Community Integration after Traumatic Brain Injury: Conceptualisation and Measurement

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Abstract

Community integration remains the ultimate goal of rehabilitation for persons affected by Traumatic Brain Injury (TBI). A number of studies have presented different definitions of community integration over the past few decades, however a standardised conceptual model of community integration has not yet been articulated. Varying definitions and a lack of agreement regarding the theoretical underpinnings of the construct community integration, has presented problems for both the measurement of community integration and its use when implementing and evaluating rehabilitation interventions aimed at improving community integration outcomes. The key aims of this research were to gain a more in-depth understanding of the concept of community integration in order to develop a comprehensive conceptual framework of community integration and inform the development of a conceptually sound, robust, culturally relevant, and contemporary measure of community integration for people with TBI.

The thesis includes a concept analysis to explore how community integration has been conceptualised in the healthcare literature pertaining to brain injury, followed by a measurement review to identify a widely used outcome measure of community integration, with acceptable psychometric properties. The empirical work used a mixed methods approach comprising of three studies which endeavoured to examine and enhance psychometric properties of the most prominent measure: the Community Integration Questionnaire (CIQ) and an updated version of the measure made available during the course of the research, known as the Community Integration Questionnaire-Revised (CIQ-R). The measure was evaluated using two quantitative studies. One study was based on a longitudinal TBI cohort and the other on cross-sectional TBI data, including 117 individuals with TBI for the CIQ-R that was collected specifically as a part of this doctoral research. These studies applied Classical Test Theory methods and Rasch analysis methods to examine psychometric properties of the CIQ and CIQ-R and enhance functioning of their items and precision of the scale. A qualitative study using a 'concurrent nested approach' was conducted with 12 people with TBI, to examine the content and appropriateness of the CIQ-R.

Several findings from this research challenge and/or enhance existing knowledge on the conceptualisation and measurement of community integration. One of the key contributions was the development of a more comprehensive definition and conceptual framework of community integration. The proposed definition describes community integration as 'being independent and having a sense of belonging within the community; having a place to live; being socially and psychologically integrated into the community; and involved in meaningful occupational activity'. The CIQ-R was found to be providing only limited coverage of the multi-dimensional construct, community integration. The quantitative work determined that the CIQ-R has sound psychometric properties while Rasch analysis identified some non-functioning items and provided a conversion algorithm to transform ordinal responses to interval-level data. The qualitative findings revealed that the content of the CIQ-R was mostly appropriate. However, the scale requires several amendments to enhance its relevance, comprehensiveness and interpretability for people with TBI.

This research makes significant contributions to the field of community integration for people with TBI in terms of conceptual clarity and raises an overarching issue that self-report measures assessing constructs such as community integration, return to work, psychosocial reintegration may not always provide very useful information when measured objectively. The study also depicted the process of outcome measure selection in research or clinical settings and alluded to advanced methods that can be applied in future practice.

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material 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.

Signature: _____   Date: <u>19/11/18</u>
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PhD Research Outputs

Journal article

Nusratnaaz M. Shaikh, Paula Kersten, Richard J. Siegert & Alice Theadom (2018): Developing a comprehensive framework of community integration for people with acquired brain injury: a conceptual analysis, *Disability and Rehabilitation*. doi: 10.1080/09638288.2018.1443163

Conference presentations

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Nusratnaaz M Shaikh, Oleg N. Medvedev, Alice Theadom, Paula Kersten, Richard J Siegert (2017, September). *Measuring Community Integration in people with Traumatic Brain Injury: Rasch Analysis of the Community Integration Questionnaire (CIQ).* Poster presented at New Zealand Rehabilitation Association Conference, Christchurch, New Zealand.

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Ethics Approval

Ethical approval was obtained from Auckland University of Technology Ethics Committee (15/237) on 7 September 2015.

Abbreviations

ABI	Acquired Brain Injury
ADL's	Activities of daily living
AIMS	Assimilation, Integration, Marginalization, Segregation
ANOVA	Analysis of variance
ASCII	American Standard Code for Information Interchange II
AUC	Area under curve
BIONIC	Brain Injury Incidence and Outcomes New Zealand in the Community
BSI-18	Brief Symptom Inventory-18
CAP	Community approach to Participation
CFA	Confirmatory Factor Analysis
CFI	Comparative fit index
CHART	Craig Handicap and Assessment Reporting Technique
CI	Class Interval
CIF	Community Integration Framework
CIM	Community Integration Measure
CIPI	Chronic Illness Problem Inventory
CIQ	Community Integration Questionnaire
CIQ-R	Community Integration Questionnaire- Revised
COOP-WONCA	Dartmouth Coop Functional Health Assessment Charts (COOP): World Organisation of Family Doctors (WONCA) Charts
COSMIN	Consensus-based Standards for the selection of health Measurement Instruments
CTT	Classical Test Theory
DIF	Differential item functioning
DRS	Disability Rating Scale
EFA	Exploratory Factor Analysis
ESN	Electronic Social Networking
FAM	Functional Assessment Measure
FIM	Functional Independent Measure
GFI	Goodness of fit index
HRQoL	Health related Quality of Life
ICC	Intraclass correlation coefficient
ICF	International Classification of Functioning
ICF-CY	International classification of functioning, disability and health: children and youth version

ICIDH	International Classification of Impairments, Disability and
IRT	Item response theory
ISEL	Interpersonal Support Evaluation List
KAS	Katz Adjustment Scale
KMO	Kaiser-Meyer-Olkin test
LB	Lower bound
LHA	Life Habits Assessment
LHS	London Handicap Scale
LOA	Limits of agreement
LSIA-A	Life Satisfaction Index-A
MDS	Multidimensional Scaling
MIC	Minimal important change
NFI	Neurobehavioral Functioning Inventory
NFI	Normed fit index
PCA	Principle Component Analysis
PSI	Personal separation index
PTA	Post Traumatic Amnesia
QoL	Quality of Life
R-CHART	Revised- Craig Handicap and Assessment Reporting Technique
RHFUQ	Rivermead Head Injury Follow-up Questionnaire
RMSEA	Root mean square error of approximation
RNLI	Reintegration to Normal Living Index
RSM	Rating Scale Model
SD	Standard Deviation
SDC	Smallest detectable change
SEM	Structural Equation Modelling
SF-12	Short Form-12
SIP-5	Sickness Impact Profile
SPRS	Sydney Psychosocial Reintegration Scale
SWLS	Satisfaction with Life Scale
TBI	Traumatic Brain Injury
WHO	World Health Organization

Chapter 1: Introduction and thesis structure

1.1 Background to the study

People with Traumatic Brain Injury (TBI) typically suffer from a wide range of deficits including physical, communicative, cognitive, behavioural, and psychological impairments. They also frequently experience limitations in activities and restrictions on participation affecting functional independence, social integration and return to work (Turner-Stokes, Disler, Nair, & Wade, 2005).

Full community integration is considered as the ultimate goal of rehabilitation for persons affected by TBI (Kreutzer & Wehman, 1990). In health-related research, the construct 'community integration' has been derived from the World Health Organization's international Classification of Impairments, Disability and Handicaps (ICIDH), based on the concept of 'Handicap' (Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993), which was viewed as the opposite of integration. the ICIDH introduced social integration as one of the six dimensions of Handicap, where 'participation' term was used as a qualifier to describe the amount/intensity of activity restriction (mainly related to occupation and social integration handicap) caused due to an impairment. And it was defined as the individual's ability to participate in and maintain customary social relationships. The term 'handicap' has now been replaced with the concept of 'Participation' in the WHO's International Classification of Functioning, Disability and Health (ICF)(M. Brown et al., 2004), which is defined as 'involvement in a life situation'. Community integration is not explicitly defined within the ICF framework; however, it is often used interchangeably with participation within the health research or considered to be underpinned by participation. The transition from ICIDH to ICF has provided the foundation for the development of an operationalised model of community integration and participation measurement (Sander, Clark, & Pappadis, 2010), however it does not provide clear distinctions between these two concepts.

Existing literature on community integration proposes several components including three common elements: physical independence, interpersonal relations, and meaningful occupational activity (McColl et al., 1998; Parvaneh & Cocks, 2012; Tate, Lulham, Broe, Strettles, & Pfaff, 1989; Trigg & Wood, 2000; Willer, Rosenthal, et al., 1993). Additionally, community integration was reported to encompass other

elements such as belonging to the community, coping, returning to previous life roles, and safeguarding against risk (McColl et al., 1998; Parvaneh & Cocks, 2012). This reflects the multidimensional and complex nature of the construct. While there are varied definitions and conceptualisations of community integration, a systematic operational model of the construct has not yet been articulated (Andelic et al., 2016; Dijkers, 2010).

Measurement of rehabilitation outcome is important to assess clinically significant change in a patient's condition and to determine the patient's level of participation and activities of daily living. In addition, outcome measurement tools also establish effectiveness of interventions and thus contribute to the process of goal setting and clinical decision making (Smith Jr, 2001). A number of measures have been developed and applied in the measurement of community integration. Most of these measurement tools were developed, validated and widely used across the Western world but are not yet validated in New Zealand. Some of these measures include the Craig Handicap and Assessment Reporting Technique (CHART) (Whiteneck, Charlifue, Gerhart, Overholser, & Richardson, 1992), the Community Integration Questionnaire (CIQ) (Willer, Rosenthal, et al., 1993), the Community Integration Measure (CIM) (McColl et al., 1998), the Life Habits Assessment (LHA) (Fougeyrollas et al., 1998), and the Rivermead Head Injury Follow-up Questionnaire (RHFUQ)(Crawford, Wenden, & Wade, 1996).

Instruments with different titles or names add to the confusion surrounding the concept of community integration (e.g., Sydney Psychosocial Reintegration Scale, Personal Integration Inventory)(Dijkers, 1998). This reflects considerable variation in the definition and measurement criteria used for the multifaceted and broad concept of community integration, making it difficult to generalise or compare community integration across different injury groups or research results (Dijkers, 2010; Yasui & Berven, 2009). To resolve these problems, a more robust framework needs to be articulated and a valid and reliable outcome measure of community integration for people with TBI in New Zealand needs to be identified.

1.2 Aims and objectives of this doctoral research

The overarching aim of this doctoral research was to inform the development of a conceptually sound, robust, culturally relevant, and contemporary measure of community integration for people with TBI.

The specific objectives of this thesis were to:

1. Develop a comprehensive conceptual framework of community integration to gain a more in-depth understanding of the concept of community integration for people with brain injury.
2. Explore existing community integration measures in people with TBI and identify an appropriate measure of community integration for further validation in subsequent phases of this doctoral research.
3. Critically examine psychometric properties of an existing outcome measure of community integration in people with TBI.
4. Explore the acceptability and appropriateness of the outcome measure in people with TBI.

1.3 Chapter structure

All four objectives identified above were addressed using a mixed methods approach. Figure 1.1 presents an overview of the chapters with the associated objectives.

Literature review	Chapter Two	Concept analysis to develop a comprehensive conceptual framework of community integration
	Chapter Three	Measurement review to identify an appropriate measure of community integration
	Chapter Four	Research methodology: Mixed methods approach for measurement studies
Quantitative research	Chapter Five	Psychometric validation: Outcome measure's reliability and concurrent validity
	Chapter Six	Psychometric validation: Outcome measure's internal construct validity and refinement
Qualitative research	Chapter Seven	Content analysis to explore acceptability and appropriateness of the outcome measure
	Chapter Eight	Integrated discussion and conclusion

Figure 1.1: Overview of chapter structure

The thesis is organised into eight chapters which are briefly outlined below:

Chapter Two presents a concept analysis of the literature pertaining to community integration and brain injury to extend the current knowledge of the concept.

Chapter Three describes the findings of a measurement review exploring the psychometric properties of popular outcome measures of community integration.

It is important to note that both the reviews in Chapter Two and Chapter Three are limited to papers published up to and including December 2016. Findings from these reviews informed development of subsequent research carried out in this doctorate thesis (enrolled in March 2014). The subsequent chapters describing empirical research are discussed in the context of more recent publications.

Chapters Two and Three are based on community integration literature involving people with Acquired Brain Injury (ABI) to understand the wider context accommodating neurological disorders such as trauma, stroke, hypoxia, tumour, infection, substance abuse or degenerative neurological disease. The series of

empirical studies conducted in this doctoral research are focused on TBI population to derive for more injury specific outcomes. This disease specific approach also takes into account population differences e.g. the stroke population being of an older average age than TBI.

Chapter Four delineates the research methodology, measurement theories and data analysis methods utilised in this research.

Chapter Five discusses the first scale validation quantitative study examining dimensionality, internal consistency, and concurrent validity of an outcome measure using factor analysis and correlational analysis.

Chapter Six reports on the second scale validation quantitative study exploring internal construct validity of the outcome measure using Rasch analysis.

Chapter Seven discusses findings from a qualitative study exploring perceptions of people with TBI on acceptability and appropriateness of the outcome measure.

Chapter Eight presents an integrated discussion of the findings of each study to recognise the key novel findings from this doctoral research and clinical implications as well as research limitations and recommendations for future research.

Chapter 2: A conceptual review of community integration[1]

2.1 Introduction

This chapter reports how community integration has been conceptualised in the acquired brain injury literature. Using concept analysis methodology, it provides a synthesis of different understandings of community integration and recognises core components from various literature. There has been a substantial increase in the past decade in research aiming to further define the construct of community integration and operationalise it in measurement terms. Publications on community integration propose several characterisations including three common components: physical independence, interpersonal relations and engagement in meaningful vocational activity (Fraas & Calvert, 2009; 1998; Parvaneh & Cocks, 2012; Tate et al., 1989; Trigg & Wood, 2000; Willer, Rosenthal, et al., 1993). Additionally, belonging in the community, coping with the situation, returning to previous roles and safeguarding against risk are also identified as elements of community integration (McColl et al., 1998; Parvaneh & Cocks, 2012). These results reflect considerable variation in definition and measurement criteria of the multi-faceted and broad concept of community integration. In the absence of a standardised operational model of the construct of community integration, it is difficult to measure, generalise or compare community integration across different injury groups or research results (Andelic et al., 2016).

To resolve these problems, a more robust framework needs to be articulated to inform operationalisation of outcome measures for community integration of people with ABI. The key aims and objectives of this conceptual review were to: 1) clarify the concept of community integration in persons with ABI, 2) identify attributes, antecedents, and process of the concept community integration, and 3) synthesise the findings of the analysis to inform the development of a robust conceptual framework of community integration.

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[1] A modified version of this chapter has been previously published. The full reference is: Shaikh, N. M., Kersten, P., Siegert, R. J., & Theadom, A. (2018). Developing a comprehensive framework of community integration for people with acquired brain injury: A conceptual analysis. *Disability and Rehabilitation*. doi: 10.1080/09638288.2018.1443136. Specific modifications are: (a) the published introduction is not included in this chapter; and (b) a 'rigour' section is included in the body of the chapter.

2.2 Conceptual review methodology and methods

Concept analysis refers to the process of exploring, unravelling, and delineating concepts. It was first introduced as the process of simplifying a complex concept by Wilson (1963) which was devoid of contextual information (Morse, Hupcey, Mitcham, & Lenz, 1996). Practical application is deemed necessary for the concepts in rehabilitation. This review exemplifies Morse's Pragmatic Utility approach (Morse, 2000; Weaver & Morse, 2006) to concept analysis which is more in line with the objective of this study of operationalising a concept for clinical and research purposes. Morse (1995) categorised these approaches into different methods, termed 'concept development, delineation, comparison, clarification, correction, and identification'. The method of concept clarification was used to guide this analysis. This facilitates development and refinement of the concept under investigation and is the most appropriate method when a concept is partially mature (Morse, 2000; Morse et al., 1996). Community integration can be considered as a partially matured concept as it does not have a clear universal definition, well-described attributes, boundaries, preconditions and outcomes according to the criteria described by Morse et al. (1996). Indeed, as explained above, whilst there has been extensive research on the concept of community integration after acquired brain injury, there still are numerous definitions and multiple explanations that make the concept less clear.

Qualitative inquiry and critical analysis of the literature can help in discovering underpinned values and outcomes of the construct. It also involves comparing and contrasting the attributes of the concept and related concepts (Morse et al., 1996). The technique of concept clarification facilitates development and refinement of the term under investigation by synthesizing the available literature to identify the concept's attributes, preconditions, and outcomes (Morse et al., 1996). This process incorporates critical appraisal of the existing research, coding of the data derived from the literature, and analytic questioning of the literature (S. F. Hawkins & Morse, 2014; Penrod & Hupcey, 2005).

2.2.1 Data sources

The search strategy development and review were done in consultation with the health sciences librarian at the Auckland University of Technology. An extensive literature search using EBSCO (including CINHAL, MEDLINE, and PsycINFO), and

SCOPUS was conducted. All relevant resources containing key terms acquired brain injury, brain injury, head injury, community integration, community reintegration, community re-entry, community participation, socialization, social integration, social participation, return to work, work participation, transition home, and in adult population were examined. Reference lists of all resources meeting study criteria were hand searched for any supplemental studies that may not have been revealed in the electronic database search. Studies included in the search were published between October 1989 and December 2016.

Articles using both qualitative and quantitative methods were included if they reported a study that sought to explore community integration, identified community integration as a key finding and were published in English language journals. Articles were excluded if they were not relevant to community integration e.g. focused on physical outcomes such as walking speed or endurance. Studies involving populations other than adult ABI were not included as mechanism, pathophysiology, rehabilitation goals, pattern of recovery, immediate and long-term outcomes of brain injury differ in adults and paediatric populations (Greenwald, Burnett, & Miller, 2003; Young et al., 2009). In addition, rehabilitation guidelines for children and adolescents are provided under a separate ICF framework: ICF-CY. Hence, we believe community integration should be conceptualised differently for youth with ABI. Also, articles exploring perspectives of only healthcare professionals, family, and caregivers that did not involve persons with ABI were excluded from the perspective of adults with ABI, who were the primary focus of this study.

All articles were screened for eligibility based on their titles and abstracts. A full-text copy was retrieved for each article that was considered possibly meeting the inclusion criteria or when relevance could not be confirmed by the title or abstract. These were then reviewed to determine their eligibility for inclusion. The primary and secondary supervisors, R.S. and A.T. reviewed a random selection of 25% of the articles to confirm eligibility.

2.2.2 Data extraction and synthesis

Each included article was read multiple times to develop a thorough understanding of the topic. Data extraction was performed by the initial coding of information which

included: definitions of community integration, attributes of community integration, conceptual or operationalised frameworks and the process of community integration. Such coding practice was instructed by Morse (1996) in order to assess or achieve maturity of the concerned concept. These findings were arranged onto separate matrices to compare similarities and differences across studies, including identification of areas with limited knowledge on the topic. Findings of these matrices are provided in the summary Table 2.1. These matrices formed the basis for synthesis and identification of key attributes of community integration after ABI and ultimately the development of the conceptual model of community integration.

2.2.3 Rigour

The data analysis was primarily conducted by the first author (N.S.), and the emerging concept and attributes were frequently reviewed by the supervisors and co-authors (R.S., P.K., and A.T.) of the published paper for consistency. The proposed model was also presented to health care and community support professionals, healthcare service providers, funders as well as people with personal experience of ABI, to validate the findings. The published conceptual analysis underwent peer review (Shaikh, Kersten, Siegert, & Theadom, 2018).

2.3 Results

2.3.1 Literature search results

The systematic literature search process and outcome are outlined in Figure 2.1. The search of electronic databases retrieved 2,337 articles in total. Following an initial title and abstract review, 2289 articles were excluded mostly as they were not relevant to community integration or ABI. The full-text of 48 articles were retrieved and reviewed. There were 20 articles that did not meet the inclusion criteria, hence excluded. Articles were excluded if the study was on a paediatric population or non-ABI sample group, or if it was on a topic other than community integration, and it was not directly about community integration but about a related concept such as functional ability or spirituality and coping. Hand searching the reference lists of included articles yielded an additional five articles.
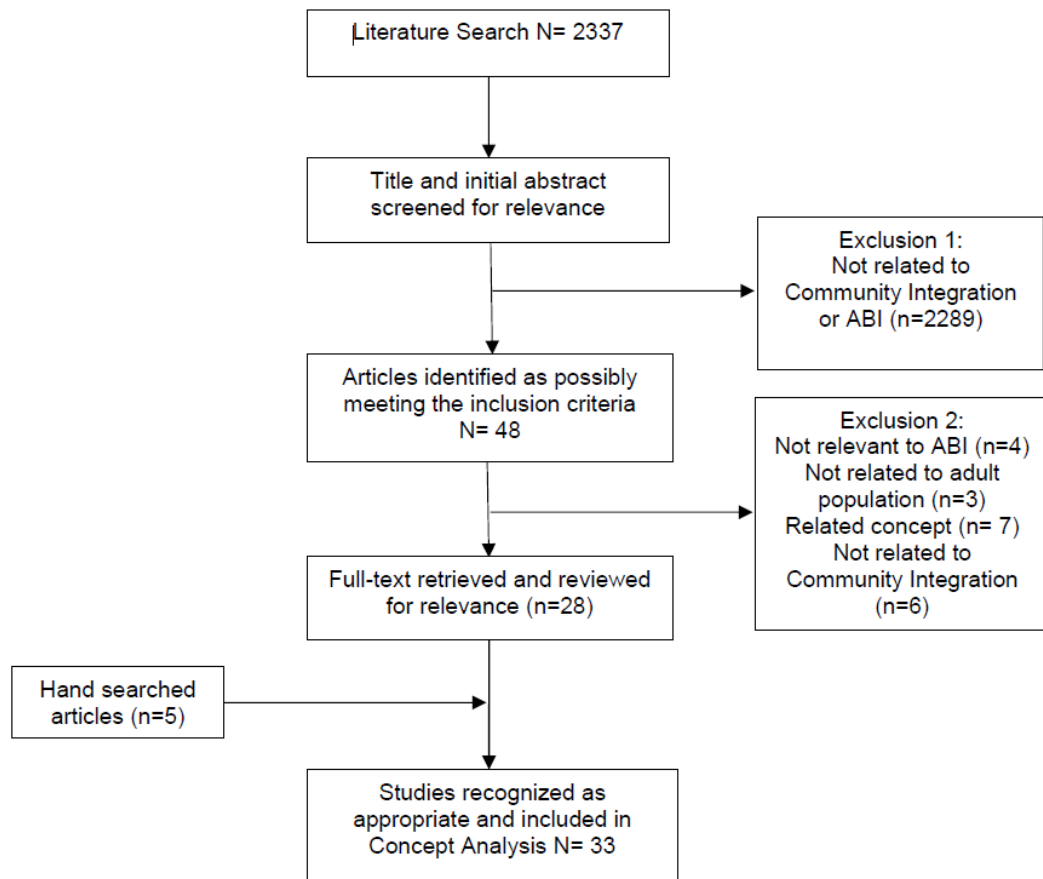
Figure 2.1: Systematic Search strategy for Concept Analysis of Community Integration

Thirty-three articles were included in the conceptual review. The selected studies represent mixed quantitative and qualitative designs. Of the qualitative studies, there were two grounded theory design(Douglas, 2013; Wood, Connelly, & Maly, 2010), three phenomenological approaches(Fraas & Calvert, 2009; McColl et al., 1998; Turner et al., 2007), one qualitative study involving focus group discussion (Willer, Rosenthal, et al., 1993), one Delphi method (Parvaneh & Cocks, 2012), five qualitative descriptive studies using semi-structured interviews, and one qualitative case study (Soeker, 2015). Two studies employed a mixed-method approach (Sander, Pappadis, Clark, & Struchen, 2011; Trigg & Wood, 2000). Six of the studies provided qualitative descriptions of existing community integration literature (Cott, Wiles, & Devitt, 2007; Dijkers, 2010; Reistetter & Abreu, 2005; Sloan, Winkler, & Callaway, 2012; Wehman, Gentry, West, & Arango-Lasprilla, 2009; Yasui & Berven, 2009), while only one study reported systemic review of intervention related studies (McCabe et al., 2007).

There were ten quantitative studies of cross-sectional, longitudinal design reporting community integration outcomes, predictors or correlations with other constructs (Andelic et al., 2016; Burleigh, Farber, & Gillard, 1998; Callaway et al., 2016; Ditchman, Sheehan, Rafajko, Haak, & Kazukauskas, 2016; Fleming, Liddle, Nalder, Weir, & Cornwell, 2014; Fleming, Nalder, Alves-Stein, & Cornwell, 2014; Gerber, Gargaro, & McMackin, 2016; Obembe, Mapayi, Johnson, Agunbiade, & Emechete, 2013; Tate et al., 1989; Williams, Rapport, Millis, & Hanks, 2014). Only one study presented experimental design with pre and post-intervention outcomes (Gerber & Gargaro, 2015).

Study populations included people who had experienced an ABI through different mechanisms including traumatic brain injury, stroke, and hypoxic brain injuries. The perspectives of adults who experienced an ABI, family caregivers, professionals, policymakers well as healthy individuals as a normative sample group were included. Sample sizes of included studies ranged from one (Sloan et al., 2012) to 1973 (Callaway et al., 2016). The information regarding the severity of injury and symptoms is missing from some of the existing research (Burleigh et al., 1998; Lefebvre, Cloutier, & Levert, 2008; Salter, McClure, Foley, & Teasell, 2011; Sander et al., 2010; Wood et al., 2010). However, it does include samples representing mild to severe injury levels living in a range of supported and non-supported community settings. A summary of the 33 included articles is presented in the summary Table 2.1.

Table 2.1. Summary of included articles

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
1989 Tate, Lulham, Broe, Strettles & Pfaff	Examined the extent of overall psychosocial disability, and measure and compare psychosocial outcome for the survivors of severe blunt head injury	Prospective longitudinal study	N=87 Blunt head injury	Not specified as study did not seek to explore community integration	Psychosocial disability was classified in: 1) vocational and avocational pursuits; 2) the ability to form and maintain significant interpersonal relationships; and 3) Functional independence (that is, the ability to live independently).	Enhanced psychosocial reintegration can be achieved by opportunities for re-entry in the vocational/ avocational areas.	Remedial/support services are required post-discharge to help patients taking charge of their own life.
1993 Willer, Rosentbal, Kreutzer, Gordon & Rempel	Described consumer-based model of Community Integration and developmental framework & Initial Validation of the Community Integration Questionnaire (CIQ)	Focus group, Cross-sectional study	1) N=14 Professionals 2) N=49(pilot-1) Moderate-severe brain injury pts;3) N=16 (pilot-2) Moderate-severe brain injury patients (4) N=94(model system sample); N=352(community samples with TBI); N=237 nondisabled samples	Defined Community Integration based on Handicap Model of the ICF: "Integration into a home-like setting, integration into a social network, and integration into productive activities such as employment, school or volunteer work."	1. Home Integration 2. Social Integration 3. Productive Activity	Not a focus of this study	Community Integration of an individual as a whole can be described as combination of all three areas (home, social, and productivity) at some level.

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
1998 McColl, Carlson, Johnston, Minnes, Shue, Davies & Karlovits	Defined Community Integration and developed a framework and operationalised model of Community Integration in TBI population. 18 adults from supported living programme were followed for 1 year and evaluated their level of Community Integration	Qualitative analysis informed by Phenomenology, Intensive semi-structured interviews	N= 116 moderate to severe brain injury living in the community N= 18 TBI living in supported living followed for 1 year	Community Integration includes independence in individual's living situation (independent living), relationships with others (social support), and activities to fill one's time (Occupation).	Community Integration was a multi-faceted construct operationalised as: General integration, Independent living, occupation and social support that include Orientation, acceptance, conformity, close and diffuse relationships, living situation, independence, productivity, and leisure.	Not a focus of this study	Positive outcomes achieved in individuals free from formal supervision.
1998 Burleigh, Farber & Gillard	Examined relationship between Community Integration and Life satisfaction	Descriptive correlational cross-sectional design	N= 30 TBI with age ranged from 26 to 60 years	Social integration was referred as a successful acquisition of a social role and adaptation of community living skills.	Social integration is a vital subtype of Community Integration.	Not a focus of this study	Social integration, component of Community Integration, was positively correlated with life satisfaction.
2000 Trigg & Wood	Developed a brief, self-report measure of social integration following stroke	Mixed methods	N= 264 Stroke Six months post-injury	Social integration was considered as perceived level of activity and integration.	(1) Activities (2) interaction, and (3) environment.	Not a focus of this study	Quality and quantity of the level of Community Integration reflect individual's ability to re-integrate into the society to his/her satisfaction.

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
2004 Sloan, Winkler & Callaway	Examined outcome literature and theoretical models of TBI and illustrated the Community approach to Participation (CAP) in the detailed case study	Literature review, Case study	N= 1 TBI case study of Sarah	The concept was considered as acceptance of people with disability in their local community.	Community Integration was described in 4 dimensions: Independent living, return to employment or study, inclusion in society and participation in leisure activities.	A community approach to participation includes: 1. Maximise participation in valued life roles in home or community. 2. Social support; 3. Meaningful occupation; 4. Self-confidence and empowerment in everyday decisions and life choices; 5. Activity independence; 6. Satisfaction with changed life.	When a long-term systematic community approach to participation is applied with clinical expertise, significant increase in Community Integration and satisfaction with life can be achieved in people with TBI.

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
2005 Reistettter & Abreu	Examined evidence to determine the best outcome measure and predictors of Community Integration. Explored relationship between Community Integration and quality of life and life satisfaction	Systematic review of the literature	NA	Community Integration was an adaptation process that was multidimensional, dynamic, personal and culturally bound. It was referred as an opportunity to have a place to live, maintain relationships and social network and be involved in a productive activity.	Severity of injury, age, and gender, education and employment level prior to the injury, living arrangement, cognitive and emotional status, functional performance, and disability have been considered as prominent predictors of Community Integration.	Not a focus of this study	Community Integration has an effect on life satisfaction whereas strong connection between Community Integration and quality of life has not been established.
2006 Winkler, Unsworth & Sloan	Assessed and identified predictive factors of community integration of people 3 to 15 years after severe traumatic brain injury (TBI)	Qualitative study, Semi-structured interviews	N= 40 Severe TBI (Average=8.8 years post-injury)	Referred to the definition given by McColl et al. (1998)	Not a focus of the study.	Not a focus of this study	Demographic factors, severity of injury, activity limitation at discharge, behavioural challenges, and social support are key predictors of community integration outcomes.

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
2007 McCabe, Lippert, Weiser, Hilditch, Hartridge, & Villamere	Examined the interventions and strategies utilised to facilitate transition from acute rehabilitation care to the community after brain injury	Systematic review	NA	Community Integration is a multidimensional concept which includes aspects of human functioning such as independence, social relationships, productivity, and leisure.	Better community outcomes depend on positive results in areas of social, emotional, occupational integration and functional independence.	The transition process from rehabilitation to community greatly involves independence and social integration, caregiver burden, satisfaction with quality of life, return to work and return to driving.	Community Integration was associated with structured cognitive rehabilitation of patient as well as support person.
2007 Cott, Wiles & Devitt	Described the process of continuity, transition, and participation following stroke and issues that survivors face on their return to the community living	Descriptive qualitative analysis of the literature	NA	Referred to the definition given by McColl et al. (1998)	The concept of Community Integration constituted an understanding of nature of the community, the notion of interdependence and client-centeredness. Satisfaction and empowerment that allows one to make choices determine successful integration.	It was described as continuity in person's experience of one's life post-injury and transition from non-disabled to disabled self, include return to meaningful roles and activities.	Not a focus of this study

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
2007 Turner, Fleming, Cornwell, Worrall, Ownsworth, Haines, Kendall & Chenoweth	Explored the transition experiences from hospital to home of a purposive sample of individuals with acquired brain injury (ABI)	Phenomenological, qualitative design	N= 13 ABI (TBI and other ABI e.g., stroke, hypoxic injury, etc.) N= 11 Family caregivers	Not specified as study did not seek to define community integration but explored transitional experience	Not a focus of this study	Transition phase was characterized by the development of greater self-awareness of deficits. Participants experienced shock upon returning home due to discrepancy between their pre-discharge life-expectations to be 'normal' and real-life experiences.	Heightened self-awareness was reported to result in emotional distress and depression. A major source of successful transition was availability of adequate support from the family.
2008 Lefebvre, Cloutier & Levert	Explored perceptions of TBI survivors and their caregivers about long-term social integration	Qualitative study, Semi-structured interviews	N= 22 TBI survivors (10 years post-trauma), N= 21 Family caregivers	Referred to the definition proposed by Reistetter and Abreu (2005)	Individuals perceived that their capacity to adjust to their physical and cognitive deficits and adapt to the living environment and available support from their loved ones were the most significant factors in achieving successful social integration.	From the perspectives of TBI survivors', social integration was an on-going process.	Not a focus of this study

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
2009 Yasui & Berven	Provided an overview of various conceptualisations of Community Integration and reviewed most frequently used outcome measures of Community Integration	Review of the literature	NA	Reiterated the definitions formulated by McColl et al. (1998)	Divided outcome measures into four broad groups based on the Community Integration models: 1) Functional Independent Model; 2) Acculturation Model; 3) Normalisation Model; 4) Subjective Experience Model	Not a focus of this study	Not a focus of this study
2009 Wehman, Gentry, West & Arango-Lasprilla	Examined the roles of cognitive and vocational rehabilitation and in individuals with acquired brain injury from minority backgrounds	Literature review	Studies from ABI Model Systems National Database	Not a focus of this study	Return to productive activity is one of the most important objectives of community integration after ABI.	Not a focus of this study	Behavioural and mental health issues post-ABI can impact employment and productivity outcomes.
2009 Fraas & Calvert	Examined the factors leading to successful recovery and productive lifestyles after acquired brain injury (ABI)	Qualitative investigations; phenomenological approach	N= 31 ABI; Average age: 43.52 (SD=13.53); 22-432 months post-injury	Not a focus of this study	Social support networks Grief and coping Acceptance of injury and redefinition of self Empowerment	Not a focus of this study	The sense of empowerment improves self-esteem and encourages individuals to contribute to the community by engaging in meaningful activities.

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
2010 Sander, Clark & Pappadis	Reviewed existing knowledge regarding the meaning of Community Integration and issues related to assessment of Community Integration after traumatic brain injury	Descriptive literature analysis, structured interviews	N= 167 TBI, 4-12years post injury	Community Integration was referred as full participation in 3 major areas such as independent living, social activity, work, leisure or other productive activity.	The priority of each area of Community Integration may differ in individuals from different age and cultural groups.	Not a focus of this study	Not a focus of this study
2010 Wood, Connelly & Maly	Examined patient's perspective of the process of Community Integration over the first year following stroke	Qualitative and longitudinal grounded theory method. N= 46 Stroke, At before discharge, and then 2,3,6 months and 1-year post discharge	N=10 Stroke (first Left hemiparetic stroke)	Community Integration refers to the engagement in meaningful role, in community living. This can be attained by maintaining balance between their expectations of themselves and their physical capacity.	Patients' expectations of their integration were influenced by care and support they received from the community support networks and their interactions with peer, informal and formal caregivers.	The process of Community Integration includes gaining physical function, establishing independence, and getting back to real living by adjusting one's expectations.	Successful reintegration was achieved in patients who could create balance between their expectations of themselves and their capacity.

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
2010 Dijkers	Explored issues in conceptualisation and measurement of participation.	Special communication	NA	Community participation is a domain of functioning which is not just limited to disability and physical performance.	ADLs, community re-entry, societal integration, social role acquisition, community or independent living, return to normalization without restriction, psychosocial functioning & equal opportunities in various life areas such as living situation, occupation, and leisure	Not a focus of this study	Participation or Community Integration should be measured as quantifying performance as well as subjective lived experience of an individual.
2011 Sander, Pappadis, Clark & Struchen	Explored perception of Community Integration in ethnically diverse population	Prospective study design, Mixed methods	N= 58 Blacks; N= 57 Hispanic; N= 52 whites TBI, 6 months post-injury	This study did not seek to define Community Integration.	Variables such as nature of surrounding environment and community, presence of family and friends, feeling respected, active involvement, being helpful to others and make positive contribution to the community was identified as facilitators to Community Integration.	Not a focus of this study	Community Integration can be perceived differently if an individual belongs to the ethnic minority group, low education, and low socio-economic group.

