that, you support each other, you clean dishes, you clean the bath. When you have got no money, nowhere to go, and you get helped out to live in this nice place, and so later on, down the track I figured out how to get more money, it's still hard, I live in a nice place now, but it's a

real process to find somewhere else. I managed to, I worked. I think the way they do it now, with peers living together, it was a good process for me, it was fantastic."

PC3: "There are quite a lot of different services now. You have Peer Support workers, those who have been through the same journey, coming alongside and walking the same journey. And they are learning from each other, it's not an us and them. There is no hierarchy or anything like that, it's a level playing field…."

TC2: "Yeah. It's healthier. It also made me look at her differently, because she had a bunch of strengths that were just not even in the friendship that we had had up until that point. So that's resilience. It's how she gets by and lives the life that she lives. So, she had a whole store of things of experience, knowledge, and wisdom that she could, down the phone. Because she can't get out much either for the same reason. She would communicate to me that was of huge comfort. I knew she knew exactly what was going on for me. So, it was totally awesome. So that whole thing about kind of the reciprocal nature, being really important, peer support. Now I'm better. It's not gone back to the way it was. It's forever changed the nature of that relationship; I think in a really good way."

WT9: "…. I've got a friend that we phone each other regularly. She phones me at least twice a week, and she would allow me to phone her, in quite a lot of distress. And she would be able to deal with that. So, with that, I'm using my will, because she suffered from the same sorts of things that I did, like agoraphobia. And I actually helped her overcome hers."

WT4: "And trying to do social things with my friends, basically, so I can reconnect with them. I've found having the peer support really useful, and that's helped me get out of the house to do stuff and getting that support from someone who's gone through mental illness into recovery and managed it themselves and being involved with [*Name of NGO*] has helped."

WT6: "I've had nothing to do with my family for 20 years. I have a lot of support people, people who have travelled the same journey as me, people in this room are doing that. [*Name of NGO*] as well, and they understand me for who I am, and I understand me for who I am. So, then I can carry on. "

WT8:" It was like connecting up with other people who had a similar experience to me. I found that really, really helpful, and being part of the *Young Voices Network* and things like that, I think was really quite helpful for me when I was much younger, because I felt really isolated in my experience. So, I think some of it was meeting up with other people who had similar experiences and being able to talk about things, together with people who understood."

Participants who had worked as peer support workers also described benefitting from being in this role. They spoke of working in the mental health and addiction sector and helping others to recover from the issues that they had experienced added meaning and

purpose to their lives. They spoke of a greater sense of social belonging, feelings of social acceptance, and of empathy and understanding from, and for others, within a role that they valued. This was also reflected upon within other module items such as understanding and empathy, the ability to connect and relate to others in authentic ways, and the candidate item of stigma - when advocating against stigma or discrimination for people in services. Themes within the NZ national items such as - belonging, respect, and control over one's life - as well as the WHOQOL-BREF item - meaning and purpose - were often reflected upon when peer support workers spoke about the work they did and by those who received it, when talking about the value of having a person with lived experience support them.

> KILGBT: "I think working in this sector and knowing or believing anyway, that I have made a difference in other people's lives, has made me a vital…person. It's put, um, meaning and purpose into my life. It's made me, it's increased my self-belief that I fulfil an important function in some people's lives. In coming back from after being off work, 4 weeks after a major operation and the reception I got from so many people was, God I mean, it's amazing, the knowledge that people actually care about me. It is brilliant, so it is really lovely to be feeling cared for….. the people I work with. So, that, how could you not be pretty well maintained mentally and emotionally, receiving that. Pretty difficult not to."

> RCG2: "Yes, supporting others can help you too, giving part of yourself helping other people, because when you go through that, you are finding understanding of others too."

> CM5: "We use the term Peer Support, that now, there are a lot of services where people with lived experience are employed to help other people, and (*name of group member*) will know about this and I think it is a fabulous service, because people like me can help other people, because I understand where they are coming from. Not only have I been there and done the journey. I have done the hard yards and I have grown tremendously from this thing called Mental Illness."

> TC3: "That's true. You are, I think when you engage with people, you really engage with people. And you see past... I reckon, actually, after these experiences, you do see past the facades of people, in a good way. Like it's okay to see that. Well, that's what I found for me. Was like, suddenly my sight had been changed. I just saw everything differently, but people especially."

M.7 Goal Achievement

As discussed in the first item discussed in Chapter 7, participants talked about their mental health crises as being like an existential crisis that suddenly changed their life in many ways. This resulted in having to reconsider their previous personal and life prospects after receiving a mental health diagnosis. This for some changed their sense of certainty about their future, created new uncertainty about what goals and plans may be affected or could be set, and placed more overall uncertainty about developmental norms and ordinary life objectives that could be threatened, or no longer possible once having this health condition.

Goal setting and achieving is a common activity during mental health service provision to support people to recover their lives (Carr and Higginson, 2001; Rose and Smith, 2018; Tabak et al., 2015)). Participants talked about setting and achieving goals as being a way that they found a positive future to focus upon. Goal setting helped them to regain positive expectations for the future, to recognise they had ability, and could regain some control over their lives. Many also discussed themes connected to other candidate items when discussing this recovery facet - such as hope, resolving fears of relapse, recognising strengths and abilities, and making recovery progress - as they moved towards and achieved their goals. The NZ national item of - control over life - was also one spoken about that became more satisfying for people by setting and achieving goals.

This item did not meet some of the CTT analysis criteria as it correlated with the NZ national item – control over your life. The national item also correlating with three existing WHOQOL-BREF questions – to what extent do you feel your life to be meaningful, how satisfied are you with yourself, and how much do you enjoy life? The question about goals also correlated with existing candidate items – to what extent do you feel you are able to cope with daily life and to what extent do you feel positive about your future? Yet it was retained

for Rasch analysis as those other candidate items were removed by CTT analysis and the correlation with the NZ national item only was insufficient reason for it to be eliminated if it still performed well during Rasch analysis for a module intended for use with the WHOQOL-BREF without the addition of the NZ national items. It is being included in this section due to the mandated requirement for goal plans to be routinely included in the service provision requirements for NGO mental health services. It is noted however that there are many ways to ask about QoL items and the IRT analysis has revealed items in the module that implicitly cover the focus of this item by asking about recovery progress (as goal progress can be measured through this item). As well as implicitly through the above WHOQOL-BREF questions that may ask about different types of goals, i.e., those that help life become more meaningful, enjoyable, or improve people's self-esteem and self-worth.

Participants with the experience of working within the mental health system discussed the dissatisfying aspects of this recovery facet. They noted that service agendas to emphasise setting goals as a solution for all service users, resulted in problems, when some service users were not able, or willing to be goal orientated at that time. This had the opposite effect to having control over one's life when other people were setting goals for them, or forcing goals upon them, that were not meaningful to them just to satisfy routine mandated service requirements.

> KILGBT: "I think having, for many people, having, for a broad brushstroke, having someone to talk to things about. I think about most of my practice, having goal plans is something that CSW's want us to do because the contract says you got to have a goal plan. But generally speaking, what people most want to do is talk about the last week. They want to talk about what is on top and help them problem solve, that's…For most clients that's what it is about, practical support, to get them place, to do things they want to do, they need to do. And it is just having someone to dump what has happened last week."

> TC3: "And the future. The future looks different, and they have to reinterpret it…. I think what I was going to say, I absolutely agree with you, but it changes throughout your life … the bits that are most affected…. But initially it was that rewriting my future…"

> KILGBT: "Yes, yes, and that's for, for many of us becomes a tension because, um, we are constantly told we are a recovery-based service, and therefore providing QOL support can become very unsatisfying perhaps …constantly trying to strive for goals which we are told that is what we are there for. Which I tell, the message that is what we are there for. How are we changing people's lives when you can't do that? It can become more difficult." …. "I am talking about people who have got Schizophrenia and are managing symptoms with medication. So, they are fairly non-symptomatic, but they have little ambition or drive to change the status quo. So, it would appear, that there is not much going on."

> KILGBT: "They're not thinking "I need to go and change" or "I need to go and do something" or "what am I going to do today?" It's a case of getting up, having a cigarette, having something to eat possibly and just watching the hours tick past. That's the way it appears to me. And, when you offer alternatives – have you thought about doing this, or what about doing that? – they don't want to engage in very much at all. Having somewhere secure to live, having enough money to come in to manage to buy tobacco first, food second, pay the power bill third. They are the priorities. That is what appears to be their priorities, I can't say actually but that appears to be the priority. It's about having security."

Participants who spoke to the satisfying and positive aspects of this recovery factor talked about goals giving them a positive view of their future, something to aspire to, and work towards. They spoke to having an increased a sense of control over their lives when they set and achieved goals. This recovery factor was closely linked to the NZ national item - control over one's life - and the tensions spoken about in the previous section also speaking to the lack of control over one's life. Setting and achieving goals was also discussed in ways that related to their ability to find the WHOQOL-BREF facet - meaning and purpose in life.

> CC10: "I get on better with the mental health, being under them. I think with the straight people, they don't seem to understand, in I'm doing the best I can do. I'm trying to do everything which I've been told to do. And I'm just trying things out and seeing how I go. Yeah. I will know when I'm ready to leave the mental health and it's not quite yet. I still feel I've got my goals that I've wanted to achieve, but if I fall back, at least I've got someone to fall on. So yeah. I want to be a peer support worker. I want to try and do one of their courses. I haven't been to school for so long. It's just going to be really hard. Getting up at a certain time. Going to it and sticking at it. The good thing about it is for me, I get a certificate at the end of it. I don't think I've ever had a certificate in my life. So that will be really good."

> PC7: "In my recovery I was able to find out, well I got direction in my life now. Cause I really had no direction, I was lost, hurting. And because I got that direction back, I just want to be out there. .... So yeah, its direction for me anyway, because I

> know where I'm going in life. So, I hope, I just throw it out there, cause we all need direction."
>
> PCL4: "So, you know, (*referring to his peer support worker*) he's didn't have any particular skills or training. But he just had the ability to make me believe that I could achieve goals. I could take some small steps, you know? So, he helped me take the initial steps."
>
> PCL4: "So, by just watching other people operate, I've seen some people are able to embrace what that person wants. So, it's about embracing what that person wants and coming from a solution discussion and being optimistic with them. And then they're like, oh, you just GET these people. Then the light goes on. They're like, I have some elements of control over my life. And that's powerful."

M.8 Hope

Hope is a predominant theme within the definition of mental health recovery within the mental health recovery literature (Bonney & Stickley, 2008; Ralph et al., 2000). Faith and hope that someone can recover was highlighted as a foundational requirement for a recovery orientated service by several mental health researchers (Anthony, 1993; Damsgaard et al., 2021; Davidson, 2016; Slade, 2010). Hope is something that a person themselves needs to hold (Deegan, 1988), is an inherent part of the personal recovery process (Leamy et al., 2011), and something others around them need to hold (Randal et al., 2009), for that person to recover.

This specific item (MH15) that asked about hope by asking people to what extent they felt positive about their future did not meet CTT criteria. It correlated too highly with three existing WHOQOL questions asking about – how much someone enjoyed life (where hope was within the facet descriptor), how satisfied a person was with themselves (self-esteem), and to what extent they felt their life to be meaningful and the NZ national item asking to what extent do you have control over your life. It also correlated with existing candidate items asking about the ability to cope (MH8) and the extent a person felt confident they can attain their goals (MH17). This way of asking about hope was not the only way of asking

about hope – the two other questions asking about belief in recovery and making recovery progress were identified by Rasch analysis as performing better for a MHRQoL module for this population.

Hope can be naturally embedded within other determinants of recovery assessed within module items such as - making progress, believing in one's recovery, recognising one has the strengths and abilities to recover, and other candidate items such as having a positive outlook for the future from having goals and aspirations for life beyond symptom relief or relapse prevention approaches to life. This was observed within discussions about other MHRQoL candidate and module items. Further quotes about hope have been included in this section due to the theme of hope being so integral to the driving force of recovery and, as discussed above, its frequent mention in the personal recovery literature as being important to encourage and facilitate during service delivery. Participants in the discussion groups spoke about hope being something they lost at times, had to recover, and that other people held for them when supporting them in their recovery. Peer Support workers talked about some of the systemic issues related to hope for people with more enduring, acute, or disabling symptoms.

> PCL4: "so somewhere in the middle, we might have somebody who's had the first episode of bipolar or maybe you know, delusions of, of reference for the first time I guess a significant area there that that has impacted is Hope. There's a lot of fear and anxiety around hope, … and tied into hope is the ability to achieve anything that has meaning for them. So, feeling very, ineffective … to have power control over their life, to achieve goals that they want. And it's, it all seems to come under and the hope. There's a lot of love that goes on with the CMHC and a lot of good, good people. And they will say something like, yeah, she's really high functioning, which is a terrible term, because people in mental health, okay, what's high functioning? And people will, what will happen is we've got people and they'll say I've been rated as high functioning. And they get a lot of hope from that. But then there's the side of people that go, well, what's wrong with me? What's going on there? You know? Why are these people so special? So, while some derive hope from it, others don't."