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
2012 Parvaneh & Cocks	Developed a descriptive model of Community Integration framework and compared it with four existing frameworks	Delphi method	N= 37, Drawn from five stakeholder groups (practitioners, researchers, policy-makers, people with ABI and family members of people with ABI)	Integration or re-integration into the community was a vital social objective for people with ABI.	7 themes describe construct of Community Integration: 1. Relationships; 2. Community Access; 3. Acceptance; 4. Occupation; 5. Being at home; 6. Picking up life again; 7. Heightened risks and vulnerability	Not a focus of this study	Not a focus of this study
2013 Obembe, Mapayi, Johnson, Agunbiade & Emechete	Determined the association of community reintegration with motor function and post-stroke depression	Cross-sectional study	N= 90 Stroke survivors	Self-perceived integration is representative of individual's perception and satisfaction with involvement and in various life situations.	Not a focus of this study	Not a focus of this study	Community Integration has positive association with motor function and negatively correlated with post-stroke depression.

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
2013 Douglas	Explored an understanding of different ways adults, living with the adverse outcomes of severe TBI, conceptualise themselves	Constructivist Grounded Theory	N=20 (16 male, 4 female) Severe TBI	This study did not seek to define Community Integration.	1) Knowledge components: personal attributes (not related to injury), personal goals (domains-physical, material, social-relational, and activity); 2) Evaluative components: self-attitude and Sense of achievement in above mentioned four domains; 3) staying connected: Sense of connection between self and society	Attaining self-concept post-injury is a dynamic and cyclic process in which involves transformation of personal pursuits to personal achievements that eventually influence one's sense of self.	A sense of social connection and social support are considered to be important measures of psychological recovery, Community Integration, family living, life satisfaction, and quality of life post severe TBI.

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
2013 Nalder, Fleming, Cornwell, Shields & Foster	Examined the lived experiences of individuals with TBI during the first 6 months following discharge from hospital	Qualitative investigation (semi-structured interviews)	N=16 TBI, 9 months post-discharge	This study did not seek to define Community Integration.	Not a focus of this study	The process of transition from hospital to community initiated by desire to overcome injury related life changes and regaining normal function followed by changed perspective on life. Dynamic interaction between the two was seen as individual life views.	Presence of social support network reported to be essential for successful transition.
2014 Williams & Rapport	Examined relationship between life satisfaction, Community Integration, and emotional distress in individuals with TBI	Longitudinal correlational study, Confirmatory factor analysis	N= 253 adults with mild to moderate TBI	Not a focus of this study	Community Integration can be categorised into two domains: 1) Objective (social participation, mobility, occupational outcomes); 2) Subjective (connectedness, social role, feeling accepted, familiar).	Not a focus of this study	Community Integration is positively associated with Life satisfaction but inversely related to emotional distress.

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
2014 Fleming, Nalder, Alvesstein & Cornwell	Described environmental barriers endorsed by individuals with traumatic brain injury during the first 6 months after discharge and determine their effect on community integration.	Prospective longitudinal study with data collected at pre-discharge and at 1, 3, and 6 months post-discharge	N=135 TBI	This study did not seek to define Community Integration.	Not a focus of this study	Not a focus of this study	Environmental factors such as physical barriers, attitude, and availability of support affect long-term physical functioning and interpersonal relationships with greater effect than policies and services.
2014 Fleming, Liddle, Nalder, Weir & Cornwell	Determined the rates, timing, correlates, and predictors of return to driving in the first 6 months after discharge from hospital following ABI	Prospective longitudinal cohort design	N= 212 ABI, N= 121 family members	This study did not seek to define Community Integration.	Return to driving is considered as a rehabilitation goal for community reintegration which represents participation in valued activities and roles as well as independent access to community locations.	Not a focus of this study	Injury severity, levels of community integration and quality of life reported impacting driving outcomes in the first 6 months post-ABI. Individuals with ABI who were unable to return to driving in the first 6 months represented poor psychosocial outcomes.

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
2015 Gerber & Gargaro	Described and evaluate a new day programme developed to provide social, recreational and skill training activities for persons living with an acquired brain injury (ABI), including persons exhibiting challenging behaviors	Interventional study, longitudinal pre-post design	N= 61 adults with moderate-to-severe ABI; N=75 family caregivers	This study did not seek to define Community Integration.	Community integration (CI) involves social interactions and participation in recreational activities.	Not a focus of this study	Limited social contact and social isolation negatively affect community integration. Training for social and leisure skills increase level of community integration and decrease caregiver burden.
2015 O'Neil-Pirozzi, Lorenz, Demore-Taber & Samayoa	Explored the understanding of views and processes of the residential transition experience from the perspective of adults with chronic acquired brain injury and identified translatable, practical ways to support the success of such transitions	Qualitative design	N= 21 adults with chronic TBI	This study referred to the community integration definitions proposed by Turner B. et al. (2008), and McCabe et al. (2007). The transition was considered to be associated with isolation and integration.	Not a focus of this study	The process of transition into the community includes: Finding a balance between support and independence, defining a new purpose in life, Transition to structure, feeling invested in the transition process, engaging in hobbies and interests and Experiencing faith, fulfilment, and acceptance.	Transition success is influenced by survivor factors (self-awareness, motivation), environmental factors (degree of family involvement, professional caregiver training, local resident attitudes towards individuals with disabilities), access to social (fitness) and recreational activities.

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
2016 Andelic, Arango-Laspeilla, Perrin, Sigurdardottir, Lu, Landa, Forslund & Roe	Assessed the trajectories of community integration in individuals with traumatic brain injury (TBI) through one, two, and five years post-injury	Longitudinal cohort study at the one, two and five-year follow-ups	N= 105 individuals with moderate-to-severe TBI	This study did not seek to define Community Integration.	Employment, leisure activities, ability to live independently and ability to drive were identified as important domains of community integration.	Not a focus of this study	Being single, employed, having higher education prior to injury, and shorter length of PTA at hospital admission were significant predictors of higher community integration at one, two, and five years post-injury.

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
2016 Callaway, Winkler, Tippett, Herd, Migliorini & Willer	Revised and updated Community Integration Questionnaire (CIQ) to include Electronic Social Networking (ESN) Domain. Examine the factor structure of the CIQ-R. Collect normative data for the CIQ-R, examining contribution of a range of independent demographic variables to community integration; and examine the test-retest reliability of the measure	A cross-sectional survey design, Community Integration Questionnaire-Revised (CIQ-R) administration	N= 1973 Australian adults; N=78 subset analysis 3 months after original administration	This study did not seek to define Community Integration. It referred to the definitions given by McColl et al. (1998); Parveneh & Cocks (2012); Willer et al. (1993).	Independence in one's own living situation, participate in meaningful activities in order to fill one's time, relationships with others, participate in electronic social networking activities	Not a focus of this study	Integration is associated with life stages and resources. Various demographic factors such as Gender, age, education, income, location of residence and living situation contribute to the level of community integration.

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
2016 Soeker	Explored and described the experiences of individuals with Traumatic Brain Injury regarding returning to work through the use of the model of occupational self-efficacy	qualitative paradigm; case study	N=10 mild to moderate brain injury	This study did not seek to define Community Integration.	Resuming work role is essential for successful re-integration into the society. Return to work provides an individual opportunity to improve functional skills and sense of contribution.	Not a focus of this study	Not a focus of this study
2016 Ditchman, Sheehan, Rafajko, Haak & Kazukauskas	Investigated factors impacting social integration for adults with brain injury using the International Classification and Functioning, Disability and Health (ICF) as a conceptual model	Cross-sectional survey	N=103 adults brain injury	Social integration was described as component of participation and community integration as 'participation in social activities'.	Integration in social role, availability of social support	Not a focus of this study	Socioeconomic Status, severity of functional limitations and social support strongly impact social integration in people with brain injury.

Author	Purpose of study	Methodology/ methods	Participant information (N)	Core findings of conceptual review			
				Definition	Attributes or components	Process	Outcome
2016 Gerber, Gargaro & McMackin	Studied predictors of community integration (CI) and health-related quality of life (HRQoL) in a sample of Canadian adult, urban, multi-ethnic persons with acquired brain injury (ABI) receiving publicly-funded community services	Cohort study	N=63 adults who sustained ABI in last 4 years	This study did not seek to define Community Integration.	Independent living, participation in social and leisure activity and involvement in work and/or other productive activity	Not a focus of this study	Level of disability was reported to impact overall community integration. Aspects of social integration were associated with quality of life post-injury.

ABI: acquired brain injury; ADLs: activities of daily living; TBI: traumatic brain injury; CIQ: community integration questionnaire; PTA: post-traumatic amnesia; CAP: community approach to participation; ESN: electronic social networking.

2.3.2 Conceptual components of community integration

From this analysis, the conceptual components of community integration, that is, definitions, the antecedents, attributes, and processes, can be identified.

Defining community integration

The analysis identified multiple definitions of community integration derived from thirteen out of the thirty-three studies. Several studies demonstrated specific commonalities in the definition of community integration such as independent living, acquisition of social role, and vocation/avocational pursuit (Ditchman et al., 2016; McCabe et al., 2007; Reistetter & Abreu, 2005; Sander et al., 2010; Trigg & Wood, 2000; Willer, Rosenthal, et al., 1993; Wood-Dauphinee & Williams, 1987). In contrast, other studies considered it as an adaptation process, a domain of functioning which is beyond physical capacity (Burleigh et al., 1998; Dijkers, 1998; Reistetter & Abreu, 2005; Wood et al., 2010). It was also referred to as psychological wellbeing (Douglas, 2013), equal opportunities and acceptance in the community (Parvaneh & Cocks, 2012; Sloan et al., 2012), and perceived satisfaction with engagement in society (Obembe et al., 2013). The range of definitions demonstrated the multidimensional nature and the diversity of conceptualisation of community integration. These findings and absence of universally accepted definition supported the rationale for current concept analysis. The definitions are specified in Table 2.1.

Antecedents of community integration

Antecedents are phenomena that help clarify the key attributes of the concept and enhance understanding of the social and environmental context in which the concept takes place. There were a number of individual, injury-related, societal and environmental factors identified in the literature that are believed to influence the development of community integration. Individual demographic factors such as age, ethnicity, cultural group, location of residence, income and level of education, may affect the priority, perception and outcome of each area of community integration (Andelic et al., 2016; Callaway et al., 2016; Ditchman et al., 2016; Sander et al., 2010; Sander et al., 2011; Wehman et al., 2009). Similarly, personal attributes such as self-awareness, attitude towards recovery, life roles, coping, motivation and empowerment are likely to influence integration (Cott et al., 2007; Douglas, 2013;

Fraas & Calvert, 2009; O'Neil-Pirozzi, Lorenz, Demore-Taber, & Samayoa, 2015). Injury-related influences such as severity of injury and the person's capacity to adjust to their physical and cognitive deficits were found to be preconditions to their level of community reintegration (Lefebvre et al., 2008). One study indicated the possibility of behavioural and mental health issues as a secondary consequence of ABI (Winkler, Unsworth, & Sloan, 2006).

Societal factors included interactions with peers and family, informal and formal caregivers (Ditchman et al., 2016; Wood et al., 2010). Other social indicators of being respected and being helpful to others by making a positive contribution to the community have been identified as the most significant factors in achieving successful social integration (Lefebvre et al., 2008; O'Neil-Pirozzi et al., 2015; Sander et al., 2011). Environmental predictors of community integration were considered as the nature and the structure of the surrounding environment and community. Physical barriers or facilitators such as the physical arrangement of home, work, or community, availability of transport, financial status, access to services and information, were identified to be influential to community integration (Fleming, Nalder, et al., 2014; Lefebvre et al., 2008; O'Neil-Pirozzi et al., 2015; Reistetter & Abreu, 2005; Tate et al., 1989).

Attributes of Community Integration

According to Walker and Avant's (2005) method of concept analysis, the characteristics of the concept that emerged repeatedly during the literature review were considered as attributes. Through this analysis, community integration was conceptualized as having the six overarching attributes: (1) independence; (2) place to live; (3) social integration; (4) occupational performance; (5) psychological integration; (6) sense of belonging. These primary areas were identified by 20 of the studies including five prominent frameworks of community integration (see Figure 2.2) that reported conceptualisation or measurement of community integration on quantified performances or subjective lived experiences of the persons with ABI (Dijkers, 2010; Williams et al., 2014). Each of these attributes is described in more detail below:
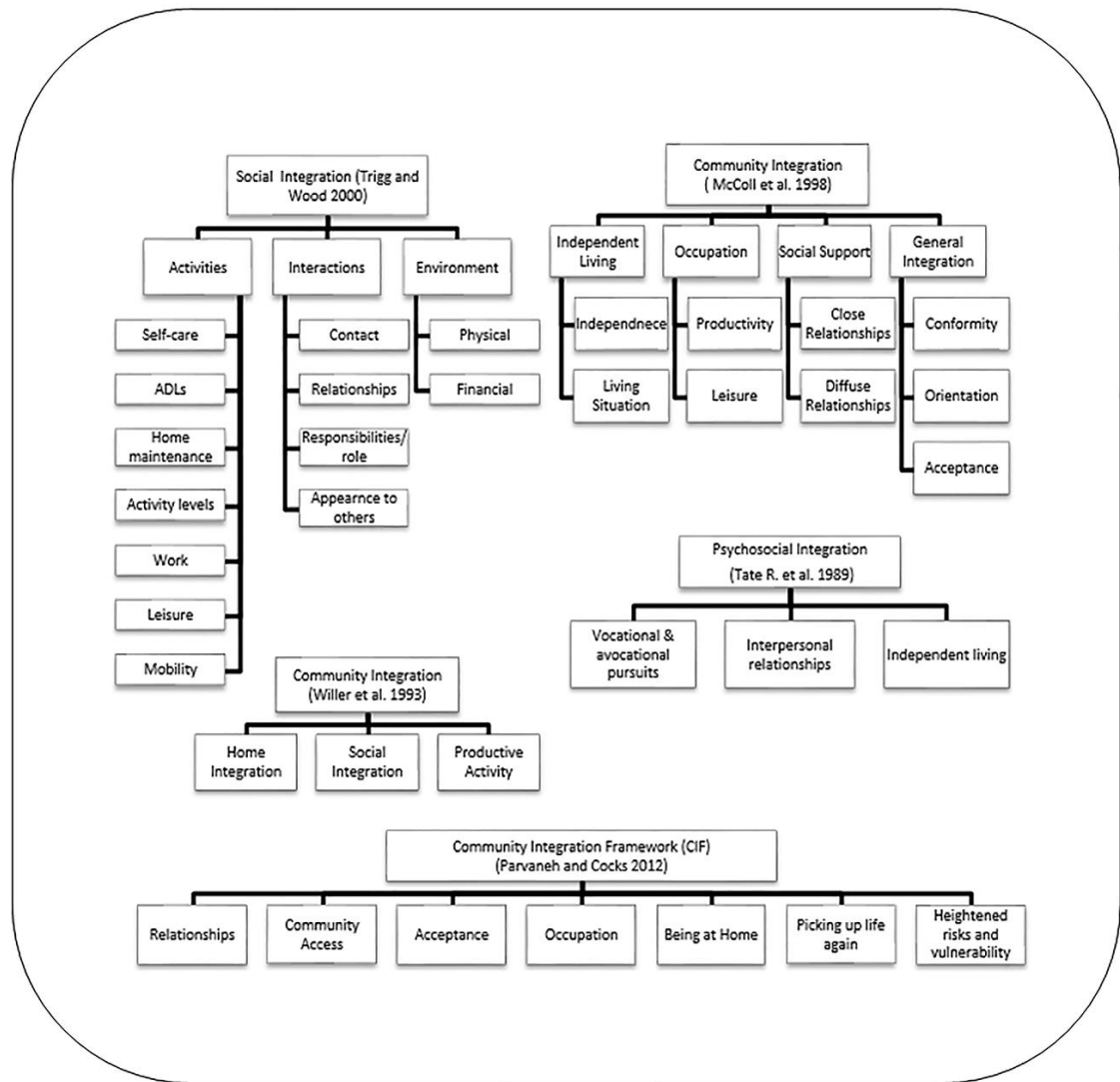
Figure 2.2: Five prominent frameworks of community integration

Independence

Independence is the most widely explored and outcome-oriented component of community integration in the ABI population. The process of establishing independence after injury is based on improved physical function in activities of daily living (Tate et al., 1989; Wood et al., 2010). Independence in household activities, successful access to community services and venues, mobility inside or outside the home, knowing one's way around in the community, and being able to drive have been categorized as important aspects of community integration for individuals after brain injury (Fleming, Liddle, et al., 2014; Fraas & Calvert, 2009; Parvaneh & Cocks, 2012; Willer, Rosenthal, et al., 1993). Independence was also explained as being empowered in making life choices and everyday decisions, and the practice of self-determination within one's capacity (McColl et al., 1998; Parvaneh & Cocks, 2012).

Place to live

Community integration has been characterised as having access to an appropriate, safe and normalised living environment (McCabe et al., 2007; McColl et al., 1998). This aspect of a person's living situation has been explained as 'home integration' and included active involvement of an individual in activities in the home (Willer, Rosenthal, et al., 1993). Similarly, the feeling of 'being at home' has been detailed as a component of the Community Integration construct, which refers to the notion of having one's own home; being able to make decisions about arrangements in the house; performing regular activities such as cooking, eating, reading, watching TV; and utilising one's own home as a base to explore and participate in community activities (Parvaneh & Cocks, 2012). One study summarized how people with disabilities perceive home ownership, accessibility to community activities and services, and a feeling of being at ease at home, improved their sense of belonging in the community (Sander et al., 2011).

Social Connection

Social connection has been widely emphasised in conceptualizations of community integration. It was defined as the successful acquisition of a social role (Ditchman et al., 2016) and adaptation of community living skills and had a strong correlation with life satisfaction and improved quality of life (Burleigh et al., 1998; Gerber et al., 2016). Social integration was referred to as participation in a range of activities outside the home, including going out for shopping, movies, and visiting friends (Willer, Rosenthal, et al., 1993). It was further explained as forming and maintaining various interpersonal relationships which are significant and satisfying and that extends beyond the family, such as having a best friend or taking part in activities with members of society who are not disabled (Gerber & Gargaro, 2015; Tate et al., 1989; Willer, Rosenthal, et al., 1993). Furthermore, social interactions with family members, friends, pets and the availability of family caregivers including the use of electronic social network were acknowledged as facilitators of higher levels of community integration (Callaway et al., 2016; Douglas, 2013; Fraas & Calvert, 2009; Lefebvre et al., 2008). Another study used the term 'Social Support' as being part of the network of family, friends and other related members of the society. It was further divided into two parts: Close relationship - having a spouse or a parent in the community, and diffuse relationship -

having relationships that are not characterised by closeness or intimacy (McColl et al., 1998).

Occupational Performance

Various broad aspects of occupational performance such as vocational or avocational activities have been recognized as indicators of successful community rehabilitation during this analysis. Being involved in some kind of occupation allows ABI survivors to contribute to society through their activities such as paid or unpaid work or other productive actions (Fraas & Calvert, 2009; Soeker, 2015; Wehman et al., 2009). Having an opportunity to participate in recreational activities helps them to express their identity and builds confidence in self, according to the perspectives of survivors of brain injury (McCabe et al., 2007).

Productivity has been explained as one of the three aspects of community integration in a framework developed by Willer, Rosenthal, et al. (1993), that includes employment, education and volunteer activities. McColl et al. (1998) considered productive and leisure activities as sub-items of the occupation domain of the client-centred framework of community integration. Individuals with moderate to severe TBI conceptualised financial stability and self-sufficiency as a personal achievement (Douglas, 2013). The underlying concept of the vocational domain was "having things to do for fun and being able to do productive activities during the main part of the day" (Tate et al., 1989). Meaningful engagement in activities such as job, social, leisure and recreational performances at home and community settings have also been described under the Occupation theme of the Community Integration Framework (CIF) (Parvaneh & Cocks, 2012). The author of the CIF added an element of choice to occupational performance that indicates the ability of the individuals to choose how to spend their time.

Adjustment

Adjustment can be explained as an improved cognitive and behavioural function that affects individuals' ability to perform in the areas of vocation, emotional bonding with the other members of the family and community and contribution to the community (Tate et al., 1989). It also involves acceptance of the injury and effectively redefines self, allowing individuals to discover new life goals (Fraas & Calvert, 2009; McColl et al., 1998). The sense of satisfaction experienced by the individuals in their newly adjusted

life situation improves their perception of community involvement and boosts their self-image (Douglas, 2013; Lefebvre et al., 2008; Tate et al., 1989).

Sense of belonging

Being actively involved in community areas improves a sense of being an important part of the community. According to the perspective of the TBI survivor, a feeling of being loved, acknowledged and supported improves their sense of stability as an inclusive but unique member of the community (Douglas, 2013; Sander et al., 2011). It involves the notion of being able to fit in and be accepted in the community(McColl et al., 1998). Successful integration was also described as being satisfied, feeling empowered to make one's own choices and having equal opportunities in various life areas (Cott et al., 2007; Dijkers, 2010).

The process of Community Integration:

Community integration is described as an ongoing process of *adaptation* throughout life (Reistetter & Abreu, 2005). This process often involves a transition from rehabilitation to the community as well as changes in functional recovery and adaptation to new limitations and changing life circumstances (McCabe et al., 2007; O'Neil-Pirozzi et al., 2015; Wood et al., 2010). A successful *transition* in the community involves improved functional abilities during patient rehabilitation and acceptance of their changes in functional abilities and *conforming* to newly adjusted priorities with their altered body and self-image, to achieve a meaningful role in society (Cott et al., 2007; Nalder, Fleming, Cornwell, Shields, & Foster, 2013). Community integration was referred to as a *continuous* process towards achieving one's goals such as regaining normality and control with the search for fulfilment and acceptance (O'Neil-Pirozzi et al., 2015; Turner et al., 2007).

The findings of this concept analysis enabled the development of a conceptual model of community integration. Figure 2.3 is a schematic presentation of the model.
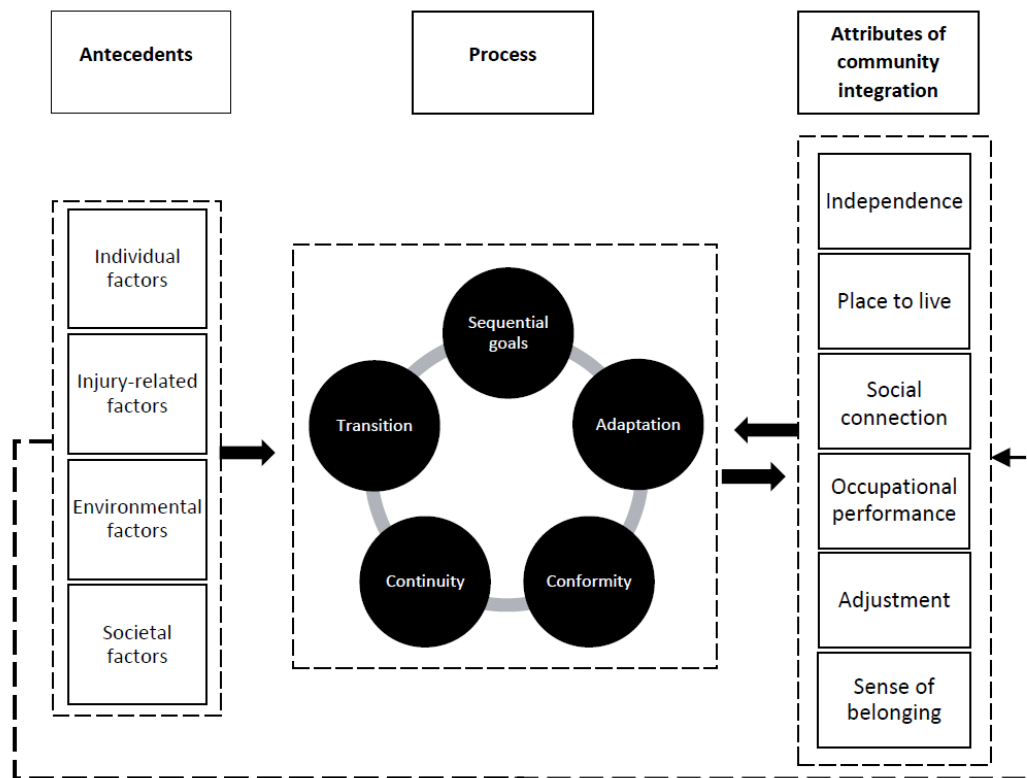
Figure 2.3: Conceptual model of Community Integration

2.4 Discussion

This concept analysis is a unique attempt to provide a comprehensive overview of the existing knowledge about community integration through a robust synthesis of the literature. Community integration was found in a multidimensional and non-linear process influenced by several individual, injury-related, social and environmental factors. Community integration was found to encompass six distinct but interrelated attributes including; Independence, place to live, social integration, occupational performance, adjustment, and sense of belonging.

The new conceptual model reflects the components of the five existing frameworks of community integration (see Figure 2.2 above) (McColl et al., 1998; Parvaneh & Cocks, 2012; Tate et al., 1989; Trigg & Wood, 2000; Willer, Rosenthal, et al., 1993). Five of the six components of the new conceptual model (physical integration, place to live, social integration, occupational performance, and being involved in the community) are consistent with domains of the consumer model of community integration proposed by McColl et al. (1998). According to the framework proposed by Willer, Rosenthal, et al. (1993), all three domains, home integration, social integration, and productive

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activity, incorporated into the conceptual model of community integration are congruent with the components of our model place to live, social integration, and occupational performance respectively. A study by Obembe et al. (2013) has suggested that independent living situation and functional ability could be the successful indicators of community integration, whereas others have emphasised the importance of social support received from the community in achieving community integration goals (Burleigh et al., 1998; Douglas, 2013; Lefebvre et al., 2008; Sander et al., 2011). Social support is considered as equally important as physical independence in our conceptual framework. Moreover, our conceptual model encompasses the attribute of 'adjustment' which was not part of any other brain injury integration framework, except for the model of psychosocial reintegration developed by Tate et al. (1989). Additionally, previous studies have focused on the physical aspects of independence, adding to that knowledge, our analysis has highlighted the importance of cognitive aspects of independence such as self-awareness, empowerment and decision making. The conceptual model depicts that the community integration following brain injury is achieved through a process which incorporates sequential goals, adaption, conformity, continuity, and transition at various phases of community living. Also, the new model emphasises personal, injury-related, environmental and social factors as contextual conditions that continuously influence integration, which can lead to positive or negative outcomes. Understanding of such influences, not only aid in identifying potential barriers to successful community integration but also support selection of rehabilitation setting, effective intervention design, and discharge planning.

Existing measures of community integration focus on ability to perform activities inside and outside home, involve in education or employment and form or maintain relationships from individual or service evaluation perspectives (Dijkers, 1998; McColl et al., 1998; Parvaneh, Cocks, Buchanan, & Ghahari, 2015; Tate et al., 1989; Trigg & Wood, 2000; Willer, Rosenthal, et al., 1993). No measures capture all attributes highlighted in the new model including sense of control over life situations, acceptance or sense of belonging, having accessibility and equal opportunity within the community. The conceptual model provides a basis to inform the design of community integration rehabilitation programs for people with ABI and offers a comprehensive

framework for the development of measures that evaluate level of integration as a clinical or rehabilitation outcome.

Moreover, it is evident that no universally-accepted or single definition of community integration exists, suggesting a scarcity of clear conceptual meanings of the construct. This analysis of multiple conceptualizations of community integration indicates that the construct has not achieved maturity and fails to meet prerequisite requirements of 'being mature': "to be well-defined, have distinct attributes, well-delineated boundaries, and well-described preconditions and outcomes, as well as to be easily and readily identifiable in the clinical setting" (Hupcey, Penrod, Morse, & Mitcham, 2001; Morse et al., 1996). This analysis contributes to advancing the understanding and maturity of the concept by providing comprehensive definition, underpinning attributes and all contextual factors in which the concept takes place.

2.4.1 The need for future research

The community integration concept presented here needs to be verified through further studies reporting perspectives of people with ABI, family caregivers, healthcare providers, clinicians and wider stakeholders. As children were excluded from this review, it remains unclear if the presented concept of community integration is relevant to this population. Provided the rehabilitation goals in younger populations may differ from majority of adults, further explanation of interactions between functional, psychological and social limitations is required (Agnihotri, Keightley, Colantonio, Cameron, & Polatajko, 2010).

The process of transition was widely explored but there were limited data about the process of achieving community integration. It would be advantageous to conduct longitudinal studies to explore the ongoing experience of community integration in a brain injury population capturing diversity in terms of severity of injury consequences. In this review, perspectives of adults encompassed those experiencing mild, moderate and severe injuries across studies, although few studies explored the severity spectrum within the same population sample. Considering the diversity of integration process and outcomes experienced by people with varying levels of severity, further research to verify the appropriateness of this model across all groups is required. This review included studies that explored perspectives of people with ABI including TBI, stroke

and other hypoxic brain injuries. It is recommended to verify this model with various injury population groups such as spinal cord injury, cancer, myocardial infarction, ABI in children, and people with psychiatric illness.

2.4.2 Clinical implications of community integration research

Community integration is a key goal of rehabilitation (Car-Blanchard, 2005). Consequently, it is important to have a clear definition and understanding of this concept to ensure rehabilitation meets patients' needs. This model highlights the need for clinicians to be aware of and assess the role of antecedents as well as the attributes of community integration itself to ensure all aspects are addressed in a manner that will enhance the recovery and improve the level of integration into the community. The finding that community integration is a non-linear process also highlights the need for rehabilitation professionals to review and revise plans over time, in response to a person's changing circumstances and recovery journey. Furthermore, the findings highlight the need to develop a measure of community integration that assesses all six attributes revealed in this review, but not recognised in previous frameworks. This analysis provides the groundwork for an operational model of community integration for the development of such an outcome.

2.4.2 Limitations of the review

There are two key limitations of this concept analysis. Firstly, the data selection process does not incorporate a full conservative quality appraisal based on a suggested approach that all articles meeting the inclusion criteria should be included in the concept analysis, irrespective of their methodological quality (Rodgers, 2000). Hence, the articles were screened for clarity of information on study design, inclusion/exclusion criteria, and usefulness of study findings in enhancing the understanding of concept of community integration but were not excluded for quality purposes.

Secondly, it is possible that not all relevant articles were included in the analysis. Whilst a number of descriptors of community integration including community re-integration, community engagement, community participation, social engagement; were used it may be the case that including other descriptors would have identified further articles. However, synthesis of the current literature and refinement of the

concept in this article clarifies the concept of brain injury population and also offers implications for future research and practice.

2.5 Conclusion

This study presents a concept analysis of community integration in people with ABI. It was revealed that community integration is a multifaceted non-linear process. This analysis provides a new, refined and multifaceted definition that describes community integration as 'being independent and having a sense of belonging within the community; having a place to live; being socially and psychologically integrated into the community; and involved in meaningful occupational activity'. Attributes identified in previous research were supported and also highlighted the role of psychological independence, especially cognitive factors. The proposed conceptual model of community integration highlights the need to develop an outcome measure to assess all six components of community integration in people with ABI.

Chapter 3: Measurement of community integration following Acquired Brain Injury

3.1 Introduction

The previous chapter on a concept analysis of community integration in people with Acquired Brain Injury (ABI) identified different components of community integration based on various conceptualisations, highlighting its multidimensional nature. A number of measurement tools have been developed and operationalised to assess community integration. These existing measures of community integration incorporate various domains representing different aspects of the concept. Additionally, their measurement criteria differ significantly, which makes it difficult to generalise or compare outcomes across populations in clinical settings, cultural contexts or research studies. The second aim of this doctoral research, followed by the conceptualisation of community integration, and the focus of this chapter, is to identify and evaluate an appropriate measure/s of community integration for use in people with ABI in New Zealand. To assist with the measure selection, the studies reporting psychometric properties of the measure were evaluated against the criteria proposed by Terwee et al. (2007), that included appropriateness, reliability, validity, responsiveness, precision, and interpretability. The quality criteria have been widely used in other evaluative studies of rehabilitation and health outcome measures (Ashford, Slade, Malaprade, & Turner-Stokes, 2008; Bot et al., 2004; Turner-Stokes & Siegert, 2013; Windle, Bennett, & Noyes, 2011). These criteria were found to be most suitable for this study considering their rigorous, meaningful and comprehensive evaluation to rate methodological quality of the study.

The initial inquiry done as a part of the concept analysis study identified five frequently used measures that represent a range of conceptualisations of community integration, all validated in ABI populations which were selected for this systematic review. The measures were selected based on their frequency of use in the current literature. Frequency of their use was determined by the number of citations in Google Scholar and Web of Science databases which is listed in Table 3.1 The selection process for these measures was also guided by the US based TBI model systems collaborative project COMBI (the Center for Outcome Measurement in Brain Injury) that reports

clinical and research applications of these measures in people with TBI. These outcome measures can be divided into two distinct groups: (1) objective/observational measures (what do people with disability *do*; e.g. frequency of the activity a person performs in a day) including the Community Integration Questionnaire (CIQ)(Willer, Rosenthal, et al., 1993), the Craig Handicap Assessment and Reporting Technique (CHART)(Whiteneck, Tate, & Charlifue, 1999) ; and (2) subjective experience-based measures (how people *feel* about what they do or cannot do; e.g. the feeling of being accepted or connected to the community) including the Sydney Psychosocial Reintegration Scale (SPRS) (Tate, Simpson, Soo, & Lane-Brown, 2011), the Re-integration to Normal Living Index (RNLI) (Wood-Dauphinee & Williams, 1987) and the Community Integration Measure (CIM) (McColl, Davies, Carlson, Johnston, & Minnes, 2001). Descriptive details of five selected measures are presented in Table 3.1 (e.g. population validation, number of total items, sub-scales, maximum score, response format, time required to minister the tool, and total number of citations as a proxy for frequency of use).

3.2 Method

This review aimed to identify published studies reporting on psychometric properties of five prominent measures of community integration as mentioned above. The review process followed in this study is described below:

3.2.1 Systematic search to identify the validation literature for five selected outcome measures of community integration

Data Source and Search Strategy

Relevant references were retrieved through electronic searches of CINHAL, PubMed, SCOPUS, PsycINFO, and Web of Science using three groups of terms combined with AND/OR: "Community Integration", "Brain Injury", and "Outcome Measurement". Through the initial search, a list of commonly used measures was compiled. Subsequent searches located data regarding the psychometric properties of each instrument using the name of each tool with the keywords 'validity OR reliability OR agreement OR responsiveness OR floor/ceiling effects'. Additionally, hand-searching of the reference lists of the selected articles was performed.

Inclusion/ Exclusion Criteria for Studies

Studies were included if they identified community integration as a central construct,

that were conducted with people with a traumatic brain injury, stroke, or other brain injury; and comprised information regarding development, evaluation or validation of the identified measures. The search included studies published up to December 2016. Studies pertaining to paediatric populations and those not translated into English were excluded.

Table 3.1. Summary description of the most commonly used measures of community integration and citations in Google Scholar and Web of Science (11th November 2017)

Outcome Measure	Language of tool (country of origin)	No. of items	Sub-scales	Response Format	Scoring	Disease specificity	Time to administer	Training Required	Citations	
									Google Scholar	Web of Science
Community Integration Questionnaire (Willer, Rosenthal, et al., 1993)	English (United States)	15	Home integration (5 items), Social Integration (6 items), Productivity (4 items)	Likert Scale (0=someone else; 1= yourself and someone else; 2=yourself alone, self-report) (Face-to-face, telephonic interview)	Max Score=29 Subscale score: Home integration: 0-10; Social integration: 0-12; Productive activity: 0-7	TBI	15 minutes	No	1860	234
Craig Handicap Assessment and Reporting Technique (Whiteneck et al., 1999)	English (United States)	27	Subscales: Physical Independence (3 items), Mobility (9 items), Occupation (7 items), Social integration (6 items), Economic Self-sufficiency (2 items)	Face to face Interviews), 7-point Likert scale; Self-report, Proxy or significant others	Max score=500	SCI, TBI, Stroke	15 minutes	No	1400	127

Outcome Measure	Language of tool (country of origin)	No. of items	Sub-scales	Response Format	Scoring	Disease specificity	Time to administer	Training Required	Citations Google Scholar	Web of Science
Sydney Psychosocial Reintegration Scale (Tate, Hodgkinson, Veerabangsa, & Maggiotto, 1999)	English (Australia)	12	Occupational Activities (4 Items), Interpersonal Relationship (4 items), Independent Living Skills (4 items)	Self-report, Clinician, Close relative (Face to face Interviews), 7-point Likert scale (0= extreme change to 6= no change)	Max score= 72, domain score=24 each	TBI	15 minutes	Yes	288	44
Reintegration to Normal Living Index (Wood-Dauphinee & Williams, 1987)	English	11	2 subscales: Daily Function (8 items), Perception of self (3 items)	Anchor Statements described on 10cm Visual Analog Scale: 'Does not describe my situation' (1 point) & Fully describe my situation' (10 points)	100	Stroke, TBI	10 minutes	No	814	62
Community Integration Measure (McColl et al., 2001)	English (United States)	10	None	Declarative statements rated on a 5-point Likert response scale (1=always disagree to 5=always agree)	Score range from 5-50	TBI	3-5 minutes	No	330	26

3.2.2 Data Extraction

The primary researcher (NS) screened all titles and abstracts to determine the eligibility of each article. Full text articles were then obtained and reviewed for all potentially eligible abstracts. Data were extracted from identified articles meeting the inclusion criteria. The primary and secondary supervisors, R.S. and A.T. reviewed a random selection of 25% of the articles to confirm eligibility. Six separate matrices were formed for all five measures to enter the extracted data for psychometric properties including content and construct validity, internal consistency, test-retest reliability, inter-rater agreement, floor/ceiling effects, and responsiveness. Descriptive details of all studies included in the review were also extracted and included in a summary table for context (See Appendix G).

3.2.3 Evaluation of Psychometric Properties

Methodological quality of included validation studies for each measurement tool was evaluated according to predetermined standards (Terwee et al., 2007). Table 3.2 outlines the proposed psychometric properties, their definition and evaluating criteria, which were applied to all papers. All studies were initially critically appraised by the primary reviewer (NS), with a subsample of 15% appraised by RS and AT to check for accuracy of interpretation. Each quality variable was rated as positive (+) for good to adequate quality, intermediate (0) for any doubtful information, negative (-) for poor quality, or unknown (?) if insufficient information was available. An overall rating for each study was obtained from the lowest rating for a specific psychometric property as suggested in the rating guidelines by Terwee et al. (2007).

Table 3.2. Quality Criteria for Psychometric Properties of Outcome Measures (Terwee et al., 2007)

Property	Definition		Quality Criteria
Content validity	The extent to which the domain of interest is comprehensively sampled by the items in the questionnaire.	+	A clear description is provided of the measurement aim, the target population, the concepts that are being measured, and the item selection AND target population and (investigators OR experts) were involved in item selection (e.g., through focus groups, surveys, etc.) AND (if translated) rigorous methods of translation and adaptation were used and described.
		0	A clear description of above-mentioned aspects is lacking OR only target population involved OR doubtful design or method (e.g., no adaptation if translated).
		−	No target population involvement.
		?	No information found on target population involvement.
Internal consistency	The extent to which items in a (sub) scale are intercorrelated, thus measuring the same construct.	+	Factor structure tested through factor analyses performed on adequate sample size (7× # items and ≥100) AND Cronbach's alpha(s) calculated per dimension AND Cronbach's alpha(s) between 0.70 and 0.95 for the total score and ≥50% of the dimensions reported.
		0	No factor analysis OR doubtful design or method.
		−	Cronbach's alpha(s) <0.70 or>0.95, despite adequate design and method.
		?	No information found for internal consistency.
Construct validity	The extent to which scores on a particular questionnaire relates to other measures in a manner that is consistent with theoretically derived hypotheses concerning the concepts that are being measured.	+	Specific hypotheses were formulated AND at least 75% of the results are in accordance with these hypotheses.
		0	Doubtful design or method (e.g., no hypotheses).
		−	Less than 75% of hypotheses were confirmed, despite adequate design and methods.
		?	No information found on construct validity

Property	Definition	Quality Criteria	
Reproducibility (agreement)	The extent to which the scores on repeated measures are close to each other (absolute measurement error)	+	MIC<SDC OR MIC outside the LOA OR convincing arguments that agreement is acceptable.
		0	Doubtful design or method OR (MIC not defined AND no convincing arguments that agreement is acceptable).
		−	MIC≥SDC OR MIC equals or inside LOA, despite adequate design and method.
		?	No information found on agreement.
Interrater reliability*	The extent to which the same results are obtained on repeated administrations of the same questionnaire, by different observers, when no change in physical function has occurred.	+	ICC or weighted Kappa ≥0.70 for >50% of ICCs/weighted Kappa values reported.
		0	Doubtful design or method (e.g., time interval not mentioned).
		−	ICC or weighted Kappa<0.70 for>50% of ICCs/weighted Kappa values reported, despite adequate design and method.
		?	No information found on interrater reliability.
Test-retest reliability	The extent to which patients can be distinguished from each other, despite measurement errors (relative measurement error)	+	ICC or weighted Kappa ≥0.70 for >50% of ICCs/weighted Kappa values reported.
		0	Doubtful design or method (e.g., time interval not mentioned).
		−	ICC or weighted Kappa<0.70 for>50% of ICCs/weighted Kappa values reported, despite adequate design and method.
		?	No information found on reliability.
Responsiveness	The ability of a questionnaire to detect clinically important changes over time.	+	In the context of an appropriate study design, SDC or SDC<MIC OR MIC outside the LOA OR responsiveness ratio of Guyatt (RR)>1.96 OR AUC≥0.70.
		0	Doubtful design or method.
		−	SDC or SDC≥MIC OR MIC equals or inside LOA OR RR≤1.96 OR AUC<0.70, despite adequate design and methods.
		?	No information found on responsiveness.

Property	Definition	Quality Criteria	
Floor and ceiling effects	The number of respondents who achieved the lowest or highest possible score	+	≤15% of the respondents achieved the highest or lowest possible scores.
		0	Doubtful design or method.
		−	>15% of the respondents achieved the highest or lowest possible scores, despite adequate design and methods.
		?	No information found on floor and ceiling effects.

MIC= Minimal Important Change; SDC=smallest detectable change; LOA=limits of agreement; ICC=intraclass correlation; SD=standard deviation; AUC=area under the receiver operating characteristics curve.

+= Positive rating; 0= indeterminate rating; − = negative rating; = no information available. Doubtful design or method = lacking a clear description of the design or methods of the study, sample size smaller than 50 subjects (should be at least 50 in every (subgroup) analysis), or important methodological weakness in the design or execution of the study.

*Modified from Terwee et al. (2007)

3.3 Results

3.3.1 Systematic search to identify the validation literature for five selected outcome measures

The database search yielded 1520 articles; 99 were identified as relevant from the title and abstract review. On further inspection, 76 articles were excluded according to inclusion/exclusion criteria. Hand searching of journals, reviews, grey literature, and references yielded an additional 11 articles, giving a total of 34 articles for data extraction. A flow diagram of literature selection and application of inclusion and exclusion criteria is displayed in Figure 3.1. Articles were grouped according to the five selected measures: The Community Integration Questionnaire (n= 13), The Craig Handicap Assessment and Reporting Technique (n= 6), The Sydney Psychosocial Reintegration Scale (n=5), The Reintegration to Normal Living index (n=5), and The Community Integration Measure (n=5).
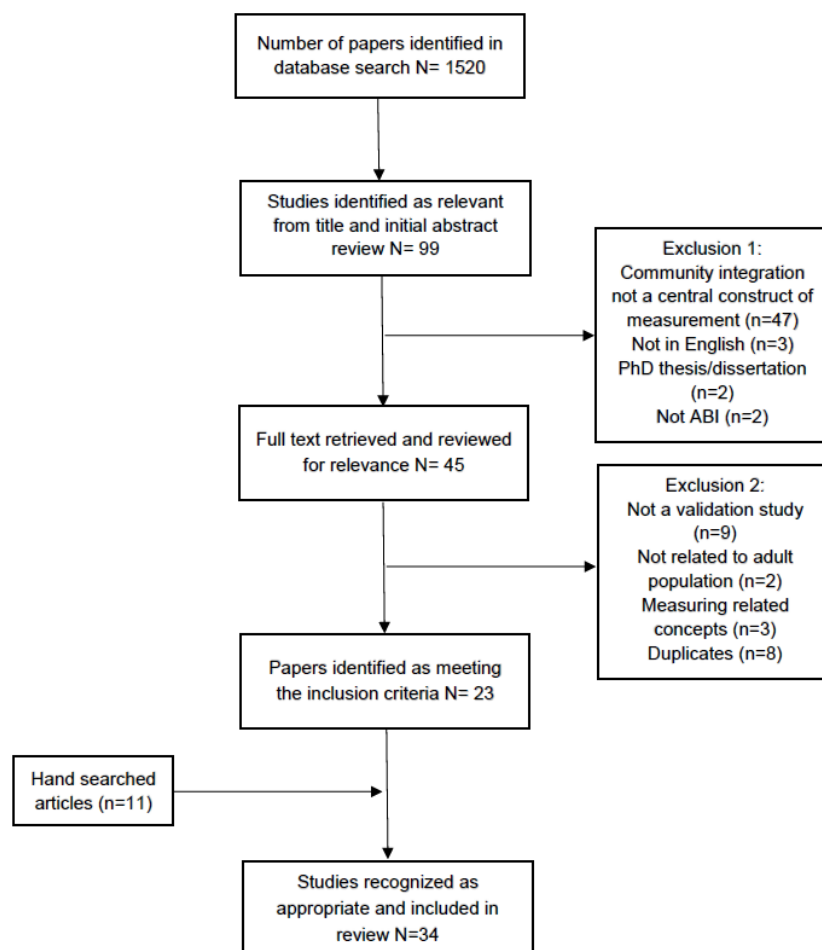
Figure 3.1: Literature search and selection process of articles

3.3.2 Data extraction and evaluation of Psychometric Properties

The data extracted from the included 34 articles are summarised in Appendix G. Psychometric data from papers were extracted for each evaluation criterion. Each criterion was rated as positive, indeterminate, negative or unknown depending on the design, methods, and outcomes of the study. Ratings for studies that examined the five chosen measures are tabulated (Table 3.3-Table 3.20). Such representation helps review and comparison between different measures (Terwee et al., 2007).

Content validity

The first development and validation study of the CIQ was carried out by Willer, Rosenthal, et al. (1993). Participants included professionals with expertise in TBI, researchers, and consumers. The study demonstrated a clear measurement aim for the target population and adequate specification of domains and items. However, limitations of the study included a lack of detail around premature reduction of items involving selection of 15 CIQ items from 47 on the basis of an extremely small sample (n=49) consisting of persons with severe TBI only. The final scale did not cover all the dimensions of the underlying concept 'handicap'. Hence, the quality of this study reporting the content validity of the measure was rated as intermediate.

The SPRS was developed based on the clinical experience of professionals, through interviews and follow-ups with patients with TBI and their relatives following discharge from rehabilitation services (Tate et al., 1999). The study reported that the scale items and domains were specific to the domain of psychosocial integration representing the concept of 'handicap'. Specific details on conducted pilot studies for initial item pool, item selection, and reduction are not given. Therefore, this scale's development and validation study were deemed as intermediate for the content validity of the SPRS. Initial development and validation of the RNLI had demonstrated clear description of the concept and theoretical structure of the concept. In addition, the target population and experts had been involved in the development process (Wood-Dauphinee & Williams, 1987), which was considered as adequate to meet the quality criterion for content validity (Terwee et al., 2007). The CIM was reported as a brief, client-centred and accessible measure. The process of item development based on a conceptual model was rigorous. The target population was actively involved, and items were

developed from the statements of participants themselves (McColl et al., 2001) exhibiting a good level of content validity.

Internal consistency

Summary of extracted internal consistency scores from the total nineteen studies is presented in Table 3.3.

Five studies included in this review investigated the internal consistency of the CIQ in a TBI population (Andelic et al., 2016; Corrigan & Deming, 1995; Kuipers, Kendall, Fleming, & Tate, 2004; Willer, Ottenbacher, & Coad, 1994; Willer, Rosenthal, et al., 1993). Of these, only three studies reported a Cronbach's alpha above the minimum acceptable threshold of 0.70 (Andelic et al., 2016; Corrigan & Deming, 1995; Willer, Rosenthal, et al., 1993). The weighted average Cronbach's alpha for the CIQ total score was 0.83. Two studies used other statistical methods, specifically Spearman's rho (ρ=0.35-0.83) (Kuipers et al., 2004) and Pearson product-moment correlations (r=0.73) (Willer et al., 1994). Their findings supported the internal consistency of the CIQ.

Five studies confirmed adequate Cronbach's alpha or internal consistency scores (between 0.69 and 0.93) for all SPRS versions in people with TBI (Kuipers et al., 2004; Tate et al., 1999; Tate, Pfaff, Veerabangsa, & Hodgkinson, 2004; Tate et al., 2012; Tate et al., 2011). However, none of them met the quality criterion of conducting a factor analysis and using the required sample size for internal consistency.

Four of the five studies from the selected data had investigated internal consistency of the RNLI. High coefficient alpha (0.84-0.91) was reported for the RNLI total scores for patients (Daneski, Coshall, Tillingand, & Wolfe, 2003; Miller, Clemson, & Lannin, 2011; Stark, Edwards, Hollingsworth, & Gray, 2005; Wood-Dauphinee & Williams, 1987). Two of these applied adequate study design for sample size, factor analysis, and consistency statistics, which were sufficiently fit for the criterion (Stark et al., 2005; Wood-Dauphinee & Williams, 1987).

For the CIM, four studies demonstrated adequate Cronbach's alpha scores (between .70 and .95) in various subgroups based on injury, home setting, and gender (Griffen, Hanks, & Meachen, 2010; McColl et al., 2001; Millis, Meachen, Griffen, Hanks, & Rapport, 2014; Minnes et al., 2003; Reistetter, Spencer, Trujillo, & Abreu, 2005). A

study by Millis et al. (2014) reported a person separation index (equivalent to Cronbach's alpha) score of 0.80 to 0.95 based on Rasch Analysis of the CIM. However, none of them met the criterion for internal consistency mainly due to inadequate sample size or lack of factor analysis.

Table 3.3. Summary findings from studies examining internal consistency

Measure	Study	Study quality	Statistics used	Sample	Sample size	Factor analysis performed	Internal consistency
CIQ	Willer, Rosenthal, et al. (1993)	0	Cronbach's alpha	TBI	49	Yes	α=0.76
	Willer et al. (1994)	0	Pearson	TBI	341	No	r=0.73
	Corrigan and Deming (1995)	0	Cronbach's alpha	Premorbid TBI	104	No	α=0.79
		0	Cronbach's alpha	Follow-up TBI	46		α=0.84
	Kuipers et al. (2004)	0	Spearman	TBI	96	Yes	ρ=0.35-0.83
	Andelic et al. (2016)	0	Cronbach's alpha	TBI	105	No	α=0.82
SPRS	Tate et al. (1999)	0	Cronbach's alpha	TBI	40	No	α=0.77-0.90
	Tate et al. (2004)	0	Cronbach's alpha	Brain injury	66	No	α=0.90
	Kuipers et al. (2004)	0	Spearman, MDS	TBI	96	Yes	ρ =0.59-0.88
	Tate et al. (2011)	0	Cronbach's alpha	ABI	40	No	α=0.90
	Tate et al. (2012)	0	Cronbach's alpha	Primary Brain Tumour	54	No	α=0.87
RNLI	Wood-Dauphinee and Williams (1987)	+	Cronbach's alpha	Cancer, myocardial infarction, central nervous system, orthopaedic disorders	109	Yes	α=0.90
	Daneski et al. (2003)	0	Cronbach's alpha	Stroke	76	No	α=0.84
	Stark et al. (2005)	+	Cronbach's alpha	SCI, MS, stroke, cerebral palsy, polio survivors	574	Yes	α=0.91
	Miller et al. (2011)	0	Cronbach's alpha	Brain injury, stroke, fractured neck of femurs, Multiple Sclerosis, spinal injuries, heart disease, Parkinson's disease, Guillain-Barre Syndrome	46	No	α=0.80-0.82

Measure	Study	Study quality	Statistics used	Sample	Sample size	Factor analysis performed	Internal consistency
CIM	McColl et al. (2001)	0	Cronbach's alpha	ABI	41	Yes	α=0.83
	Minnes et al. (2003)	0	Cronbach's alpha	ABI	64	Yes	α=0.79
	Reistetter et al. (2005)	0	Cronbach's alpha	ABI	51	Yes	α=0.72-0.83
	Griffen et al. (2010)	0	Cronbach's alpha	TBI	279	No	α=0.87
	Millis et al. (2014)	0	Separation ratio (Rasch analysis)	TBI	279	No	0.80-0.95

MDS: Multidimensional Scaling, TBI- Traumatic Brain Injury, ABI- Acquired Brain Injury, SCI- Spinal Cord Injury, MS- Multiple Sclerosis
+ = positive rating; 0 = intermediate rating

Construct validity

Seven studies reported having examined the construct validity of the CIQ (Gontkovsky, Russum, & Stokic, 2009; Hirsh, Braden, Craggs, & Jensen, 2011; Kaplan, 2001; Lequerica et al., 2013; Rintala et al., 2002; Sander et al., 1999; Willer, Rosenthal, et al., 1993; Zhang et al., 2002) (Table 3.4). All but two studies (Kaplan, 2001; Willer, Rosenthal, et al., 1993) specified the use of appropriate correlation coefficients and three studies had formulated hypotheses prior to the testing of measures (Burleigh et al., 1998; Dalemans, de Witte, Beurskens, van den Heuvel, & Wade, 2010; Zhang et al., 2002). All studies reported strong correlations between sub-scale scores and total scores and low to moderate correlations were reported between sub-scales. Only one study (Zhang et al., 2002) claimed to have confirmed the 75% of the hypotheses achieving the positive rating for the methodological quality prescribed by Terwee et al. (2007).

Four of the seven reviewed studies have examined the construct validity of the CHART (K. M. Hall, Bushnik, Lakisic-Kazazic, Wright, & Cantagallo, 2001; Segal & Schall, 1995; Whiteneck et al., 1999; Willer, Rosenthal, et al., 1993; Zhang et al., 2002) (Table 3.5). The CHART total score demonstrated moderate correlations (0.53 to 0.68) with other measures and correlations between measures' subscales varied from low 0.35 to moderate 0.58. However, the coefficients reported on the social integration subscale were low in magnitude in all reported studies. One study investigated convergent validity of the modified CHART with an additional R-CHART Cognitive subscale (K. M. Hall et al., 2001). Results demonstrated a strong correlation (0.84) between the R-CHART cognitive subscale and the Patient Competency Rating Scale (PCRS) total score. However, no other significant correlations were reported for R-CHART scale in this study. Of the four studies, one study was deemed as acceptable to meet the criteria for adequate construct validity (Zhang et al., 2002).

Tate et al. (1999) investigated the construct validity of the SPRS and reported it to be strongly correlated with London Handicap Scale, Katz adjustment scale, Glasgow outcome scale and sickness impact profile. The majority of correlations confirmed the hypotheses, which was adequate for the study to fit the criterion. A study by Kuipers et al. (2004) reported moderate correlation coefficient scores without a pre-defined hypothesis, hence rated as intermediate. Another study investigating the clinical utility

of the SPRS 5-point scale established strong correlations for interpersonal relationships and living skills subscales, however, coefficients for the occupational activity subscale and total score were not significant (Tate et al., 2011) (Table 3.6).

Daneski and colleagues (2003) investigated convergent validity of the RNLI. This study demonstrated a strong correlation between total scores of the RNLI and other scales such as the Barthel Index, Frenchay Activity Index, SF-36 and the Hospital Anxiety and Depression Scale. Construct validity examined in this study was rated as intermediate due to an absence of any pre-defined hypothesis (Table 3.7).

Construct validity of the CIM was evaluated in four studies (Griffen et al., 2010; McColl et al., 2001; Minnes et al., 2003; Reistetter et al., 2005) (Table 3.8). Studies by McColl et al. (2001)and Reistetter et al. (2005) formulated hypotheses and demonstrated acceptable coefficient values for the CIM total scale and subscales. Strong and positive correlations were reported between the CIM and the ISEL (interpersonal support evaluation list), CIQ-R and SWLS (Satisfaction with life scale. These two findings support the construct validity of the CIM.

Table 3.4. Summary findings from studies examining construct validity of the CIQ

Source	Study quality	Correlation statistics	Hypothesis formulated	Comparator criterion	Participant sample	Sample size	Home integration	Social integration	Productivity	Total integration
Willer, Rosenthal, et al. (1993)	0	Not specified	No	CHART	TBI	16	NS	0.52	0.55	0.62
Burleigh et al. (1998)	-	Spearman	Yes	LSIA-A	TBI	30	NS	0.37	NS	NS
Sander et al. (1999)	0	Spearman	No	DRS	TBI	312	-0.46	NS	-0.58	-0.58
				FIM			NS	NS	NS	NS
				FAM			0.46	0.41	0.57	0.60
Kaplan (2001)	0	Not specified	No	CIPI	Brain tumour	33	NS	-0.46	NS	-0.45
Zhang et al. (2002)	+	Pearson	Yes	CHART	TBI	70	0.53	0.40	0.47	0.68
				DRS			-0.46	NS	NS	-0.43
Kuipers et al. (2004)	0	Spearman	No	SPRS	TBI	96	0.42	0.45	0.42	0.56
Dalemans et al. (2010)	-	Spearman	Yes	Barthel Index	Stroke	150	NS	NS	NS	0.41
				COOP-WONCA			NS	NS	NS	-0.16
				Life Satisfaction Questionnaire			NS	0.35	NS	NS

LSlA-A: The Life Satisfaction Index-A, CIPI: Chronic Illness Problem Inventory, DRS: Disability Rating Scale, Dartmouth Coop Functional Health Assessment Charts (COOP): World Organisation of Family Doctors (WONCA) Charts
+ = positive rating; 0 = intermediate rating; - = negative rating.

Table 3.5. Summary findings from studies examining construct validity of the CHART

Source	Study quality	Correlation statistics	Hypothesis formulated	Comparator criterion	Participant sample	Sample size	Independence	R-CHART Cognition	Mobility	Occupation	Social integration	Total CHART score
Willer, Rosenthal, et al. (1993)	0	Not-specified	No	CIQ	TBI	16	NS	NA	NS	0.55	0.35	0.62
Segal and Schall (1995)	0	Spearman	No	FIM	Stroke	38	0.68	NA	0.60	0.62	NS	0.53
K. M. Hall et al. (2001)	-	Pearson	Yes	NFI	TBI	48	NS	-0.71	NS	NS	NS	NS
				PCRS			NS	0.84	NS	NS	NS	NS
(Zhang et al., 2002)	+	Pearson	Yes	CIQ	TBI	70	0.53	NA	0.45	0.42	0.38	0.68
				DRS			0.44	NA	0.36	0.26	NS	0.53

NFI: Neurobehavioral Functioning Inventory, PCRS: Patient Competency Rating Scale
+ = positive rating; 0 = intermediate rating; - = negative rating.

Table 3.6. Summary findings from studies examining construct validity of the SPRS

Source	Study quality	Correlation statistics	Hypothesis formulated	Comparator criterion	Participant sample	Sample size	OA	IR	LS	Total Score
Tate et al. (1999)	+	Spearman	Yes	KAS	TBI	40	NA	NA	NA	0.76
				LHS			NA	NA	NA	-0.85
				SIP			-0.72	-0.76	-0.58	-0.76
Kuipers et al. (2004)	0	Spearman	No	CIQ	TBI	96	0.42	0.45	0.42	0.56
Tate et al. (2011)	-	Spearman	Yes	SIP- 5 point	TBI	40	NS	-0.78	-0.61	NS

KAS: Katz Adjustment Scale, LHS: London Handicap Scale, SIP: Sickness Impact Profile
+ = positive rating; 0 = intermediate rating; - = negative rating.

Table 3.7. Summary findings from studies examining construct validity of the RNLI

Source	Study quality	Correlation statistics	Hypothesis formulated	Comparator criterion	Participant sample	Sample size	Daily function	Perception of self	Total integration
Daneski et al. (2003)	0	Spearman	No	Barthel Index	Stroke	76	0.48	NS	0.42
				Frenchay Activities Index			0.74	NS	0.69
				Short Form 36			0.73	0.44	0.74

0 = intermediate rating

Table 3.8. Summary findings from studies examining construct validity of the CIM

Source	Study quality	Correlation statistics	Hypothesis formulated	Comparator criterion	Participant sample	Sample size	Total integration
McColl et al. (2001)	+	Not specified	Yes	CIQ	Brain injury survivors (n=41); significant others (n=36), college students (n=15).	92	0.34
				ISEL			0.42
Minnes et al. (2003)	0	Not specified	No	CIQ-R	ABI	64	NS
				AIMS			
				QOL			
Reistetter et al. (2005)	+	Not specified	Yes	CIQ-R	Brain injury (n=51); Healthy adults (n=40)	91	0.34
				SWLS			0.515
Griffen et al. (2010)	+	Not specified	Yes	CHART	TBI	279	NS
				BSI-18			0.37
				SPS			0.55
				SWLS			0.32
				SF-12			0.37

ISEL: Interpersonal Support Evaluation List; AIMS: Assimilation, Integration, Marginalization, Segregation; SWLS: Satisfaction with Life Scale; BSI-18: Brief Symptom Inventory–18; SPS- The Social Provision Scale; SF-12 Health Survey

+ = positive rating; 0 = intermediate rating; - = negative rating.

Interrater reliability

None of the studies discussed reproducibility of the outcome scores in relation to Minimal Important Change (MIC) and Smallest Detectable Change (SDC). Hence, interrater reliability was considered for further discussion.

The interrater reliability of the CIQ was demonstrated to be acceptable (Willer, Rosenthal, et al., 1993). The Intraclass correlation coefficient (ICC) is considered a more appropriate measure according to the criterion (Terwee et al., 2007). This study used a Pearson correlation coefficient to calculate agreement between 16 individuals with TBI and their proxies, which was not sufficient to confirm the agreement. Sander et al. (1997) demonstrated moderate to substantial correlations amongst TBI samples and family members for Home and Social Integration ranging from 0.42 to 0.70 and strong agreement (0.69 - 0.94) for the productive activity subscale in a sample of 122 TBI patients. This measurement was rated positively on quality criteria as the scores and sample size are in accordance with the criteria (Table 3.9).

Two studies reported having examined the interrater reliability of the CHART (Table 3.10). Segal and Schall (1995) investigated the interrater reliability of the CHART between stroke survivors and their caregivers. The ICC for total score showed good agreement but poor to moderate ICCs were reported for subscale scores. This study was rated as intermediate according to the criterion. Another study demonstrated strong proxy agreement (ICC= 0.71) for CHART total scores for TBI sample (n=199)(Cusick, Brooks, & Whiteneck, 2001) which supported the interrater reliability of the CHART.

Two studies calculated interrater reliability of the SPRS scores rated by two clinicians for a small participant sample of 20 (Tate et al., 1999) and 40 (Tate et al., 2011) reporting very high correlations from 0.63 to 0.94. Another study reported similar findings for interrater agreement between two clinicians, however ICC for Interpersonal relations (ICC=0.37) and Living Skills (ICC=0.52) was relatively low between clinicians and patient relatives (n=25) (Tate et al., 2004) (Table 3.11).

Moderate interrater agreement (0.62) was demonstrated between patients and their significant others for RNLI total scores. However, a low correlation was reported between scores of health professionals and patients (0.39) (Wood-Dauphinee &

Williams, 1987), which was not adequate to meet the criterion, thus rated as poor. Another study examined interrater reliability with weak to moderate correlation coefficients ranging between 0.24 and 0.55 (Tooth, McKenna, Smith, & O'Rourke, 2003). The quality of this study was intermediate (Table 3.12).

Table 3.9. Summary findings from studies examining interrater reliability of the CIQ

Source	Study quality	Statistics used	Respondents	Sample size	Home integration	Social integration	Productivity	Total integration
Willer, Rosenthal, et al. (1993)	0	not specified	TBI patients and family members	59 pairs	0.81	0.74	0.96	0.89
Sander et al. (1997)	-	Kappa coefficient	Brain injury patients and family members	122 pairs	0.55	0.51	0.84	NA

- = negative rating; 0 = intermediate rating

Table 3.10. Summary findings from studies examining interrater reliability of the CHART

Source	Study quality	Statistics used	Respondents	Sample size	Physical independence	Cognitive independence	Mobility	Occupation	Social integration	Economic self-sufficiency	Four-scale total (excl. EcoS)
Segal and Schall (1995)	0	ICC	Stroke patients and family members	40 dyads	0.35	0.65	0.68	0.27	0.75	0.75	0.68
Cusick et al. (2001)	+	Kappa coefficient	Brain injury patients and family members	983 pairs	0.70	0.66	0.78	0.73	0.61	0.68	0.80

+ = positive rating; 0 = intermediate rating

Table 3.11. Summary findings from studies examining interrater reliability of the SPRS

Source	Study quality	Statistics used	Respondents	Sample size	Occupational activities	Interpersonal relationships	Living skills	Total integration
Tate et al. (1999)	0	ICC	2 clinicians	20	0.63	0.70	0.82	0.84
Tate et al. (2004)	+	ICC	2 clinicians	66	0.63	0.70	0.82	0.84
			Clinician & relative	25	0.71	0.37	0.52	0.67
Tate et al. (2011)	+	ICC	2 clinicians	40	0.93	0.85	0.93	0.94

+ = positive rating; 0 = intermediate rating

Table 3.12. Summary findings from studies examining interrater reliability of the RNLI

Source	Study quality	Statistics used	Respondents	Sample size	Daily functioning	Perception of self	Total Score
Wood-Dauphinee and Williams (1987)	0	Not specified	Patients (mixed conditions) and significant others	109 (not specifically mentioned)	NA	NA	0.62
		Not specified	Patients (mixed conditions) and health professionals	109 (not specifically mentioned)	NA	NA	0.39
(Tooth et al., 2003)	-	ICC	Stroke patients and caregivers	57 pairs	0.24	0.55	0.36

0 = intermediate rating; - = negative rating.

Test-retest reliability

Test-retest reliability for the CIQ was examined by Willer, Rosenthal, et al. (1993) and Dalemans et al. (2010)(Table 3.13). Both these studies reported correlation coefficients confirming excellent reliability adequate to meet the quality criteria. However, the stability of the scale was examined in a very small sample, hence both the studies were rated as intermediate.

Test-retest reliability for the CHART was measured using an Interclass Correlation Coefficient (ICC) that demonstrated excellent reliability ranging from 0.81 to 0.93 for the CHART total scores and subscale scores in a combined sample of 16 (N. Walker, Mellick, Brooks, & Whiteneck, 2003). This study was considered sufficient to meet the criterion but was only rated as intermediate due to a small sample size (Table 3.14).

Three studies concluded that the SPRS has good test-retest reliability (Table 3.15). Of these, two studies by Tate reported excellent reliability for Form B and a 5-point version of the SPRS Form A in a small sample of 20 and 46 participants respectively, thus the quality rating given was intermediate (Tate et al., 1999; Tate et al., 2004). Tate et al. (2011) confirmed high coefficient values in a relatively large sample (n=510), which was deemed adequate according to the criterion.

Test-retest reliability for the RNLI was measured by Daneski and colleagues (2003) using the Kappa coefficient that demonstrated excellent scores for four of the eleven items of the scale (>0.70) in individuals with stroke (Table 3.16). However, it was considered intermediate as it was assessed in a very small sample of 26 participants. According to the criterion ICC or Kappa score has to be at least 0.70 in a sample size of at least 50 patients (Terwee et al., 2007).

Table 3.13. Summary findings from studies examining test-retest reliability of the CIQ

Source	Study quality	Statistics used	Time interval (mean)	Participant sample	Sample size	Home integration	Social integration	Productivity	Total integration
Willer, Rosenthal, et al. (1993)	0	Pearson's correlation coefficient	10 days	Brain injury	16	0.93	0.86	0.83	0.91
				Family members	16	0.96	0.90	0.97	0.97
Dalemans et al. (2010)	0	ICC	12 days	Stroke with aphasia	20	NA	NA	NA	0.85

0 = intermediate rating

Table 3.14. Summary findings from studies examining test-retest reliability of the CHART

Source	Study quality	Statistics used	Time interval (mean)	Participant sample	Sample size	Physical independence	Cognitive independence	Mobility	Occupation	Social integration	Economic self-sufficiency	Total integration
N. Walker et al. (2003)	0	ICC	2 weeks	SCI, traumatic brain injury, stroke, Multiple Sclerosis	16	0.82	0.87	0.89	0.81	0.81	0.81	0.93
				Percentage Missing Stroke Amputation Burn								

0 = intermediate rating

Table 3.15. Summary findings from studies examining test-retest reliability of the SPRS

Source	Study quality	Statistics used	Time interval (mean)	Participant sample	Sample size	Occupational activities	Interpersonal relationships	Living skills	Total integration
Tate et al. (1999)	0	ICC	Up to 3 months	TBI	20	0.93	0.77	0.88	0.90
Tate et al. (2004)	0	ICC	1 week	Brain injury	46	0.86	0.76	0.93	0.90
Tate et al. (2011)	+	ICC	1 month	Severe brain injury	510	0.94	0.80	0.87	0.91

+ = positive rating; 0 = intermediate rating

Table 3.16. Summary findings from studies examining test-retest reliability of the RNLI

Source	Study quality	Statistics used	Time interval (mean)	Participant sample	Sample size	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11
Daneski et al. (2003)	0	Kappa coefficient	2 weeks	Stroke	26	0.88	0.92	0.67	0.86	0.56	0.64	0.44	0.75	0.45	0.38	0.69

0 = intermediate rating

Responsiveness

Corrigan and Deming (1995) demonstrated a significant difference in people with TBI from their pre-morbid status. Similarly, a significant change over time was reported before and after rehabilitation interventions in a brain injury sample (Seale et al., 2002)(Table 3.17). These studies reported good responsiveness for the CIQ, but they did not use the methods recommended by the present criteria such as calculating SDC and defining MIC.

A significant change was reported over time in two studies, which was calculated using the Wilcoxon signed rank test in a TBI population for Sydney Psychosocial Reintegration scale (Tate et al., 1999; Tate et al., 2011) (Table 3.18). These studies were rated intermediate as they used the equivalent method to that of the quality criterion (e.g. SDC, MIC, RR) and the time period between measurements was clearly specified.

Table 3.17. Summary findings from studies examining responsiveness of the CIQ

Source	Study quality	Statistics used	Participant sample	Sample size	Home integration	Social integration	Productivity	Total integration
Corrigan and Deming (1995)	0	Significant mean difference	Premorbid and follow-up TBI	Premorbid n=104 Follow-up n=46	-0.51	4.20	6.62	3.81
Seale et al. (2002)	0	Reliable Change (RC)	Head injury	23	0.71	0.70	0.63	0.81

0 = intermediate rating

Table 3.18. Summary findings from studies examining responsiveness of the SPRS

Source	Study quality	Statistics used	Participant sample	Sample size	Occupational activities	Interpersonal relationships	Living skills	Total integration
Tate et al. (1999)	0	Wilcoxon Matched-Pairs Signed-Ranks (z), p <0.001	TBI	20	-3.30	-3.82	-3.62	-3.82
Tate et al. (2011)	0	Wilcoxon Matched-Pairs Signed-Ranks (z), p <0.001	TBI	20	NA	NA	NA	-3.11

0 = intermediate rating

Floor and ceiling effects

Floor and/or ceiling effects were examined for four of five selected outcome measures. Results from reviewed studies are listed in Table 3.19.

For the CIQ, Corrigan and Deming (1995) reported that the scores were normally distributed for home subscale, social subscale and total scale. However, productivity subscale scores were positively skewed for long-term (average 7 years post-injury) TBI sample (n=46). A study by Karyl M Hall et al. (1996) concluded that the CIQ Home and Social integration subscale scores have a ceiling effect when compared to the score of individuals without a disability. Furthermore, the samples scored in the higher range on the Social Integration Subscale and in the lower range on the Productive activity subscale displaying floor and ceiling effects ranging between 3% and 39.1% (Sander et al., 1999). These studies were considered of poor quality due to potential floor and ceiling effects in two of the three subscales of the instrument.

K. M. Hall et al. (2001) demonstrated significant ceiling effects for CHART subscale scores in a TBI population. More than 25% of their participants achieved subscale scores in the highest possible range, which is beyond the acceptable limit (<15%). Tate and colleagues reported significant ceiling effects (18.2%-28%) for the SPRS (Tate et al., 1999; Tate et al., 2012). Research conducted on a relatively large sample of TBI demonstrated no floor/ceiling effects when current status of patients was measured using a 5-point rating scale version of the SPRS (Tate et al., 2011). Only this study was rated positively on the quality criterion.