> KILGBT: "If someone has had a better life in the past, then you can say, well, this is where you were before you …. you had this and this and this, that's what we want to get back to. We've got some hope. If you've got someone in their 50's or 60's who had early onset schizophrenia, it's always going to be harder. They have got nothing to pin their hope on because they have never had it before. It's always been like this before, and it always will be like this. So, it's being able to identify the people that

> you need to give that extra push to. Having said that, it doesn't mean to say you write the other people off. Which, yeah, that sounded like what I was saying, but it is not what I am saying. But that is sort of a reality. There are some people that you are going to get in a service, hopefully, give them a couple of years and they are going to be able to cope, manage and thrive in society."

Research has highlighted that a progressive deterioration of satisfaction across increasing facets of QoL is a precursor linked to people who attempt suicide (De Abreu et al., 2012; Ponizovsky et al., 2003). A loss of hope has also been linked to depression and risk of suicide (Liu et al., 2015). QoL PROMs in this way can be also used as clinical risk management tools. For example, the WHOQOL-BREF facets - overall quality of life, negative feelings, along with an increasing number of QoL facets being rated lower can be potential markers of a risk for suicide, unmet clinical needs, or relapse for a person with mental health problems (Alves et al., 2016; De Abreu et al., 2012; De Freitas Melo et al., 2022; Ponizovsky et al., 2003). Participants who spoke about struggling with being able to hold hope for their individual situation spoke about it in relation to their particular diagnosis, what they were recognising among their peers, and how loss of hope can lead to cases of people taking their lives.

> RC1: "No, and it doesn't necessarily get better either. It can get worse. It can affect you, less often, but when it does affect you, it can be quite severe. So, it's quite difficult to maintain hope, which is a lot. People talk about hope a lot in recovery. And staff talk about holding the hope when the person doesn't have lost hope, and I think that's really important."

> TC3: "I think of the people I know, who have taken their own lives and I've known a few, and they didn't have that anymore. That, thing in their life, that person or people. And i think they, and I've watched people drink themselves to death as well and shoot up themselves to death. Similar sort of thing. They had lost hope. They had lost their sense of being important enough to somebody.

> PC2: "I just been at (*named CMHC service*) the last 6 years, so I think I learned a lot from the people there. Go for my IMI and medication, just, yeah, I just made friends there. I think we are all on the same journey. That is what I have come to understand and believe. Just waiting for that day, you know, that day I suppose where, you know, just being surrounded by your immediate family and hopefully things will come right there for me. Hoping that will happen. That's what I need to say. It's just things like

> we are all striving to be a better person. And they are there, most people are there, just like me getting the IMI, getting the IMI every fortnight, they don't seem to be struggling, …hoping for a better life really. Hope."

When participants spoke about the satisfying or more positive aspects to the experience of hope, they spoke about why hope was important to recovery, as it offered people the potential for things to change for the better in the future. This then allowed them to find the will do things that would help them to move forward, which brought about an improvement to their quality of life. Hope could be an aspect of the module item - having a belief in recovery, the candidate item focussing on - the motivation and determination to recover, and the WHOQOL-BREF facet finding - meaning and purpose in life beyond the experience of it as a positive feeling as it sits currently within the WHOQOL-BREF.

> KILGBT: "Hope, a belief in themselves that things can be different. Knowledge that, knowing that it can be different, that it doesn't have to be like this for ever. That's the most important part, having self-belief and some motivation."

> AE: "A lot of people talk about hope. Hope is huge. A lot of people talk about belief, somebody believed in me. All those things that are kind of counter to what I was just talking about before, about the low expectations and you know, kind of being doomed really."

> TC2: "I think it's about finding hope. That's about the things that you value."

> PC1: (*in response to question about what about hope was important*) "…there is something more to live for. Keep trying, keep trying, that's what it's all about. "

> PCL4: "It's having someone be there who, who's optimistic! You know, I use optimism rather than hope. But yeah, just, just optimism, you know that people can, you know, you can have that meaningful life and it's okay whatever that meaning is, as long as it's, you know, as long as you're happy with it."

M.9 Loneliness

Loneliness was a question that did not come from the original codes yet was often discussed in the discussion meetings in the context of social isolation, withdrawal, and lack of capacity or opportunity to be in relationship with others in meaningful ways. When

considering how to language the item greater social networks differently than the social support facets in the existing WHOQOL-BREF were written, this item emerged based on how people were discussing this need for greater social connection. In this sense this candidate item can be covered by the module item - relating to others - as well as items in the NZ national items such as – belonging - or the existing social domain questions within the WHOQOL-BREF - satisfaction with relationships with family, friends, and personal relationships. Some of the participants with lived experience of mental health and addiction issues discussed times of intense loneliness that are exampled in the below quotes:

> CC10: “I've been very isolated. I just stay to myself. I don't really go out and about at all. So, I don't have any family, or friends at all.”
>
> KILGBT: “I think the isolation that people with a mental illness experience. That probably comes from a lack of confidence and going out. It probably comes from having been rejected from other people, multiple reasons.”
>
> PC3: “When I first crashed it was fantastic, all these TV dinners and food parcels and stuff had been left on our doorstep. But people stopped … so, there was a terrible isolation…many of those, years ago.”
>
> PCL4: “You know, you’re going to be scared of these strong emotions. You've got to introduce an external physical object to correct the brain chemistry. and some of that works, it's certainly worked for me, and that's great, but it didn't take away my inability to form relationships with people that had led me there in the first place. Fear of being different because my parents were divorced, is pretty much where it all started, you know, and the traumatic event of my father walking out. So that's the event that happened. And if that had been dealt with effectively and identified, you know, I probably still would have needed medication, I don't know. I can't say, I'm not, I'm not anti-medication, but you know, it certainly didn't cure my loneliness**.** I took those pills. I felt a lot more confident, but I still found, I was still only letting people in a certain distance, then detracting them with an appropriate humour, so they didn't get too close, and they pushed off again. They bring them back in, you know, this whole thing of bringing them back into, see if they come back, toying with them because I've been pushed away. So, I'll bring them in and then push them away. So, I had that, you know, so that's, that's where a pill, didn't help me undo that.”
>
> RCG3: “Definitely, I think I, basically I had turned off all my emotions, that I did not allow myself to feel emotions, so I was self-harming, and yeah um, but, because yeah, I had no friends, just really really lonely.”
>
> RCG5: “I do feel isolated and my life from where I am living now, um, my previous lifestyle, um, it’s now different, it has for quite a while. It was, I suppose I can say it,

> smoked cannabis, a number of years, so I hung out with, those particular people. When I stopped hanging, associating with those people, there was no one. All those people that I knew from my Youth to my older years, well not that I am that old, I have just turned 60, mid-50's …or my, 50's actually, I stopped doing drugs and I didn't have that bond with all those other people that I was associated with. So, it is very hard to try and make or become friends. To find friends. So that is one of the things with me."

Participants also talked about their experiences of trying to alleviate loneliness or resolve this experience for themselves that improved their mental health and QoL:

> WT3: "I've found that one thing that really helped me was, I had a little cat. And, she was my constant companion, she was not like a cat. She was more like a little dog; I trained her to do things. And she was so lovely, and at the beginning of last year, I had to have her put down. She had; I think it was liver problems. Because, and the vet said, "Oh, I could do a blood test for $80, but you realize it's a tumour." I said, "Look, the cat's suffered enough. Just put her down." And I thought, I was devastated when I lost her. And I thought, "I'll never cope without her." But funnily enough, I've actually found strength to deal with life without my little companion. Now I've got room in my life for something else. I was going to do puppy walking, for the guide dogs, but they kept me waiting so long that, I noticed there was an article in the paper for detector dogs, and just recently, they had another article saying they only got one family, so I thought, "Right." So, I've written in and applied for that, so I'm waiting to hear back from that. Yeah. Animals are really, marvellous therapy. Stroking a cat, lowers your blood pressure and everything."
>
> WT3: Animals are really, marvellous therapy. Stroking a cat, lowers your blood pressure and everything.
>
> WT4: They've done studies, I know, to show that.
>
> WT3: Yeah.
>
> WT4: It's helped with mental illness.
>
> WT4: I found my cat's really good when I was living alone, especially, so.
>
> WT3: Yeah. They are affectionate and they don't judge me.
>
> WT4: Yeah.
>
> WT6: They take all the crap you give them. [*Group laughter*]

The resolution of loneliness can also be recognised within the discussions of the candidate items relating to others, receiving empathy, and understanding, and when people started feeling more connected socially again when re-engaging in their life. Re-engaging in life can be reflected by a pattern of responses being seen in a QoL PROM - satisfaction with

more facets within the WHOQOL-BREF meaningful to that person or the NZ national item of – belonging.

M.10 Having things to do

This item was discussed in ways that highlighted some of the inherent barriers or realities for people receiving mental health services, as well as in ways that people themselves tried to resolve this issue to improve their mental health and quality of life. People talked about being compromised at times by medication reducing their capacity to do things, having too few resources or opportunities to do things when not working, there was a greater need for the relief of boredom through the circumstance of unstructured living on low incomes, with no work, meaningful social roles, or personal relationships.

> KILGBT: “They don’t do anything. I think a lot of people spend a lot of time doing very, very little. I’m thinking of a couple of people in my mind, and they seem to be in a state of suspended animation. They smoke and they just do a lot of, very, very, little. “For some people is you get them out of bed in the morning. I think for many people there is a whole lack of structure to life. I’m thinking about some young men who were in our service that were living at home with their parents, and they were, you know, in bed at 1pm in the afternoon. They probably stay up playing play-station games all night long. So, the structure in their life was turned upside down – there is no structure. I think if people can get some structure in their life and have a reason to get out of bed in the morning, a reason to not stay up all night, there is a whole better chance of, of recovery and change in their life. Cause I think having gainful employment, or groups, or things to do during the week is really, really important. People need structure, reasons to get up, reasons to do things. So, the people who make better recovery’s have more……prospects…. people who have a better structure in their life have some expectation of doing things and they want to change.”

> WT2: “…because I had to stop work, didn't have the income, didn't have that self-esteem of going to work, and then you also start spending more money on the internet and shopping, that kind of thing… it was a compensation, really, because I'd been busy, busy, busy, working. And then, when I wasn't working, you're bored. What are you doing? You're trolling the internet, you're looking at things, you may be buying to make yourself feel better, and the internet allows you to do shopping without actually spending the cash, which is, I want to say, it's spending money without actually spending money. So, you're not really counting how much money you've got, so your credit card mounts up, and you're not passing cash over, which means that then, you're not thinking, "I really shouldn't be spending this money," because internet money is really not money.”

> PC8: "Well I personally like to keep busy; I'm always doing something. If I'm not working, I'm doing craft or I'm on the computer. I have a little bit of a problem at the moment because I have this large dose of medication, it's affected my skills. It's made it very difficult to function."

When participants spoke about the resolution of this candidate item theme, they spoke about recognising the importance of having things to do each day gave them structure to their days, a capacity to feel a sense of achievement, or as ways to improve their mood and wellbeing. This candidate item could also be reflected in a person's satisfaction with the 'activities of daily living' facet within the WHOQOL-BREF.

> PC8: "I've found it's important to keep an organised life …. have a few ideas of what you are going to do the next day. Organise the things so that you can do then. And tomorrow you will have a little success. Very important. Like today, I got up and I did my housework, and I had a shower and got changed and I came in here. To a lot of people that wouldn't say much, but it is an ordered, structured life."

> PC3: "A similar sort of thing – I actually have a little pocket diary of the things to do… like, as a reminder. Things, one of the things that have helped me is things, is like basic things like eating properly…sleeping properly, trying to go to bed at the proper time. Changing from the pressure of perfection, which I used to be a terrible perfectionist, to one of excellence. Quite a paradigm-shift. One thing, akin to journaling, was actually writing poetry – I have done that for 4 years now. And love it. My next project, I've been challenged, is to write a book. And so, I would like to write a book of recovery….'There is hope'."

M.11 Exercise

It is widely understood that exercise is helpful to people's mental health and overall health and wellbeing and may be prescribed or recognised as helpful by recovery supporters (Ristau, 2020). Participants did not frequently talk about exercise specifically, as a significant part of their restoration of mental health or quality of life within the discussion groups. When participants did talk about it, they also did not discuss exercise as having any negative impact upon their mental health or quality of life. Participants with lived experience within the Phase 1 discussion groups spoke about exercise helping them with mood management, as a way to manage specific symptoms of their mental health diagnosis, or as ways to improve their overall health.