No studies from the data set of five studies investigated floor/ceiling effects of the Reintegration to Normal Living index. Latest evidence found in a study by Millis et al. (2014) demonstrating low ceiling effects for the CIM where 9% of the participants scored in maximum range. This result was acceptable according to the criterion.

Table 3.19. Summary findings from studies examining floor-ceiling effects

Measure	Study	Study quality	Sample	Sample size	Percentage of respondent received highest or lowest scores
CIQ	Corrigan and Deming (1995)	0	Premorbid TBI	104	NS
			Follow-up TBI	46	Positive Skew
	Karyl M Hall et al. (1996)	-	TBI	132	33-48% ceiling effect
	Sander et al. (1999)	-	TBI	312	3-39.1% floor & ceiling effects
CHART	K. M. Hall et al. (2001)	-	TBI	48	25-81% ceiling effect
SPRS	Tate et al. (1999)	-	TBI	40	18.2% ceiling effect
	Tate et al. (2011)	+	TBI	510	NS
	Tate et al. (2012)	-	Brain tumour	54	28% Ceiling effect
CIM	Millis et al. (2014)	+	TBI	279	9%

+ = positive rating; 0 = intermediate rating; - = negative rating.

Overall quality

Only a few studies gave an adequate description of the study design and met the methodological quality criteria selected for this review. One study did not adequately describe its study group (Wood-Dauphinee & Williams, 1987) and in seven studies (Griffen et al., 2010; Kaplan, 2001; McColl et al., 2001; Minnes et al., 2003; Reistetter et al., 2005; Willer, Rosenthal, et al., 1993; Wood-Dauphinee & Williams, 1987) information about data analyses such as specific statistical methods used, was missing. Furthermore, information about non-response, subjects lost to follow up, and missing data were often lacking. Table 3.20 shows the quality assessment of the five measures of community integration, summarising each property as good (+), doubtful (0), or poor quality (-). A question mark indicates insufficient information about an aspect of quality. The final rating was based on the quality of the validation study and lowest rating for the criteria for evaluation.

This review and psychometric evaluation of community integration measures validated in acquired brain injury populations, demonstrated that the CIQ and the SPRS are the tools with the strongest psychometric properties. The CIQ was found to have excellent content validity and fair internal consistency, reproducibility, and responsiveness. However, it did not meet the criteria for construct validity. Additionally, it was found to have potential ceiling effects (Karyl M Hall et al., 1996; Sander et al., 1999) and in several studies, at least one subscale of the CIQ had a Cronbach's alpha < 0.7. The SPRS demonstrated good content validity and intermediate levels of internal consistency, interrater and test-retest reliability and ability to detect change over time. It was found to have a low completion rate due to the complexity of the questionnaire, suggesting that it may have been burdensome for patients with severe injuries (Kuipers et al., 2004). The RNLI and the CIM, the subjective measures of community integration have been developed and validated for an ABI population, also showed good to fair content validity and internal consistency. However, they require further psychometric testing in a number of areas such as test-retest and interrater reliability, responsiveness, and floor-ceiling effects. The CHART demonstrated good test-retest reliability, however, it was found to have scored poorly overall, reflecting low internal consistency, agreement, and significant ceiling effects. Most of these measures have been developed and validated for a western population and lack evidence for cultural

appropriateness in more diverse population of New Zealand. Also, none of these measures currently score perfectly on all relevant psychometric criteria; indicating the need for further research and development of more appropriate outcome measures and validation in different cultural contexts.

Table 3.20. Summary of overall quality assessment of five community integration measures

Outcome Measure	Content Validity	Internal Consistency	Construct Validity	Agreement	Test-Retest Reliability	Responsiveness	Floor/ Ceiling Effect
CIQ	+	0	-	-	0	0	-
CHART	?	0	-	-	0	?	-
SPRS	+	0	-	0	0	0	-
RNLI	+	0	0	-	0	?	?
CIM	+	0	0	?	?	?	+

+ = positive rating; 0 = indeterminate rating; - = negative rating; ? = no information available.

3.4 Summary of findings

This review examined the psychometric characteristics of the two subjective and three objective scales of community integration for people with acquired brain injury. None of the outcome measures demonstrated satisfactory results for all criteria. Overall, the CIQ and the SPRS received the best ratings for their psychometric properties.

The CIQ was found to be the most widely used and validated tool in the assessment of community integration for people with TBI. The scale development was based on clear measurement aims and involved an expert panel that included individuals who had experienced TBI suggesting evidence of content validity (Willer, Rosenthal, et al., 1993). The CIQ displayed a good level of reliability (Dalemans et al., 2010; Sander et al., 1997; Willer, Rosenthal, et al., 1993) and the ability to detect change over time (Corrigan & Deming, 1995; Seale et al., 2002). However, the scale is reported to have ceiling effects (Karyl M Hall et al., 1996; Sander et al., 1999) and does not provide a comprehensive assessment of handicap or community integration, when evaluated against the definitions provided by the International Classification of Functioning, Disability, and Health (ICF). When mapped on the new conceptual model of community integration as described in the previous chapter, the CIQ mapped on three of the six dimensions of the concept. Furthermore, there have been problems with the factor structure of the scale including items such as childcare, finance, and frequency

of shopping which affect the construct validity of the CIQ (Sander et al., 1999). In addition, the CIQ scores are reported to be influenced by age, gender and level of education (Dijkers, 1997; Kaplan, 2001), hence studies have suggested to interpret the score with care. Recently, the scale was revised, and the new electronic domain was added to measure social integration via electronic devices (Callaway et al., 2016). Validation of this revised scale, CIQ-R is yet to be conducted in a TBI population.

The CHART was originally developed and validated for individuals with spinal cord injury, however, it was revised to add items to assess cognitive independence which was then reported to be reliable and valid for individuals with TBI (Mellick, Walker, Brooks, & Whiteneck, 1999; Whiteneck et al., 1992). The CHART was demonstrated to have moderate to good reliability, but no evidence was found to support the content validity, internal consistency, and responsiveness of the overall scale. Four of the six sub-scales (physical independence, occupation, social integration, cognitive independence) can be mapped on the derived new conceptual model of community integration. The CHART scores have been reported to have substantial ceiling effects (K. M. Hall et al., 2001) and be influenced by age, race or ethnicity, education and occupation at the time of evaluation (Karyl M Hall et al., 1996; Segal & Schall, 1995).

The RNLI and CIM are brief assessment tools that focus on subjective experiences of the individual. The RNLI was originally developed and validated in a stroke population, however, it has been used in the assessment of community integration of people with TBI, unlike the CIM which is a TBI-specific measure. The CIM was reported to fit 1-factor and 3-factor solutions (McColl et al., 2001; Minnes et al., 2003; Reistetter et al., 2005), however it was recommended to add more items to improve item endorsibility (targeting) to the sample (Minnes et al., 2003). Development of the RNLI and the CIM have been thoroughly grounded in the perspectives of individuals from the target population providing strong evidence for their content validity, although there is limited or no evidence available to support these scales' reliability, construct validity or responsiveness.

The SPRS was operationalised based on a definition of handicap according to the WHO model (Tate et al., 1999). Scale development was founded on clinicians' experience representing perspectives of individuals with TBI (Tate et al., 1989). The original scale -

that measured change from pre-injury integration levels- was modified in content and number of items to evaluate current competency levels and reduce respondent burden respectively (Salter, Foley, Jutai, Bayley, & Teasell, 2008). All psychometric properties are examined for the SPRS and it appears to have moderate to excellent levels of validity, reliability, and responsiveness. However, it is reported to have ceiling effects (Tate et al., 1999; Tate et al., 2012). Additionally, the SPRS has significant congruence with the conceptual model of community integration.

The quality criteria for psychometric properties used in this review provide a robust approach that can be applied in the development and evaluation of outcome measures and also facilitate the selection of outcome measures before implementing them into clinical practice (Terwee et al., 2007). However, the criteria indicated the need for additional empirical evidence and further refinement in terms of improving the specificity of hypothesis testing, incorporating wider aspects of construct validity, and clear guidelines around ratings to reduce ambiguity. Additionally, all included measures are ordinal scales which are technically not suitable for measuring subjective attributes such as community integration. For parametric testing, interval-level data is warranted to calculate accurate outcomes. Hence, further validation and selection of good outcome measures is recommended using the Rasch model based on the Item-Response Theory (IRT) (Kersten & Kayes, 2011).

3.5 Conclusion

This review provides information for researchers and clinicians to facilitate the choice among the existing questionnaires for recording reliable data to better inform progressive community integration. Further evaluation using more standardised checklists such as COSMIN is recommended to aid the selection of appropriate outcome measures. Despite a number of weaknesses, the CIQ and the SPRS were demonstrated to have an adequate level of psychometric properties and considerable congruence with the conceptual model of community integration. The CIQ, CIQ-R and SPRS are yet to be validated in people with ABI in New Zealand. A series of studies were carried out exploring the psychometric properties of the CIQ, CIQ-R, and SPRS to determine the appropriateness of the scale items and scoring system. Details of this work are described in the subsequent chapters.

Chapter 4: Research Methodology

4.1 Introduction

This chapter describes the present research methodology and rationale for the research approach. Also, underpinning measurement theories and data analysis methods utilised in this research, are presented. Research methods for individual studies are detailed in respective chapters.

4.2 Methodology

This research was conducted using a mixed methods approach integrating quantitative and qualitative methodologies as originally defined by Campbell and Fiske (1959). The research was based on a particular mixed-methods approach termed a 'Concurrent Nested Strategy' (Creswell, 2014). The study includes a larger quantitative study with a smaller qualitative study nested within it. Both quantitative and qualitative research are considered to provide different types of information which can be helpful in understanding complex constructs addressed in an outcome measure. This approach is often applied in measurement studies where quantitative study reports on quantifiable psychometric properties of a measure and qualitative study helps analyse the content of the measure which cannot be quantified (Morse, 1991). In studies evaluating conceptual and psychometric adequacy to establish cross-cultural validity of a measure, quantitative and qualitative methods are considered complementary (Pasick, 1997; Pope & Mays, 1995; Stewart & Napoles-Springer, 2000). Both quantitative and qualitative data were analysed and reported separately and compared later in the discussion chapter (Creswell, 2014).

4.2.1 Quantitative Research: Measurement theories and data analysis

Classical test theory

Classical test theory (CTT) is the traditional statistical approach to examine psychometric properties of an outcome measure. CTT methods have been widely used for development and evaluation of measures representing latent trait variables in rehabilitation and other health related research (Cohen, Swerdlik, & Phillips, 1996). CTT stipulates that a respondent's observed score (O) on an item comprises both a true score (T) and an error score (E). The mean score obtained by repeated testing of a measure for an infinite number of times provides a true score. Error is believed to

occur due to variability in testing conditions, administration methods, respondent's idiosyncrasies (Streiner, Norman, & Cairney, 2015). CTT determines reliability of an item by calculating correlation between observed score and true score, this helps in deciding whether the observed score is a good indicator for the true score. A scale's reliability depends on item-to-total correlations as well as correlations among the scale items (DeVellis, 2006). Cronbach's coefficient alpha is considered by many/most analysts to be the most common estimate of scale reliability determining internal structure of a scale, which is expressed on values between 0 and 1 (Cronbach, 1951). It explains the extent to which all items in the scale are interconnected, hence measuring the same construct. Apart from correlation between test items, the alpha coefficient is also affected by the total number of items in a scale. A scale with limited number of items may display low alpha values despite high correlations between scale items (Nunnally & Bernstein, 1994; Streiner, 2003). Additionally, Cronbach's alpha score may differ with each population sample, hence established alpha estimates may not be dependable and should be calculated each time the scale is administered in a new sample (Streiner, 2003). CTT also applies correlational methods to establish dimensionality of a scale, using factor analysis to determine internal structure of a scale (McDonald, 1985). More modern statistical approaches determining dimensionality of a scale involve exploring factor structure using exploratory factor analysis (EFA) for a new or unestablished scale and then confirming the structure to establish psychometric properties using confirmatory factor analysis (CFA)(Nunnally & Bernstein, 1994).

Exploratory factor analysis is used to identify the number of factors (dimensions) represented by a set of items in a scale and define the purpose and context of each factor. EFA identifies the extent to which the items represent the particular dimension (DeVellis, 2012; Furr & Bacharach, 2014). In the process of EFA, it is important to establish adequacy of the dataset. Preliminary steps include checking the correlation matrix to ensure inclusion of correlations exceeding 0.3 (Tabachnick & Fidell, 2013). This is followed by Bartlett's test of sphericity, which requires a significant result ($p<0.05$) to confirm the hypothesis that the included variables are correlated, to proceed with the factor analysis. Lastly, the Kaiser-Meyer-Olkin (KMO) test establishes

the adequacy of the dataset if the KMO value is greater than 0.6 (Norman & Streiner, 2014).

The next phase of EFA involves factor extraction which can be performed using two approaches: principal component analysis (PCA) and principal axis factoring (PA). Both the approaches are comparable and a researcher can use one or the other, provided the resultant factor structure is simple and theoretical expectations are met with clear set of items per factor (DeVellis, 2012; Tabachnick & Fidell, 2013). Each factor is described by its eigenvalue which is the amount of total variance explained by that factor. Factors with eigenvalues greater than 1.0 should be accepted as they provide meaningful information accounting for higher variance. Another way to confirm the number of emerging factors is through Cattell's Scree Test for eigenvalues. The factors displaying above the scree on a plot are accepted (Norman & Streiner, 2014). All factors are then extracted on a factor loading matrix which demonstrated the correlations between each variable and the factor they are representing (also referred to as 'loading on').

The interpretation of initial factor solution is often very difficult; hence it is rotated to enhance its interpretability. There are two common methods used for factor rotations: orthogonal rotation and oblique rotation. There is no specific guidance around the selection of rotation approach. Research may wish to select either of the approaches most suitable for the purpose which is mainly to provide a simple, interpretable solution that meets theoretical expectations (Tabachnick & Fidell, 2013). Orthogonal method, in particular varimax rotation is widely used in measurement research. In this rotation, factors are rotated to the point where they are presented by only a small number of variables with high loadings. This approach helps minimise the number of variables with poor loadings and provide a stable factor solution which is easy to interpret (Norman & Streiner, 2014). All of the above described computations are easily conducted using statistical software such as IBM SPSS. Specific details on statistical steps applied in this doctoral research are presented in Chapter Five.

Factor model derived by the EFA is tested using a structural equation modelling (SEM) technique known as confirmatory factor analysis (CFA) using a software, e.g. IBM SPSS Amos. CFA is considered a very useful tool in constructing validation and estimation of

scale reliability (T. A. Brown, 2006). All underlying dimensions (factors) of a scale and relationship patterns between individual items (variables) and factors are verified by the CFA to confirm or reject the hypothesis, if a model with these specified dimensions and items fit the data. The process of CFA begins with specifying the measurement model including the number of factors, set of items associated with (loading on) each factor, and possible association between factors. The maximum likelihood (ML) model is the most widely used model in application of CFA (Curran, West, & Finch, 1996; Hu, Bentler, & Kano, 1992). ML model is based on an underlying principle which identifies the model parameter estimates, to maximise the probability of the data to fit the certain model. All this information is used to compute the items' variances and covariances and assess the adequacy of the model. Adequacy of the hypothesised model is examined against the fit indices. One of the most commonly evaluated indices is chi-square which indicates the mis-fit to the model as an evidence against the hypothesised model. High, significant chi-square value is interpreted as a mis-fit. Chi-square is considered to be very sensitive to total sample-size, hence it is typically used in conjunction with other indices of model fit (Furr & Bacharach, 2014). These may include comparative fit index (CFI), normed fit index (NFI), root mean square error of approximation (RMSEA), goodness of fit index (GFI). These indices when considered together, provide a reliable evaluation of the fit to the hypothesised model (Brown, 2006). Several studies have provided guidelines around cut-off criteria for above mentioned fit indices to determine acceptable model fit. For the CFI, NFI and GFI findings values above 0.9 and for RMSEA value below 0.08 are considered as indicators for acceptable fit to the model (T. A. Brown, 2006; Hu & Bentler, 1999; Kline, 2015; Marsh, Hau, & Wen, 2004).

CTT continues to be a widely used method for scale development or validation due to relatively easy application and availability of number of statistical software packages. However, there are certain disadvantages of CTT application. A scale developed through CTT methods does not undergo rigorous item-level scrutiny. CTT-based evaluation treats all scale items as equal contributors in measurement of latent trait. This may cause a scale to capture differential scores mainly in the centre score range (DeVellis, 2006). Moreover, CTT is based on an assumption that each scale item acts as an effect indicator which reflects or is dependent on an underlying trait and it is

demonstrated by factor analyses involving an inter-item and item-total correlation matrix. This assumption is not valid for a formative scale where items are causal indicators that collectively contribute to the underlying construct but are not dependent on it (Fayers, Hand, Bjordal, & Groenvold, 1997). For example, indicators such as years of education, occupation, and income collectively form the construct Socioeconomic Status (SES) but they are not dependent on the SES score. Most psychometric scales are based on effect indicators, hence their development through reflective measurement model and evaluation using CTT can be justified. However, development and appraisal of measures such as Quality of Life (QoL) that are comprised of both causal (e.g. wealth, communing time) and effect (e.g. anxiety, depression) should be done with caution. Community integration might be considered one such variable and further research is crucial to distinguish between the composite or latent nature of the construct to determine the appropriate validation method for the instruments. More importantly, causal and effect indicators should be distinguished at the stages of new scale development as CTT and SEM methods are only applicable for reflective instruments where scores from multiple items can be combined to present homogenous summary of the total scale (Borsboom, 2005; De Vet, Terwee, Mokkink, & Knol, 2011).

The Rasch measurement model

The Rasch model is a probabilistic and unidimensional model based on principles of invariance which was introduced by Rasch (1960). The fundamental property of the Rasch measurement model is that comparison of two individuals should be independent of which scale items from the total set of scale items they completed. Similarly, comparison of two scale items should be independent of which particular individuals were scored on them (Bond & Fox, 2013; Rasch, 1960, 1961). Therefore, the Rasch model requires scale items and their response categories to meet certain criteria in order to fit the model. The unidimensionality criterion of the Rasch model requires the scale to estimate only one parameter of the latent trait being measured. A Rasch measurement unit known as 'logit' represents scale values which are mapped at equal intervals on the continuum of a latent trait, hence the scale depicts interval level measurement. This interval scale displays values relating to the 'item parameter' and 'person parameter'. The item parameter refers to the level of difficulty of each item (in health-related measures difficulty of each task) on the latent trait. The person

parameter represents the level of a person's ability on the latent trait (Andrich, 1978; Rasch, 1960, 1961). The likelihood of a person responding to a particular item or item response is influenced by the person's ability on the construct being measured and the level of difficulty of item or item response options. This probabilistic expectation can be specified by a formula first developed for the dichotomous Rasch model (Rasch, 1960), which is:

$$Pi \ (\theta) = \frac{e^{(\theta - \delta i)}}{1 + e^{(\theta - \delta i)}} \qquad (1)$$

In the formula (1), $Pi \ (\theta)$ represents the probability of a person with θ ability responding positively to an item i, and δi represents the parameter of item difficulty. This formula refers to a simple logistic model, where the probability to respond to a dichotomous item positively or negatively is equal.

For health related measurements with polytomous items, probabilistic expectations are calculated using the Partial Credit model (Masters, 1982), which is an extension of the Rating Scale model developed by Andrich (1978). This polytomous model estimates a threshold for each response category, which is the level of latent trait represented by the individual category. The probability of any of the response categories being chosen by a respondent is the same. The main difference between the Rating Scale model and Partial Credit model is that the former assumes that the variation in threshold distances are uniform across all items. In contrast, the Partial Credit Rasch model allows for the variation in threshold distances across all items to differ (Masters, 1982). Prior to the selection of the polytomous model for Rasch analysis, the likelihood-ratio test is conducted which determines whether the threshold distances for individual items are uniform or different (Tennant & Conaghan, 2007). In the current PhD research, unrestricted Partial Credit model will be used, which can be expressed as:

$$Pij \ (\theta) = \frac{e^{(\theta - \delta ij)}}{1 + e^{(\theta - \delta ij)}} \qquad (2)$$
$$\text{where } j = 1, 2, \ldots, n$$

In the formula (2), $Pij \ (\theta)$ represents the specific probability of choosing the (j) category from n possible categories of an item (i) that estimates threshold parameter for each individual item (δij) separately.

Once the Rasch model is selected, outcome measurement data will undergo a vigorous iterative process involving investigation of ordering of item thresholds, individual item fit as well as overall fit to the Rasch model. This is based on item-trait interaction, dimensionality of the scale, and item bias based on personal attributes (Tennant & Conaghan, 2007). The Rasch measurement model is widely used in health-related measurements, mainly to examine and improve psychometric properties of existing ordinal scales (Lundgren Nilsson & Tennant, 2011). It also provides an algorithm that allows transformation of ordinal scores to an interval level data enhancing the precision of scale (Brogden, 1977; Rasch, 1961). This indicates considerable advantages of advanced Rasch measurement model over traditional CTT methods allowing more meaningful targeting and comparison between samples.

4.2.2 Qualitative research

Conducting qualitative research to establish content validity for an existing health-related outcome measure, is considered vital to a robust instrument validation process. This research uses qualitative content analysis (Hsieh & Shannon, 2005) as an assessment of content validity to ensure that the conceptual framework, item content and measurement approach represent the perspective, experience and words of the people completing the measurement. In addition, relevancy of formatting, instructions and response options, and interpretability and acceptability of the measure are also very crucial in this investigation (Brod, Tesler, & Christensen, 2009). The method of content analysis was initially applied in either qualitative or quantitative studies and predominantly used to describe the qualitative data using statistical inference (Berelson, 1952; Morgan, 1993). Nandy and Sarvela (1997) established a method of qualitative content analysis highlighting its potential for application in health research. It has been applied in several empirical research studies (Berthelsen, Hakanen, Kristensen, Lönnblad, & Westerlund, 2016; Öhrvall & Eliasson, 2010).

Qualitative content analysis can be referred to as "a research method for subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns" (Hsieh & Shannon, 2005, p. 1278). It is considered an 'atheoretical approach' to examining informational content of the data. Unlike other methods of qualitative inquiry such as grounded theory or phenomenology, it does not bring theoretical perspective, hence provides a more

unrestricted approach to understanding the concept of interest (Forman & Damschroder, 2007). Qualitative content analysis can be used to examine the textual data collected through any methods including open-ended surveys, focus groups, interviews, observations, articles, books, as well as interactive media (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). The use of qualitative content analysis derived from face to face interviews is justified as the focus of this doctoral research was to examine the content of the outcome measure to determine its appropriateness and acceptability.

Hsieh and Shannon (2005) delineated three techniques for conducting qualitative content analysis based on the naturalistic paradigm: (1) Conventional content analysis, (2) Directed content analysis, and (3) Summative content analysis. Conventional content analysis represents an inductive approach that uses coding categories which are derived directly from the data (Mayring, 2014). Whereas, directed content analysis makes a deductive use of a theory by relying on an existing theory or research to design initial codes (Potter & Levine-Donnerstein, 1999).

A summative content analysis explores contextual use of certain words or content by quantifying them. Despite the availability of the conceptual frameworks and existing outcome measures, it was deemed appropriate for this study to apply conventional content analysis to derive information directly from the subjective experiences of people with TBI. This approach allows the researcher to stay close to the data and provides new insights which may not have been previously identified (Kondracki, Wellman, & Amundson, 2002). A unique characteristic of qualitative content analysis is that the researcher can code the manifestation and/or extend the coding interpretations to the latent content (Graneheim & Lundman, 2004). However, interpretations are subjective and a text from the content can have multiple meanings. Hence, this approach demands complete understanding of the context of the data between the research and the respondent, otherwise it can pose a threat to its trustworthiness and affects credibility (Lincoln & Guba, 1985).

4.3 Conclusion

A mixed-methods approach, involving larger quantitative research with a smaller qualitative component, is an emerging methodology in measurement studies. It is

congruent with the research aim of detailed psychometric evaluation of an outcome measure to establish its robustness and also provides further directions. This chapter demonstrates the methodological concepts informing the research process undertaken in this doctoral study. The next chapter describes the first empirical study detailing the quantitative methods aiming to investigate construct validity, reliability and concurrent validity of the CIQ and CIQ-R.

Chapter 5: Psychometric Validation (1)- Evaluating factor structure, internal consistency and concurrent validity

5.1 Introduction

As reported in Chapter Three, psychometric properties of the CIQ have mostly been well established, with adequate test-retest reliability, internal consistency (Willer et al., 1994), inter-rater reliability (Sander et al., 1997) and validity reported (Sander et al., 1999). A few studies have also examined the factor structure or dimensionality of the CIQ (Hirsh et al., 2011; Sander et al., 1999), although with varied and sometimes contradictory results. Additionally, there has been criticism around the distribution of the subscale scores (Corrigan & Deming, 1995; Karyl M Hall et al., 1996). Kratz, Chadd, Jensen, Kehn, and Kroll (2015) provided a recommendation to revise the original CIQ to incorporate an aspect of technology based social integration to make the measure more contemporary.

Callaway et al. (2016) developed and piloted a revised CIQ (CIQ-R) which examines the use of electronic social networking (ESN) along with home integration, social integration and productivity domains of community integration. After initial piloting followed by scrutiny for clarity and appropriateness, the three new ESN items were added to the original CIQ. These new items included questions regarding frequency of social contact with the help of the internet, online video link and phone. The initial dimensionality and correlation analysis of the CIQ-R in Australian normative sample reported a four-factor model with strong correlation between total CIQ-R score and ESN subscale. Further evaluation of the CIQ-R measuring the electronic social networking as a component of community integration in people with TBI, has not yet been reported.

Considering the widespread use of the CIQ and availability of the revised version CIQ-R, it was important to establish that these measures have robust psychometric properties before their wider use can be advocated in the different neuro-rehabilitation contexts. If the factor structure and appropriateness are not clarified, it could lead to measurement errors in clinical trials and the risk of the measure not accurately reflecting peoples' experiences and components of integration. Hence, the third aim of this doctoral research, and the focus of this chapter was to critically

evaluate psychometric properties of the measure of community integration. Two different datasets, one for the CIQ and another for the CIQ-R, were used to examine dimensionality and internal consistency using factor analyses (exploratory and confirmatory) and Cronbach's alpha statistics.

This study also furthers the psychometric evaluation of the CIQ-R and examines the concurrent validity by comparing it with the Sydney Psychosocial Reintegration Scale (SPRS). The original CIQ measure has been recognised to be the standard measure for community integration after brain injury (McColl et al., 2001). It is also reported to have correlated well with other measures of handicap and functioning including the CHART the DRS, the FIM+FAM combined measure (Sander et al., 1999; Zhang et al., 2002) and the SPRS (Kuipers et al., 2004). Findings based on examination of five widely used measures of community integration against the quality criteria stated by Terwee et al. (2007), detailed in Chapter Two, identified the CIQ and the SPRS as the measures with strongest psychometric properties. Both the CIQ and the SPRS were developed based on the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (Tate et al., 1989; Willer, Linn, & Allen, 1993; Willer, Rosenthal, et al., 1993; World Health Organization, 1980), which is now known as the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001).

Three domains of the CIQ (Home integration, Social Integration and Productivity), were reported to have moderate correlations with the three SPRS subscales of occupational activities, interpersonal relationships, independent living skills respectively. Kuipers et al. (2004) confirmed these two scales to be measuring related but different constructs despite their conceptual resemblance. With an addition of a new domain named Electronic Social Networking (ESN) in the revised CIQ measure (CIQ-R), the correlation analyses are necessary to be replicated to establish the utility of these measures. This study extended to determine concurrent validity of the CIQ-R and examine interrelations between objective indicators of community integration (CIQ-R) and individuals' subjective feelings about them (SPRS) among people with TBI. The expectations with regards to associations between the CIQ-R and the SPRS were set based on theoretical underpinnings. The hypotheses were:

- Home Integration domain of the CIQ-R is expected to correlate well with the Independent Living Skills domain of the SPRS

- Social Integration domain of the CIQ-R is expected to correlate well with the Relationships domain of the SPRS.

- Productivity domain is expected to correlate well with the Work and Leisure domain of the SPRS.

- Electronic Social Networking domain is expected to correlate with Work and Leisure and Relationships domains of the SPRS.

- Total scores for the CIQ-R and the SPRS are expected to have moderate correlation despite one measuring activity frequency and the other scoping subjective quality of the activity.

5.2 Method

Structural validity and internal consistency of the original CIQ were explored using data collected through a longitudinal questionnaire study. Data for the CIQ-R and the SPRS were collected through a cross-sectional questionnaire study.

5.2.1 Participant recruitment

Dataset 1 (Longitudinal CIQ data)

The data used in this analysis were collected as a part of a longitudinal, population-based study of TBI incidence known as Brain Injury Incidence and Outcomes New Zealand in the Community (BIONIC) conducted in the Hamilton and Waikato Districts of New Zealand (NZ). The study was funded by the Health Research Council of NZ. The BIONIC team invited all medically confirmed cases of TBI to take part in follow-up assessments at baseline (within 2 weeks of the injury), 1, 6, and at 12 months post-injury (±4 weeks) (1 March 2010 through 28 February 2011). The CIQ measure was completed as part of the assessment either in-person or over the telephone with a researcher. This sample offered the advantage of enabling access to verified injuries within a well-controlled timeframe post-injury. As 95% of the sample were classified as having a TBI of mild severity, only adult mild TBI cases were extracted for the purposes of the analysis, to prevent the small proportion of moderate and severe injuries affecting the results. Mild TBI severity was defined using the Glasgow Coma Scale (GCS; 13–15) and/or post-traumatic amnesia (<24 hours). All cases meeting the TBI inclusion criteria that did not have a recorded GCS score were classified as mild in severity.

Sampling adequacy criteria for exploratory analysis, recommend that the number of subjects in the sample should be at least five times the number of variables being examined (Hair, Black, Babin, & Anderson, 2014), whereas, Nunnally and Bernstein (1994) suggested that, a sample of at least ten subjects per item is required to minimise sampling error. From the BIONIC data, the largest sample that contained 296 cases was part of the 12-month follow-up assessment (Dataset 1a) which was considered appropriate for Exploratory factor analysis (EFA) of the 15-item CIQ scale (Willer, Rosenthal, et al., 1993). For the Confirmatory factor analysis (CFA), 6- months mild TBI data (Dataset 1b) for all consenting participants (≥16 years) were extracted from the BIONIC dataset (N=202). In this analysis, data from a different time-point than the data used for the EFA were used to ensure a more robust examination and stability of the factor-structure derived by the EFA (Costello & Osborne, 2005). Ethical approval for this study was obtained from the Northern Y Health and Disability ethics committee of New Zealand (NTY/09/09/095) and the Auckland University of Technology ethics committee (09/265).

Dataset 2 (Cross-sectional CIQ-R and SPRS data)

Participants for this cross-sectional study were recruited through healthcare providers from the greater Auckland and Waikato regions. Such providers included: ABI rehabilitation, Think NZ, and the Brain Injury Association. Advertisements were placed in healthcare facilities, newsletters, on their websites, and in Facebook pages. Potential respondents were given an opportunity to choose from postal or online survey options to complete their questionnaires.

The information pack posted to potential participants included a covering letter written by the recruiting locality on behalf of the research team (see Appendix D), plus a participant information sheet (See Appendix E), a consent form (see Appendix F), a demographic information sheet (See Appendix G), questionnaires (see Appendix H and Appendix I) and a self-addressed stamped envelope. People were eligible to participate if they self-reported that they had experienced traumatic brain injury at least six months prior to taking part in this study and had been living in the community. Interested participants completed the consent form and questionnaires and returned them to the research team in the envelope provided. People who wanted to complete the survey online could request a weblink by email, freephone or a text message. The

study was approved by the Auckland University of Technology Ethics Committee (15/237) (See Appendix A).

A total of 117 consenting participants (≥16 years) with mild to severe TBI completed the CIQ-R (Callaway et al., 2016) and the SPRS (Tate et al., 2012). The sample size was deemed adequate according to the criteria by Hair et al. (2014) as the sample had >5 cases per item and also enabled analysis across the severity spectrum of TBI.

5.2.2 Outcome measures

Community Integration Questionnaire (CIQ)

The CIQ is a 15-item self-report questionnaire with three subscales: Home Integration (domestic activities, items 1-5), Social Integration (social and leisure activities, items 6-11), and Productivity (educational, vocational or volunteer work outside the home, items 12-15) (Willer, Rosenthal, et al., 1993). Most of these items give a choice of three answers on a 0-2 Likert scale. The total score can range from 0 – 29 with higher scores representing greater community integration and lower scores reflecting low integration. Most items are scored individually, however for the Question 4 (*Who cares for the children in the home?*), if the participants' response is 'Not applicable', then the score calculated was the average for their scores to questions 1, 2, 3 and 5. Additionally productivity sub-scale items 13-15, asked about current educational, vocational and volunteer activities which are combined to form a single *Jobschool* item. Hence the present psychometric analysis was conducted on 13 items rather than 15.

Community Integration Questionnaire-Revised (CIQ-R)

The CIQ-R comprises the three original subscales home integration (items 1-6), social integration (items 7-11) and productivity (items 12-15) as well as an additional three items of ESN subscale (16-18) (Callaway et al., 2016). The ESN items are scored on a 0-2 Likert scale with a total subscale score ranging from 0 to 6. The total CIQ-R score contains the sum of all items (1–18), with possible scores ranging from 0 to 35. The scoring method was consistent with the scoring of the CIQ and with the combined *jobschool* item, the psychometric analysis was conducted on 16 items of the CIQ-R rather than 18.

The Sydney Psychosocial Reintegration Scale (SPRS)

The SPRS includes 12-items equally distributed across three subscales of psychosocial function: occupational activities (items 1-4), interpersonal relationships (items 5-8) and independent living skills (items 9-12) (Tate et al., 2012). Each item is scored on 0-4 Likert scale with a low score indicating poor psychosocial integration and a score of 4 indicating higher integration. Total scores range from 0-48 and subscale scores from 0-16.

5.2.3 Data Analyses

Descriptive statistics, reliability and exploratory and correlation analyses were conducted using IBM SPSS v.23 to examine dimensionality and internal consistency of the CIQ and the CIQ-R and establish concurrent validity of the CIQ-R. The confirmatory factor analysis was conducted using AMOS SPSS v.23. Descriptive statistics for all the CIQ, the CIQ-R, the SPRS and their subscales were also calculated to examine any possible floor and ceiling effects (Streiner et al., 2015). Additionally, independent t-tests were conducted to compare means for sub-scale scores for both datasets to assess differences or similarities in their integration levels.

Exploratory Factor Analysis

Dimensionality was examined using exploratory factor analysis (EFA), involving a principal component analysis with varimax rotation. The decision as to the number of factors to extract and rotate was based upon consideration of the following criteria: (a) number of eigenvalues greater than 1.0, (b) inspection of the scree plot, and (c) previous studies which reported two or three factor solutions for the CIQ (Dalemans et al., 2010; Sander et al., 1999) and four factor solution for the CIQ-R (Callaway et al., 2016).

Loadings of CIQ and CIQ-R items onto each factor, communalities (h^2), and percentages of variance explained by each factor are presented. In accordance with Tabachnick and Fidell (2013) a minimum loading of 0.32 is taken as the threshold for an item, which equates to approximately 10% of shared variance within the factor. Loadings of less than 0.32 are replaced by zeros in the table of results to aid interpretation. Where an item loaded >0.32 onto more than one factor, all loadings are presented (Nunnally & Bernstein, 1994, p. 536).

In addition to the factor analyses, the internal consistency (i.e. Cronbach's α) of the items comprising each factor was also calculated by testing the Cronbach's coefficient alpha (Nunnally & Bernstein, 1994).

Confirmatory Factor Analysis

In order to test goodness of fit, Confirmatory Factor Analyses (CFA) were conducted on the participants' 6-month post-injury data for Dataset 1 and the same cross-sectional data for Dataset 2. CFA provides a quantitative index of how well the covariance matrix used fits the models exhibited by the EFA solutions. Therefore, it goes beyond choosing the best EFA solution simply by inspecting the resulting factor loadings. The CFAs were completed using the AMOS 19 structural equation modelling software package. A two-factor model was examined for the CIQ and three-factor and four factor models were examined for the CIQ-R based on the results of the EFAs to identify the model with the best fit. For each model tested, six fit indices to indicate a good fit to the data were obtained. Firstly, Chi Square was used where a low non-significant value would indicate a close fit between the data and the model. As this index can be misleading with large samples five indices were used in addition to Chi Square.

The first of these was a Chi-square to degrees of freedom ratio (chi-square/df) which is considered to indicate a good fit with the value below 2.0. The second index was Comparative Fit Index (CFI) (Bentler, 1990) which indicates the extent to which the model explains the variance. A CFI of < 0.95 was judged to be a good fit to the model (Hu & Bentler, 1999). The model was next tested for Normed Fit Index (NFI) with the value of <.90 indicating a good fit (Bentler, 1990). The fourth index was the goodness of fit index (GFI) where a high value (preferably >.95) was sought to indicate a good fit (Mulaik et al., 1989). Finally, the fifth index was the root mean square of approximation (RMSEA) (Steiger, 1990) which gauges badness of fit. A RMSEA value lower than .08 was considered as a reasonable fit by Marsh et al. (2004), while Hu and Bentler (1999) recommended a cut-off value of .06 or lower for better approximation of the fit. A study by Byrne (2016) suggested that RMSEA value of less than .05 indicates a good fit, between .05 and .08 is reasonable; whilst a value above .08 shows an average fit. In this case, a low value (preferably <.05) was sought to illustrate a good fit.

For further exploration of the dimensions of a construct, a 'higher-order factor' model was examined. Theoretically, community integration is believed to be a single construct and home integration, social integration, productive activity and electronic social networking subscales are interpreted as dimensions of a more abstract concept 'Community Integration'. The CFA was further examined to check if the first-order factors compose an abstraction for a higher-order.

Correlational analysis for concurrent validity

The Spearman's rho was used to examine the covariance of ratings among the scales, such as various subscales and total score comparisons between the CIQ-R and the SPRS. Correlation coefficients of $P<.01$ were considered statistically significant. An r value below 0.25 was categorised as poor or no correlation; r = 0.25–0.50 was considered fair; r = 0.50–0.75 was moderate-to-good; and r > 0.75 was deemed good-to-excellent (Portney & Watkins, 2009). The above-mentioned cut-off values will be considered as an indication only rather than a rule of thumb. This is to support the main goal of the study that the revised measure is examined for its concurrent validity using theoretically relevant measure and whether the prior hypotheses are satisfied as recommended by Terwee et al. (2007).

5.3 Results

5.3.1 Sample characteristics

As mentioned above, Dataset 1 is a part of a longitudinal study including mild TBI samples who completed the CIQ at 12-months and 6-months post-injury. The 12-month mild TBI data (N=296) for all consenting participants (aged ≥16 years) were extracted from the Dataset 1 for the EFA. The sample comprised 177 (60%) males and 119 (40%) females with a mean age of 38 (SD=17.70, median= 33, range 16-91). The 6-month mild TBI data (N=202) for all consenting participants (aged ≥16 years) were extracted from the Dataset 1 for the CFA. This sample comprised 119 (59%) males and 83 (41%) females with a mean age of 39 (SD=18.19, median= 35, range 16-91).

Dataset 2 (N=117) involved adults with TBI with varying severity who completed the CIQ-R and the SPRS after at least 6-months post-injury. There was no upper limit set for 'time since injury' for these participants to examine community integration over a more varied timeframe post-injury and to take longer trajectories of recovery into

account. The sample comprised 58 (49.6%) males and 59 (50.4%) females with a mean age of 49.05 (SD=17.74, median= 48, range 18-85). This dataset was used to conduct both EFA and CFA as well as internal consistency and concurrent validity statistics for the CIQ-R.

Table 5.1 presents descriptive statistics for age, gender, ethnicity demographics and average time since injury for Dataset 1 and 2.

Table 5.1. Descriptive statistics: Age, Gender, Ethnicity, and Time since injury

	Dataset 1 (Longitudinal study)				Dataset 2 (Cross-sectional study)	
	CIQ analysis mild TBI 12-months sample		CIQ analysis mild TBI 6-months sample		CIQ-R and SPRS analysis TBI sample	
	N=296		N=202		N=117	
Age (mean, SD)	37.82	17.71	39	18.19	49.08	17.74
Ethnicity (n, %)						
European	169	57.1	133	65.8	82	70.1
Maori	108	36.5	53	26.2	17	14.1
Other	19	6.4	16	7.9	18	15.4
Gender (n, %)						
Male	177	59.8	119	59	58	49.6
Female	119	40.2	83	41	59	50.4
Time since injury (year)		1		0.5	23.5 (mean) 9.35 (SD)	

Descriptive statistics for the CIQ mild TBI (6-month and 12-month), the CIQ-R and the SPRS TBI samples are presented in Table 5.2Table 5.1 for total scores and sub-scales scores. A pronounced ceiling effect on the CIQ-R home integration subscale is evident with 18.8% of participants scoring at the highest point of the scale according to the cut-off point of 15% proposed by Terwee et al. (2007). However, the subscale scores did not display any significant skew (-.03). The productivity sub-scale scores for the 6-month (-1.12) and 12-month (-1.19) mild TBI CIQ sample were negatively skewed indicating ceiling effects. To probe this further, item frequency for the 'jobschool' item (item 13) on the productivity subscale in both the datasets was calculated to estimate the impact on productivity (employment, school, and leisure) post-injury. For 6-month

and 12-month datasets, the percentage of adults with mild TBI who scored minimum and maximum productivity ranged between 12.5 and 13.9, while for the CIQ-R dataset, 20.1% of the total sample displayed lowest score on 'jobschool' item and only 4.3% of the sample had a highest level of productivity. This indicates better outcomes for productivity for people with mild TBI within the first year of their injury in comparison to the long-term outcomes for a group of people with varying severity of the injury. For the SPRS, items for all three subscales showed high negative skew. These findings necessitated the use of non-parametric statistical analyses for these two scales.

Though not a principal aim of this study, independent t-tests were conducted to examine whether the sub-scale scores of three participant groups used in this study are significantly ($p < .05$) different from, or similar to, one another. All three participant groups had similar scores on home integration sub-scale. A statistically significant mean difference was found for the social integration and productivity subscales between the mild TBI CIQ samples and the CIQ-R sample (Table 5.3). The level of social integration and productivity was significantly higher in mild TBI samples.

Table 5.2. Descriptive statistics: CIQ, CIQ-R, SPRS total score and sub-scale scores (CIQ 6-month post-injury mild TBI, N=202; CIQ 12-month post-injury mild TBI, N=296; CIQ-R and SPRS TBI, N=117)

	Scale/ Sub-scales	Participant Group	Total possible maximum score	Mean	Std. Deviation	Skewness	Kurtosis	% cases with lowest score	% cases with highest score
CIQ	Home Integration	6-month CIQ	12	5.15	2.547	.17	-.55	3.5	5.4
		12-monthCIQ		5.17	2.638	.15	-.74	3	7.1
	Social Integration	6-month CIQ	10	8.91	2.162	-.97	1.65	.5	10.4
		12-monthCIQ		8.94	2.090	-.63	-.04	.3	9.8
	Productivity	6-month CIQ	7	5.05	2.074	-1.12	.02	1	12.4
		12-monthCIQ		5.01	1.874	-1.19	.04	2.4	13.5
	Total Score	6-month CIQ	29	18.97	4.575	-.75	1.26	.5	1.5
		12-monthCIQ		19.11	4.470	-.77	1.15	.3	1
CIQ-R	Home Integration		12	5.51	3.098	-.03	-.90	6	18.8
	Social Integration		10	6.91	2.366	.17	-.60	.9	2.6
	Productivity		7	3.97	1.995	-.29	-1.33	2.6	4.3
	ESN		6	3.27	1.710	-.21	-.79	6.8	10.3
	Total Score		35	19.67	6.030	-.62	.41	.9	.9
SPRS	Work Leisure		16	10.78	4.315	-.69	-.28	1.7	15.5
	Relationships		16	11.71	3.785	-.83	-.30	1.7	15.5
	Independent Living Skills		16	13.36	3.201	-1.61	2.73	0.9	31.0
	Total score		48	35.85	10.139	-.85	.19	0.9	8.6

Table 5.3. Comparing CIQ mild TBI (6-month and 12-month) and CIQ-R participant groups

Participant groups		Independent t-test and effect size calculations for Equality of Means						95% Confidence Interval of the Difference	
		t	df	Cohen's D	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
6-month CIQ & 12-month CIQ	Home Integration	-.100	496	0.01	.920	-.024	.237	-.490	.443
	Social Integration	-.172	496	0.04	.864	-.033	.193	-.413	.347
	Productivity	.267	496	0.04	.790	.048	.179	-.303	.399
6-month CIQ & CIQ-R	Home Integration	-1.136	317	0.13	.257	-.364	.321	-.995	.267
	Social Integration	7.658	317	0.88	.000	1.991	.260	1.480	2.503
	Productivity	4.581	317	0.53	.000	1.089	.238	.621	1.556
12-month CIQ & CIQ-R	Home Integration	-1.124	411	0.11	.262	-.341	.303	-.936	.255
	Social Integration	8.538	411	0.91	.000	2.025	.237	1.559	2.491
	Productivity	4.993	411	0.54	.000	1.041	.208	.631	1.451

5.3.2 Exploratory Factor Analyses

Dataset 1: CIQ analysis for mild TBI sample at 12-month

Factor analysis was performed on the 13 items of the CIQ at 12-month post-injury. As shown in Table 5.4, three and two factor solutions were found.

Three factor analysis

Prior to performing PCA, the suitability of the data for factor analysis was assessed. The Kaiser-Meyer-Olkin value was 0.77, exceeding the recommended value of 0.6 and Bartlett's test reached statistical significance supporting the factorability of the correlation matrix (Pett, Lackey, & Sullivan, 2003). Principle components analysis revealed the presence of three components with eigenvalues exceeding one and accounting for 54.44% of total variance.

Item loadings on the first principle component were all above 0.3 for items 1 – 7. This component can be referred to as a 'home competency factor' that had loadings from the household items (i.e. cooking, grocery shopping, childcare, and finance). Items 8 to 10, 12 and 13 all loaded on the second principle component above 0.6 which can be considered a 'social activity factor' that included social integration items (e.g. visit friends and family, leisure activities, travel outside home) and productive activity items (e.g. work situation, school/training, and volunteering). Item 5 (social arrangements) also loaded (0.362) on the third factor along with item 11 (have a best friend) with the loading of 0.876. Of the three components only two were interpretable when rotated and the third comprised only items 5 (0.414) and 11(0.881). However, item 7 cross-loaded on factor 1 (0.378) and 2 (0.332). Based on the results of the three-factor analysis and Cattell's (1966) scree test, it was decided to retain two components for further investigation (Figure 5.1). Consequently, a two-factor solution was then explored. Cronbach's α was very high for Factor 1 (α=0.80), acceptable for Factor 2 (α=0.66) and very low for Factor 3 (α=0.22).
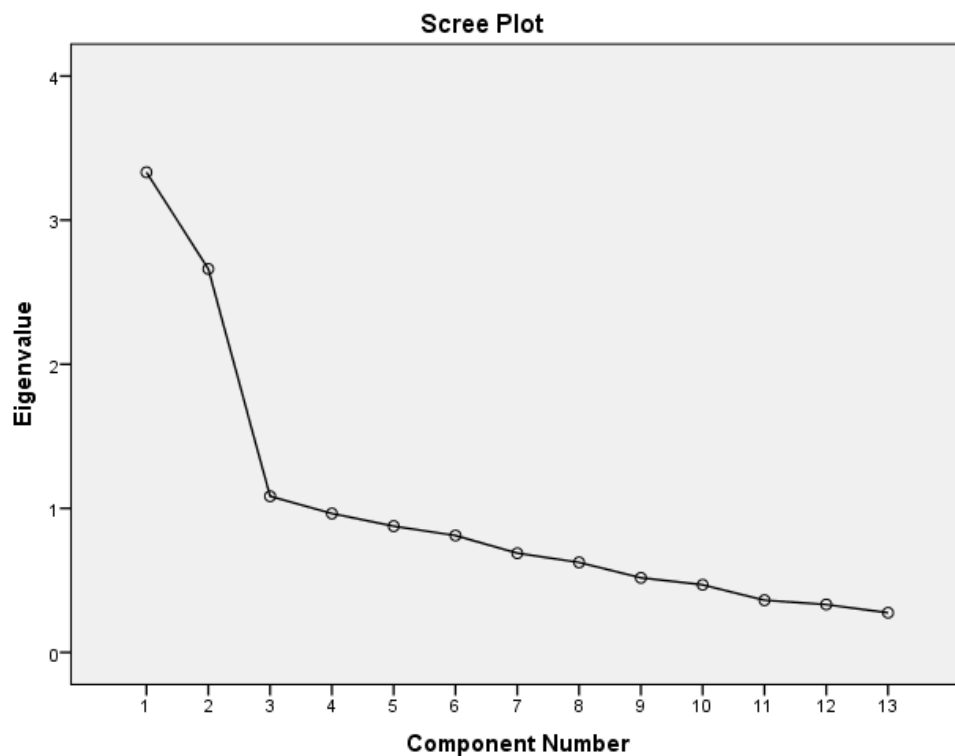
Figure 5.1: Scree plot for three factor solution for the CIQ

Two factor analysis

This two-factor solution accounted for 46.1% of the total variance. The first factor consisted of seven items, all of which related to home competency (Table 5.4). Five items loaded high on the second factor all relating to social activity and productivity. Item 11 did not load high on either factor. Cronbach's α was very high for Factor 1 (α=0.80) and acceptable for Factor 2 (α=0.67).

Dataset 2: CIQ-R analysis for TBI sample

Exploratory factor analysis was performed on the 16 items of the CIQ-R. As shown in Table 5.4, four and three factor solutions were found.

Four factor analysis

The data were found to be suitable for the factor analysis with the Kaiser-Meyer-Olkin value of 0.80. Four components were identified with eigenvalues exceeding one and accounting for 64.44% of total variance.

Items 1-6 loaded on the first principle component with no loadings less than 0.7 which are considered to belong to the home integration subscale. Item 7 cross-loaded on factors 1 and 2, however the loading on factor 2 was higher (0.591). The second

principle component representing the social integration subscale comprised items 7-11, all of which loaded above 0.320. Items 12 and 13 (jobschool) displayed high loadings on the third factor, which corresponds with the productive activity subscale of the theoretical framework suggested by Willer, Rosenthal, et al. (1993), however, the Cronbach's α was very low (α=0.35) for Factor 3. The fourth factor consists of three ESN items 14-16. Cronbach's α was very high for Factor 1 (α=0.92), acceptable for Factor 2 (α=0.61) and 4 (α=0.61). Consequently, a three-factor solution was explored based on the Scree plot (Figure 5.2).
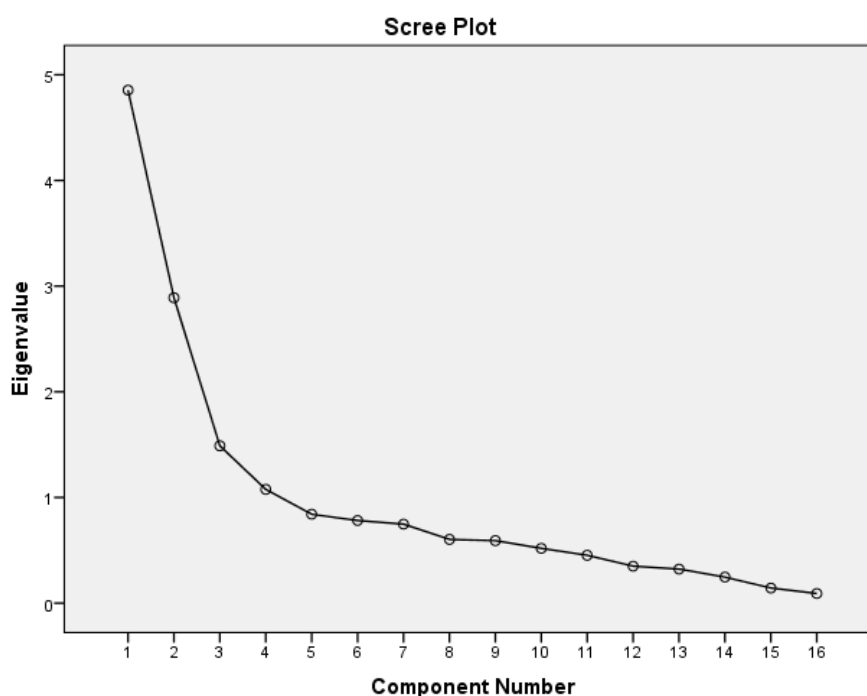
Figure 5.2: Scree plot for four factor solution for the CIQ-R

Three factor analysis

The three-factor solution explained 57.7% of the total variance. The factors 1 and 2 consisted of items 1-6 and 7-11 respectively, corresponding with the previous factor solution. While, items 12-16 which related to productivity and ESN subscales loaded on the third factor (Table 5.4). Cronbach's α was very high for Factor 1 (α=0.92) and acceptable for Factor 2 (α=0.61) and Factor 3 (α=0.58).

Table 5.4. Factor loading of the CIQ items, communalities (h2), and percentage of variance explained by each factor

| | CIQ (N=296) | | | | | | | CIQ-R (N=117) | | | | | | | | |
| | Factors | | | | Factors | | | Factors | | | | | Factors | | | |
CIQ item	1 (α= 0.80)	2 (α= 0.66)	3 (α= 0.22)	h²	1 (α= 0.80)	2 (α= 0.67)	h²	1 (α= 0.92)	2 (α= 0.61)	3 (α= 0.35)	4 (α= 0.61)	h²	1 (α= 0.92)	2 (α= 0.61)	3 (α= 0.58)	h²
Shopping for household items	**.805**	.000	.000	0.662	**.809**	.000	.659	**.871**	.000	.000	.000	.778	**.867**	.000	.000	.777
Meal preparation	**.805**	.000	.000	0.668	**.800**	.000	.666	**.866**	.000	.000	.000	.799	**.866**	.000	.000	.794
Everyday housework	**.751**	.000	.000	0.580	**.740**	.000	.560	**.833**	.000	.000	.000	.730	**.827**	.000	.000	.723
Childcare	**.850**	.000	.000	0.724	**.844**	.000	.712	**.935**	.000	.000	.000	.885	**.934**	.000	.000	.885
Planning social gatherings	**.548**	.000	**.414**	0.478	**.580**	.000	.347	**.770**	.000	.000	.000	.605	**.771**	.000	.000	.604
Personal finances	**.480**	.000	.000	0.296	**.484**	.000	.293	**.762**	.000	.000	.000	.584	**.760**	.000	.000	.578
Frequency of shopping	**.378**	**.332**	.000	0.257	**.379**	.000	.243	**.428**	**.591**	.000	.000	.539	**.424**	**.557**	.000	.491
Frequency of leisure activities	.000	**.771**	.000	0.601	.000	**.761**	.580	.000	**.824**	.000	.000	.722	.000	**.777**	.000	.680
Frequency of visiting friends/relatives	.000	**.635**	.000	0.409	.000	**.634**	.409	.000	**.670**	.000	.000	.524	.000	**.677**	.000	.521
Participation in leisure activities	.000	**.659**	.000	0.517	.000	**.641**	.440	.000	**.612**	.000	.000	.471	.000	**.484**	.000	.347
Having a best friend	.000	.000	**.881**	0.783	.000	.000	.016	.000	**.406**	.000	.000	.545	.000	**.614**	.000	.489
Frequency of travel outside the home	.000	**.704**	.000	0.542	.000	**.713**	.531	.000	**.321**	**.770**	.000	.719	.000	**.458**	**.538**	.516
Jobschool variable	.000	**.718**	.000	0.562	.000	**.734**	.540	.000	.000	**.763**	.000	.635	.000	.000	**.439**	.263
Social contact using the internet								.000	**.366**	.000	**.586**	.526	.000	.000	**.632**	.437
Social contact using a video link								.000	.000	.000	**.815**	.698	.000	.000	**.744**	.612
Social contact using a phone								.000	.000	.000	**.335**	.550	.000	.000	**.656**	.516
Percentage of variance	25.48	20.43	8.54		25.60	20.50		30.34	18.06	9.30	6.73		30.34	18.06	9.30	

5.3.3 Confirmatory Factor Analyses

Dataset 1: CIQ analysis for mild TBI sample at 6-month

Drawing on the results of the EFA at 12 months (Part 1), the CFA at 6 months was computed on the 11 items which represented two factors of the CIQ. For this analysis, item 7 ('frequency of travel outside home for shopping?') and item 11 ('having a best friend') had to be excluded to obtain a good fit. The path diagram for the best two factor model is demonstrated in

Figure 5.3 and the results presenting a good model fit to the data are shown in Table

5.5. This two-factor structure displayed a good fit to the data as illustrated by the Chi-square/df value of 1.494 and the CFI value of greater than .95. The NFI and GFI values

for the two-factor model were .904 (equal to Bentler (1990), .90 cut-off) and .947

(close to .95) (Mulaik et al., 1989) respectively. The RMSEA was .05 suggesting a good

fit with the data.

Table 5.5. Confirmatory Factor Analysis of the CIQ: Model fit Indices

Factor structure	No. of items	Chi-square/df	CFI	NFI	GFI	RMSEA
Two factor	11	1.494	.965	.904	.947	.050

Drawing on the good fit indices to the data and moderate to significant item loadings

on their respective factors ranging from .35 to .82, the two-factor model provides

empirical evidence supporting the previous theoretical conceptualisation of the

construct consisting of home integration and social integration subscales. For the two

factor model Cronbach's α was 0.80 for Home Competency (6 items), 0.65 for Social

Integration and Productivity (5 items).
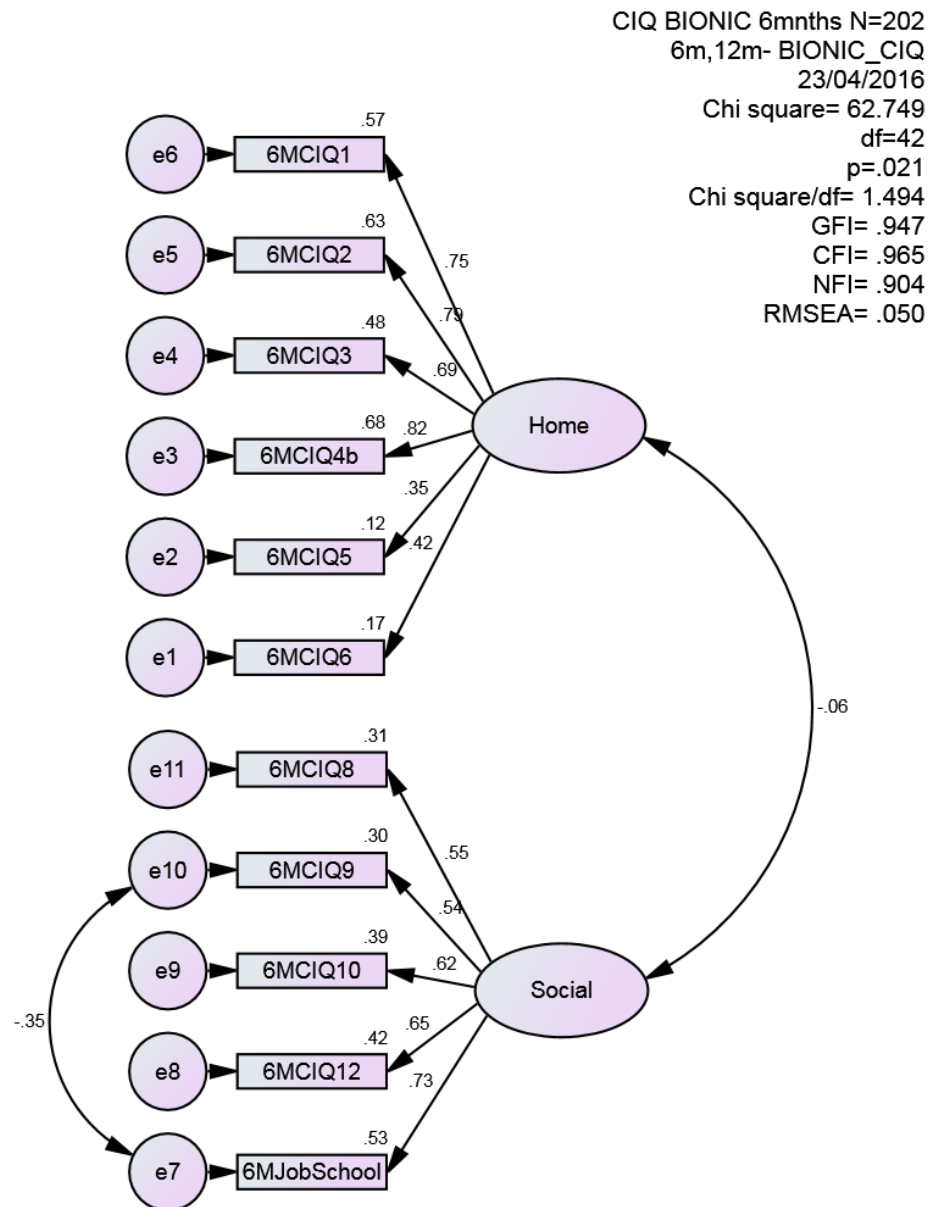
Figure 5.3: Confirmatory factor analysis of the CIQ two factor model

Dataset 2: CIQ-R analysis for TBI sample

For the cross-sectional data for CIQ-R, previous findings from the EFA were confirmed for the model fit. The CFA were computed on a total of 18 and 14 items representing three factors and four factors of the CIQ-R.

The path diagrams for the three and four factor models are demonstrated in Figure 5.4 and Figure 5.5 respectively. The summary statistics presenting a model fit to the data are shown in Table 5.6. Systematic comparison of all goodness of fit indices for both three and four factor models confirmed the best fit for the four factor model which was illustrated by the acceptable Chi-square/df value of 1.521 and the CFI value of .95.

The NFI value for the four-factor model was .875, which was slightly lower than the acceptable cut-off of .90. The RMSEA was .067 suggesting a reasonable fit with the data. However, for the four factor model, item 7 ('frequency of travel outside home for activities such as shopping') and item 11 ('Do you have a best friend in whom you confide?') had to be excluded to obtain a good fit. Additionally, the internal reliabilities of the groups of items comprising the corresponding third and the fourth factors in the three and four factor models were notably different. For both the models, Cronbach's α was 0.92 for Home integration and 0.61 for Social Integration. For the three factor model, Cronbach's α was 0.58 for third factor which had combined items (5 items) of Productivity and Electronic Social Networking subscales. Whereas, for the four factor model Cronbach's α was 0.35 for the Productivity subscale (2 items) and 0.61 for the Electronic Social Networking subscale (3 items).

Table 5.6. Confirmatory Factor Analysis of the CIQ-R: Model fit Indices

Factor structure	No. of items	Chi-square/df	CFI	NFI	RMSEA
Three factor	18	1.855	.897	.804	.086
Four factor	14	1.521	.952	.875	.067

CIQ-R N=117
Chi Square=187.336
Df=101
P=.000
Chi Square/df=1.855
CFI=.897
NFI=.804
RMSEA=.086
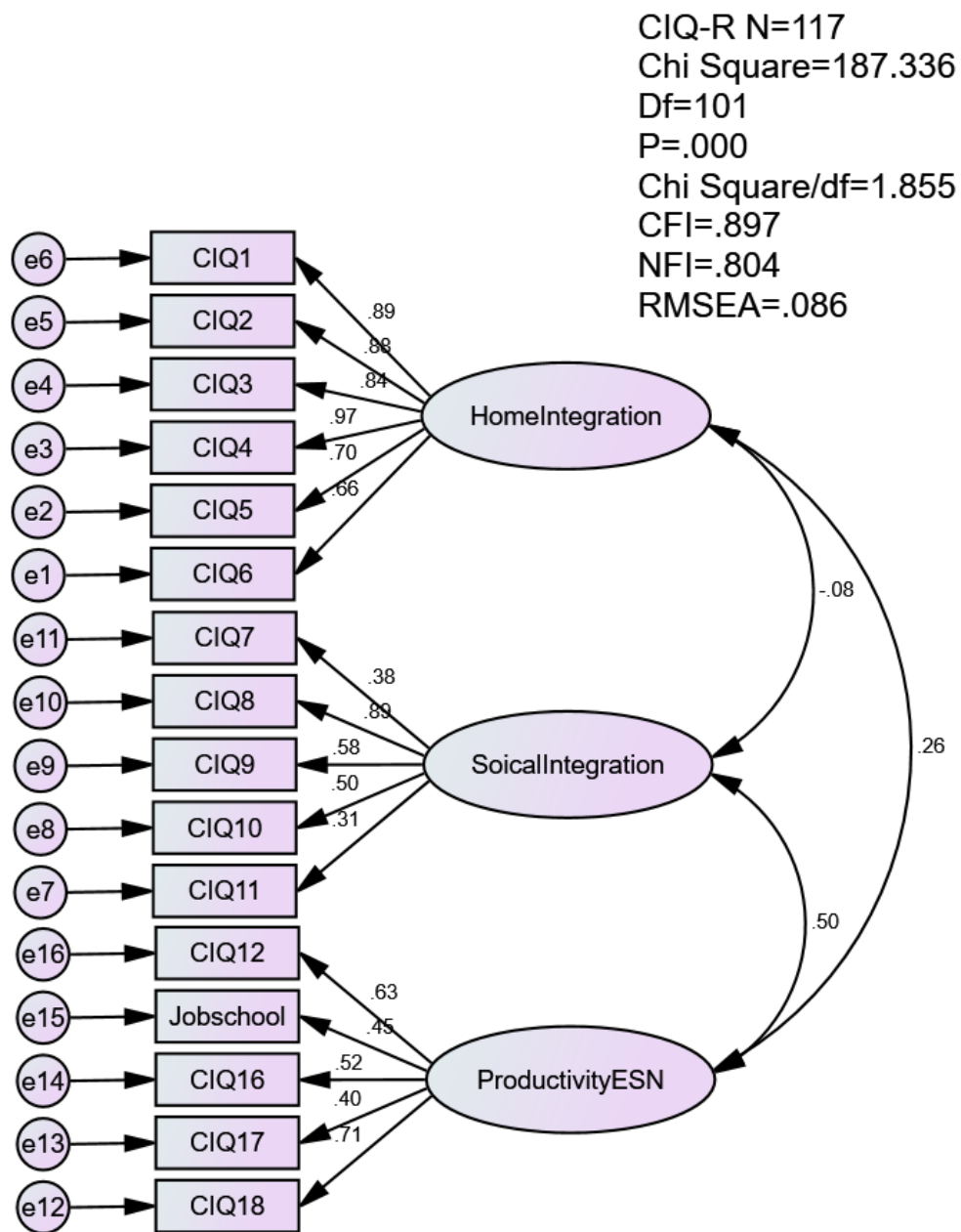
Figure 5.4: Confirmatory factor analysis of the CIQ-R three factor model

CIQ-R N=117
Chi Square=108.016
Df=71
P=.003
Chi Square/df=1.521
CFI=.952
NFI=.875
RMSEA=.067
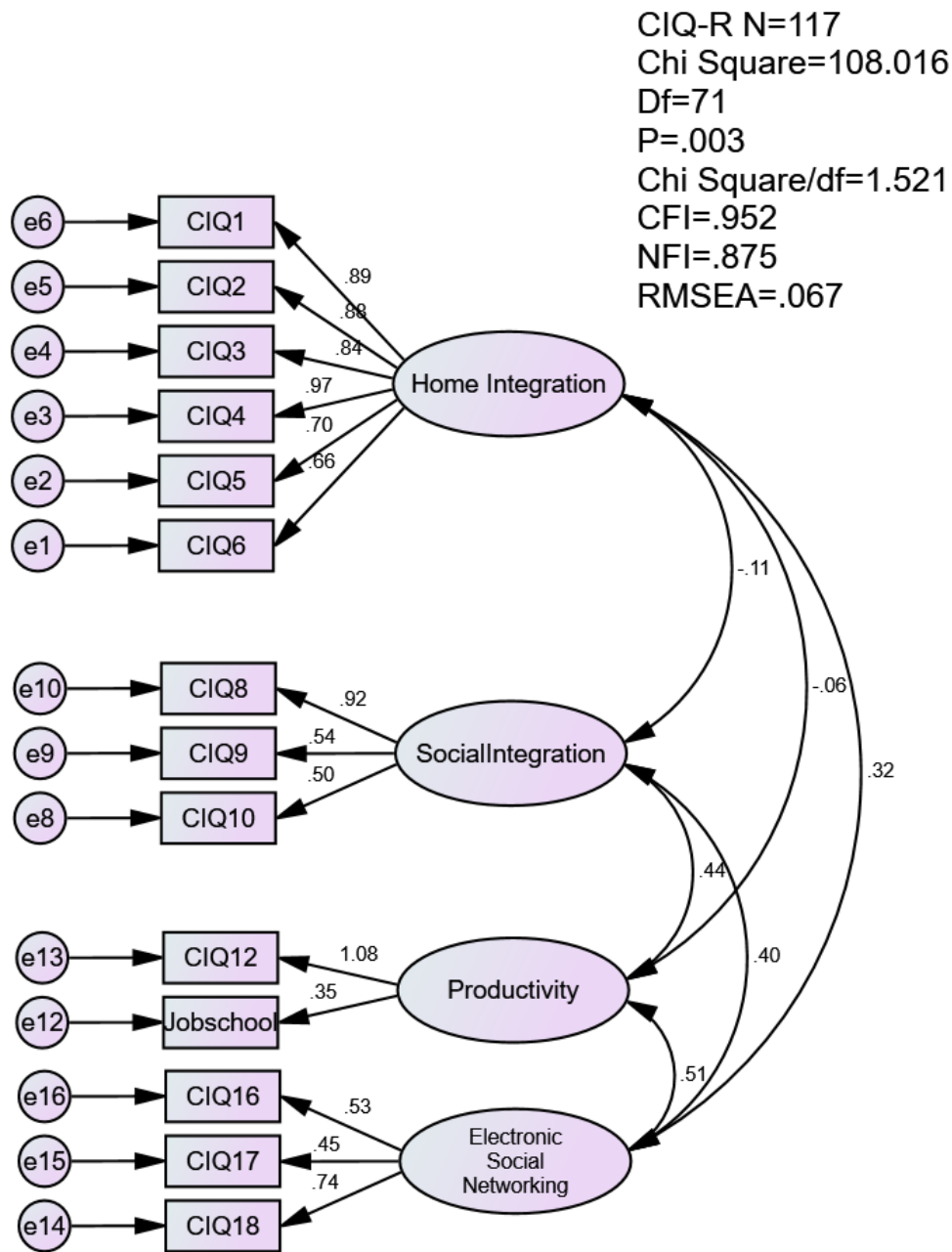
Figure 5.5: Confirmatory factor analysis of the CIQ-R four factor model

CIQ-R as a higher-order factor

Table 5.8 provides the correlations between the four dimensions. Theoretically an increase in one dimension suggest an increase in the other dimensions too (Marsh & Hocevar, 1985). It appears that the home integration dimension does not correlate well with the other three dimensions. For statistical verification, modelling of CIQ-R as a higher order factor comprised of four dimensions was carried out. The higher-order factor structure of the CIQ-R is displayed in Figure 5.6. Model fit indicates CIQ-R represents a higher-order factor, with four first-order dimensions (X^2 = 121.981; df = 73, $p<.000$ X^2/df = 1.671, CFI = .937, NFI = .859, RMSEA = .076).
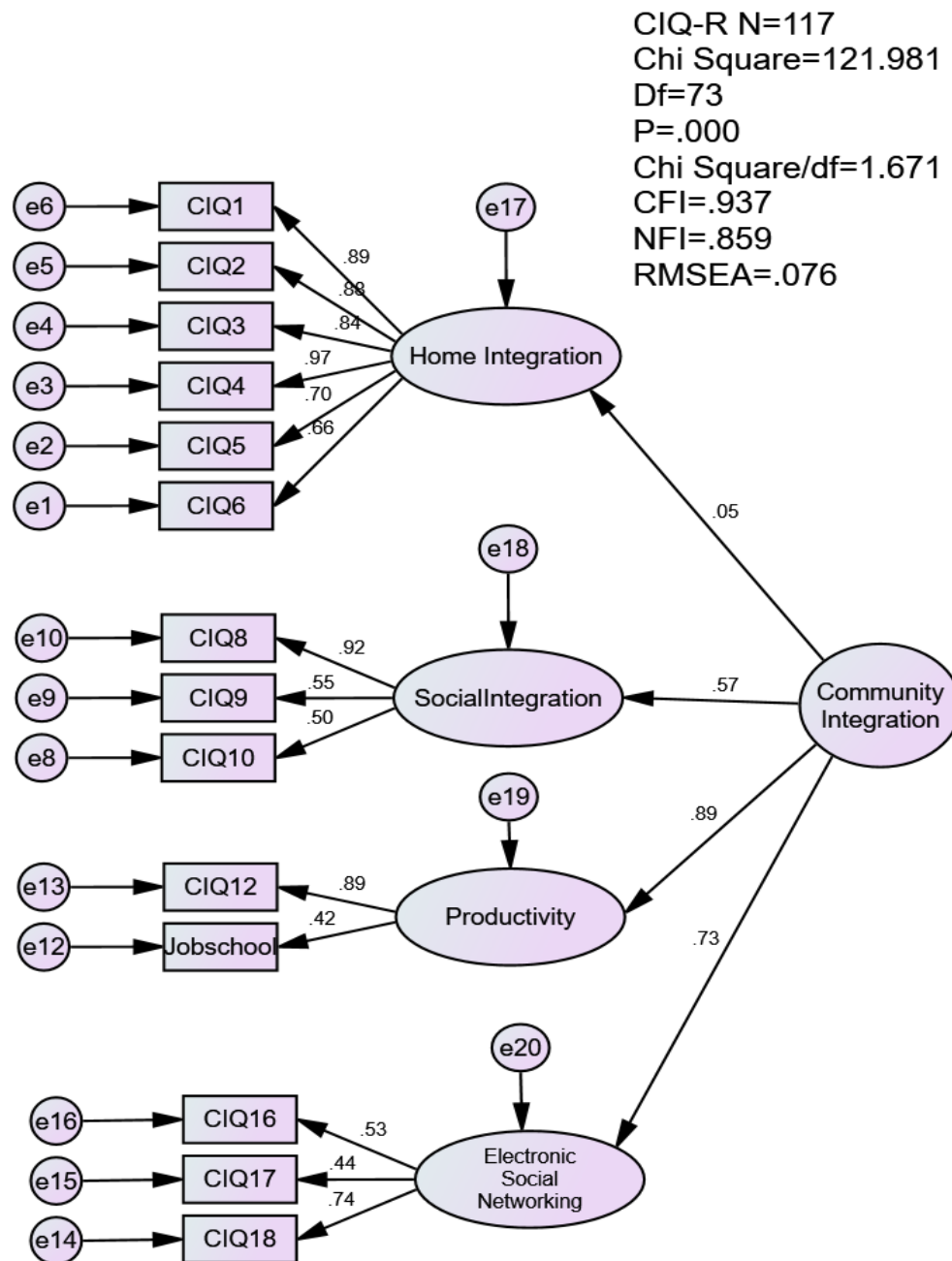
Figure 5.6: Confirmatory factor analysis of the CIQ-R higher-order factor model

5.3.4 Concurrent validity of the CIQ-R

A matrix of correlations between the CIQ-R and the SPRS total scales and subscales is shown in Table 5.7. The CIQ-R total score had fair correlations with level of re-integration as measured by the SPRS total score (r = 0.456, $p < 0.01$). The correlations between subscales of the CIQ-R and the SPRS were fair to moderate ranging between 0.223 to 0.575. All expectations with regards to the correlation between these subscales were met, however the strength of correlations was lower than expected. The Home Integration (CIQ-R) had a fair level of correlation with the items of

Independent Living Skills domain (SPRS) (r = 0.332, $p < 0.01$), while Social Integration (CIQ-R) had rather lower than expected association with the Relationships domain of the SPRS (r = 0.311, $p < 0.01$). The Productivity subscale displayed the highest correlation with the Work and Leisure subscale of the SPRS. Additionally, it significantly correlated with all other subscales of the SPRS and the total scale. Contrary to expectations, the ESN subscale of the CIQ-R showed better correlations with the Independent Living Skills subscale (r = 0.352, $p < 0.01$) of the SPRS than the Work and Leisure (r = 0.311, $p < 0.01$) or Relationship subscales (r = 0.291, $p < 0.01$).