CC1: “Walking, watching TV, reading, resting, changes how you feel, sometimes you need a certain amount of exercise in a day, or you can feel anxious. It helps me feel better.”

CC2: “Getting some exercise … trying to do some exercise, walking, yeah. Instead of staying up all night cleaning my house because I had heaps of energy. So yeah.”

CC10: “Playing my sport, I find it can release negative thoughts in energy, I suppose. And it's a good, healthy way too.

CM4: “I need to get regular exercise, good hard exercise 3-4 times a week… So, I am much healthier, because I have to be, if I don’t get out and exercise, I feel horrible. I am grateful for it.”

RCG6: “Exercise, is good, exercise. Therapy.”

RC1: “I, like to get a decent amount of exercise. That really helps me.
“I like to walk, so I do a lot of walking.”

M.12 Spirituality

The spirituality candidate item did not discriminative between those with and without mental health difficulties, so was not retained after CTT analysis. It has been included for discussion in this section because the theme the item was asking about remains important to the restoration of QoL for some people and cultures during their recovery. Spirituality has been associated with benefitting both quality of life (Skevington et al., 2012) and mental health recovery (Lucchetti, et al, 2021). Reviews have highlighted that some of the benefits of spirituality, religious beliefs, or practices include improving people’s coping mechanisms to deal with difficult life crises and daily challenges associated with mental health problems, can help to improve people’s mood and symptom presentation, offering opportunities for social connectedness, increase people’s sense of meaning and purpose in their lives, as well as having added physiological benefits (The Mental Health Foundation, 2006).

Some participants in the Phase 1 discussion groups reframed their mental health problems in terms of them being an existential crisis or ‘spiritual’ emergence. Participants

who discussed mental health problems in this way spoke of it as being transformational for them. The mental health crisis had changed how they viewed themselves, life, others, what was important and the meaning of life for them.

> CM3: "I personally question that term *mental illness*, and the way I have approached it, has been, seeing it as a spiritual crisis that needs to be addressed and resolved. To use old fashioned terms, my soul or something somewhere knew that something had to change, until that was addressed, and reengineered, and followed, then the bad feelings wouldn't go away and now mostly, they have …. But it has been hard and scary, I wouldn't have made it without that support, it got very close."

> *When discussing what is unique about mental illness compared to other health issues:*
>
> T2: "…If you want to be really spooky about it, it borders on the spiritual…. It's like a disruption in your spiritual existence in the world. And that carries with it enormous power. But it also in our societies are really scary because we have disconnected from that, certainly in European society. Because, in other countries, that really treasure their folk who might, otherwise, we would say are completely off the planet and suffering from mental illness."

> TC3: "I think that's true. Interestingly enough, one of the things my grandmother used to say to my mum when I was in my teens and early 20s, was that she should get me exorcised. (*Laughs*), so, ..., people call it psychic attack as well or spiritual crisis. Definitely, you're absolutely right. There is something about that. There's this thing, I know other people feel it too, not everybody, who experience mental health problems or things like that. But there is a thing where you feel like somehow all you can feel is the world's sadness. The whole world's pain and sadness that somehow you know you're absorbing it or picking it up. And you wonder how people aren't feeling that. And also, how you can carry this. So, it does feel like that. That is true."
>
> TC2: I think you lose all your filters.
>
> TC3: Absolutely
>
> TC2: You lose all your filters. And so, everything's just like ... Poof!
>
> TC3: You're right. Because everything looks different as well. The colours are different. The sounds are different, things taste different. It is, it's an alien world. It's a weird thing and terrifying.
>
> TC2: Intense.

> TC3: "For me, I think there's not enough done in mental health places. Addiction does it better. But in mental health places, about spirituality, that we haven't understood the importance of that for a lot of people. So, it's often been a kind of missed somehow. And I do think today as a society, we kind of miss the norms of, well, for us, it was Catholicism when we were girls, as deviant and weird as that was, it was an external belief in something bigger than you and more important than you. And I think that there's a lot of lost people that, could do with support. I know a lot of the things I've made sense of my experiences and sometimes survived my experiences, because

> they've had a spiritual meaning to me. A couple of times I felt like I've been rescued by angels, from just surviving that moment."

Not all discussions about spirituality however were positive. For some people, other people's beliefs about spirituality and it links to mental health problems increased social marginalisation, feelings of being shamed by their culture, or of being an embarrassment to their family. Existing beliefs of people around them were challenged by their experience of mental illness in some cases. Some felt compromised when trying to access support for their mental health condition if religious beliefs or spirituality was incorporated into the services.

> RCG5: "I've been going to a group called GROW…. It is a 12-step programme, like AA, or NA, or all of them, however, they are more about mental health. Mental health. And it does work quite well, the only problem that I have it, that I have with it, which, some of you will not agree with, is that I can't do this God thing. …. Like I say, the only thing that gets me, is that they all want, they are talking about God all the time. Because a priest founded it. So, he, of course went that way."

> TC3: "The biggest thing is that people make meaning of what's happened to them. And for a lot of us, that does contain a spiritual element. And it's not often talked about in services. My last psychiatrist did. However, she was a born again Christian, it was a bit much. Didn't quite align. But. For me, there was the making meaning stuff, that is the most important thing we do. And you can only really do that well, with your own people."

> CM6: "Well I don't know…my experience it is all, shh…. keep your Wairua, it must be you, you walked over somebody's garden or whatever. You know, you didn't shame the family or whatever."

> WTF: "If the family had proper education, they would have been, much more capable to support, because when he began to deteriorate and get worse, you know, people came up with different ideas. It was said he was demonic, that the devil had come into him. He went, to the wars, and got devils, so the devils were disturbing him. And there were different opinions. And still, in the villages at times, they were now going to get the local traditional healers to get involved. And all of this made the situation more complex and more frightful... You're not able to take the tablets and swallow them and you feel …better in three hours. It's not like that kind of a thing. All of that education and explanation, you know, really helps the person, the service team, the family support, and it helps the family to stand strong, because they know what's going on, and they know that this is not devils, it's not demons. You know that kind of thing. But when people are in the dark, you know, anybody says whatever, …they just accept it. Things like that."

> WT2: "Yes. That. I'm speaking a lot, what she said triggered a thought now, because it definitely does affect the spiritual as well, because I lost my, apart from losing my

> mind and my physical health, I lost my spiritual health, in that, I didn't, I couldn't be true to myself. I didn't know that I wasn't being true to myself, because I was experiencing things that I didn't know that I was experiencing... If I use an example, in my, not necessarily spiritual practice, but in being true to myself, I was seeing the world in a totally different way, and I didn't realize that I wasn't actually using my belief in a spiritual being to my own benefit. So, it was like a sort of, "why is it happening to me?" "God's punishing me", that kind of thing. And that didn't really happen to me before because I've always been a strong person. I've had a strong family life, I've had a strong financial background, strong education, work, all the rest. Everything like, was just in place and stable. But as soon as the one thing started crumbling, I started blaming the spiritual side. And I kept on thinking, "Why am I being punished?" And that then comes back to un-punishing myself, and it was going into my body and so my mental and my physical and my spiritual way of being, was being triggered on that, very much. And I've never thought of it that way, and what you were saying, is right."

Some participants spoke to the satisfying aspects of this candidate item by discussing the role of their personal spiritual or religious beliefs as a way of helping them to make sense of, or feel supported through, the difficulties they were experiencing. Participants also spoke about the social parts of belonging to a spiritual group or religion. This candidate item appeared to be often spoke about in the context of discussions about other candidate items, such as - personal growth and transformation, as well as the module item - self-awareness/insight, the WHOQOL-BREF item - social support, meaning and purpose, and the NZ national item - belonging.

> CC3: "What keeps me going, is I meditate, 3 times a day, transcendental meditation, take fish oil, exercise. The meditation I do is about relaxed awareness, and to de-stress. So, I've been learning it from 20 years old, I am 39 now, so about 20 years I have done meditation, I wouldn't have coped without it, it is more than a will thing, it is deeper than that, I have to do it to cope, I do it because I have to, I do it because it is good for me. It helps to process things, I wake up and do my meditation and then if stressed at lunch time I meditate, it helps it really does."

> CC2: "Going to church, meeting different people, good friends, you make new friends there, people who visit you at home and if you have some problem, they can pray for you sometimes."

> CC3: "Being positive, having spirituality, to sing, pray, that helps with being anxious, and feel connected to the light, the wind, to nature, having a spirituality is important to mental illness, connecting to your higher self. So, one of the positives, QoL from process of recovery is being Christian."

CM4: “Figuring out what your soul wants to create? Future Direction, what it is that satisfies you, in contrast to what’s depressing me?”

PC7: “…By the grace of God… now 19 years and I’m not going to start. I had to walk away from it. It took a life sentence to wake me up I suppose. Here I am smoke free, drug free, 19 years later. I got a bad habit, I can’t ...counsellors …. don’t worry you can do psychology…psychology helps me not go back to the old world I came from. I sometimes see my gang mates and they say would you like to come back …. I say I’m in a bigger gang, God’s army. That’s me, but I’m just happy to be here today. Happy to meet new faces, I just love and respect people…. doesn’t matter what gender, doesn’t matter what colour of skin colour or language. Show love and respect because people…I thought I would just share that. Great to be on the other side. I’m hoping that the door is open for me to go back into the prisons to minister to people. That would be a rush.”

PC8: “Anyhow, I gave up prostitution and I went to Church, and it’s been 15 years since I left the streets. Those 15 years have been spent in the Mormon Church where I have had a lot of support, but I have still had those admissions to hospital at Christmas time, you know, which I resent.”

PC7: “Our Church, not so long ago, had an awareness on suicide…in families, it’s real. There are a lot of hurting people out there and they need love and acceptance. Not locking them up and throwing away the key or putting them in hospitals. So, you know, good on you.”

PC3: “Something that really helped me was, the first time it was, there was a group of Roman Catholic sisters who came one Sunday afternoon. I didn’t know they were coming, and they did a lot of singing, and that really lifted my spirits up no end. And then another time I saw a locum at my usual GP, that I haven’t seen before or since and she prayed for me afterwards, and that had the same effect of lifting my spirits up. Totally different to the pills….”

PC3: “Yeah, there was one verse I really hung onto, Isaiah 45 verse 3….it says ‘I will give you the treasures of…riches stored in secret places so that you will know that I am God. And so there is…. diamonds and rubies, I’m a precious jewel…that are in the deep dark parts of the earth. Well diamonds for example, ……created through pressure and heat, and is changed into the hardest and most precious of the jewels. So, it’s been sort of lessons, it’s been learned through that tough time.”

RCG4: “Do you think that church can be helpful in this kind of, for mental people, for us people facing these kinds of issues, I find that church can be helpful as they are also focusing on this area of human expression or human spirt and soul … I find prayer, church very helpful.”

RCG2: “I find church helpful too.”

RC1: “Well, I've had, I went to a spiritual healer once that was really helpful. I joined Shaman at some, as I mentioned before, that's been really helpful for my recovery.”

> RCG4: “So it is kind of like … kind of like what you call spiritual growing and personal growth, personal development” “… basically you become more spiritual, more, you know intuitive, more, wise, you know, yeah.

> RCG1: “You know what God does? If you go to Church, and you, go with Christians, good people, Christians, every religion, you know Baptist, Brethren, all the religions, you are either an atheist or you are a Christian. Now all Christians are good people. Now I believe, when you mix with a Christian, they heal you. When you mix with a Satanist Priest, they prod and poke you …Satanist Priests. That was the reason you were hearing voices, it was Satan and his worshippers, that were getting into your brain. Not Christians. They don’t poke and prod you. You were being poked and prodded in your own subconscious mind.”

> RCG2: “Yes, I find going to church is good, it is like a big family, even though they don’t know what I am going through, because they have no idea. “

A participant described the role of their religious beliefs, and what they believed would support their recovery the most, was also something they considered that some people may attribute to a symptom of mental illness. When people were supportive of this belief, this belief helped to facilitate their recovery in more satisfying ways than the more traditional treatments being offered did. This account highlights the importance of considering and including a person’s spiritual or religious beliefs when providing recovery orientated services to them, to help them to resource themselves in ways that improve their QoL and recovery.

> RC1: “I have a belief system as well, that people may be of the opinion that it's to do with mental illness, but I believe it's to do with spirituality. …Well, I am interested in, and I am involved in shamanism. And since I became involved with shamanism, it's really helped my mental illness, mental health issues. And I really find it very good; and I believe that I'm engaged to the spirit of the wind, and I'm planning to have a ceremony about that next year. So, most people that I tell, are really excited for me, and know how important it is for me. But there would be some people I wouldn't tell that information to. Because I would be afraid that I would perceive that, as being a mental health issue. …Acquaintances. Yeah. And I have told people in services about it, and I'm not sure how they perceive it, and I don't really care. Yeah. But I will be very careful about who I invite to the ceremony. And I will only invite people that I believe will truly support what I'm trying to do to it.”