Table 5.7. Correlations between CIQ-R and SPRS subscales and total scores

	Home Integration	Social Integration	Productivity	Electronic Social Networking	CIQ Total
Work Leisure	.17	.05	.58**	.31**	.40**
Relationships	.06	.31**	.41**	.29**	.39**
Independent Living Skills	.33**	.22*	.46**	.35**	.51**
SPRS Total	.17	.20*	.54**	.35**	.46**

*Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.01 level (2-tailed).

Table 5.8 and Table 5.9 demonstrate correlation between subscales of the CIQ-R and the SPRs respectively. For the CIQ-R, Social Integration subscale does not have significant correlations with the other three subscales. Correlations between Home Integration, Productivity and ESN subscales are considered fair ranging from 0.225 to 0.371 ($p<0.01$). In contrast, all three subscales of the SPRS have significantly high correlations amongst them.

Table 5.8. Correlations between CIQ-R subscales and total scores

	Home Integration	Social Integration	Productivity	Electronic Social Networking	CIQ Total
Home Integration	1.00				
Social Integration	.13	1.00			
Productivity	.23*	.18	1.00		
Electronic Social Networking	.26**	.16	.37**	1.00	
CIQ Total	.70**	.55**	.63**	.59**	1.00

*Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.01 level (2-tailed).

Table 5.9. Correlations between SPRS subscales and total scores

	Work and Leisure	Relationships	Independent Living Skills	SPRS Total
Work and Leisure	1.00			
Relationships	0.73**	1.00		
Independent Living Skills	0.69**	0.64**	1.00	
SPRS Total	0.93**	0.90**	0.80**	1.00

**Correlation is significant at the 0.01 level (2-tailed).

5.4 Discussion

5.4.1 Factor analysis and internal consistency

In this chapter, EFA and CFA were used to examine the factor structure of the CIQ and CIQ-R in two NZ community-based samples.

For the CIQ, both two and three factor solutions were identified. However, only a two factor solution appeared promising in the EFA and this was found to be consistent with previous studies, which have reported two stable factors (Dalemans et al., 2010; Kuipers et al., 2004). For data collected at the 12-month time point, EFA demonstrated a two factor model comprising a Home Integration factor (items 1-6) and a Social Integration factor (items 7-13). In this model, item 6 which is related to managing one's own finances represented a household responsibility in line with the findings of Sander et al. (1999). In the original CIQ scale, item 6 was included in the social integration domain (Willer, Rosenthal, et al., 1993). The CFA confirmed this two factor model for the six months post-injury sample (n=202) with an exclusion of items 7 (frequency of shopping) and 11(having a best friend).

For the CIQ-R, both three and four factor solutions were investigated using EFA and CFA. The four factor model demonstrated relatively good model fit consistent with the previous study by Callaway et al. (2016). Similar to the previous findings of the CIQ dataset, item 6 (financial responsibility) appeared to be relating to the Home Integration subscale. The Electronic Social Networking Subscale (ESN) emerged as a unique factor and 93.8% of total participants appeared to have used telephone, mobile, media and internet based social networking. The ESN can be identified as an essential component of modern-day community integration and could be used to help

form more meaningful rehabilitation goals. These data support the inclusion of these items as a distinct subscale. Additionally, similar to the CIQ, a satisfactory model fit was achieved for the CIQ-R after removing items 7 (frequency of shopping) and item 11 (having a best friend).

Item 7 representing the shopping frequency either demonstrated low factor loading or loaded equally well on Factor 1 (home integration) and Factor 2 (social integration) for both CIQ and CIQ-R. It was conceptually included in a social integration subscale (Willer, Rosenthal, et al., 1993), whereas the current findings displayed ambiguity around shopping for household necessities (which is already represented by item 1) as opposed to leisure shopping. The wording of the item also appears to overlap with the item 12 -'travel outside home' which is included in a productive activity domain. It is recommended to remove the frequency of shopping item from the CIQ and the CIQ-R or to reword it to include both household goods and leisure shopping to avoid repetition and further confusion. Item 11 (having a best friend to confide in) also appeared to be problematic for both the scales examined in this study due to low factor loading. It could be due to restrictions posed by the response options 'Yes' and 'No', which do not consider the possibility of having a best friend who may not be around whenever needed. It also poses an assumption that people only confide in a person who they consider a best friend. In the current sample, for item 11, the term 'best friend' could be clearly defined or expanded to include a friend, partner, spouse, or relative as post-injury outcomes could lead to loss of existing friendships or development of new roles played by acquaintances. Rewording or removal of this item as well as revising response options are recommended for improved factor structure.

The reliability analysis (summarised above in Table 5.4) revealed a considerable drop in the Cronbach's alpha of the Factor 3 in a four factor model for the CIQ-R, as compared to Factor 1 and Factor 2. This Factor 3 represents a productivity factor with two items- items 12 and 'jobschool'. Low internal consistency for the two-item Productive Activity sub-scale has previously been identified by some researchers as problematic (Sander et al., 1999). In reporting the internal consistencies of the subscales, there is some contradicting evidence with regards to the appropriateness of examining the reliability of a two-item factor using coefficient alpha (Eisinga, Te Grotenhuis, & Pelzer, 2013). To explore this further, the 'jobschool' variable which was a composite item based on

items 13 to 15, was split and all three items were scored separately on a 0-2 Likert scale. Four factor model fit for the CIQ-R was achieved by CFA after excluding items 7, 11, 14 and 15, however, internal consistency did not show any improvement on reliability analysis. Given the lack of variance (as displayed in Figure 5.5 and Figure 5.6) for the composite jobschool item, encompassing three items relating to work, education and volunteering, it is not surprising that a factor of this kind does not emerge clearly or displays low internal consistency. It might be necessary to develop some new items for using the CIQ with populations with such a varied level of disability and consider including leisure activities and unpaid yet meaningful work, as for many, opportunities for paid employment are not always available post-injury. A useful starting point then might be some qualitative interviews with people with this degree of disability to better understand their perspective on what 'productive activity' means. Alternatively, a new measure of productivity can be developed to be used in conjunction with the CIQ or CIQ-R.

The home and social integration subscales of the CIQ appeared to be sensitive to the impairments caused by the mild TBI within the first year post-injury, however the productivity subscale displayed mild ceiling effects with nearly one third of the sample obtained scores in the higher range (>5). For the CIQ-R, the home integration subscale displayed a significant ceiling effect with more than 15% (Terwee et al., 2007) of total participants with the maximum scores. This limits the sensitivity of the scale in detecting varying level of impact based on home integration subscale. Corrigan and Deming (1995) and Karyl M Hall et al. (1996), emphasised that the scores should be interpreted by comparing them with premorbid scores or normative sample scores. The current scale and subscale data were compared to the scores for Australian normative group (Callaway et al., 2016). For the CIQ mild-TBI sample, mean scores for the social integration and productivity subscales were higher than the people without disabilities. This finding confirmed the ceiling effect identified in the current study for the productivity subscale in the mild TBI sample. This also means that people with mild TBI were well integrated into their communities 1 year post-injury. While for the CIQ-R TBI sample, scores for social integration and electronic social networking scales were comparable with the scores of normative group. This might indicate successful return to pre-injury function or inability of the scale to differentiate between people with

varying degree of functioning. Additionally, approximately only one third (35%) of the total sample achieved comparable mean scores for the productivity subscale and CIQ-R total scale, indicating significant impact of the injury in the long-term.

It can be argued that within first 12 months of the injury, most people receive rehabilitation services including return to work or training for independence programme as well as ergonomics through occupational therapy which may support an individual to prepare for employment or training (Kreutzer et al., 2003; Shames, Treger, Ring, & Giaquinto, 2007; Van Velzen, Van Bennekom, Edelaar, Sluiter, & Frings-Dresen, 2009). Sustainability of such rehabilitation input is not often assessed within the first year so does not provide a definitive answer to the question of whether people can return and retain their employment or training in the long term. Moreover, the impact of age-related, injury-related, personal, and environmental factors which is believed to potentially affect the overall integration outcome after the injury, has not been measured in this study. The sensitivity of the CIQ-R should be examined further.

Findings based on descriptive statistics (as displayed in Table 5.3) demonstrated no considerable difference in level of productivity at 6-months and 12-months in people with mild TBI. Additionally, higher productivity amongst people with mild TBI was reported as compared to the adults with long-term TBI with more varied severity of the injury. These findings need to be interpreted with caution as they display comparison between two different samples (longitudinal and cross-sectional), that underwent different recruitment and data collection methods.

This study provides strong evidence of dimensionality and internal validity of the CIQ and CIQ-R based on two different samples. It also highlights the issue with a number of items affecting overall scale performance and poor reliability of the productivity subscale with limited items, hence the subscale scores should not be considered in isolation from the total score. There is another threat to interpretation of the score with the CIQ-R being an ordinal scale. Total scores cannot be entirely dependable as two people with the same total score can have different functional limitations and integration status. Examining CIQ-R using alternative statistical methods such as Rasch analysis can provide a more in-depth picture of individual item functioning to aid in

enhancing scale precision. It can also convert the ordinal scale to interval-level scale for better interpretation of the rehabilitation outcome across the sample.

5.4.2 Concurrent validity

The current study aims to examine the concurrent validity of the revised measure CIQ-R using the New Zealand based data of individuals post-TBI. The main finding of the study supported significant but fair correlations between the total scores (r= 0.456, p<0.001), and only provided fair to moderate links for the sub-scale scores (r = 0.291-0.575, p<0.001) of the scales CIQ-R and SPRS. Hypotheses expecting relations between conceptually similar sub-scales Home Integration and Independent Living Skills , Social Integration and Relationship, and Productivity and Work and Leisure were reasonably supported. The ESN sub-scale displayed fair correlations with all three sub-scales and total score of the SPRS with highest correlation with Independent Living Skills sub-scale (r = 0.352, p<0.001). This may indicate that the use of electronic social network/media to be a home-based activity subject to availability of a living situation with an access to technology. The findings of this study correspond with the study conducted by Kuipers et al. (2004), that demonstrated positive yet moderate interactions between Home Integration, Social Integration, and Productivity subscales of the CIQ with Independent Living Skills, Interpersonal Relationships, and Occupational Activities subscales of the SPRS, respectively. These correlation findings, though modest, support the concurrent validity of the CIQ-R in relation to the theoretically relevant measure of community integration (Terwee et al., 2007).

Considering intercorrelation between the subscale scores and total scores, the SPRS demonstrated to have relatively good structural validity with values ranging from 0.639 to 0.932 (p < 0.001) (Table 5.9). In the psychometric study, Kuipers et al. (2004) demonstrated that the SPRS had sound psychometric properties as compared to the CIQ. Higher correlations between the SPRS subscales indicate that people who rate themselves as 'very good' in one area have similar feelings about their performances in other areas. This is in contrast to the CIQ-R subscales, where subscales are relatively independent, thus a person with a high level of integration in social tasks may not have good integration in work-related tasks. This indicates that the CIQ-R may lack strong statistical associations (correlations) which is one of the key principles to be considered a good outcome measure (Streiner et al., 2015). This necessitates the

modification in content, scoring structure or response format of the CIQ-R to enhance its psychometric properties before it can be used as a standard measure of community integration.

Both the CIQ-R and the SPRS, have the common foundation of the original handicap model of the ICIDH which is now represented by the ICF Framework. Kuipers et al. (2004) concluded that the CIQ and the SPRS measure different but related constructs, in particular 'Activity' and 'Participation' components of the ICF, respectively. However, it can be argued that both are conceptually designed to measure a level of participation in community-related activities (Tate et al., 1989; Willer, Rosenthal, et al., 1993). It is evident that the CIQ-R closely measures objective aspects of task completion and fulfilment of life roles, such as the frequency or the intensity of community-based activities, while the SPRS recognises community integration as viewed by an individual and his/her subjective feeling about quality of their performance in vocational, social and home-based roles and activities. Moderate correlations between the CIQ-R and the SPRS total scale and subscales indicate that the high frequency of an activity performed, may not necessarily yield the high quality of performance in that activity. For example, an individual may be able to work part-time, however he/she may only be able to carry out light duties or may make mistakes in a demanding work situation, hence the perceived quality of work may be compromised. A study investigated the relations between participation in community activities and satisfaction with these activities using the 47-item CIQ measure in its original format and concluded that the association between frequency of activities and their subjective appraisal was weak (Johnston, Goverover, & Dijkers, 2005). This means the measurement of the objective performance of an individual alone does not adequately portray the 'real picture' of his/her true level of integration. Subjective measures reporting based on individuals' perceptions have been identified to predict rehabilitation outcomes more accurately than the objective measures (Friedly, Akuthota, Amtmann, & Patrick, 2014; Greenhalgh, 2009; Kayes & McPherson, 2010). However, it is difficult to quantify or verify observations based on subjective outcomes. Additionally, subjective perceptions may differ each time, based on changes in a person's internal standards, values, conceptualisations as well as pre-cognitive, personal and environmental factors which limit reproducibility and reliability of the

results (Schwartz & Sprangers, 1999). The importance of taking an integrative approach was highlighted for measurement involving both objective and subjective reporting methods for achieving more accurate outcomes (Kayes & McPherson, 2010). It is recommended to implement a combined scale including the CIQ-R with its subjective counterpart for most robust measurement of level of integration.

5.5 Conclusion

The findings from this study confirm two factors for the CIQ and four factors for the CIQ-R. The original CIQ contains subscales Home Integration (items 1-6) and Social Integration (items 8-10,12-15). It is recommended to use the CIQ-R for future research, which is formed by four subscales, Home Integration (items 1-6), Social Integration (items 8-10), Productive Activity (items 12-13) and Electronic Social Networking (items 16-18). This study is the first in New Zealand to implement the CIQ-R with additional items that measure contemporary (electronic) ways of integrating into the community. It provides evidence for the internal validity of the CIQ and CIQ-R, indicating the total scale to be clinically and theoretically meaningful. The home integration subscale of the CIQ-R displayed ceiling effects and total score as well as productive activity subscale demonstrated slight negative skew. The CIQ-R would benefit from further revision to enhance reliability and sensitivity of the measure. This study evidently establishes the concurrent validity of the revised measure CIQ-R. Although the CIQ-R displayed weak to fair intercorrelations between subscales, which indicates the need to carefully examine the structure of the scale using a more robust statistical method such as Rasch analysis.

The study should be replicated with different measures as well as different groups involving patients and proxies to support the convergent and discriminant validity of the CIQ-R. Despite conceptual similarity, the CIQ-R and the SPRS measure different yet critical aspects of the construct community integration. Further work is required in refining the CIQ-R in order to accurately represent the ICF concept of community integration which is clinically meaningful. This chapter established dimensionality, internal consistency and concurrent validity of the CIQ-R, the next chapters present findings from the study that examined internal construct validity of the CIQ-R.

Chapter 6: Psychometric Validation (2)- Assessing internal construct validity and scale precision using Rasch Analysis

6.1 Introduction

The previous chapter described findings suggesting issues with the structural validity of the CIQ and CIQ-R based on two analytical approaches, namely, principal components analysis (PCA) and Confirmatory factor analysis (CFA). The study confirmed the bi-dimensional structure of the CIQ where problematic items reflecting productivity at work, school and volunteering did not stand out as a separate domain underpinning the theoretical structure of the construct according to Willer, Rosenthal, et al. (1993). The original CIQ scale and its subscale scores were identified to display non-normal distribution (Corrigan & Deming, 1995). Although both PCA and CFA methods allow the use of non-normally distributed data as suggested by Willer et al. (1994), they do not provide detailed interpretation of the data in their study and do not completely resolve distribution issues for an ordinal scale. In an exploratory factor analysis of the CIQ-R, 64.43% of variance in the data was explained by four factors, which was interpreted as support for the four factor model of the CIQ-R (Callaway et al., 2016). Confirmatory factor analysis supported the four-factor model and confirmed an overarching second-order community integration factor; however, the subscale Home Integration did not correlate well with the other three subscales and the Productivity subscale was reported to have low internal consistency ($\alpha=0.35$). To address these issues and improve the measurement precision of these ordinal scales, a more robust measurement theory referred to as item response theory (IRT) should be applied. Rasch analysis is one such method that uses advanced strategies to improve item functioning of both scale and individual items (Tennant & Conaghan, 2007).

The probabilistic Rasch model demands the construct measured, be unidimensional and has a good spread of scale items measuring the varying levels of the latent construct (e.g. community integration) (Rasch, 1960). Rasch analysis examines the above prerequisites as well as construct validity of the measure. It is also used to improve scoring and interpretability of the items aiding their precision. Rasch analysis investigates local dependency of items, potential item bias, and their ordering on the latent trait. When these parameters are satisfied and fit to the Rasch model is

achieved, ordinal data (raw scores) can be transformed to an interval scale using an algorithm that prepares the data for parametric statistics (Rasch, 1960; Tennant & Conaghan, 2007). The aim of this study was to apply Rasch analysis to investigate the internal construct validity of the CIQ and the CIQ-R and to explore strategies to improve item functioning and precision of the scale and subscales in people with TBI.

6.2 Methods

6.2.1 Data Analysis

This analysis builds on the descriptive statistics, reliability and exploratory and confirmatory factor analysis detailed in Chapter Six. Data from the SPSS file (reported on in chapter 5) were then arranged and saved as an ASCII file to enable the data to be imported into the RUMM2030 software (Andrich, Sheridan, & Luo, 2009) to perform a Rasch analysis to investigate fit to the Rasch model.

The Rasch model is a probabilistic mathematical framework based on the comparison between the amount of construct represented by the respondents (e.g. level of integration into community) and the extent to which the item measuring the construct is likely to be endorsed (e.g. difficulty of an item). A key requirement of the Rasch model is that the scale should be unidimensional measuring only one latent construct. Masters (1982) suggested to apply an Unrestricted Partial Credit model if the assumption of unidimensionality is not met. Prior to the main analysis, the likelihood-ratio test was computed for each CIQ and CIQ-R subscales which indicated that the assumptions of the Rating Scale Model (RSM) were not met. This supported the suitability of the unrestricted Partial Credit model which was used to complete the Rasch analysis. A series of tests were performed to determine the suitability of the data to fit the Rasch model. Analytical criteria and fit statistics followed to perform the Rasch analysis are discussed below. A brief outline of these criteria is displayed in Table 6.1.

Rasch analysis is conducted as an iterative process that begins with the overall evaluation of the Rasch model fit, followed by identifying any disordered thresholds for individual items by inspecting the threshold map. If the model fit is not achieved and any items displaying disordered threshold are identified, various strategies are applied to achieve a good fit. For instance, items with disordered thresholds are re-

scored or the closest response categories are collapsed meaningfully to achieve an ordered threshold. Once ordered thresholds are achieved, items displaying poorest fit are removed and the overall model fit is re-tested. The iteration process is followed until all individual item thresholds are appropriately ordered, satisfactory overall and individual item fit to the model are achieved, and unidimensionality is evident. An interaction between the item and latent trait reflected by an overall and individual item chi-square fit statistic should be non-significant (p>0.05, Bonferroni adjusted). In the case of an excellent fit to the Rasch model, the overall item and person fit-residuals, are expected to have a mean close to 0.00 and a standard deviation close to 1.00. Individual items should have fit residuals between -2.50 and +2.50.

The next step includes investigating local dependency between individual items in a subscale, which are examined using a residuals correlation matrix. Generally, a cut off 0.30 above the mean residual correlation is used as an indicator of local dependency among items. If local dependency is found between items, instead of removing locally dependent items, these items can be unified into a subtest (Wainer & Kiely, 1987), and the overall fit to the model is re-tested.

In the analysis process, Differential Item Functioning (DIF) is examined for the variables that are considered to be potentially affecting the level of integration after a TBI such as age and gender (Andelic et al., 2016; Kaplan, 2001). No significant differences in DIF (Bonferroni adjusted) should be evident in item functioning for such variables. In the DIF analysis, ANOVA method is used in which the distributions of individual scores aggregated by class intervals (CI) mean scores are compared between groups of each person variable and for each individual item. Any significant result indicating the effect of a person variable for an item follows an examination of the CI means for all groups plotted on the item characteristic curve (Andrich & Hagquist, 2015). If DIF for a specific person variable is identified in one or more items, that item(s) can be split into relevant categories (e.g. male and female, age group, diagnostic group). This allows for an unbiased measurement of different groups independently without the need to delete the item (Wainer & Kiely, 1987).

The following step checks for unidimensionality. Dimensionality is examined using the method recommended by Smith Jr (2002) that utilises an independent-samples *t* test to

compare person-estimates for two sets of items. The items with the highest factor loadings on the first principle component form one set and equal number of items with highest negative loadings form another set. Unidimensionality of each subscale is tested individually because of multidimensionality and weak relationships between subscales of the CIQ. The percentage of significant *t* tests is processed with the binominal confidence interval of +/- 95%. If the percentage of significant *t* tests computed for the lower bound of the binominal confidence interval does not exceed 5%, the scale is accepted to be unidimensional (Tennant & Pallant, 2006).

Reliability of the subscales is determined by the person separation index (PSI) in Rasch analysis, which reflects the ability of a measure to discriminate between groups at different trait levels (Fisher, 1992). PSI is considered similar to Cronbach's alpha numerically and expresses the proportion of true variance of person estimates distribution along the measurement construct relative to the total variance. However, PSI has an advantage over Cronbach's alpha as it allows calculations with missing data employing non-linear transformation of the raw scores.

When the essential criteria for fit to the Rasch model are met, Person-item threshold distribution of a final solution is examined to determine how well the range of individual abilities on a measurement construct is covered by the range of item difficulties on individual item thresholds (Tennant & Conaghan, 2007). A positive or negative skewness of the person distribution on the graph indicate prevalence of patients with high or low levels of integration being uncovered by the item distribution range. The Rating Scale Model (RSM) is one of the Rasch model parameterisations which assumes an equal distance between thresholds across items, which is represented by the interval level scales (Andrich, 1978). Outcomes measures which are typically used in rehabilitation practice such as CIQ or CIQ-R provide ordinal data which means the person who scores 2 on an CIQ item cannot be considered twice as integrated as a person who scores 1 on the same item. To address this, ordinal-to-interval transformation scores is computed that allow users to transform ordinal data to an interval level scale to enable more meaningful clinical comparisons between people with injury.

Table 6.1. Brief outline of Rasch Analysis steps and criteria

Rasch Analysis concepts assessed	Test used	Acceptable value criteria
Person fit	Mean fit residuals (SD); range	Mean close to 0 and SD close to 1; range −2.5 to 2.5; χ2 should be nonsignificant with a Bonferroni correction
Item fit	Mean fit residuals (SD); range	Mean close to 0 and SD close to 1; range −2.5 to 2.5; χ2 should be nonsignificant with a Bonferroni correction
Item threshold ordering	Visual inspection of response thresholds for each of the items	Must show a logical progression across the trait being measured
Local dependency	Residual item correlation matrix between all items	Correlations between the residuals <0.20 above the average residual correlation
Differential Item Functioning	ANOVA	Should be nonsignificant with a Bonferroni correction
Unidimensionality	Principal component analysis of the residuals	The 95% CI of the proportion of significant tests should include 5%
Reliability Index	Person separation index	Values of ≥0.70 allow for group comparisons (eg, in research trials); ≥0.85 for individual clinical use.
Overall fit to the Rasch Model	Person separation index	Should be nonsignificant with a Bonferroni correction

ANOVA- Analysis of variance; CI- Confidence interval; DIF- differential item functioning; SD- standard deviation

6.3 Results

6.3.1 Rasch analysis findings for the CIQ at 12-month timepoint

Preliminary test of the overall fit to the Rasch model

Initial analysis for the total scale showed overall poor fit to the Rasch model with significant chi square for interaction ($\chi^2(26)$ =116.42, p<.001) and PSI of 0.68, and evidence of multidimensionality (Table 6.3, Total- initial). Table 6.2 shows the initial fit residual and location or difficulty of each item on the Rasch model in probability units or logits. At this stage, residual correlations were examined that indicated local dependency between items of the home integration domain, social and productivity domains (e.g. residual correlations deviating from the mean of residual correlations for more than 0.2). Therefore, the items of each domain were combined into two subtests (home and social) which was also supported by the EFA findings where a large amount of the total variance (46.1%) was explained by these two factors as described in the previous chapter. After creating subtests, the overall fit improved and item-person interaction was no longer significant ($\chi^2(6)$ =9.15, p>.05) however the PSI value dropped below the acceptable level (PSI=0.31) (Table 6.3, Total-final). Therefore, further analysis was conducted for individual domains.

Table 6.2. Rasch model fit statistics including item locations (difficulty), item fit residuals and Chi-square (χ^2) for the initial analysis of the CIQ.

Number	Subscale/item	Item location	Item fit residual	χ^2
Home				
1	Who shops for necessities in the household?	0.31	-1.64	5.95
2	Who prepares meals?	0.16	-2.37	6.30
3	Who does everyday housework?	0.38	0.06	0.23
4	Who cares for children?	-0.21	-2.15	8.42
5	Who plans social arrangements?	0.19	2.71	5.69
6	Who looks after personal finances?	-0.83	2.28	6.15
Social				
7	Frequency of shopping	-0.13	2.71	6.57
8	Frequency of leisure activities	1.04	-1.37	16.97
9	Frequency of visiting friends/ relatives	-0.18	0.29	7.76
10	With whom do you participate in leisure activities?	0.00	-1.40	4.71
11	Do you have a best friend?	-0.14	0.80	15.86
12	Frequency of travel outside the home	-1.07	-2.27	11.38
13	Jobschool	0.48	-1.32	6.82

Rasch analysis for Home Integration Subscale

Initial analysis for the home domain shows an acceptable PSI of 0.75 but overall model fit was unsatisfactory (χ^2(12) =32.74, p<0.01). However, the subscale was strictly unidimensional as evidenced by the small number of significant t-tests below 5% (Table 6.3, Home-Initial). At this stage no items display significant misfit. Then, the residual correlation matrix was examined showing a residual correlation between item 2 and item 6, which deviated from the mean of all residual correlations by more than the conventional 0.2 cut-off point. Both items are related to management of resources. Items 2 and 6 were combined resulting in better fit with a PSI of 0.77, but chi square was still significant (χ^2(10) =21.99, p<0.01). At this stage, item 5 (social arrangement planning) showed an unacceptably high fit residual of 3.55 and high chi square value of 9.46 and was deleted. This resulted in the best model fit (χ^2(8) =10.55, p>0.05) and evidence for strict unidimensionality was also obtained with 4.73% significant t-tests and LB 2.25% (Table 6.3, Home-final). No DIF was identified. Figure 6.1 shows the person-item threshold distribution of the CIQ subscales where person ability and item difficulty are plotted on the same logit scale. The targeting of person abilities by the Home integration subscale items thresholds was satisfactory (Figure 6.1, Home).

Table 6.3. Summary of fit statistics for the sequence of Rasch analyses of the CIQ total scale and two subscales Home Integration and Social Integration

Analyses		Item fit residual		Person fit residual		Goodness of fit			PSI	Independent t-test 95%CI (%)	
		Value	SD	Value	SD	χ2	*df*	p		Higher Bound	Lower Bound
Total	Initial[a]	0.11	1.23	-0.27	1.17	116.42	26	0.000	0.68	19.26	16.77
	Final[b]	0.28	2.16	-0.30	0.84	9.15	6	0.169	0.31	4.39	1.91
Home	Initial	-0.18	2.25	-0.46	1.35	32.74	12	0.001	0.75	2.36	0.00
	Final	-0.06	1.32	-0.41	1.05	10.55	8	0.228	0.73	4.73	2.25
Social	Initial	-0.37	1.73	-0.23	0.78	70.06	14	0.000	0.52	0.34	0.00
	Final	-0.18	1.95	-0.27	0.68	40.41	36	0.282	0.62	1.69	0.00

[a]Initial refers to the analysis results of the raw original data
[b]Final refers to the analysis results of the Rasch transformed data

Rasch analysis for Social Integration Subscale

Both the exploratory and confirmatory factor analyses reported in Chapter Six indicated that items of the productivity and social domains, load on the same factor with the exception of item 11. Therefore, all items (7-15) of both domains were included in the initial analysis. The initial overall fit was poor (χ^2(14) =70.06, p<0.01) and the PSI displayed an unacceptably low value of 0.52 (Table 6.3, Social-Initial). At individual item level, item 11 showed significant misfit with a chi square value of 24.69 which was consistent with EFA and CFA results showing factor loadings below 0.2 for this item. Therefore, item 11 was deleted and slight improvement of the overall model fit was observed, but the item-trait interaction was still significant (χ^2(12) =61.24, p<0.01, PSI=0.55). At this point, local dependency between items was examined that indicated local dependency between several items with the highest values between items 8 and 13 as well as items 7 and 10, which were then combined into subtests resulting in a good model fit for this subscale (χ^2(24) =28.97, p>0.05, PSI=0.61). DIF analysis indicated significant DIF for gender in the subtest that combined items 7 and 10. This subtest was split for DIF, which produced the best model fit for the social domain (χ^2(36) =40.41, p>0.05, PSI=0.62). At this stage, no misfitting items were evident and the subscale was strictly unidimensional as evident by the number of significant t-tests below 5% (Table 6.3, Social-Final). The gender-based person-item threshold distribution was plotted which demonstrated that the scale was reasonably well targeted (Figure 6.1, Social) with a positive mean person location suggesting the people had, on average, higher levels of social integration than is targeted by the subscale measure.

Home Integration

Social Integration
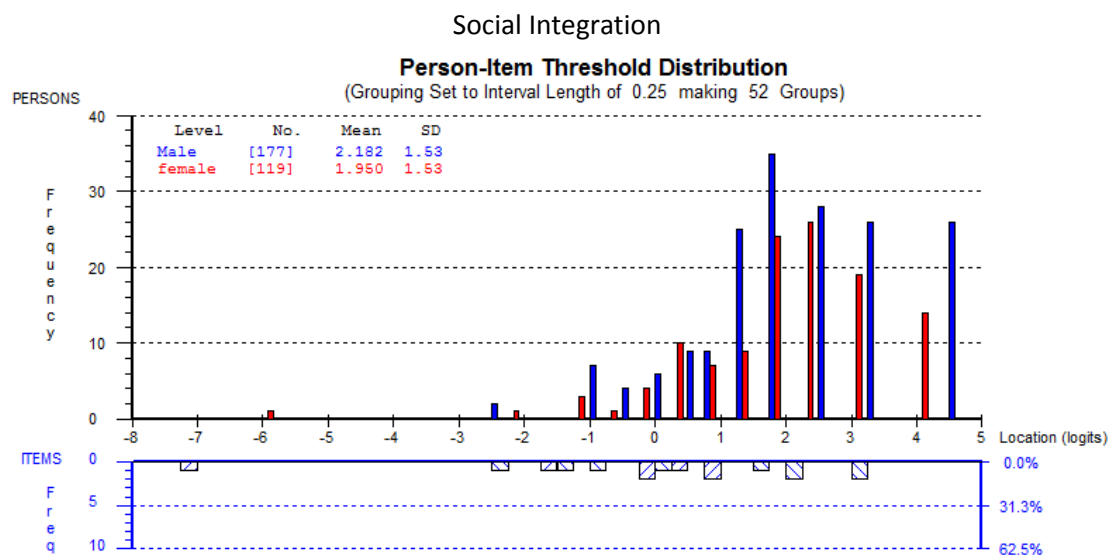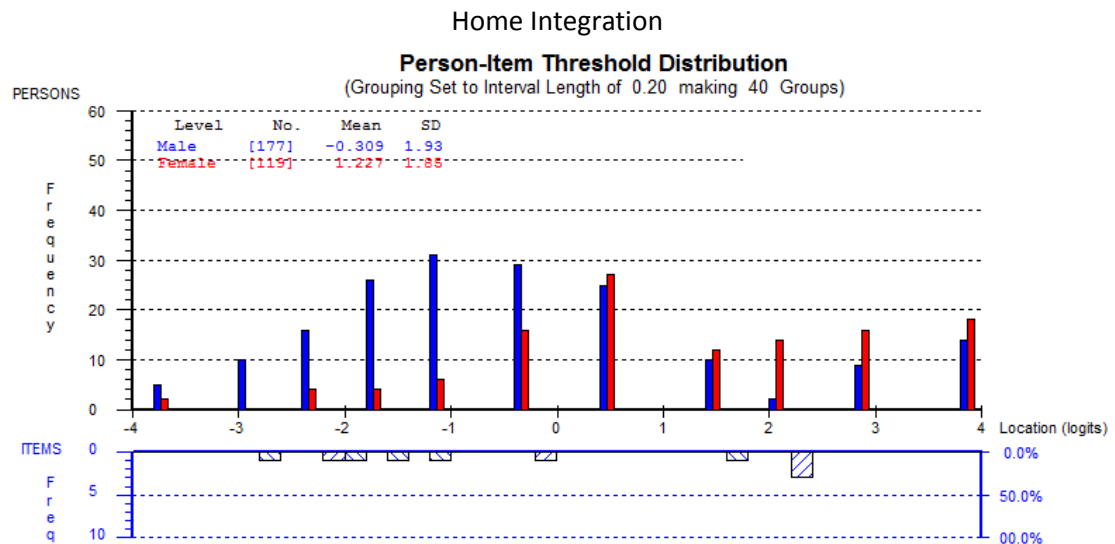
Figure 6.1: Person-item distribution maps for all CIQ subscales including male (blue) and female (red) thresholds

6.3.2 Rasch analysis findings for the CIQ-R:

Analytical pathway 1: Preliminary test of the full 16-item scale for overall fit to the Rasch model

The person separation index (PSI) of 0.79 indicated good reliability. However, unsatisfactory overall fit to the Rasch model was evident (χ^2(32) =88.47, p<.001), and item 13 displayed clearly disordered thresholds (Table 6.5, Test 1). Therefore, rescoring of the CIQ-R item 13 was done prior to any further analyses.