One participant also spoke about spirituality in the context of describing a helpful therapeutic alliance, as being associated with a felt sense of deep empathy and understanding:

> PCL4: “You know, there's something about the way he holds himself. He talks his time that makes him believable, and you come out of there feeling you like, you just

> feel that something really valuable has occurred, Oh, it's almost spiritual. You know, I just feel that, and maybe this is a bit of what spirituality is, people really connecting. And that we do have this power, you know, and he's not power, but the human spirit and the human mind has the ability to achieve a lot of things. People have the ability within them to do lots of fantastic stuff. And he just has an ability to awaken that in people. And he did it in such a way, where people feel quite empowered to go away and work on things themselves. So, it was hard to describe. It's a whole slew of things that he holds in really quite intricate balance. So, it's I guess, it's therapeutic alliance. I guess the simple goodness. ... yeah, that would probably be the term ... he has that ability to influence someone in a way that has a significant impact. The people would say afterwards it is for the good, but it doesn't always work for him, you know... People that don't like him ... But having said that, when you see the effort that you see him go through, it'd be tiring to be honest."

This candidate item was of significance and importance to participants recovering from mental illness in both negative and positive ways. It was not something all participants endorsed as important, however for those whom it was important, it had a greater impact upon their wellbeing and QoL. The existing item within the WHOQOL-BREF that is designed to pick up spirituality is therefore of value to explore further with people when working with those whose religion or spiritual beliefs are a significant part of their ways of coping or can help them to access a wider social support system.

Appendix N

Phase 2 Research Surveys

N1 Paper Survey

HEALTH RELATED QUALITY OF LIFE QUESTIONNAIRE

AUCKLAND UNIVERSITY OF TECHNOLOGY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Instructions:

This questionnaire asks how you feel about your quality of life, health, and other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the **last two weeks**.

For example, thinking about the last two weeks, a question might be:

How much do you worry about your health?				
Not at all	A little	A moderate amount	Very much	An extreme amount

You should choose the answer that best fits how much you have worried about your health over the last two weeks. So you would **tick** "Very much" if you worried about your health "**Very much**".

How much do you worry about your health?				
Not at all	A little	A moderate amount	Very much ✓	An extreme amount

If you have worried "**Not at all**" about your health you would **tick** "Not at All" instead.

Please read each of the following questions, assess your feelings, and tick the descriptor on the scale for each question that fits best for you.

Health Related Quality of Life Survey:

Please read each question, assess your feelings, and tick the box matching the descriptor on the scale, for each question, that gives the best answer for you.

		Very Poor	Poor	Neither Poor nor Good	Good	Very Good
	How would you rate your Quality of Life?					

		Very Dissatisfied	Dis-Satisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
	How satisfied are you with your Health?					
	How satisfied are you with your Mental Health?					

The following questions ask about **how good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very Dis-satisfied	Dis-satisfied	Neither Satisfied nor Dis satisfied	Satisfied	Very Satisfied
	How satisfied are you with your capacity for work?					
	How satisfied are you with the amount of physical activity you engage in?					
	How satisfied are you with your transport?					
	How satisfied are you that you are able to meet the expectations placed upon you?					
	How satisfied are you with your access to health services?					
	How satisfied are you with the conditions of your living place?					

4

The following questions refer to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite Often	Very often	Always
	How frequently do you feel bored?					
	How often do you have negative feelings such as blue mood, despair, anxiety or depression?					
	How often do you feel discriminated against?					

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very Dis-satisfied	Dis-satisfied	Neither satisfied nor dissatisfied	Satisfied	Very Satisfied
	How satisfied are you, with your sex life?					
	How satisfied are you that there are people there for you when you need them?					
	How satisfied are you that other people recognise your strengths?					
	How satisfied are you with your recovery?					
	How satisfied are you with your ability to perform your daily living activities?					
	How satisfied are you with the support you get from your friends?					
	How satisfied are you with yourself?					
	How satisfied are you with your sleep?					
	How satisfied are you with your personal relationships?					
	How satisfied are you that people really understand you?					

5

The following questions ask about **how much** you have experienced certain things in the last two weeks:

		Not At All	A Little	A Moderate Amount	Very much	Extremely
	To what extent are you confident you can attain your goals in life?					
	To what extent are you motivated by people who have overcome similar problems, that you have?					
	To what extent do you feel positive about your future?					
	To what extent do you feel you have control over your life?					
	How healthy is your physical environment?					
	How safe do you feel in your daily life?					
	How confident are you, that when well, you can stay well?					
	To what extent do you have feelings of belonging?					

The following questions ask **how completely** you experienced, or were able to do, certain things over the last two weeks:

		Not at all	A Little	Moderately	Mostly	Completely
	To what extent do you have the opportunity for leisure activities?					
	How well are you able to get around physically?					
	To what extent do you consider that you are fit and able to work?					
	How well do you feel you can relate to others?					

6

		Not at all	A Little	Moderately	Mostly	Completely
	How well have you been able to adjust to what has happened in your life?					
	To what extent do you feel respected by others?					
	To what extent do the health and social services meet your needs?					
	To what extent are you able to manage personal difficulties?					
	How available to you is the information you need, in your day-to-day life?					
	To what extent does understanding why you have a problem, help you to resolve it?					
	Do you have enough money to meet your needs?					
	Are you able to accept your body appearance?					
	Do you have enough energy for everyday life?					
	To what extent do you feel you are able to cope with daily life?					
	To what extent are you determined to recover your health when not well?					
	To what extent do spiritual values help guide your life?					
	To what extent do you recognise the positive strengths you have?					
	How well are you able to concentrate?					
	To what extent do you believe you can recover from illness?					
	To what extent have you made changes for the better?					
	To what extent do you feel lonely?					

7

The following questions ask about **how much** you have experienced certain things in the last two weeks

		Not at All	A Little	A Moderate Amount	Very Much	An Extreme Amount
	To what extent do you feel your life to be meaningful?					
	How much do you enjoy life?					
	How much do you need medical treatment to function in your daily life?					
	To what extent do you feel that physical pain prevents you from doing what you need to do?					

Do you have any comments you would like to make about this research topic / your survey answers?

To be able to include the survey answers you have given in this research, we need to ask you a few general demographic questions.

Please let us know a little about yourself on the following page.

About You

Please mark the answer that best fits for you / fill in your answers in the space provided:

What is your gender? □ Male □ Female □ Gender Diverse

Do you consider yourself to be:
Heterosexual or Straight: □ Yes □ No **Homosexual [Gay / Lesbian]:** □ Yes □ No
Bisexual: □ Yes □ No **Other**: □Yes [*Please specify*] _____ **Prefer not to say** □

What year were you born e.g. 1950: _____

Which ethnic group do you belong to? *Mark the space or spaces that apply to you:*
□ NZ European □ Maori □ Samoan □ Cook Island Maori □ Tongan □ Niuean □ Chinese
□ Indian □ Other (*such as DUTCH, JAPANESE, TOKELAUAN*). Please specify: _____

What is the highest level of education you have completed?
□ None at all □ Primary school □ High school □ University / Tertiary

Which of the following categories best describes your employment status?
□ Working Full time [32hours+] □ Working Part time □ Unemployed □ Student □ Retired
□ Volunteer □ Other: _____

Which of the following describes your current relationship status?
□ Single □ Married □ Living as married / De facto □ Separated □ Divorced □ Widowed

What area of New Zealand do you live in?
□ Northland □ Auckland □ Central North Island □ Wellington / Lower North Island
□ Christchurch □ Nelson, Malborough □ Island off NZ coast □ Canterbury, excluding CHCH
□ Otago Southland

Do you live in a City / Town or a Rural / Remote area? □ City / Town □ Rural

Do you have a chronic physical health condition? [e.g. cancer, diabetes, kidney disease, etc?)
□ No □ Yes [Please specify] _____

Do you have a physical disability or injury? □ No □ Yes [Please specify] _____

Do you have a mental health diagnosis? □ No □ Yes [If yes, tick any diagnoses you have been given]
□ Mood Disorder [e.g. Depression / Anxiety / Bipolar Disorder] □ Psychosis [e.g. Schizophrenia]
□ Personality Disorder □ Other: _____

Are you currently experiencing or recovering from an addiction that has caused problems for you in any of the following: your health, relationships, work, or the law? □ Yes □ No
Please name the addiction/s: _____

If you are not currently recovering from mental illness / addiction – have you ever experienced a mental illness or addiction in the past? □ Yes □ No

Thankyou for participating ☺

N2: Online Survey

Health Related Quality of Life Survey

You are invited to take part in a Health-Related Quality of Life Research Study

Quality of Life can be affected in many different ways by health conditions and the treatment of these.

We are interested in how quality of life is affected when people experience mental illness or addiction issues, compared to people who do not have a mental illness or drug addiction issue.

You may have already read the participant information sheet sent with an email invitation. If so, please proceed straight to the survey, by clicking the NEXT button below.

If you haven't read it yet, it is important that you read and understand this information, before deciding to participate in this research. The participant information sheet tells you more about this research: what will be done with the results, how your information will be treated, any research risks and safety issues, and a list of people to contact if you have questions or concerns.

The information sheet will open in a new page alongside this one. You can come back here, by clicking back on the tab to the left of the new information sheet tab on your browser, or by clicking the link - Back to Survey - on the information sheet.

To read the participant information sheet, please click the following link.

Participant Information Sheet

If you have any questions after reading the information sheet - please contact me:

Melissa Rowthorn - email: hrqolresearch@gmail.com or text/phone - 022 123 6619.

Thank you for thinking about participating in this research.

When you are ready to proceed to the survey, please click on the **NEXT** button below.

Instructions

This questionnaire asks how you feel about your quality of life, your health, and other areas of your life.

Please answer all the questions with only one answer per question.

If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can be your first response.

Please keep in mind your own standards, hopes, pleasures and concerns.

We ask that you think about your life over the last TWO WEEKS.

For example, thinking about the last two weeks, a question might ask:

How much do you worry about your health?

Not at All A Little A Moderate Amount Very Much An Extreme Amount

Click the description that best fits how much you have worried about your health, just over the last two weeks.

So, you would click "Very Much" if you worried about your health “Very Much”, or you would click “Not at all” if you have worried “Not at All” about your health.

Please read each of the following questions, assess your feelings and click on the answer for each question that is the best fit for you.

Note - the numbers after the questions were not visually apparent to the participant – they are provided to indicate what score each response received that was stored by Qualtrics and downloaded into a CSV file for excel inclusion with paper survey results.

Q1 How would you rate your quality of life?
- ❍ Very Poor (1)
- ❍ Poor (2)
- ❍ Neither Poor nor Good (3)
- ❍ Good (4)
- ❍ Very Good (5)

Q2 How satisfied are you with your health?
- ❍ Very Dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q3 How satisfied are you with your mental health?
- ❍ Very Dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q4 To what extent do you feel physical pain prevents you from doing what you need to do?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ A Moderate Amount (3)
- ❍ Very Much (4)
- ❍ An Extreme Amount (5)

Q5 How much do you need medical treatment to function in your daily life?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ A Moderate Amount (3)
- ❍ Very Much (4)
- ❍ An Extreme Amount (5)

Q6 How much do you enjoy life?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ A Moderate Amount (3)
- ❍ Very Much (4)
- ❍ An Extreme Amount (5)

Q7 To what extent do you feel your life to be meaningful?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ A Moderate Amount (3)
- ❍ Very Much (4)
- ❍ An Extreme Amount (5)

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

Q8 To what extent do you feel lonely?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q9 To what extent have you made changes for the better?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q10 To what extent do you believe you can recover from illness?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q11 How well are you able to concentrate?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q12 To what extent do you recognise the positive strengths you have?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q13 To what extent do spiritual values help guide your life?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q14 To what extent are you determined to recover your health when not well?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q15 To what extent do you feel you are able to cope with daily life?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q16 Do you have enough energy for everyday life?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q17 Are you able to accept your body appearance?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q18 Have you enough money to meet your needs?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q19 To what extent does understanding why you have a problem help you to resolve it?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)

- ❍ Mostly (4)
- ❍ Completely (5)

Q20 How available to you is the information you need in your day-to-day life?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q21 To what extent are you able to manage personal difficulties?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q22 To what extent do health and social services meet your needs?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q23 To what extent do you feel respected by others?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q24 How well have you been able to adjust to what has happened in your life?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q25 How well do you feel you can relate to others?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q26 To what extent do you consider that you are fit and able to work?

- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q27 How well are you able to get around physically?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

Q28 To what extent do you have the opportunity for leisure activities?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ Moderately (3)
- ❍ Mostly (4)
- ❍ Completely (5)

The following questions ask about how much you have experienced certain things in the last two weeks.

Q29 To what extent do you have feelings of belonging?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ A Moderate Amount (3)
- ❍ Very Much (4)
- ❍ Extremely (5)

Q30 How confident are you that when well, you can stay well?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ A Moderate Amount (3)
- ❍ Very Much (4)
- ❍ Extremely (5)

Q31 How safe do you feel in your daily life?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ A Moderate Amount (3)
- ❍ Very Much (4)
- ❍ Extremely (5)

Q32 How healthy is your physical environment?
- ❍ Not At All (1)

- ❍ A Little (2)
- ❍ A Moderate Amount (3)
- ❍ Very Much (4)
- ❍ Extremely (5)

Q33 To what extent do you feel you have control over your life?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ A Moderate Amount (3)
- ❍ Very Much (4)
- ❍ Extremely (5)

Q34 To what extent do you feel positive about your future?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ A Moderate Amount (3)
- ❍ Very Much (4)
- ❍ Extremely (5)

Q35 To what extent are you motivated by people who have overcome similar problems, that you have?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ A Moderate Amount (3)
- ❍ Very Much (4)
- ❍ Extremely (5)

Q36 To what extent are you confident you can attain your goals in life?
- ❍ Not At All (1)
- ❍ A Little (2)
- ❍ A Moderate Amount (3)
- ❍ Very Much (4)
- ❍ Extremely (5)

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

Q37 How satisfied are you that people really understand you?
- ❍ Very Dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q38 How satisfied are you with your personal relationships?
- ❍ Very Dissatisfied (1)

- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q39 How satisfied are you with your sleep?
- ❍ Very Dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q40 How satisfied are you with yourself?
- ❍ Very Dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q41 How satisfied are you with the support you get from your friends?
- ❍ Very Dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q42 How satisfied are you with your ability to perform your daily living activities?
- ❍ Very Dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q43 How satisfied are you that other people recognise your strengths?
- ❍ Very Dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q44 How satisfied are you that there are people there for you when you need them?
- ❍ Very Dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q45 How satisfied are you with your sex life?
- ❍ Very Dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q46 How satisfied are you with your recovery?
- ❍ Very Dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

The following questions refer to how often you have felt or experienced certain things in the last two weeks.

Q47 How often do you feel discriminated against?
- ❍ Never (1)
- ❍ Seldom (2)
- ❍ Quite Often (3)
- ❍ Very Often (4)
- ❍ Always (5)

Q48 How often do you have negative feelings such as blue mood, despair, anxiety, or depression?
- ❍ Never (1)
- ❍ Seldom (2)
- ❍ Quite Often (3)
- ❍ Very Often (4)
- ❍ Always (5)

Q49 How frequently do you feel bored?
- ❍ Never (1)
- ❍ Seldom (2)
- ❍ Quite Often (3)
- ❍ Very Often (4)
- ❍ Always (5)

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

Q50 How satisfied are you with the conditions of your living place?
- ❍ Very dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)

- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q51 How satisfied are you with your access to health services?
- ❍ Very dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q52 How satisfied are you that you are able to meet the expectations placed on you?
- ❍ Very dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q53 How satisfied are you with your transport?
- ❍ Very dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q54 How satisfied are you with the amount of physical activity you engage in?
- ❍ Very dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q55 How satisfied are you with your capacity for work?
- ❍ Very dissatisfied (1)
- ❍ Dissatisfied (2)
- ❍ Neither Satisfied nor Dissatisfied (3)
- ❍ Satisfied (4)
- ❍ Very Satisfied (5)

Q 56 Do you have any comments you would like to make about this research topic / your survey answers?

Option to add qualitative information in the dialogue box.

To understand whether the people participating in this study, represent the diverse groups of people living in Aotearoa New Zealand, we need to ask a few general questions about the different groups that you belong to.

Please let us know a little about yourself on the following page.

Please choose the answer that fits best for you and/or fill in your answers in the space provided:

Q57 What is your gender?
- ❍ Male (1)
- ❍ Female (2)
- ❍ Gender Diverse (3)

Q58 Do you consider yourself to be:
- ❍ Heterosexual or Straight (1)
- ❍ Homosexual - Gay or Lesbian (2)
- ❍ Bisexual (3)
- ❍ Other (4)
- ❍ Prefer not to say (5)

Q59 What year were you born? e.g., 1950.

Q60 Which ethnic group do you belong to? Mark the space or spaces that apply to you:
- ❑ New Zealand European (1)
- ❑ Māori (2)
- ❑ Samoan (3)
- ❑ Cook Island Māori (4)
- ❑ Tongan (5)
- ❑ Niuean (6)
- ❑ Chinese (7)
- ❑ Indian (8)
- ❑ Other (such as DUTCH, JAPANESE, TOKELAUAN). Please specify: (9) _____

Q 61 What is the highest level of education you have completed?
- ❍ Primary School (1)
- ❍ High School (2)
- ❍ University (3)
- ❍ Other (please specify) (4) _____

Q62 Which of the following categories best describes your employment status?
- ❍ Working full time (32hours+) (1)
- ❍ Working part time (2)
- ❍ Unemployed (3)
- ❍ Student (4)
- ❍ Retired (5)
- ❍ Volunteer (6)
- ❍ Other (please specify) (7) _____

Q63 Which of the following describes your current relationship status?
- ❍ Single (1)

- ❍ Married (2)
- ❍ Living as Married / Defacto (3)
- ❍ Separated (4)
- ❍ Divorced (5)
- ❍ Widowed (6)

Q64 What area of New Zealand do you live in?
- ❍ Northland (1)
- ❍ Auckland (2)
- ❍ Central North Island (3)
- ❍ Wellington / Lower North Island (4)
- ❍ Christchurch (5)
- ❍ Other South Island location (6)
- ❍ Island off New Zealand coasts (7)

Q65 Do you live in a City / Town, or a Rural / Remote area?
- ❍ City / Town (1)
- ❍ Rural (2)

Q66 Do you have a chronic physical health condition? (e.g., cancer, diabetes, kidney disease, etc.)
- ❍ No (1)
- ❍ Yes (please name) (2) _____

Q67 Do you have a physical disability or injury?
- ❍ No (1)
- ❍ Yes (please name) (2) _____

Q68 Do you have a mental health diagnosis? (Please choose any that apply)
- ☐ Yes - Mood Disorder (e.g., Depression, Anxiety, Bipolar, etc.) (1)
- ☐ Yes - Psychosis (e.g., Schizophrenia, etc.) (2)
- ☐ Yes - Personality Disorder (3)
- ☐ Other (please specify) (4) _____
- ☐ No (5)

Q69 Are you currently experiencing or recovering from an addiction that has caused problems for you in any of the following: your health, relationships, work, or the law?
- ❍ No (1)
- ❍ Yes (please specify the type of addiction/s) (2) _____

Q70 If you are not currently experiencing an addiction or mental health condition – have you ever experienced a mental illness or addiction in the past?
- ❍ No (1)
- ❍ Yes (2)

Reminder at the completion of the survey

If anything about your own life comes up after reflecting on your answers to the questions in this survey, you may want to talk to someone close to you or a health service professional.

Alternatively, 24-hour telephone support lines are available for you to talk to someone.
- Telephone Support Lines (*A link to the Mental Health Foundation website phone line list*)

If you are interested in activities that improve your well-being you can find out more about the "Five Winning Ways to Well-being". These are simple activities proven by research to increase our well-being when we do them regularly. You will notice that one of these is - Give - by choosing to participate in this research you have achieved one of these already! Your answers will help us to better understand the quality-of-life issues experienced by people recovering from mental health and addiction issues. The discussion of this research is on helping to find ways to improve how people's quality of life can be addressed by the health service. Thank you for your contribution to this research.

If you would like to enter the draw for a $50 grocery voucher and /or would like to receive a summary of the research findings, please click here:

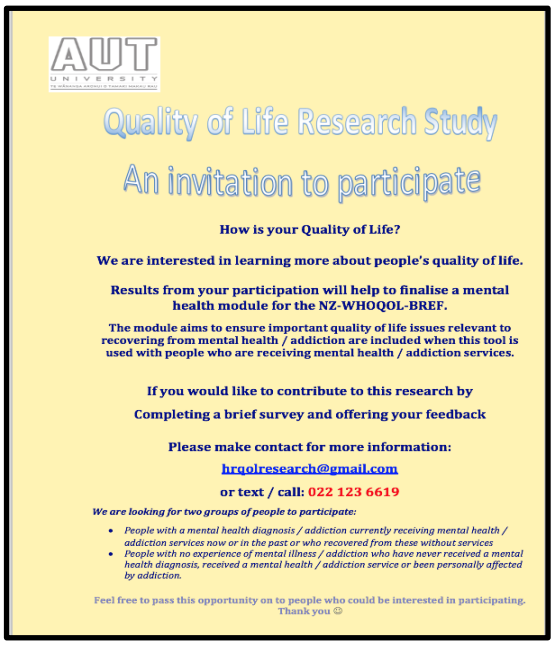
Enter the draw / Send me a copy of the results.

Otherwise, this is the end of the survey. Thank you again for choosing to participate in this study.

If you know of anyone else who might like to participate in this research, please forward the survey link on to them.

Appendix O

Phase 2 Promotional Material



On NGO and community noticeboards

General public advertising notice boards

For use in CMHC settings with drop box

Tear off poster for community settings

Mailbox flyer

Appendix P

Phase 2 Information Sheets and Informed Consent

Participant Information Sheet

Who am I?
Melissa Rowthorn – a psychologist currently working in an NGO called Connect Supporting Recovery in Auckland. I am studying quality of life in mental health recovery as part of a research degree called a PhD at AUT. The research I am doing is part of the learning requirement for the PhD.

What is the research about?
We want to develop a small set of questions that focus on the most important quality of life issues for people recovering from mental illness / addiction, then form a mental health module from their answers. People and services can use this module alongside a quality of life survey called the WHOQOL-BREF when they are working towards their recovery in those services.

What would I be doing?
You will be asked to fill in a survey – there are two versions. One is a pen and paper copy and the other is an online survey version. It is your choice which version you want to complete. The survey asks a series of questions about different areas of your life and asks you to tick or click an answer that best fits for you and your life. It will probably take about 15-30 minutes to complete.

Are there any risks?
No. If any questions on the surveys are uncomfortable for you to answer, you don't have to answer them. If you have questions when filling the survey out you can access support from people around you or you can contact myself to have these answered. You can choose not to participate in this research.

Is it private?
Yes. Only the researchers will see the forms you fill out. No names will be on the forms. No one where you work, or receive services from, will know what you've written unless you choose to share this and nothing will change about your services if you choose to participate, choose not to participate, or if you want to pull out later.

What are the benefits?
By helping to make this module, people can help improve recovery services for people with mental illness / addiction by helping to let us know more about the most important quality of life issues for people during their recovery. Services can then use this information to evaluate their services / improve the ways they can meet these needs. People who complete the survey can also choose to enter a draw for a $50 grocery voucher on the consent form or at the end of the online survey.

Will it cost me anything?
No. People who choose to participate can do so online. If you choose to do a paper survey you will be given a return envelope to send the survey back. You could also choose to scan and email your survey back to me. It should take less than 30 mins to fill out the survey.

Who do I contact if I have questions or concerns?
Text or email me and I'll call to arrange a time to discuss things further: 022 123 6619 hrqolresearch@gmail.com If you have concerns about the research, call my supervisor Rex Billington on (09) 921 9999 extension 9466. For ethics: Kate O'Connor, *ethics@aut.ac.nz*, 921 9999 ext. 6038.

How do I sign up? Any of the below ways that suit you best:

1. Click on or copy the below link into your browser for the online survey
   https://aut.au1.qualtrics.com/SE/?SID=SV_5inHYNpgkbfpk5D OR
2. Sign the consent form if doing a paper version, complete the paper survey, and hand it in / post it back with the consent form in the envelope provided. OR
3. Email a scanned copy of the signed consent form & completed survey to the email above.

Date Information Sheet Produced: 24.08.2014. **Project Title:** Developing a Mental Health Module for the NZ-WHOQOL-BREF. **AUTEC reference: 14/227 Approval Date: 25.9.2014**

Consent Form

Project Title: **Developing a Mental Health Recovery Module for the WHOQOL-BREF**

Project Supervisor: **Professor Rex Billington**

Researcher: **Melissa Rowthorn**

- ○ I have read and understood the information provided about this research project on the information sheet dated 24 August 2014.
- ○ I have had an opportunity to ask questions and to have them answered.
- ○ I understand that my identity will be kept confidential and no information on this survey will be linked back to me or used outside this research process.
- ○ I understand that I may withdraw myself, or any information that I have provided at any time, without any loss of support I receive from any services or from the research providers.
- ○ If I withdraw after completing the survey, I understand that any survey I have completed will be destroyed and not used in the analysis and write up.
- ○ I agree to take part in this research.

Participant signature: .....

Participant name: .....

Date: …….

Contact details required for the below options:

- ○ I wish to receive a copy of the report from the research: Yes ○ No ○
- ○ I wish to enter the draw for a $50 grocery voucher: Yes ○ No ○

Please **only** complete the contact details if **you want** to be contacted. The options are:

Phone: ……..

Email: ……..

Postal Address: ……...

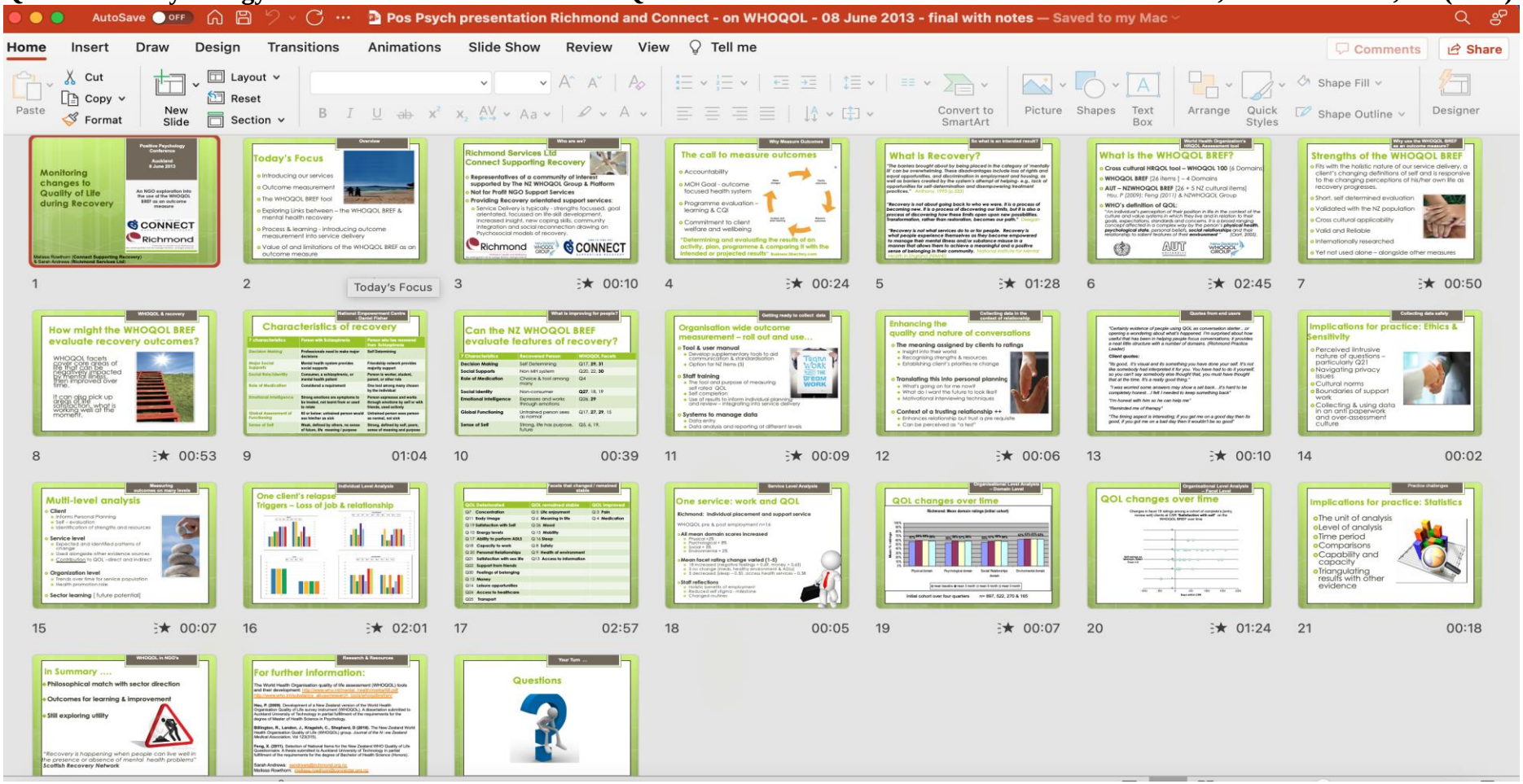
Best time and day to contact me: ……

Approved by the Auckland University of Technology Ethics Committee on: 25th September 2014 AUTEC Reference number 14/227. *Note: Please retain a copy of this form for your own records*

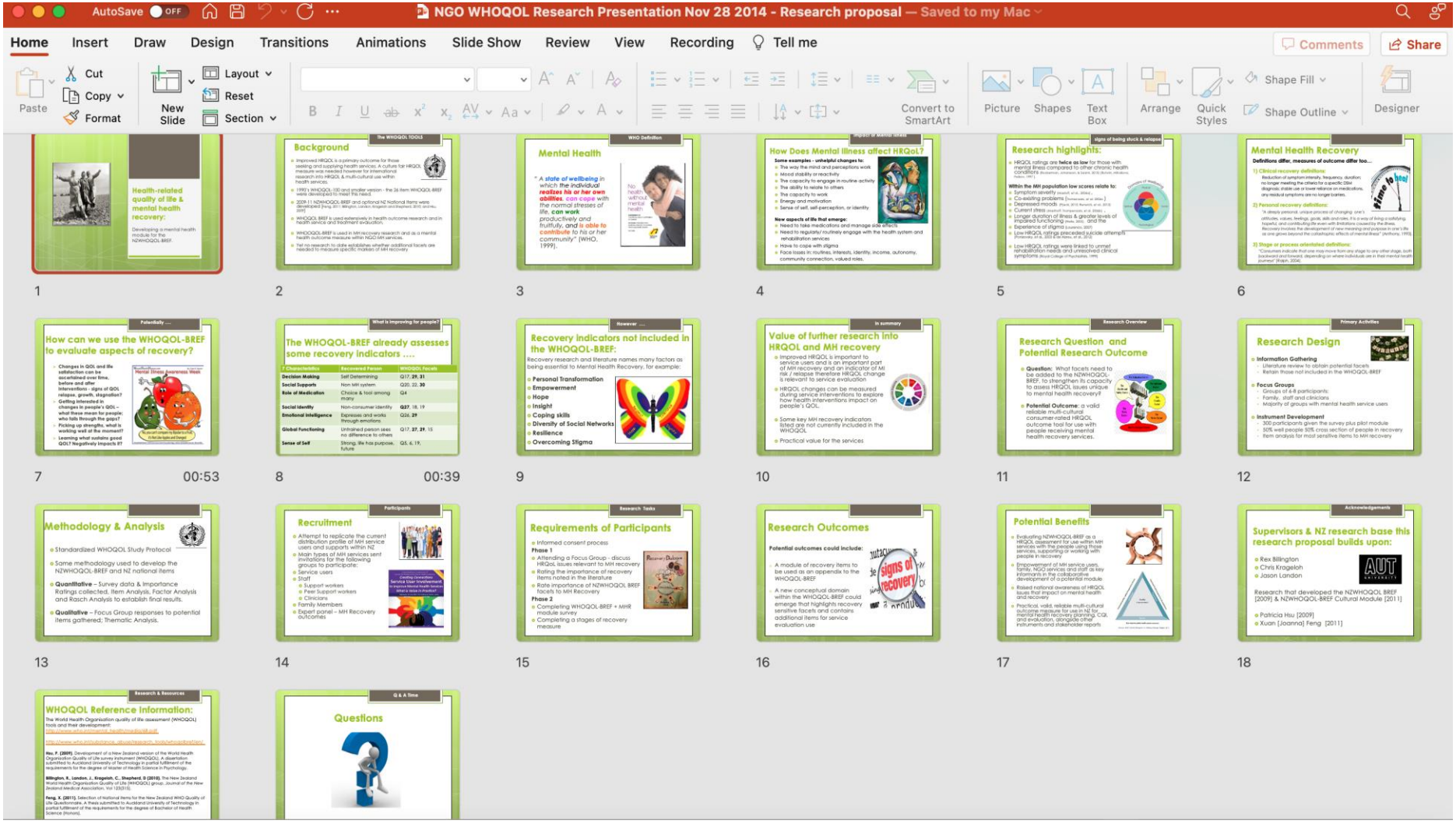
Appendix Q

Wider Stakeholder Engagement Presentations

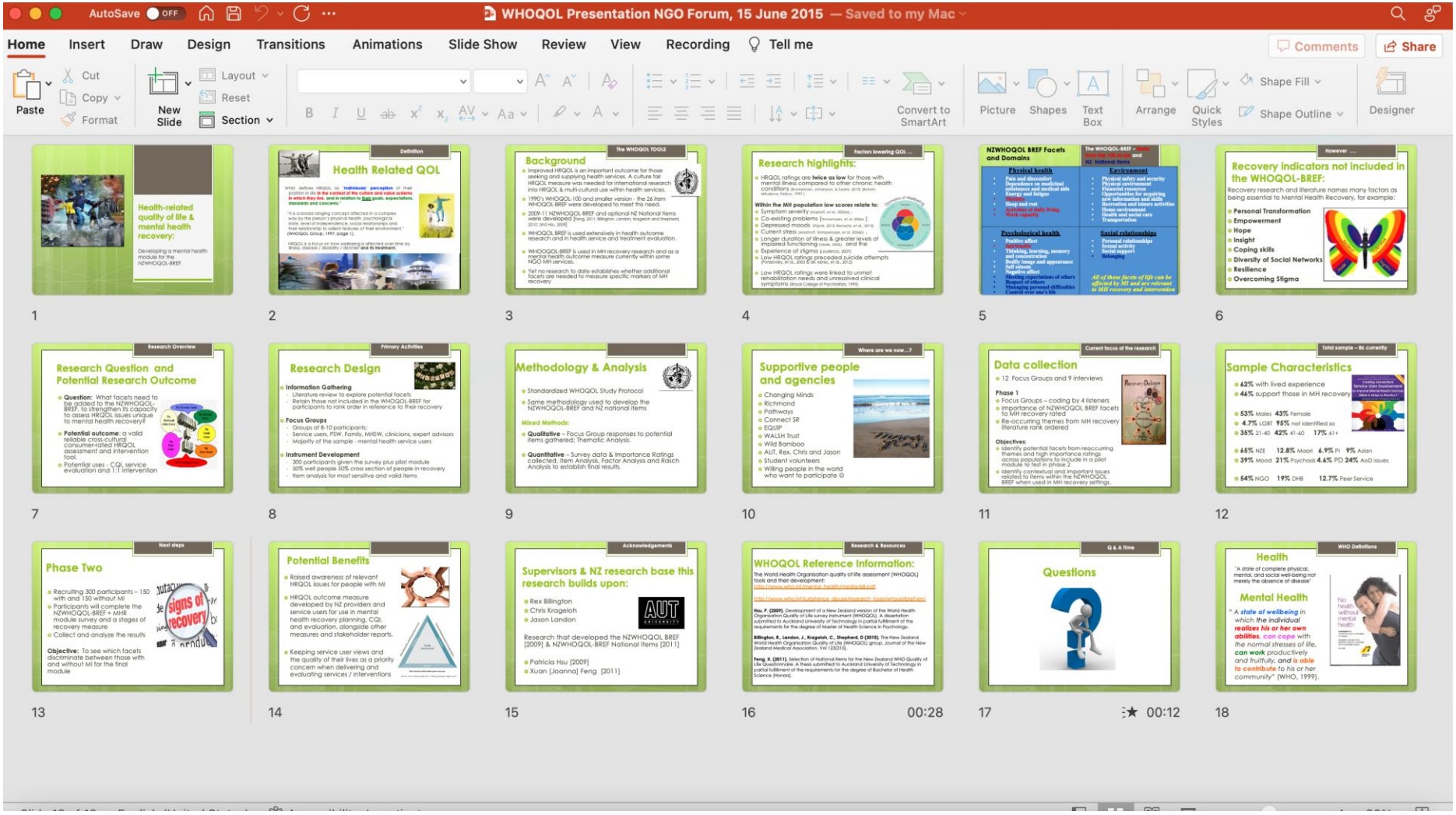
Q1. Positive Psychology Presentation – Use of the WHOQOL-BREF in Mental Health as a PROM – Andrews, S & Rowthorn, M. (2013)