Analytical pathway 2: Test analysis with re-scoring

Iterative rescoring of item 13 showed that optimal ordering of thresholds and goodness of fit could be achieved using uniform rescoring. The 6-point response scale items were rescored by collapsing response category 1 with 2 and 3 (rescored as 1), and response category 4 with 5 (rescored as 2). Figure 6.2 shows an example of the effect of rescoring item 13 on the category response probability curves. The disordered thresholds became ordered after uniform rescoring, and overall fit to the model was improved, yet still not at acceptable levels (χ^2(32) =65.53, p<.001; PSI= 0.78) (Table 6.5, Test 2). Hence, a decision was made to remove items with highest fit residual that displayed poorest fit and subsequently fit to the model was tested.

Analytical pathway 3: Test analysis with removal of non-fitting items

Fit residuals for all 16 items were analysed before (1) and after (2) rescoring of item 13 (Table 6.4). Items 10 (*Leisure activities with others*) and 11 (*confiding in a best friend*) displayed the highest fit residuals and chi square values, indicating poorest fit to the Rasch model, hence they were removed. Table 6.4 displays fit residuals and chi square values for all CIQ-R items after removing non-fitting items 10 and 11 (3). At this stage, all the remaining 14 items had satisfactory model fit, with fit residuals below 2.60. The PSI value showed substantial improvement, however, the model fit did improve and chi square for overall person-item interaction was still significant (χ^2(28) =64.39, p<0.001; PSI=0.83) (Table 6.5, Test 3). To achieve the model fit for the total scale, the next step was to investigate local dependency between items, as it is known to affect model fit estimations. The 14-item CIQ-R scale after rescoring item 13 and removing items 10 and 11 was used for further testing.
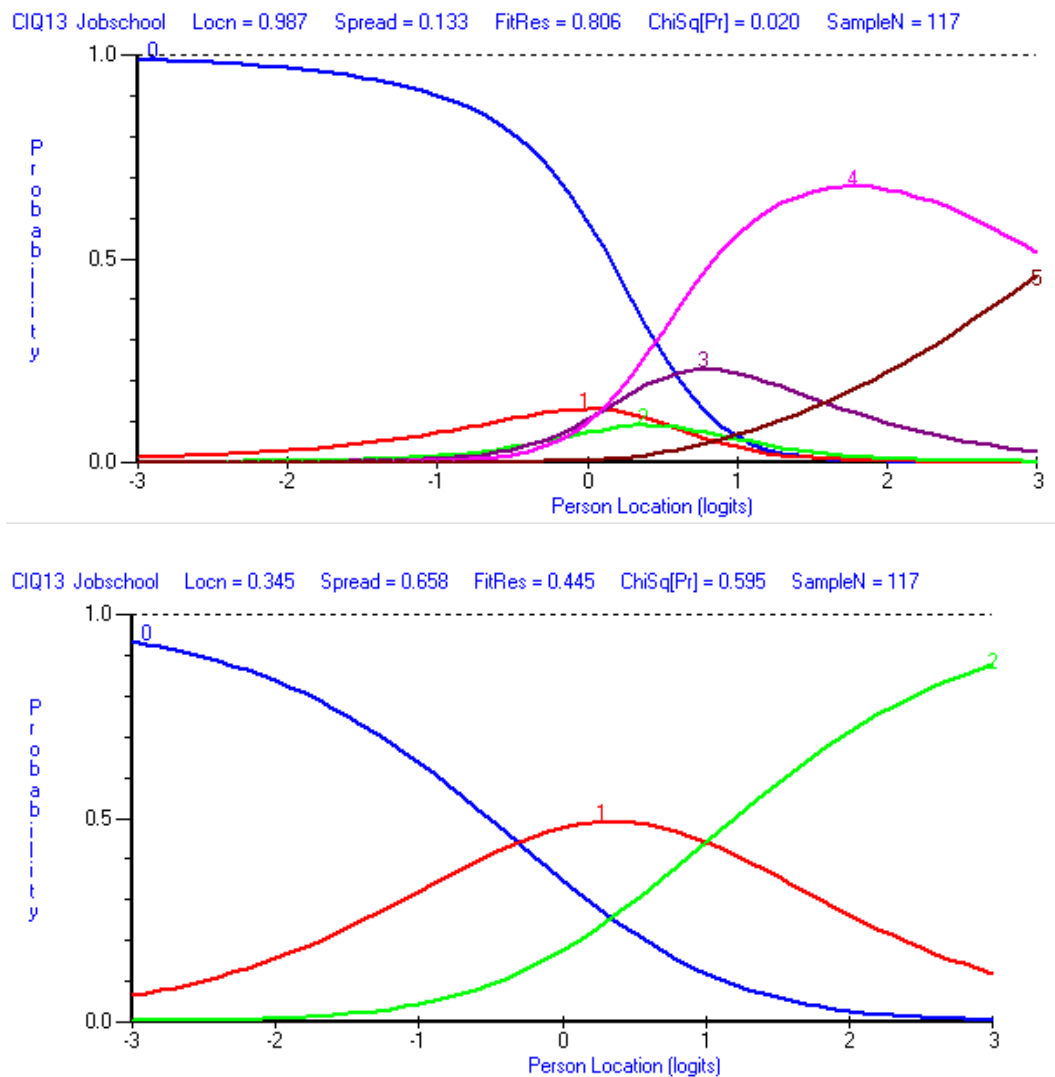
Figure 6.2: Item category probability curves illustrating disordered thresholds for CIQ-R item 13 before rescoring (top pannel) and orderly thresholds after rescoring (bottom panel)

Analytical pathway 4: Testlet analysis based on local dependency and factor structure

At this stage, a 'testlet' approach was used in accordance with the method used by Lundgren Nilsson et al. (2013). The residual correlations were examined and indicated local dependency between four groups of locally dependent items displaying residual correlations deviating above the acceptable level of 0.2 of the mean of residual correlations (Marais & Andrich, 2008). This finding was confirmed by a principal component factor analysis that supported the presence of four factors explaining 64.43% of the total variance (see Table 5.4 on page 101). The four-factor structure representing four distinct domains of the scale formed the basis for the testlet formation. One larger group included items of the home integration subscale (1-6); a second group of items were related to social integration (7-9), the third group only had

two items representing travel and productive activity (12 and 13); the fourth group included items focused on social networking using technology (16,17 and 18). Locally dependent items were combined into four subtests revealing an improved model fit without removing any further CIQ-R items (χ^2(8) =11.95, p>.05; PSI= 0.68) (Table 6.5, Test 4). However, low PSI value indicated that the CIQ-R does not meet the criteria for reliability index which require a scale to have a PSI value of Values of ≥0.70 for group comparisons in research and ≥0.85 for clinical use. The next step was to examine and solve local dependency issues between items of different domains.

Analytical pathway 5: Testlet analysis based on local dependency

In this pathway, 16 items of the CIQ-R were examined for local dependency using residual matrix and locally dependent items were combined to form a single testlet. Unlike the previously applied pathway, these testlets were not based on the scale's factor structure and the residual correlation was found between inter-domain items. The first set of analysis supported the formation of eight testlets where 16 individual items were paired with another item based on their local dependence (Testlet 1- items 4 and 8; testlet 2- items 2 and 10; testlet 3- items 1 and 9; testlet 4- items 3 and 11; testlet 5- items 5 and 12; testlet 6- items 6 and 13; testlet 7- items 7 and 18; testlet 8- items 16 and 17). These testlets were considered as 'super-items' and Rasch model fit statistics were calculated which demonstrated improved PSI value (0.84), however person-trait interactions were still significant (χ^2(32) =85.05, p<0.001). Investigating the residual matrix for these eight super-items identified high correlation between two pairs of super-items which were combined, and model fit statistics for resulting six super-items were re-examined. This provided non-significant chi-square for person-trait interactions with high PSI (χ^2(42) =45.21, p>0.05; PSI=0.83) (Table 6.5, Test 5) and model fit was achieved without removing or rescoring any items.

Rasch Analyses for four CIQ-R subscales

Initial testing of the six-item Home Integration subscale of the CIQ-R revealed a good fit to the model with a non-significant chi-square for overall person-trait interaction (χ^2(12) =11.88, p>0.05) and reliability (PSI) of 0.84 (Table 6.5, Home Integration). Similarly, the Social Integration subscale (items 7 to 11) displayed satisfactory fit to the Rasch model (χ^2(10) =14.84, p>0.05), however the PSI value (0.55) was slightly below the acceptable limit (Table 6.5, Social Integration). The assumption of

unidimensionality was satisfied for both home integration and social integration sub-scales as indicated by the Binomial test result below the 5%cutoff point on the lower bound. The Productivity subscale (items 12 and 13) displayed overall lack of fit to the model with significant chi-square values ($\chi2(4)$ =22.77, $p<0.001$) and the ESN subscale (items 16 to 18) achieved satisfactory fit to the model ($\chi2(6)$ =13.59, $p>0.01$) (Table 6.5, Productivity and ESN). Both Productivity and ESN subscales had significantly low reliability (PSI) of 0.45 and 0.44 respectively. Additionally, these two subscales were not investigated for unidimensionality as the binominal test for unidimensionality cannot be applied to scales with three or less items. Test for unidimensionality employs an independent-samples t-test that compares person estimates for two item groups with the highest positive and highest negative factor loadings on the first principal component (Smith Jr, 2001). With low reliability and lack of evidence for unidimensionality for two out of four subscales, it was decided that the integration levels should be calculated based on a total scale.

Examining Differential Item Functioning (DIF)

Differential Item Functioning (DIF) was examined for gender and age for final six testlets. The analysis demonstrated to significant DIF effects for these group variables. This indicated that people with the same ability from different age or gender group respond consistently and similarly to a CIQ-R item.

Testing for Unidimensionality

Unidimensionality was tested for the final testlet model solution by comparing the set of person estimates from the subtests 1 and 5 with the highest positive loadings on the first principal component with the set of estimates from the subtests 2 and 6 with the highest negative loadings. The final solution proved to be strictly unidimensional with the percentage of significant t-tests below 5% (Table 6.5, Test 5)

Item difficulty

Table 6.5 presents the relative difficulty (location) of each item of the CIQ-R. Easy items are expected to be scored high by persons with high levels of examined construct community integration in this case, whereas difficult items are expected to be scored low by persons with low levels of construct.

Item-person Threshold Distribution

Figure 6.3 demonstrates the person-item threshold distribution for all four CIQ-R subscales as well as for the total CIQ-R scale (Table 6.5, Test 5- Final Solution). In this distribution, people's level of integration (represented by person ability) and task difficulties (represented by item difficulty) on the latent trait are plotted on the same logit scale. The plot confirms that people's abilities are reasonably well targeted by the item-threshold distribution for the Social Integration subscale and the total CIQ-R scale. For the Home Integration, Productivity and ESN subscales person-thresholds are moderately targeted, however, the plots for both Home Integration and ESN displayed evidence of highest and lowest scores on person-ability not being entirely represented by the subscale item-thresholds.

Table 6.4. Rasch model fit statistics including item loadings on the first principal component (PC1), item locations (difficulty), item-fit residuals and Chi-square (χ^2) for the initial analysis before rescoring (1), and item-fit residuals and chi square values after rescoring Item 13 (2), and removing Items 10 and 11 (3) of the CIQ-R.

Item No.	Subscale/item	Item loadings on PC1	Item-to-total correlation	Item location	Item fit residual			χ^2		
					1	2	3	1	2	3
Home Integration										
1	Who shops for necessities in the household?	0.81	0.63	0.19	-1.05	-1.35	-2.06	4.61	7.22	6.64
2	Who prepares meals?	0.84	0.57	0.23	-0.81	-1.02	-1.76	1.70	5.11	3.64
3	Who does everyday housework?	0.77	0.61	0.02	-0.18	-0.62	-1.35	9.36	11.14	7.00
4	Who cares for children?	0.90	0.67	0.02	-1.32	-1.71	-2.57	11.59	14.42	12.26
5	Who plans social arrangements?	0.63	0.59	0.05	-0.84	-1.03	-1.33	6.47	5.00	2.40
6	Who looks after personal finances?	0.61	0.50	-0.13	-0.79	-0.30	-1.01	2.89	1.89	1.59
Social Integration										
7	Frequency of shopping	0.03	0.44	-0.93	0.45	0.29	0.93	3.18	3.37	1.11
8	Frequency of leisure activities	-0.65	0.31	-0.11	0.84	0.82	2.33	3.32	3.45	12.38
9	Frequency of visiting friends/ relatives	-0.43	0.43	-0.07	0.29	0.22	1.16	2.41	2.70	2.26
10	**With whom do you participate in leisure activities?**	**-0.57**	**0.16**	**0.07**	**4.54**	**4.73**	**-**	**7.45**	**13.06**	**-**
11	**Do you have a best friend?**	**-0.41**	**0.14**	**0.48**	**2.91**	**3.03**	**-**	**20.79**	**33.05**	**-**
Productivity										
12	Frequency of travel outside the home	-0.56	0.45	-1.37	0.16	0.30	1.01	2.11	0.97	5.47
13	Jobschool	-0.19	0.61	0.99	0.81	-0.04	0.35	7.84	1.35	0.96
Electronic Social Networking										
16	Frequency of writing to people using the Internet	-0.25	0.51	0.29	-0.16	-0.02	0.79	2.72	0.41	1.89
17	Frequency of talking to people using an online video link	-0.12	0.37	1.24	0.97	0.97	1.42	0.29	0.73	5.54
18	Frequency of talking to people or texting using a phone	-0.23	0.46	-0.98	-0.27	-0.34	0.01	1.73	0.37	1.23

Removed misfitting items 10 and 11 are presented in bold

Ordinal-to-Interval Conversion Table

Table 6.6 comprises conversion scores from an ordinal-to-interval level scale for first two CIQ-R subscales (Home Integration & Social Integration) and the total CIQ-R scale. Raw scores for the Home Integration subscale include items 1 to 6 and for Social Integration subscale include items 7 to 11. The other two subscales Productivity and Electronic Social Networking did not adequately fit the Rasch model, hence the ordinal-to-interval conversions were not applied to these subscales.

The raw scores for the total CIQ-R scale are derived after the item 13 (job school) was rescored and locally dependent items were combined to form testlets. To rescore the item 13, response categories 1 to 3 have been collapsed and rescored as 1 and response categories 4 and 5 have been rescored as 2. It is important to note that the raw score to interval score transformation score as demonstrated in the table is only applicable in the case of complete individual data. Once the model fit is achieved (using testlets in this case), raw scores and corresponding logit scores are tabulated using Equating tests function in the RUMM software. Transformation of these logit scores into interval level scores is done utilizing the following formula:

$$y = m + (s * \text{Logit score}) \qquad (3)$$

where:

s = (wanted range) / (current range)

m = (wanted minimum) – (current minimum * s)

Worked example for the current CIQ-R total score:

To calculate 's';

The original scale is scored 0-35, therefore the Wanted range of person score = 0 to 35

Current range of person score = -4.78 to 5.47 (given in logits) = 10.25

$$\begin{aligned}
S \quad &= (\text{wanted range}) / (\text{current range}) \\
&= (0\text{-}35 = 35) / (\text{-}4.78 - 5.47 = 10.25) \\
&= 35 / 10.25 \\
&= 3.415
\end{aligned}$$

To calculate 'm';

Wanted minimum of the CIQ-R = 0,

Current minimum scale value = -4.78,

S = 3.415

m   = (wanted minimum) – (current minimum *s)

             = 0 – (-4.78 * 3.415)

             = 0 – (-16.32)

             = 16.32

Once values for 'm' and 's' are obtained, logit score for the CIQ-R score can be transformed with:

y = m + (s * Logit score)

y = 16.32 + (3.415 * Logit score)

Paired t-test analysis demonstrated no significant mean difference between original raw scores and Rasch modified CIQ-R total scores (t = 1.035, p < 0.01).

Table 6.5. Summary of fit statistics for the sequence of Rasch analyses of the original CIQ-R version (1), after uniform rescoring of item 13 (2), after removing items 10 and 11 (3), after combining items into four subtests (4), after combining items based on local dependency (5), and for four CIQ-R subscales- Home Integration, Social Integration, Productivity and Electronic Social Networking (ESN)

Tests	Item fit residual		Person fit residual		Goodness of fit			PSI	Paired t-test	
	Value	SD	Value	SD	χ^2	df	p		% of sig. t-test	Lower Bound 95%CI (%)
1	0.34	1.52	-0.18	1.54	88.47	32	0.0000	0.79	35.04	7.69
2	-0.33	3.26	-0.19	1.51	65.53	32	0.0004	0.78	27.35	5.98
3	-0.13	1.55	-0.39	1.61	64.39	28	0.0001	0.83	22.22	13.68
4	0.96	1.56	-0.12	0.89	11.95	8	0.1531	0.68	0.00	0.00
5	0.39	1.47	-0.20	0.96	45.22	42	0.3391	0.83	4.27	0.32
Home Integration	-1.03	2.01	-0.95	1.62	11.88	12	0.4551	0.84	1.71	0.00
Social Integration	0.442	1.09	-0.52	1.39	14.84	10	0.1381	0.55	0.00	0.00
Productivity	0.06	1.35	-0.09	0.41	22.77	4	0.0001	0.45	-	-
ESN	-0.13	0.03	-0.27	0.52	13.59	6	0.0344	0.44	-	-

SD- Standard Deviation; χ^2- chi square; *df*- Degree of freedom; PSI- Person Separation Index; CI- Class Interval

Home Integration Subscale

Social Integration Subscale

Productivity Subscale

Electronic Social Networking Subscale
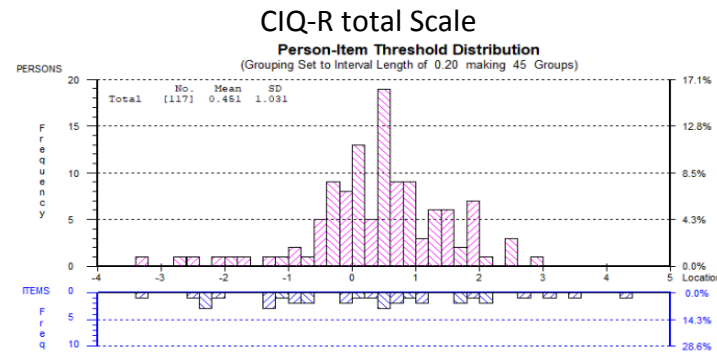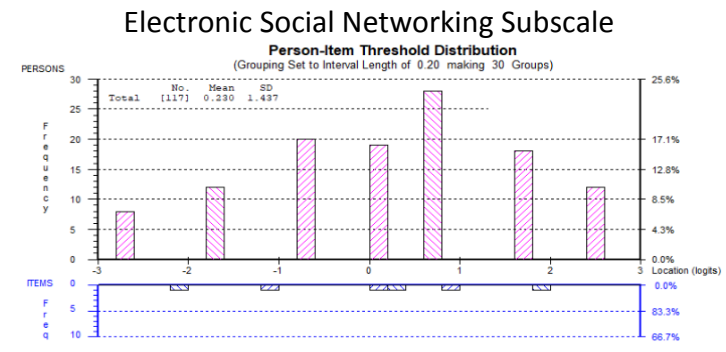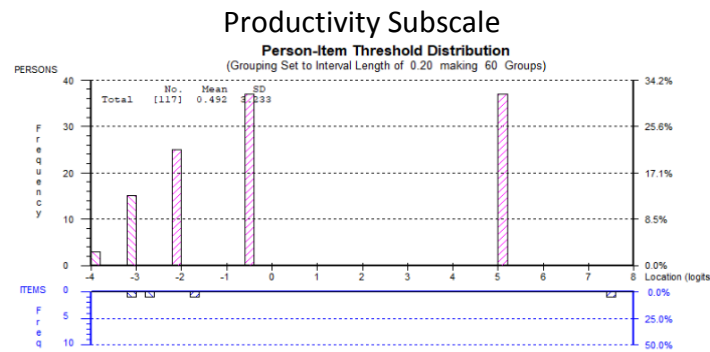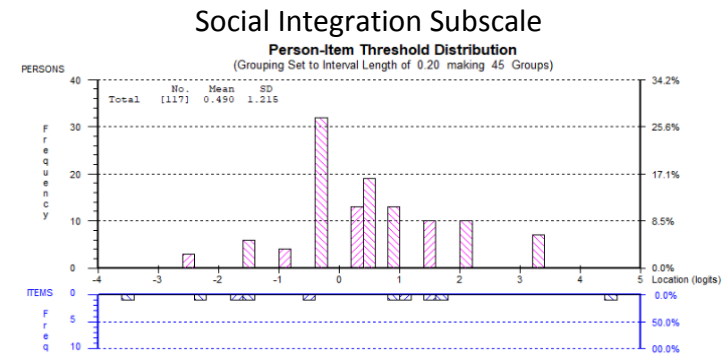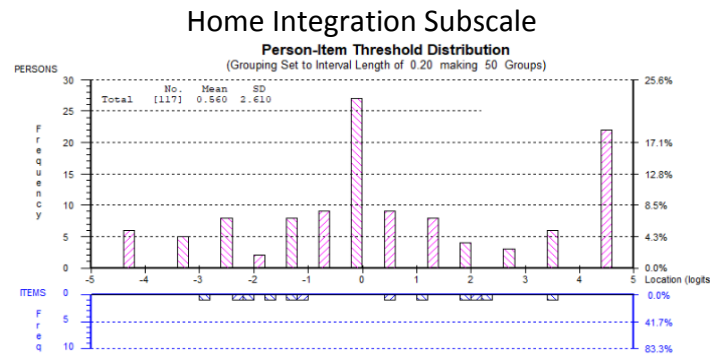
CIQ-R total Scale

Figure 6.3: Person-item threshold distribution map for the CIQ-R subscales and the final solution for the total scale

6.4   Summary of findings

The CIQ (Willer, Rosenthal, et al., 1993) and the CIQ-R (Callaway et al., 2016) have been investigated for their overall construct validity, individual item and subscale functioning using Rasch analysis. This study identified a number of issues affecting psychometric properties of the CIQ and the CIQ-R which have been raised in previous studies (Corrigan & Deming, 1995; Dijkers, 1997; Hirsh et al., 2011; Sander et al., 1999). The strategies of Rasch modelling were successfully applied to enhance the structure of the scales, fine tune individual subscales, improve item functioning and overall scale precision.

Table 6.6. Converting from ordinal-to-interval-level scores for the subscales Home Integration and Social Integration and total scale for the CIQ and the CIQ-R

Home Integration Subscale scores			Social Integration Subscale scores			Total scores		
Raw Score	Logit	Interval	Raw Score	Logit	Interval	Raw Score	Logit	Interval
0	-4.27	0.00	0	-3.53	0.00	0	-4.78	0.00
1	-3.33	1.27	1	-2.49	1.53	1	-3.87	3.11
2	-2.57	2.31	2	-1.59	2.85	2	-3.22	5.32
3	-1.94	3.16	3	-0.81	3.99	3	-2.76	6.88
4	-1.35	3.96	4	-0.22	4.86	4	-2.40	8.12
5	-0.74	4.79	5	0.20	5.47	5	-2.10	9.15
6	-0.09	5.67	6	0.56	6.00	6	-1.84	10.04
7	0.58	6.59	7	0.94	6.56	7	-1.61	10.83
8	1.25	7.49	8	1.44	7.28	8	-1.40	11.55
9	1.91	8.39	9	2.17	8.37	9	-1.20	12.22
10	2.62	9.35	10	3.29	10.00	10	-1.02	12.85
11	3.49	10.53				11	-0.84	13.45
12	4.56	11.99				12	-0.67	14.02
						13	-0.51	14.57
						14	-0.36	15.10
						15	-0.21	15.60
						16	-0.07	16.07
						17	0.06	16.53
						18	0.20	16.99
						19	0.33	17.44
						20	0.46	17.90
						21	0.60	18.37
						22	0.75	18.87
						23	0.90	19.39
						24	1.06	19.96
						25	1.24	20.57
						26	1.44	21.25
						27	1.66	22.00
						28	1.91	22.84
						29	2.18	23.78
						30	2.50	24.85
						31	2.85	26.07
						32	3.27	27.50
						33	3.79	29.27
						34	4.50	31.69
						35	5.47	35.00

Initial analysis of the CIQ suggested the bi-dimensional (Home and Social) factor structure which was supported by the study reported in the previous chapter. Items from both the social integration and productivity subscales displayed high local dependency, therefore these subscales were combined and treated as one. Both subscales, Home Integration and Social Integration, were unidimensional that fit the pre-requisite criteria for Rasch Analysis. Satisfactory fit to the Rasch model was achieved by a few modifications of the CIQ subscales that involved deleting two non-fitting items (item 5 and 11) and combining locally dependent items (2 and 6; 7 and 10; 8 and 13). Results for studies reporting reliability and internal consistency of the CIQ have not been conclusive (Corrigan & Deming, 1995; Sander et al., 1997; Willer, Rosenthal, et al., 1993). Internal consistency for the CIQ total score was noted to be acceptable, however, the Social Integration and Productivity subscales values were notably low (Corrigan & Deming, 1995; Heinemann & Whiteneck, 1995; Willer, Linn, et al., 1993; Willer et al., 1994).

The present study confirmed these findings using the Rasch model. For the Home Integration subscale, the Person Separation Index (PSI) was 0.73, indicating that the subscale can differentiate between two groups of people at different levels of home integration. Whereas Rasch modified Social Integration subscale with the PSI of 0.63 lacks the precision needed to distinguish between two groups, hence it may not be used as a standalone sub-scale measuring person's social integration level (Streiner et al., 2015). Additionally, the Social Integration subscale accounted for the Differential Item Functioning (DIF) effect for gender where female respondents appeared to have scored low as compared to the male group. This finding contradicted the results from a previous study which reported higher social integration scores for females (Kaplan, 2001). The reason for this discrepancy could be due to the combined subscale which included Social Integration and Productivity items to achieve an improved fit to the Rasch model. Furthermore, careful examination of the person-item threshold distribution for both Home and Social Integration subscales (Figure 6.1) indicates acceptable yet relatively higher person ability than targeted by the subscale items. This finding proposes limitations of the clinical utility of the CIQ. As discussed in the previous chapter, the CIQ-R appears to have relatively good structural validity and internal consistency, it is believed to be modern and more promising measure of

community integration. The present study tested the structure and functioning of the scale items and proposed adjustments to improve their precision.

Initial analysis of the total CIQ-R scale confirmed the multidimensionality (t=7.69, LB 95%CI) and acceptable internal consistency (PSI= 0.79) of the construct. However, a significant chi square value indicated that the item or item group may not efficiently measure person ability as expected. Out of 16 items, only one item-item 13 (*jobschool*) displayed disordered thresholds (Figure 6.2) which originally had six response categories (0-5) to incorporate work/study/volunteering activities. This *jobschool* item is a combination of three items with different number of response options- item 13 (5 responses), item 14 (4 responses) and item 15 (3 responses). These responses are combined into six response categories prior to the rating scores (0-5) are applied, which is believed to have been responsible for the poor reliability of the Productivity subscale (Corrigan & Deming, 1995). To improve the functioning and threshold of this item, it was uniformly rescored to match the scoring of the other 15 items. The *jobschool* item/items and response categories should be reworded or consistently re-scored in the future to improve the scale performance and/or some new items developed.

Two non-fitting items (items 10 *participating in leisure activities with others* and item 11 *confiding in a best friend*) had to be removed prior to testing the four CIQ-R subscales. The excluded items provided very little information on the latent trait. Possible reasons could be a selection bias as the response with the lowest score (*mostly alone*) is listed first unlike the other items where the first response option clearly indicates a higher level of integration. Also, the response of 'participating in leisure with family' is scored lower than the score on 'participating in leisure with friends without a disability', there is a possibility that a person may find it more difficult to engage in such activities with family due to high demand or expectations. Consistent with the findings of the previous chapter, item 11 may not work well due to ongoing post-injury changes in relationship dynamics limiting or expanding availability of the '*best friend*' to confide in. Future research should propose modifications in wording or response categories of these items which might improve the psychometric properties of the CIQ-R.

When removing items 10 and 11 did not yield a good fit for the scale, all four subscales with their original items were tested separately for fit to the model. The findings reported strong construct validity of the subscales Home Integration and Social Integration, however, subscales Productivity and ESN were identified to have poor fit. Lack of fit to the model also limits the use of ordinal-to-interval-level scale conversion for the Productivity and ESN subscale scores. Out of four subscales, only for the Home Integration subscale, the Person Separation Index (PSI) was more than 0.85, which indicates that the subscale has the ability to distinguish among more than 3 groups of people with different amounts of the latent construct. On the contrary, Social Integration, Productivity and ESN were reported to have a PSI value below 0.60, which indicates that these subscales lack the precision required in a clinical tool. Additionally, the Productivity and ESN subscales have a limited number of items which make them too short for meaningful clinical use. This may restrict their ability to effectively differentiate among people at different levels of their integration. This finding indicates that these three subscales should not be used independently from their contribution to the CIQ-R total score. It is recommended to develop more items reflecting the latent trait to be added to these subscales to enhance their psychometric properties.

Based on local dependency of sub-scale item groups, the Rasch modified version of the CIQ-R was identified which has four subtests/subscales Home Integration (1-6), Social Integration (7-9), Productivity (12-13), and Electronic Social Networking (16-18). The adjusted CIQ-R scale did not include items 10 (*participating in Leisure activities with others*) and item 11 (*confiding in a best friend*). This subtest analysis of the CIQ-R revealed to have acceptable model fit, however the PSI dropped to 0.63 reflecting the scale's inability to differentiate between groups.

Ultimately, another approach to retain as many items as possible while ensuring satisfactory fit to the Rasch model was applied. Local dependency between various items across different sub-scales provided the direction for Rasch modification of the scale. Locally dependent items were paired to form six testlets. This version of the scale revealed to have acceptable model fit confirming that the psychometric properties of the CIQ-R following the above-mentioned adjustments are robust, including good construct validity and internal consistency (PSI=0.83). The high value of

Person Separation Index (PSI) indicates that the scale has the ability to differentiate well among more than 3 groups of people with differing levels of integration, hence is well suited to use for the clinical or research purposes (Streiner et al., 2015). This finding also insinuates that all testlet items should be used in conjunction to ascertain the accurate measure of the latent trait. The local dependence of the items from different subscales could be explained by 'response dependence', where the response to 1 item influences responses to other related items (Lundgren Nilsson & Tennant, 2011; Medvedev, Turner-Stokes, Ashford, & Siegert, 2018). This influence could be positive or negative; For example, items from testlet 1 (items 4 and 8) may indicate that person who is looking after children may not have limited leisure function due to time restriction or fatigue, hence the person scoring high on item 4 may have low score on item 8. This version of the scale supports the inclusion of all 16 items without removing any items, therefore helps maintain the clinical integrity of the scale.

Findings for unidimensionality were positive for the testlets version of the CIQ-R as well as for Home Integration and Social Integration subscales. The unidimensionality for the Productivity and ESN subscales could not be assessed due to insufficient number of items per subscale. The precision of the 16-item scale can be further enhanced by using the ordinal-to-interval conversion table. The Rasch analysis supports the construct validity and unidimensionality of the modified 16-item CIQ-R scale indicating that raw scores of the total scale can be transformed into interval-level scores using the metric in the Table 6.6. This ordinal-to-interval-level conversion can enhance the precision of the scale and provide meaningful scores for community integration level to be used by clinicians and researchers.

6.5 Conclusion

The current study applied Rasch analysis to address previously reported shortcomings of the CIQ and provided evidence for internal construct validity and internal consistency of the revised measure CIQ-R in people with TBI. Two items were identified to be less consistent with the latent trait and to substantially affect the person estimates. However, the study confirms that the CIQ-R meets the Rasch model requirements with good reliability and accurate targeting of the scale without deleting an item in the TBI population. The study provided the ordinal-to-interval conversion tables in order to optimise the precision of the CIQ-R.

Chapter 7: Qualitative Analysis- Evaluating content validity, acceptability and appropriateness

7.1 Introduction

Content validity is defined as "The extent to which the domain of interest is comprehensively sampled by the items and their content in the questionnaire" (Terwee et al., 2007, p. 39). Content validity also reflects measure's accuracy and representativeness of the definition of the construct, the intelligibility and linguistic aspects of the items, and the appropriateness of the response format. The original CIQ was developed using a traditional content validation process (Streiner et al., 2015) which included expert review of relevance and coverage of a measure based on theoretical definition of the construct 'community integration', which was followed by pilot studies and quantitative analyses resulting in the final measure (Willer, Rosenthal, et al., 1993). In an attempt to revise the CIQ, three additional items pertaining to the Electronic Social Networking (ESN) domain were developed by experts from various disciplines including psychology, occupational therapy and social work (Callaway et al., 2016). The construct validity and internal consistency of the revised measure CIQ-R was evaluated using quantitative methods in Chapters Five and Six. However, a better understanding of whether the item content is comprehensive, appropriate and reflective of the meaning of a construct in diverse populations, is yet to be determined. This chapter addresses the fourth aim of the doctoral research exploring the acceptability and appropriateness of the CIQ-R to establish its content validity in people with TBI using the qualitative method.

7.2 Method

7.2.1 Research question

How well does the Community Integration Questionnaire-Revised (CIQ-R) capture community integration in New Zealand?

7.2.2 Study design

The design was a qualitative descriptive study (Hsieh & Shannon, 2005) conducted at one timepoint which was employed after the cross-sectional quantitative survey study detailed in Chapter 5 and Chapter 6.

7.2.3 Participant recruitment

Participants were recruited from the initial sample pool who participated in the quantitative survey and who had accessed services from community-based patient support providers or TBI service providers in two New Zealand regions (Greater Auckland and Waikato). To be eligible, participants needed to: be aged over 18 years, have experienced a TBI at least 6 months before, and be able to provide informed consent. Participants who completed survey questionnaires were invited to take part in an optional qualitative interview. People who expressed their interest were contacted by telephone and were advised that this aspect of the study aimed to explore their experience of completing the questionnaire and their perception about the appropriateness of contents of the questionnaire. TBI severity was categorised as mild, moderate or severe based on the person's medical record where this was available. All participants who met the study's inclusion criteria but who did not have accessible medical records and reported persistent problems were classified as 'severity unknown'. The interview process was explained to participants, providing them with the opportunity to ask further questions. A time was arranged to meet with the participant either at their home or other mutually convenient location. Informed, written consent was gained from all participants before commencing the interview. Participants were made aware about their right to withdraw from the study at any stage.

7.2.4 Data collection

The data were collected in the form of face-to-face semi-structured interviews using a brief interview guide (Table 7.1). The informants were asked to provide feedback on the measure's content coverage and appropriateness for their condition. Informants were asked to discuss whether they felt the measure represented their post-injury community integration status. The informants were also asked to provide their feedback on the response options of the measure to ensure that each response scale accurately represented the degree of the measurement that was relevant to the person's condition. The interviews were audio-recorded using a digital voice recorder and transcribed verbatim.

Table 7.1. Interview guide

- How did you find completing the questionnaire?
- How did you find the wording and structure of these questions?
- How did you find the response options of these questions?
- How relevant were the questions in relation to the impact of the injury on your life?
- Is there anything you feel should be in the questionnaire?
- Can you tell me about any activities/things that you currently do that you were not asked about in the questionnaire?
- Can you tell me about your current use of electronic social media? i.e. text, email, facebook, skype, twitter, whatsapp
- Can you tell me about anything you were asked about, that may not be relevant or important to you?
- Is there anything else you would like to tell us about the questionnaire?