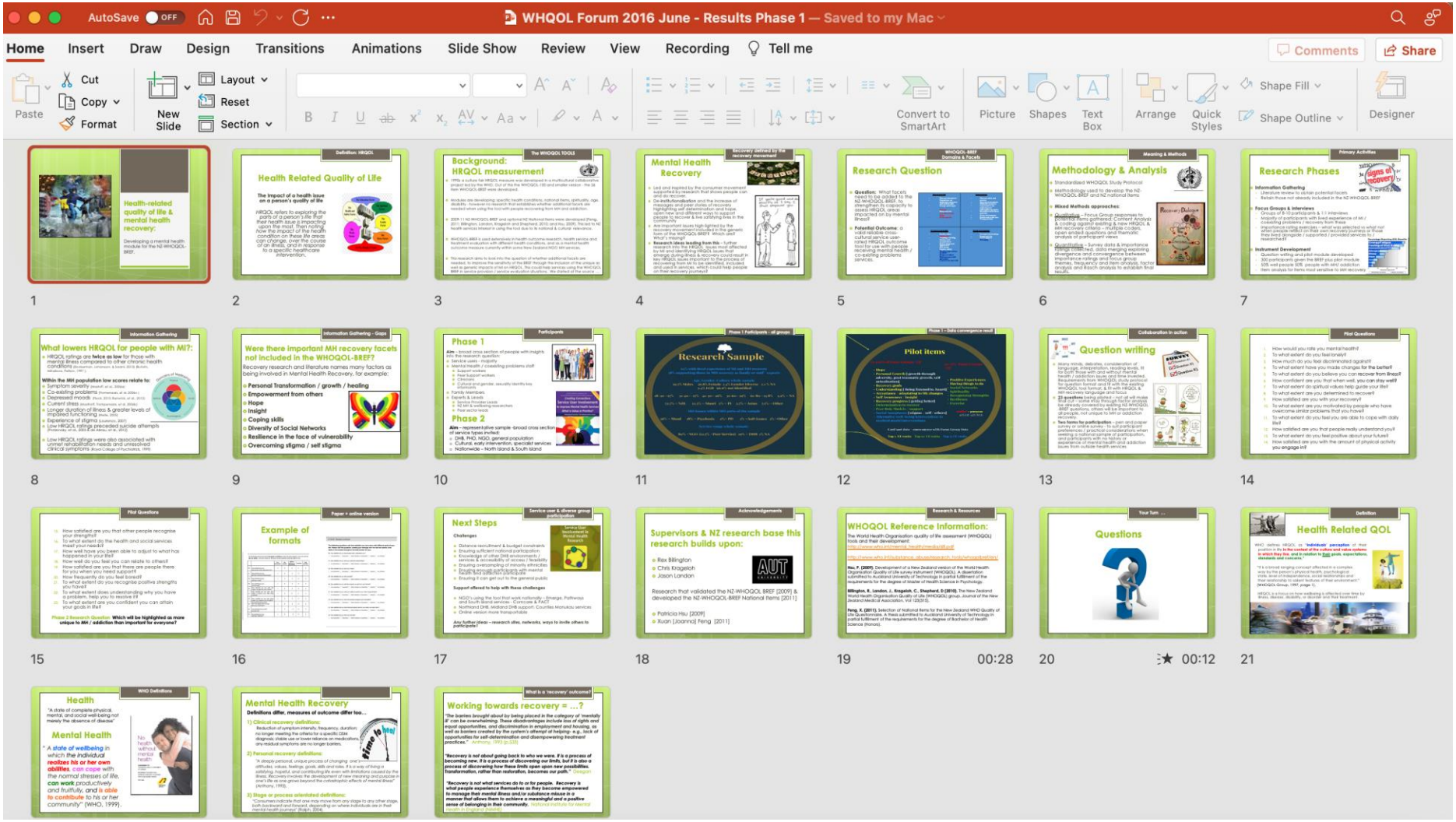
Q2: Nov. 2014. Presentation to SIG, Platform Trust, WHOQOL FORUM - Research Concept – research question, benefits, feedback.



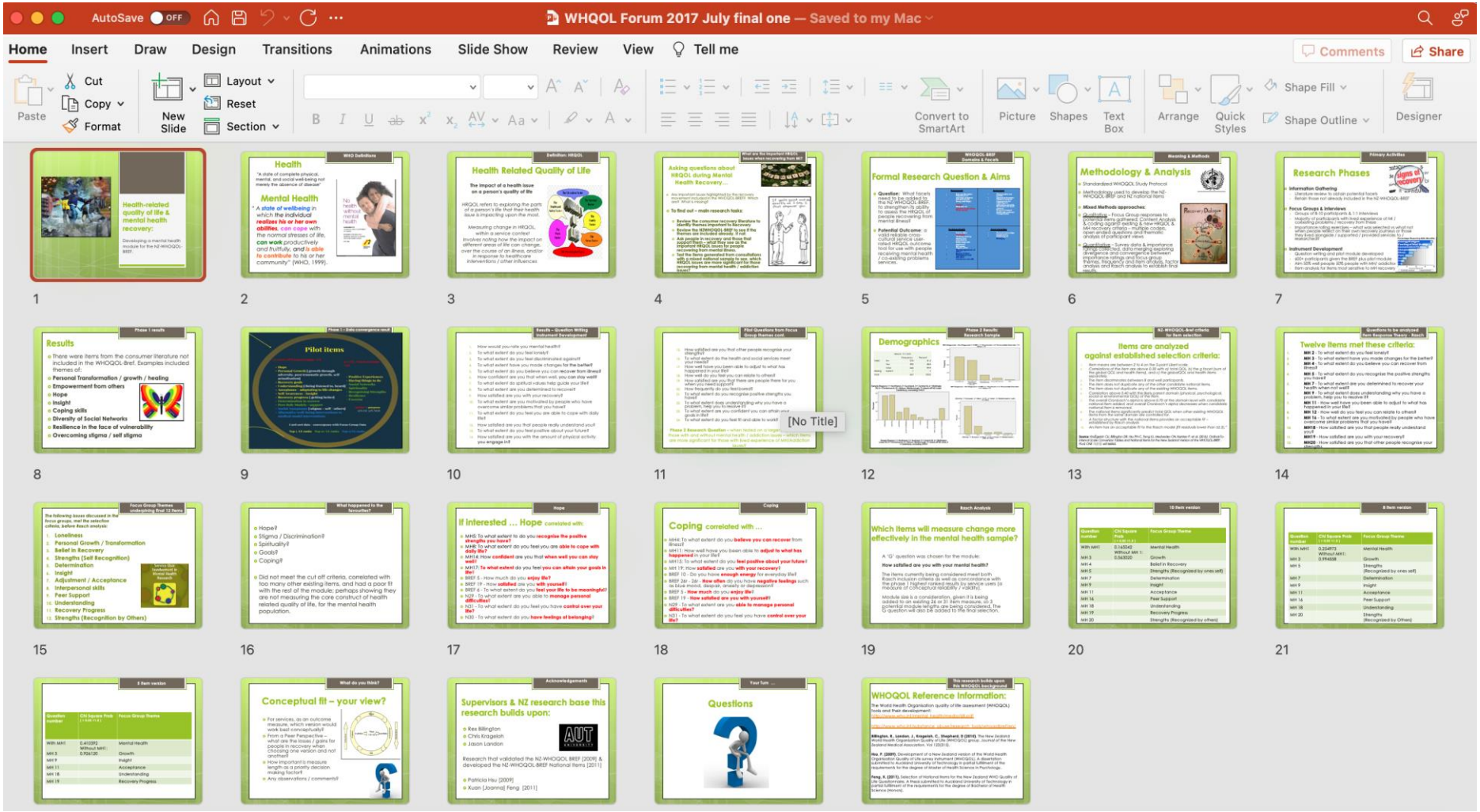
Q3: June 2015. Presentation to SIG, Platform Trust, WHOQOL FORUM - Research Plan – aims, rationale, methods, & background.



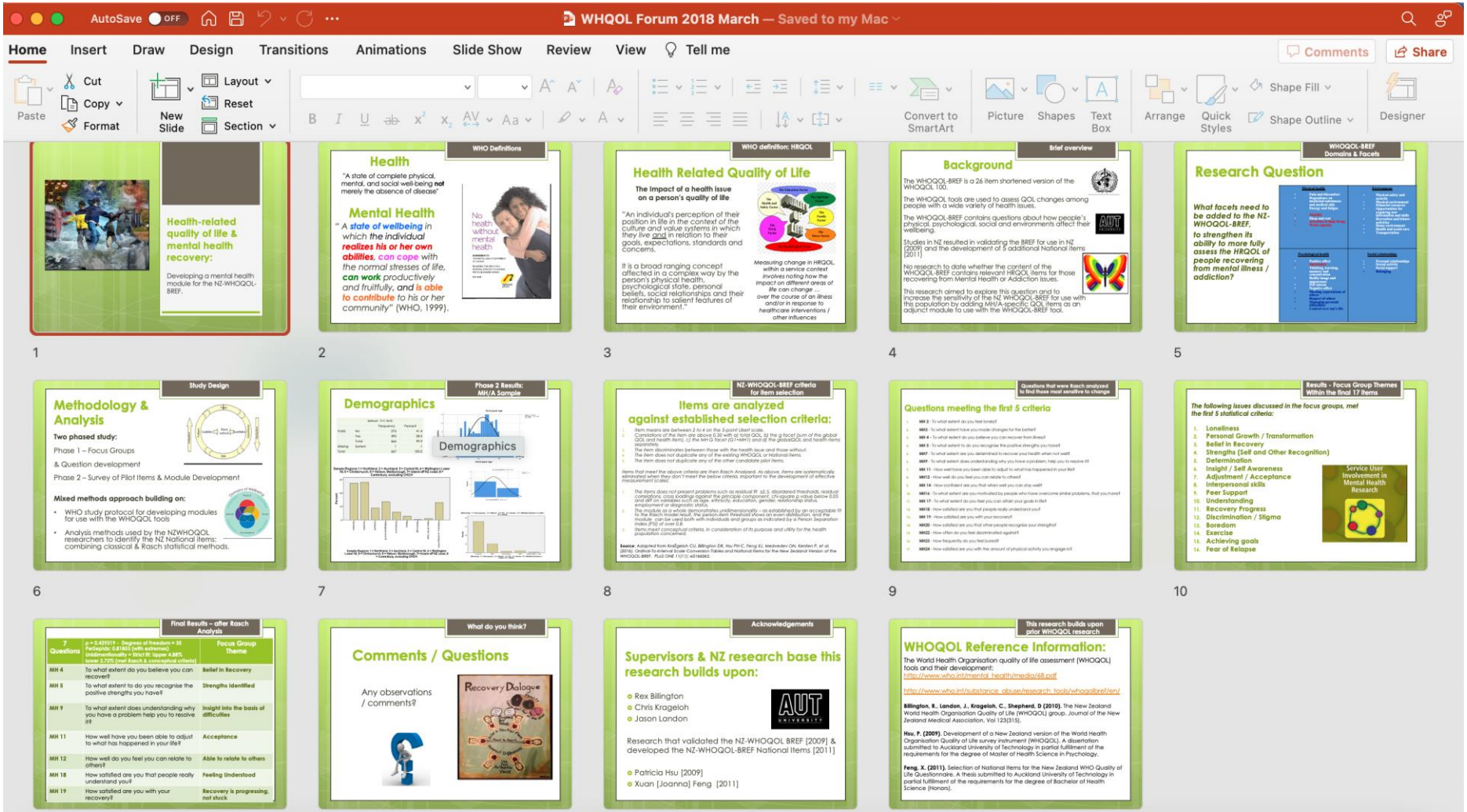
Q4: June 2016. Presentation to Platform Trust SIG, WHOQOL FORUM - Phase 1 Results - Pilot items and survey questions – feedback



Q4: July 2017. Presentation to SIG, Platform Trust, WHOQOL FORUM - early Phase 2 results - module size and content – pros/cons.



Q5: March 2018. Presentation to SIG, Platform Trust, WHOQOL FORUM – Final Results and Feedback Session.



AGENDA

Mental health & addictions
NGO Outcomes Group

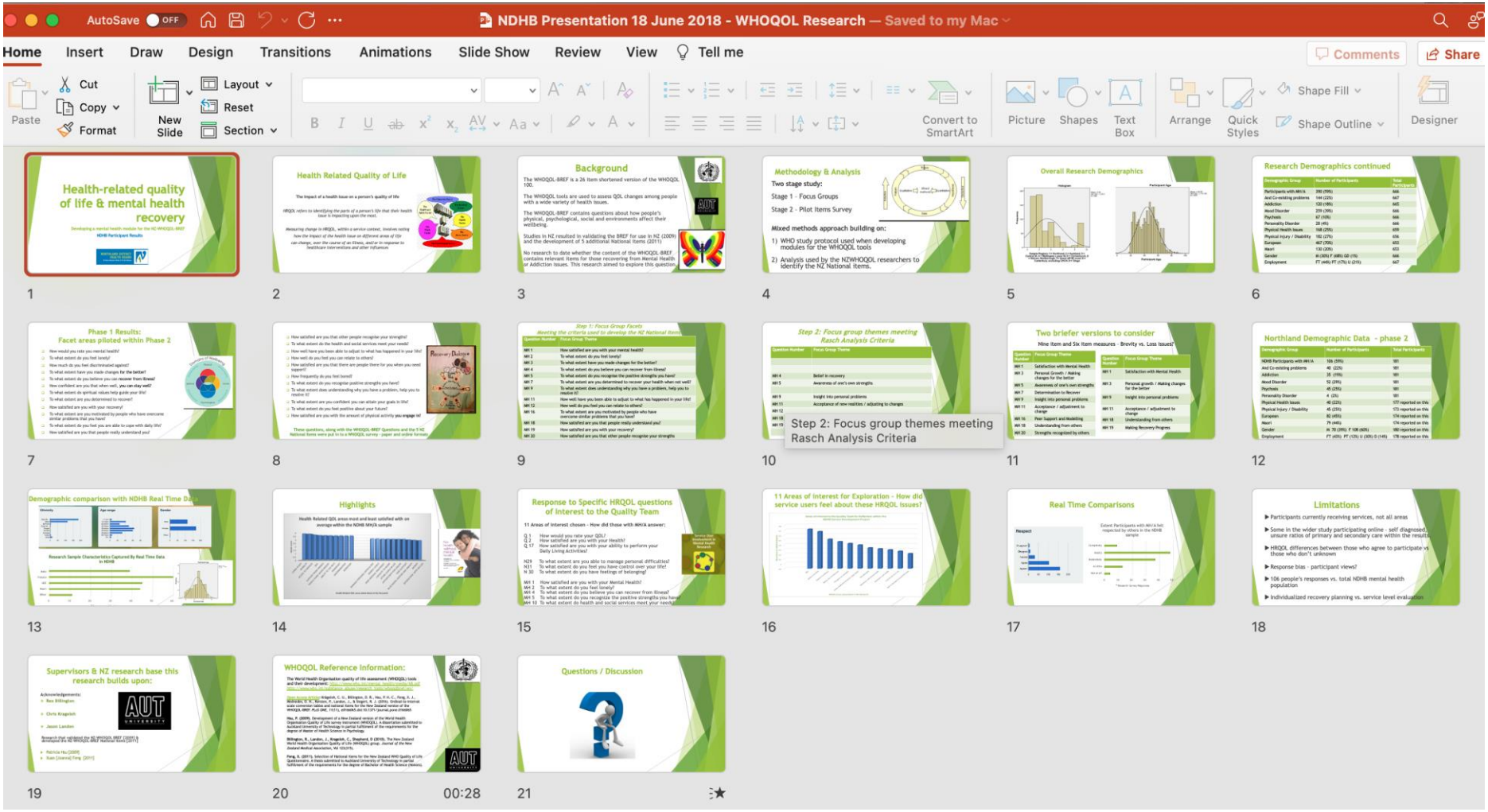
Date: Friday 23 March 2018

Time: 10.00am – 3.00pm

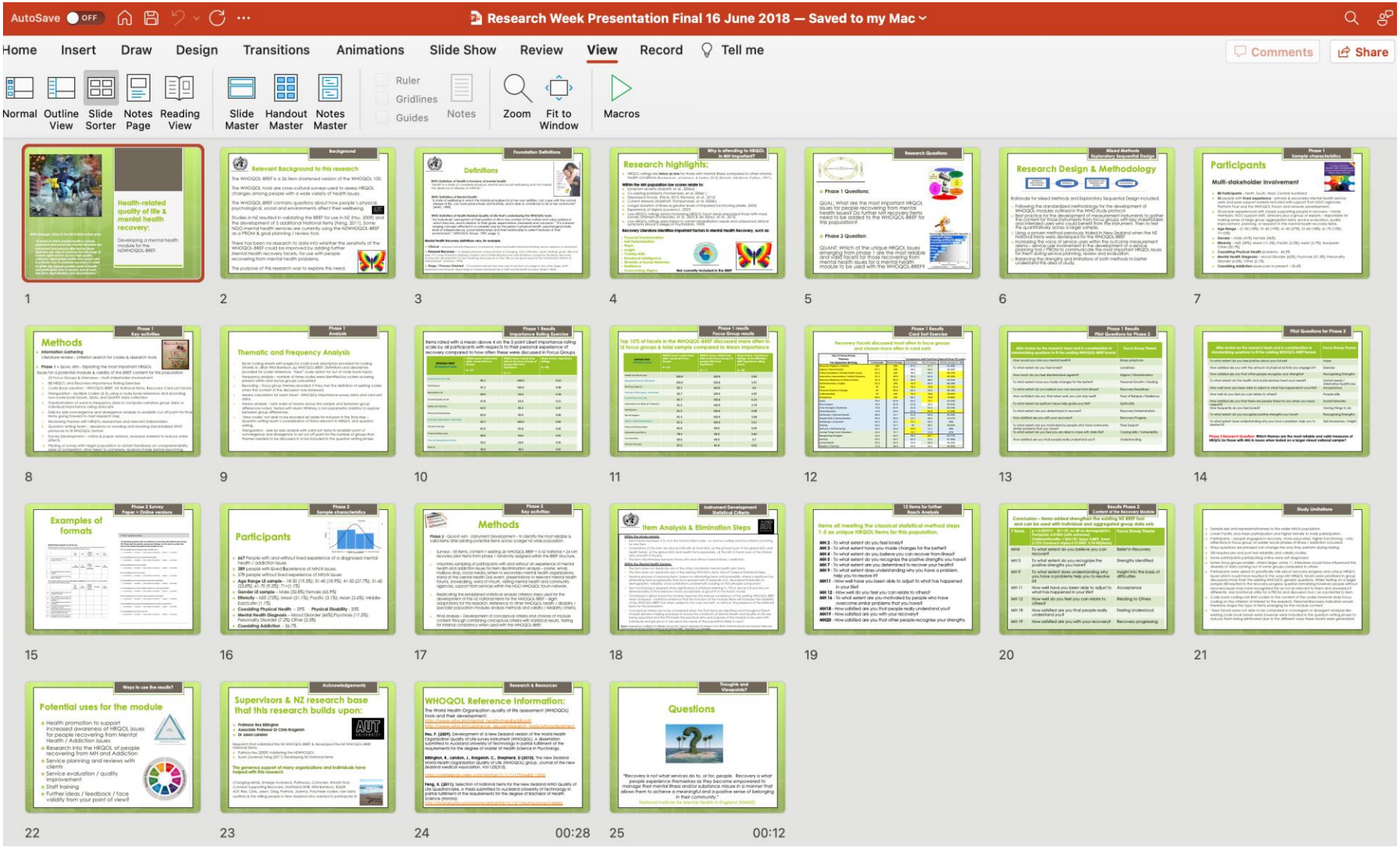
Venue: Kowhai meeting room, Te Pou, 8 Nugent St, Grafton, Auckland.

Time	Item	Presenters
9.30am	**Coffee and tea available on arrival**	
10.00am	Welcome and apologies	Rex Billington
	Minutes of the last meeting and actions arising	Rex Billington
	Update from all members – what assessment tools/approaches are you using and what is their perceived value to service users and to your organisation?	Everyone
	Presentation by Pathways	Ross Phillips
	Presentation via skype - The social investment agenda and the implications for the NGO health and social sector.	Doug Lambert (Social Investment Agency)
12.00pm	**LUNCH** **Please note that lunch will be provided by Platform Trust**	
1.00pm	Some measurement concepts underlying outcome assessment.	Chris Krageloh
	Update from Melissa – the development of the mental health module for the NZ WHOQOL-BREF.	Melissa Rowthorn
	Brief presentation of the social outcome data that has been collected via PRIMHD (includes data from both NGOs and DHBs).	Paul Hanton
2.00pm	**AFTERNOON TEA**	
	Presentation via skype - Future directions for the MH&A sector (including the focus on outcomes).	Kevin Harper (Ministry of Health) - to be confirmed
	Final comments and wrap up	Rex
3.00 pm	**CLOSE**	

Q6: June 2018. Presentation to Northland DHB management - Research Results in Reference to NDHB Real Time QoL Results.



Q7: 16 June 2018. Counties Manukau Research Day Presentation – Overview of the Research from Proposal to Final results.



Appendix R

MHRQoL Module

MENTAL HEALTH RELATED QUALITY OF LIFE QUESTIONNAIRE

Mental Health Recovery Module
An adjunct for the WHOQOL tools

AUCKLAND UNIVERSITY OF TECHNOLOGY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

The WHOQOL tools assess generic HRQoL issues common to all health conditions and are essential to include in the HRQoL assessment of people recovering from mental health and addiction issues.

The mental health module for the WHOQOL-BREF is intended to be used with the WHOQOL tools when module users are interested in assessing mental health related QoL (MHRQoL). The module contains personal recovery items that measure MHRQoL.

Instructions:
This questionnaire asks how you feel about your quality of life, health, and other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the **last two weeks**.

For example, thinking about the last two weeks, a question might be:

How much do you worry about your health?				
Not at All	A Little	A Moderate Amount	Very Much	An Extreme Amount

You should choose the answer that best fits how much you have worried about your health over the last two weeks. So, you would **tick "**Very much" if you worried about your health "**Very much**".

How much do you worry about your health?				
Not at All	A Little	A Moderate Amount	Very Much ✓	An Extreme Amount

If you have worried "**Not at All**" about your health you would **tick** "Not at All" instead.

Please read each of the following questions, assess your feelings, and tick the descriptor on the scale for each question that fits best for you.

Mental Health Recovery Module for use with the NZWHOQOL-BREF

Please read each question, assess your feelings, and tick the box matching the descriptor on the scale, for each question, that gives the best answer for you.

The following questions ask about **how completely** you experienced or were able to do certain things in the last two weeks

		Not at all	A Little	Moderately	Mostly	Completely
MH1	To what extent do you believe you can recover from illness?					
MH2	To what extent do you recognise the positive strengths you have?					
MH3	To what extent does understanding why you have a problem help you to resolve it?					
MH4	How well have you been able to adjust to what has happened in your life?					
MH5	How well do you feel you can relate to others?					

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very Dissatisfied	Dis-satisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
MH6	How satisfied are you that people really understand you?					
MH7	How satisfied are you with your recovery?					

Mental Health Recovery Module for use with the NZWHOQOL-BREF

Scoring Guide

Please read each question, assess your feelings, and tick the box matching the descriptor on the scale, for each question, that gives the best answer for you.

The following questions ask about **how completely** you experienced or were able to do certain things in the last two weeks

		Not at all	A Little	Moderately	Mostly	Completely
MH1	To what extent do you believe you can recover from illness?	1	2	3	4	5
MH2	To what extent do you recognise the positive strengths you have?	1	2	3	4	5
MH3	To what extent does understanding why you have a problem help you to resolve it?	1	2	3	4	5
MH4	How well have you been able to adjust to what has happened in your life?	1	2	3	4	5
MH5	How well do you feel you can relate to others?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very Dissatisfied	Dis-satisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
MH6	How satisfied are you that people really understand you?	1	2	3	4	5
MH7	How satisfied are you with your recovery?	1	2	3	4	5

Scoring instructions:

1. Add total scores for the module. Maximum score = 35, minimal score =7.
2. Locate the raw score just calculated on the left-hand side of the following table.
3. Record the corresponding interval score on the right-hand side of the table as the person's module score for this recording period.
4. Baselines for individual scores can also be tracked and scores compared, if the recovery issues are targeted for intervention, without use of the conversion table.

Ordinal-to-interval conversion scores

Ordinal	Interval	
Scale	Logit	Scale
7	-4.18	7.00
8	-3.36	9.49
9	-2.80	11.21
10	-2.41	12.39
11	-2.11	13.31
12	-1.85	14.09
13	-1.63	14.77
14	-1.43	15.38
15	-1.24	15.95
16	-1.06	16.49
17	-0.89	17.02
18	-0.72	17.53
19	-0.56	18.04
20	-0.39	18.55
21	-0.22	19.07
22	-0.04	19.61
23	0.15	20.18
24	0.34	20.77
25	0.55	21.41
26	0.78	22.10
27	1.02	22.86
28	1.30	23.69
29	1.61	24.63
30	1.95	25.69
31	2.34	26.88
32	2.80	28.26
33	3.34	29.92
34	4.06	32.11
35	5.01	35.00