7.2.5 Analytic approach

The data were analysed and coded by two researchers (NS & AT) independently using the conventional content analysis approach (Hsieh & Shannon, 2005). This approach allows researchers to stay close to the data to extract an accurate account of the concept as perceived and interpreted by the participants (Sandelowski, 2000). Key themes were identified using an inductive approach to coding where codes are derived from the data, as opposed to the directed approach that uses pre-determined codes.

Initial interpretations from the interviewer (NS) were noted as digital comments in the right margin of the typed transcript and all relevant phrases were highlighted within the transcript. Transcripts were then printed in hard copy given the small number of transcripts, to enable the researchers to remain close to the data and due to limitations of qualitative software in extracting data easily. Transcripts were read in full several times to increase familiarity with the data. Each point made by the participant in relation to the CIQ-R measure was concisely summarised in the right margin facilitated by the interviewer comments already noted. The participant quotes and descriptions with a participant identifier were then cut out of the transcript and manually grouped into meaningful clusters (Coffey & Atkinson, 1996; Patton, 2002). Initially, 12 broad clusters were formed (Morse & Field, 1995).

Transcript extracts were then individually explored within each cluster to check for any inconsistencies between participants and to describe the content within each cluster. The content of clusters was then further analysed for relationships to create fewer, more comprehensive themes. A non-sequential hierarchical structure diagram was generated with a central concept (based on the research question) to represent the relationships between themes (Morse & Field, 1995). All themes were colour-coded for distinction and all extracts were labelled by participant ID number. Themes were then reviewed, refined and named to ensure that the theme accurately represented the raw data and their interpretations.

A priori estimation of sample size was not determined, rather the study sample was based on 'information power' aiming to gather data that provided sufficient and comprehensive understanding of the perception about the use of the CIQ-R (Malterud, Siersma, & Guassora, 2016). The data collection process was continued until no new issues were raised and all existing issues had been discussed in greater detail.

Participant descriptives including gender, injury severity, employment status at injury and at present are tabulated in Table 7.2. Direct quotations from participants were used as exemplars for interpretations of each theme. Each quote is presented with information on gender, age, and injury severity to maintain participant anonymity while providing context.

7.2.6 Rigour

To ensure credibility of the findings and safeguard against any bias, several strategies were used. During the interview and analysis, the researcher attempted to capture participant perspectives and represent their experiences as closely as possible by avoiding any preconceived ideas or categories (Hammell, 2002; Kondracki et al., 2002). The data were collected through open-ended questions and follow-up probes to seek deeper understanding of meanings in participants' responses. The credibility of the qualitative work also relies on the competence of the researcher. To address this the researcher ensured familiarity with the issues related to research question and study objectives as well as a thorough understanding of the background literature was done to ensure consistency with the qualitative research methodology (Howitt, 2016).

Additionally, an extensive consultation process took place with experienced researchers and research ethics advisors who were familiar with the common issues that may arise due to TBI related factors such as fatigue, sensitivity, and emotional lability. This study was performed under the guidance of the PhD supervisors who assisted through the process including verifying the overall research design, data collection method, as well as ensuring accuracy of interpretation of the findings.

The text of the interview within the transcript was checked against the audio recording to ensure accuracy of the transcription. Transcripts were read repeatedly to obtain a sense of the overall context followed by detailed word to word reading to derive themes (Miles & Huberman, 1994; Morse & Field, 1995). Analysis of the data by independent researchers supported the reliability of the findings based on consistency of the derived themes. As discussed above, direct extracts from participant transcripts were selected for each theme and its sub-themes to ensure that the interpretations accurately represented the theme and reflected the raw data (Kondracki et al., 2002).

7.3 Findings

Interviews with twelve participants were conducted between June 2016 and May 2018 and each lasted between 40 and 90 min. All participants identified as NZ European. Analysis revealed six themes: (1) antecedents not captured; (2) meaningfulness of tasks; (3) context not taken into account; (4) complexity of tasks; (5) "how I do it" is important and; (6) wording of questions is important. Each theme comprised several components, referred to as sub-themes which are explained below. Pertinent quotations from the participant interview transcripts are presented as an illustration of the sub-themes. The participant gender, age, and injury severity are indicated in brackets at the end of each quote used to provide some context of the person providing the quote.

Table 7.2. Characteristics of interview participants with TBI (n=12)

Characteristics	Subgroup	Number of participants
Gender	Male	7
	Female	5
Age Mean (SD)	57.8 (10.15)	12
Time post-TBI	<24 months	2
	>24months	10
TBI Severity	Mild	3
	Moderate	1
	Severe	5
	Not known	3
Employment status at injury	Full-time	7
	Part-time	4
	Retired	1
Current employment status	Full-time	1
	Part-time	2
	Retired	1
	Unemployed	8
Relationship status at injury	Partnered	7
	Non-partnered	5
Current relationship status	Partnered	7
	Non-partnered	5

7.3.1 Theme 1: Antecedents not captured

Injury related symptoms

Participants talked about the difficulties with dealing with long-term symptoms resulting from their injuries. Their daily activities and work were particularly affected by their fatigue, difficulties with memory, sleep and concentration. Most participants reported that they needed to use various strategies to cope with the on-going difficulties from their TBI. For those who were employed prior to their injury, on-going symptoms limited both the efficiency and quality of their work. Participants found that the measure was focussed on ability to perform certain tasks, however it does not consider the lengths participants often had to go through to enable them to complete an activity.

Participants reported that in many cases, they were only able carry out the activities stated in the measure provided they had planned things well and had sufficient rest in between throughout the day. Any unexpected event or demanding situation could increase the physical and emotional burden and would be disruptive, rendering an individual very tired and less efficient. Participants felt the over-simplified activities included in the measure, seemed very complex and difficult to do – even if they could do them with planning and preparation.

> The number one thing for me is fatigue and what impact that has on my life. I don't think any of that [questionnaire] talks about fatigue. Fatigue affects everything else. What I find is I can do things, I just need to plan, and I need no pressure and I need to have lists. So, if I have any pressure, anything emotional, anything that's extra demanding, then I get tired because I sleep every day, and so that's how I manage my fatigue. But if I've got something extra happening that makes me tired then as soon as I start to get tired all my symptoms come back and then I can't manage any of it. I can't drive when I get tired. I can't prepare a meal. There's no balance and I struggle to do this sort of thing, I can't think, I can't get the order, it just all becomes a big mess in my mind and I struggle. (Female, 39 years, severe TBI)

Encouragement and support from others

Participants identified positive impact of social support as a contributing factor to their successful integration. Their ability to complete activities stated in the measure was often dependent on the support of others. There were concerns that the amount or type of social support that enabled them to integrate has not been captured in the measure which could overestimate ability.

> I just think the questions need to allow for different stuff to come through. I guess there's a set thing for measuring whether you are this or not, but it actually doesn't allow for anything else that you could be. There's a lot not covered in there, the impacts it has and I've had really good support, which a lot of people haven't from different ones I've talked to. So, I'm really grateful for that and it has helped me. (Female, 39 years, severe TBI)

For most participants, they commented that they were particularly dependent on others to organise social and leisure activities.

> I spend a lot of time with my family doing various things. Like with my daughter, my sister here in Auckland, if they're doing something or if they are going to be having a social arrangement at their place, they

will invite me over to be part of it with their friends. I'm not really doing a whole lot of planning for social arrangements. They're keeping me involved. (Male, 55 years, mild TBI)

Timing, access and qualities of the environment

For a number of participants, efficiency of carrying out tasks was dependent on time of the day, accessibility and convenience of the environment. Participants could function better if the environment was not too busy as well as if the light and noise levels were manageable. Participants reported that they avoided crowded or noisy places such as movies, concerts or restaurants that could trigger their symptoms, which ultimately resulted in limited social engagement. Participants felt that these aspects of being able to engage in activities in the community were not adequately captured in the measure.

> Being unable to do things, even at different times of the day, because of noise and light and just the whole thing like that. So late night, or later opening of supermarkets and things like that can work quite well because there's not many people around then, but then you've got to have enough energy to get there as well. It [the question] could maybe have a couple more squares to tick like timing as well. What time of the day because that's one of the major ones for grocery shopping because if you go later too there's not so many queues because pain can kick in with standing in the queues. What's worse now is all the mega shops because you've got to go so far round and everything you want is down the back end. (Female, 62 years, severe TBI)

A number of participants could function better at a certain time of the day especially mornings or after a period of adequate rest which was a factor that limited people's lives, but participants felt this was not adequately captured by the measure.

> Well, [Name of partner] tends to do um most of it [meal preparation] because um the afternoons I get really tired in the afternoons and the evening is really bad so um she just tends to do it and she likes it so that works out really well. But um what I used to find before [Name of partner] was here, I would I would really struggle. Sometimes come home late in the afternoon, four o'clock or whatever, and I had to have sleep, or I had to rest and it's really good, you know having her there, we can work in a partnership because I am fine I just you know, the mornings I can do my things, no worries. Um do, um but the afternoons can get really tough depending on what I have been doing so yea. (Male, 64 years, mild TBI)

Participants also raised their concerns around limited transport options affecting their community access. For some, social contacts and friends were not always accessible

due to time constraints. They would have had to travel long distance to be able to meet their acquaintances. These factors have seemed to affect integration despite participants' ability to engage in various social or occupational activities.

> I'm in an area that there aren't any buses or trains or boats. You've got to go a distance to get there to do anything, so if it got to the stage where I couldn't drive, I don't know what would happen really. I suppose you'd have to use a taxi. Community services are un-applicable unless I shift. (Female, 59 years, mild TBI)

Coping, acceptance and sense of belonging

Interview data highlighted the persistent struggle of participants with the psychological impact of their injuries. Participants had experienced depression and anxiety and they needed professional help in order to learn how to cope with long term emotional issues. The problem emerged as a result of frustration due to inability to do things like before, fear of other peoples' reactions or judgments, as well as emotions related to self-doubt. These factors had significantly impacted participants' engagement in their homes, work based as well as social situations. Participants who could successfully manage their emotions and other psychological aspects of their lives, displayed an enhanced level of community integration. This finding indicates that the activity restrictions are not always due to physical impairments; psychological wellbeing plays an integral role in successful integration outcome which is currently not well addressed by the measure.

> Another thing that I've really struggled with is because I find social stuff so difficult, but I enjoy it, it's what I want to do, I get anxious. I get anxious before it because I'm worried, I'm not going to be able to cope and then that makes me not manage things. As soon as I get anxious that makes me more tired. As soon as I'm more tired and then, I can't cope. I had to have psychologists help me a few months back because it got to the point where if someone rang to say they were coming for a cup of coffee and I was just in tears, just because they were coming for a cup of coffee. I've got to be able to do that. That was because I was thinking I don't know if I can make the coffee and talk to them. So, it definitely has affected social. (Female, 39 years, severe TBI)

Participants had to make significant adjustments and it took them some time to come to terms with the impact of their injury. They had to deal with the sense of loss and accept the changes in their abilities, lifestyles and relationships in order to successfully

integrate in their community. This was an ongoing process of acceptance and moving from one goal to another. This aspect of integration is not addressed in the measure.

> I had to really get used to the idea that I had no work to go to and it was a really big shock and I had no licence either. That was such a terrible thing, no licence for a man like me who has always been independent and hardworking all his life, to have no licence was a terrible shock. It was a huge part of my life. My wife and I, we owned a lifestyle block and I used to work there in the weekends and it was my whole life… I'm starting to come to terms with it. I just accept that I have a new life and that's how I look at it. If I study, it too much it gets too depressing, so I don't study it. I just say I've got a new life now and that's how I cope. (Male, 64 years, severe TBI)

Participants reported to enjoy being involved in routine, leisure or celebratory social events with family and friends. However, they felt they had the chance of being who they really were when being part of a group of people who had similar injuries and life struggles. The measure rated participation in activities with friends without disability as high, however participants emphasised the importance of feeling normal and having a sense of belonging in a group of people with disability. The feeling of 'being able to be who you are' and 'you are not the only one' had helped participants engage in various social or occupational tasks.

> I found this ladies head group, this coffee group we go to the first Thursday of every month, and that was the best thing for me because everyone's similar and you can relate to what they say. That's the only time I feel normal because you don't have to apologise or excuse who you are, you're allowed to be yourself. So, things like that I think are excellent. I go every time because it uplifts me. (Female, 59 years, mild TBI)

7.3.2 Theme 2: Meaningfulness of tasks

Meaningful concepts captured

Participants reflected on the perceived importance of tasks and activities in the measure. The importance of being able to organise or participate in social events or leisure activities with family and friends was highlighted many times. Participants also upheld the value of being able to travel outside home, shop for themselves or their families, and manage their finances. These aspects affirm the relevance of the content of the CIQ-R measure relating to social activities to the set of the population interviewed in this study.

> That is something I really wanted to do and that's to take control of my finances. When me and my wife separated, I then took over, I then had control and found the control I needed. Something my brother told me about that, having all the bills paid by direct debit, so then I didn't have to worry about it. (Male, 55 years, mild TBI)

Participants emphasised the importance of being able to work or be involved with activities that are meaningful to them. Employment, studying or volunteering had been crucial in terms of financial security, productivity and a sense of independence. Most participants felt that going to work helped them to form and maintain social contacts. These aspects of productive activities have been felt to be well captured in the measure. However, the factors related to why they were not able to work were not.

> Not working at all. See that's been a really hard thing for me, psychologically as well, because when I first had the brain haemorrhage, I was just so focused on getting back to work. It was all I could think about and they were going to try and get rid of me early on and I managed to get them to hold my job for a year. I used to have a job as quality coordinator, so that was sitting at a desk with bits of paper and being able to process it and I could do that, so it was working, but what stopped it working was the fact that they wanted me to do an eight-hour day. I gave up trying to get back to work because that had failed, something I'd wanted so much. So, I haven't gone down that track, I'm not looking for work because it didn't work last time. I know I could do it if it was for just a couple of hours but being able to do jobs how they want it. (Female, 39 years, severe TBI)

In most cases, participants believed that technology and social media had helped them better reintegrate into the community. Use of smart phones had improved every day functioning through reminders and emails. Participants reported that phones and computers had enhanced social integration through texts, Facebook, skype and gave them opportunities to engage in leisure activities such as online games. Participants felt more connected through social media with their distant families and friends in the absence of face to face interactions and it gave them a sense of inclusion. These findings support inclusion and usefulness of electronic social networking as a component of the measure of community integration.

> It (social media) keeps you in touch. I'm more of a voyeur in respect of Facebook. Nothing's happening in my life so there's nothing to report, but my family, they travel a lot, so I get to see their photos and I get to

see what the kids are doing. So, because I'm an auntie I'm more in tune on what's going on and I love that. If they didn't have that, like before, you wouldn't know what was going on. (Female, 59 years, mild TBI)

Meaningfulness of social participation

Despite the access and ability to engage in social interactions through text, skype or Facebook, some participants did have limited social integration. This was because social interactions were often stressful for participants. This finding challenges the assumption of the measure that social contact is both a desired and positive outcome.

> No, I don't feel the need to have a friend. I'm okay. My life is very good. I don't have a cell phone for starters, but I used to Skype people. I guess I have the intention of doing it but don't get around to it. People don't Skype me. As far as Facebook goes, I'm on Facebook but same again, I don't post on there. I don't really have much social contact outside work. That's one thing about brain injury and why I live by myself, because I don't have to... it's a bit stressful relating to people at times. (Male, 60 years, TBI severity unknown)

Participants supported the importance of having family and friends for social and leisure activities, however they pointed out that the measure does not capture the importance of meeting new people to form intimate relationships. Participants considered having confidence and ability to explore the possibility of finding a partner as very crucial. Participants also discussed aspects of physical intimacy with the spouse or partner as missing from the measure.

> I've got friends that I play tenpin bowling with and I've got friends and family that do come to visit, but no partner. Meeting new people... I don't know how to word this. Yes, learning to get back into maybe finding a partner. Mind you, you get the same feelings sometimes you know. For somebody who hasn't got a physical disability like me it's probably easier to find a partner and places to go. Places to go and stuff like that and having confidence to get out there. That's something I've got, the confidence to go somewhere. That there is quite... it is an important question. It's finding a partner that's sincere, that's the other thing. It's finding a partner that's sincere and not a partner that's going to take advantage. There's a lot of things like that and the ones who have got the ability to sustain... once again it's confidence. Having the confidence to find a partner. (Male, 55 years, mild TBI)

Participants indicated that the activities included in the measure were not always pertinent to them. For example, sports, restaurants, movies. Some participants had limited ability to carry out such activities, however some reported that they never

enjoyed these activities and so did not do them because of this lack of enjoyment rather than lack of ability. Participants talked about several activities that were meaningful to them but not included in the measure, such as gardening, taking part in religious activities, doing yoga, spending quiet time reading or tramping with a small group of friends.

> Well see I have never been in movies for a decade may be movie person so you know. that's not just me. (Male, 67 years, severe TBI)

Importance of independence

Participants highlighted how vital their independence had been to them. Being able to do things had provided them with a sense of satisfaction and achievement. Participants had linked independence with their ability to contribute as measured by the CIQ-R. Dependence or co-dependence often had adverse effects on integration due to the psychological burden of lacking the ability and always needing help.

> Well I have to say is that um my first, when I got home, I felt I was good. Right um so that I lived by myself and I cooked my own food and did my housework, did my clothes washing. So, and that's what I did before and that's what I did after I came away. So that um I don't think my life changed. I didn't, the only thing that changed because maybe I said that I still don't drive at six months. Um so that my daughter had my car so if I was wanted to do shopping um a reasonable amount of shopping I am talking about, because it was either that or walk. And the town centre is just down the down there, but I had to, how would you say, limit what I bought if I was walking because I have to carry it back home. Whilst if there is a slight rise then you got your arm with some groceries you know that weight is dead and the further you walk, the heavier it gets. So that um I used to go down there and buy a little bit of shopping, but I'd never buy a sort of bottle of milk or anything like that because you know its just dead weight you got, and you got to carry that home um so that between my daughter and my fable feet that's how I do my shopping. (Male, 67 years, Severe TBI)

Participants reported that their independence had led to more social interactions. If they could drive or travel on their own, they had limited restrictions on meeting people from their social circle or going for shopping or work. Independence was also associated with an ability to keep themselves safe as often participants needed an oversight or help to prevent any risks of injury.

It's just ability and knowing I can do it by myself and not having anybody there to… for security or… security or safety. I don't have to have anybody there. (Male, 55 years, mild TBI)

Lack of relevance

Participants with significant recovery or less severe injury had difficulty relating to the questionnaire. They felt the questions were directed at people with severe disability and limited function. According to them, the measure does not capture the impact of injury on their lives as they are functioning and mostly independent.

> I'd say I'd get full marks for all of these. I can do emails. I can do work. I just can't do it in the way… you know. I can use the phone, I can use emails, I can do text messaging, I can do stuff so I'm not completely socially isolated. If you looked at a scale of… maybe I am better than what I think because if it is I am so great, compared to how bad you can be, but it doesn't mean that it hasn't had a huge impact on my life and my family's life. It's not the life that I could have had. I might be okay. I might be living and breathing and able to do the food shopping and stuff, but it's not, but it's just I don't know whether this is aimed at just people that are really… at one point they might be in a nursing home and that sort of thing. There can be those sorts of impacts, but when you're not and you're able to… does that mean that you're fine because you can … It's not just as simple as oh yeah, you can send a text message so you're okay. I can send a text message, it's not that my fingers don't work, or my brain doesn't know how to push the buttons, it's just that you can't coordinate and remember and what a relationship requires. (Female, 39 years, severe TBI)

Some participants also had difficulty associating themselves with the questions, in particular tasks mentioned in those questions. They had concerns in regard to the questionnaire being developed overseas and lacked relevance to their lives in New Zealand.

> The ladies head group that we go to, they discussed it afterwards and some of them got angry and I thought why you would get angry or they got frustrated because it's like they're silly questions and it meant nothing to them. So, I thought maybe I should say maybe you need to reword it, change it. A lot of the ladies who tried to answer the thing, they just said that was useless, it wasn't applicable for me. Because you say it's an overseas one, we do things differently here I suppose. (Female, 59 years, mild TBI)

7.3.3 Theme 3: Context not taken into account

Pre-injury status not considered

Participants indicated the need to compare their existing status with their pre-injury status. The measure does not have any provision to make that comparison that might indicate the change or improvement in a person's condition. For some participants, their functioning had not changed after their injury. They had never participated in the activities mentioned in the questions prior to their injury, hence the participant response would not portray an accurate picture of a person who had been impacted by the injury.

> Some of these things were, already like that um like for instance the shopping for groceries before umm my husband and I would have done that together always now its him but before he did the cooking anyways so some of these things are not a change in response to the injury um that's just how it was , yes, so can't really tell it might have shown a degree of dependency but some of those things were already my husband likes cooking and I hate it so it is. Of course, if all of them ask someone else so you know obviously it builds up an affect you but um there must ahh there must be cases where perhaps um if somebody travels a lot or something all of these things would be done by someone else anyway, so this doesn't give a good picture of the change. (Female, 59 years, TBI severity unknown)

Participants also questioned the accuracy of quantifying the tasks described in the measure. The measure indicates the level of integration based on pre-defined frequency of activities, which did not match the frequency as expected by the participants.

> Yea no I think that it's all relevant to build up a picture of someone's life um it's just as you have got a before and after. Because before I would have done much more leisure and been much more involved with friends and um and you know now that has changed yes. (Female, 59 years, TBI severity unknown)

Some of the changes in participants' lifestyle were caused by circumstances other than their injury; however, it would be rated as low level of integration due to the structure of the questionnaire which does not consider the impact of non-injury related factors.

> All our friends have all got kids so it's sort of not really, we don't really get out a lot because of that. That's the part of the main reason

nothing to do with the brain injury. (Male, 34 years, TBI severity unknown)

Task non-essential/redundant

The measure captures participation in various activities and life roles, however participants identified some tasks as non-essential for them. Often participants received support from others including family members or funding providers despite their ability to perform certain tasks. Participants would prioritise other aspects of their lives while tasks such as meal preparation, shopping, or cleaning would be taken care of by other people.

> The meals are prepared by a company and I get them that way and I find it so much easier for myself. As you might understand it makes things so much easier doing that way or I could be just going to a supermarket and buying a meal that's already cooked, bring it home and heat it up. (Male, 55 years, mild TBI)

People who take part in volunteer activities on the top of their part-time or full-time employment would be scored higher according to the measure. However, for some participants it was not possible to do paid work and be involved in volunteer work not just because of the brain injury.

Inability to drive

Participants expressed concerns over their inability to drive and how this aspect of their recovery is not captured in the measure. They strongly felt that difficulty in driving had affected their integration in household management tasks as well as social activities. It also impacted their level of independence and limited the activities they could do on without any assistance causing a decrease in their level of integration.

> So, I had to really get used to the idea that I had no work to go to and it was a really big shock and I had no licence either. That was such a terrible thing, no licence for a man like me who has always been independent and hardworking all his life, to have no licence was a terrible shock. (Male, 64 years, severe TBI)

Participants also expressed their frustration over inadequate transport services which affected their integration. They had to take up driving to get to places even though they did not feel safe or confident to drive again. The aspects of difficulties with

accessing transport or driving have not been addressed as a source of positive or negative outcome of integration in the measure.

> I was forced to go back to driving before I felt I was totally ready because the bus service kept changing. I had to get to the Hospital to the eye clinic. Four buses, yea it was going to be three, the bus that was supposed to pick me up down [name of road] was late, I missed the connection. They didn't give me another option if the connection was missed...I cannot go from here to the hospital, I can't do that, that's too much for me. I wish it was easier, to get public transport. (Female, 67 years, moderate TBI)

Reaction of others

Participants were aware about societal expectation and had difficulty adjusting to those standards after their injury. Organising or participating in social activities had been overwhelming and made them very anxious about their behaviour, communication, as well as physical function and balance. The fear or anxiety about getting things wrong in public, had often restrained people from participating in social events, which had affected their integration. The measure does not consider the subjective aspects of integration discussed above.

> It doesn't take a long to run out of words and also now I am not so coordinated and so I knock things over and you know and I, I so it's a little bit frightening especially noise in the restaurant because you could hold the input from the business, so you then do drop something or knock something over you know, the normal social occasions can be quite scary. Social occasions become so difficult unless it's a small group in a quiet room. You must stop and think before you talk so, so it's a new problem for me but and now there is stress in our social environment and then especially when you are nervous you just you um yea organising and initiating I talked about it, um the venues, there are so many venues are not appropriate, loss of identity, self-esteem, it's hard to feel sociable when you don't know who you are anymore, vulnerability um I cry easily now my it's like my skin is only one layer deep and its I am nervous of social situations in case I might cry or you know yea. (Female, 59 years, TBI severity unknown)

Participants often had opportunities to socialise and engage in conversation, however they realised that people in their social groups did not relate to their feelings. They felt they were misjudged by other people as they did not have physical signs of injury and identified their injury as an 'invisible' one. This led to limited interactions and isolation when they did not feel accepted for being who they were. This finding suggests that

individuals with TBI, despite having the ability to carry out home-based, social or occupational tasks, had decreased integration due to negative impact of reaction of others. The measure does not capture the person's efficiency of doing a task if the task is not performed due to adverse social environment.

> You know people say, how are you? You don't really want to tell them because they don't really want to know. But if you do say they don't… quite often people will say oh yes, that's understandable forgetting, gosh I forget things, so they minimalise what you're saying, whereas those things of forgetfulness or going from one room to the other and forgetting why you're there it's exaggerated more than them. When you say something, they try to relate to what you're saying as an example - oh yes, I can relate to what she said, but really, they don't because it is still different. (Female, 59 years, mild)

7.3.4 Theme 4: Complexity of tasks

Task difficulty

Some participants reported some tasks to be too difficult to perform and the measure did not allow for varying complexity of tasks in the questions. Participants could prepare meals that were not too complex but would fail if they tried to prepare many dishes or cook for a large group of people. Participants queried the type of leisure activities listed in the questions as they could participate in small events and simple games, however they did not feel confident to return to their pre-injury sports such as surfing or paddle-boarding. According to some participants, the measure does not seem to accurately measure their level of integration as it cannot differentiate between varying levels of complexity involved in different tasks.

> I was thinking maybe I don't know if it has to do with brain injury, but I carried sports that kind of thing coz I would be I meant to keeping out in the water and going I have got a bought myself a stand-up paddle board so that was after the brain injury and I like to get out on that. only it is a bit tricky by me and want to have someone watching you just in case. (Male, 34 years, TBI severity unknown)

A number of participants discussed about their struggles with multitasking and how that had affected their overall wellbeing. They could cope with daily activities when ordered appropriately. Any demanding situation or unexpected event could lead to less productive outcomes. The tasks included in the measure do not represent real-life situation where participants had to deal with multiple things at the same time.

I have ideas and I like paint finishes so I go to art demonstrations at Gordon Harris. I want to be up to date with the new mediums and I get excited about how I can approach it, but it's starting it. I start doing it and again I get distracted, the phone goes. I could have nearly burnt my house down once. I went to go the letterbox to get mail and then someone rang me. I forgot I was cooking something and I'm thinking where's the smoke - are they doing a barbeque next door? I forgot it was me. So, I can't multitask so I'm a headless chook all day long and that's tiring. (Female, 59 years, mild TBI)

Task efficiency varies

Interview data highlighted that participants had difficulty choosing an appropriate answer that describes their ability of task completion or frequency of activity. Their task efficiency often varied depending on the complexity of the task, time of the day or access and convenience of the environment. Participants reported that the measure does not capture nuances or allow for any variability of tasks.

What happens is when you do something, and you try to finish it you're tired so whether you can do two hours or three… like when you're asked how many hours can you do a week? Well it's not consistent. You might do eight or ten and that was a good week, but consistently and every task is different, more challenging. I'm often short circuiting trying to find a word or understand what I'm trying to say. It's like - [buzzing sound] trying to get the word. Sometimes it connects and sometimes it doesn't. So, this is what it's like all the time, you're short-circuiting. (Female, 59 years, mild TBI)

Most participants indicated that contingencies were important to their level of integration. Participants could work but they could do limited hours only, they could drive shorter distances, engage in less demanding leisure activities for shorter durations. They had to deal with physical, cognitive as well as psychological demands of the situation which required more contingencies in place to successfully complete the task with consistency apposite to the participants. The measure does not seem to capture these contingencies as prerequisites to the integration.

I'm doing the banking yes, no problem with the banking. I guess the big thing is I just have to remember because I do have really bad short-term memory issues, so as long as I've got everything written down, then I can manage things. (Female, 39 years, severe TBI)

Takes longer to complete

A few participants were concerned that the measure represented them as well integrated based on their ability to engage in various activities, however they would usually spend longer than usual to execute the particular task. Often it was a vicious cycle, the longer it would take to complete, it would become more difficult to achieve due to injury or environment related interferences e.g. loud noise, fatigue. This would again vary based on task complexity and participants' efficiency.

> My partner does most of the supermarket shopping. Um yea. I mean I just get, I can do it, but it takes me a lot longer and um I get distracted quite often um that's yea. Basically, um in my case the, my head injury is frontal lobe damage which has affected the um what executive functions really so planning and thinking through stuff um and just concentrating you know can, if I am tired, that's quite difficult, so yea. I get distracted. There is plenty of stuff that's going on in supermarket that um you know brings out stress. yea but that's ok I mean I know I can do it, but I have found it quite difficult you know whilst I'd get distracted spent too much time you know yea. (Male, 64 years, mild TBI)

Keeping things simple

Considering all the complications related to symptoms, complexity, pressure to meet the demands, participants often decided to choose alternative methods or make adjustments to how they do things in order to remain integrated. The measure is focussed on ability and frequency of activities, it does not consider all the modifications and substitutions required to demonstrate that ability or frequency.

> I was 8 months in rehab and had to deal with hospital food. I was dying to get home. I made myself do that, but I'd never minded doing that. But I have cut corners. I often do just one pan meals. I do cut corners, a lot. It's easier, it's quicker and I focus on one thing. It would probably the focussing on the one thing as much as anything. It's easy for me. (Female, 67 years, moderate TBI)

7.3.5 Theme 5: "How I do it" is important

Quality not quantity matters

A number of participants raised an important concern that the measure captures the quantity of tasks or activities, but it does not evaluate participants based on quality of their work. According to some participants, it was not the number of tasks or frequency that could define their level of integration, but how well they participated

could represent the best picture of their functioning. Participants felt they should be measured based on quality of their household tasks, social interactions, as well as duties at work or training.

> It says how many times but it's not saying how does it impact because it's not just about how many times you visit friends or relatives, it's whether you can visit them, you know, you could go and see someone for five minutes and you used to be able to be there for an evening and that might classify as higher, but it doesn't actually capture how it impacts, how does it impact you visiting friends and relatives and what support would you need. (Female, 39 years, severe TBI)

Analysing the questions of the CIQ-R, some participants expressed their disagreement with the measure which represented them as well integrated with a high score. However, according to them they were only functional and not as optimal as they expected to be. Participants talk about the possibility of having a timepoint or comparative variable that could measure if they are meeting their goals of integration or functioning at their highest capacity, in comparison to their previous level of functioning.

> I think there needs to be some sort of question around does the patient feel that they're making progress and how rapid the progress is making and whether the answer would be different in 12 months' time to what it is now. There needs to be some sort of reference to that because it's a big part in me anyway, the improvement that I make. (Male, 64 years, severe TBI)

Task competence

Most participants talked about their individual struggles and how they differ from one another in their competence, hence they needed to be assessed differently. They sometimes changed the ways they do things or skipped the task or interaction if they felt they could not do it properly. Often, they would get things wrong if they carried on with the task. At times, they resort to easier tasks or seek help. The variability of task competence affected participants' independence and productivity. The outcome measure could consider task competence for more thorough measurement of integration.

> I look after my personal finances, banking and paying bills. No one else does that for me. um I might have my daughter, her opinion on something but I organise it. I don't always do it well, I went, I skipped

slipped up this week. I thought I had everything covered and went to pay my registration and there wasn't quite enough, because the rates in the insurance had come out yesterday. (Female, 67 years, moderate TBI)

Planning and organisation

Most participants had to learn to organise themselves in order to do things they like doing or justify their life roles. The planning and organisation had been essential for managing contingencies. Participants used different techniques including writing things down, setting reminders, managing fatigue with frequent rest and planning ahead for environmental disruptions. The measure does not capture all the background work that goes into enabling individuals to make everyday tasks possible.

> I have to do everything by schedule or I get to the end of the day and I look in the mirror as I start brushing my teeth and I realize I haven't brushed my hair and I have been all day you know that so there is a little bit of fear that I am not going to do things right. (Female, 59 years, TBI severity unknown)

7.3.6 Theme 6: Wording of questions is important

Difficulty of questions varies

Most participants found the questionnaire straightforward and were able to complete it without any support. However, some participants expressed concerns over some of the questions being too difficult to understand. They often did not realise the struggle understanding them initially, although when their answers were discussed during an interview, they corrected themselves stating that their initial response did not quite represent them. Some of them needed help to complete the questionnaire, in particular making sure that they understood questions right.

> I got someone a friend of mine to come and sit beside me when I answered it um and there were a couple there that you know I probably sort of how you say, um, your answers say yourself alone. Um so that um you know we have actually agreed with the answers that I was putting in, so it was not a problem. (Male, 67 years, severe TBI)

Participants indicated that the questions were long winded and burdensome. One of them suggested to have simple keywords and bullet points for people to better understand the topic such as household management, childcare, social arrangements, or work situation.

Really what I am saying is that um at least the reader sees what the question well not so much the question, what the topic you are asking straight away. You know that's really where I am coming from. You got a, I think um you got to make it fairly simplistic for the reader so that he knows, what, the person knows that your this question is about x,y,z type of thing. So like bullet points. That's what I would suggest rather than you know having to read the whole thing all the time. And I think that's where people probably get sick and tired of oh not another oh. (Male, 67 years, severe TBI)

Participants often had confusion between three questions regarding 'shopping for groceries' and 'shopping outside home' as well as 'travel outside home'. They asked for clarification if shopping for groceries would be covered under shopping outside home. Additionally, they queried if the travel outside home would include buying milk and bread. Considering the structure of the measure, these three topics are covered in three different sub-scales home integration, social integration and productivity respectively. Also, some participants assumed that travel outside home only includes driving one's own car, not public transport. This indicates the need to clarify the questions for better understanding.

Approximately how many times a month do you participate in shopping outside your home? I suppose 4 times a month, once a week, it wouldn't be more than that, it could be less. Now this is apart from supermarket you mean, don't you? (Female, 67 years, moderate TBI)

Wording problematic

Apart from the confusing words in shopping and travel related questions as mentioned above, participants suggested that the questions about 'cares for the children' could be modified to add grandchildren. Participants often had grown-up children who did not need looking after but they would sometimes care for grandchildren or nephew.

Participant: Who usually cares for the children in your home? Not applicable because we don't have any children.

Wife: We do have a grandchild though.

Participant: Yes, one day a week he comes here. We share that job. [Name of wife] looks after him and I put him in the pushchair and take him for a walk.

Wife: You could say grandchildren maybe?

Participant: Yes, you could add the word grandchildren in there. (Male, 64 years, severe TBI)

Participants agreed with the idea of having a best friend, however it did not match with their real-life situation and the term itself was unclear about who was a 'best friend'. Mostly, after the injury participants tend to confide in their partners as their best friends.

Interviewer: Do you have a best friend in whom you confide?

Participant: My husband does probably, he gets the lot.. Different ones I'll talk to about different things. I don't have one person who I feel I can tell everything to, but my husband I talk to about everything. He probably gets quite sick of it as well I think (laugh). (Female, 39 years, severe)

Do you have a best friend in whom you can confide? I said yes but that's my wife. (Male, 64 years, severe TBI)

Moreover, some participants had more than one friend who they could confide in for different things. Participants who did not have partners or close friends, relied on their family members for support. Participants made suggestions about re-wording the question replacing 'a best friend' to include someone they feel close to.

Do I have a best friend whom I confide? I have got yes, ok what I meant... I confide in most with most of close friends and with my daughters so probably it's true, it's not a best friend. Yea and we share, we share, and I might share more with some another's or different things with others because it would probably be something that they are sharing with me, so yea ok so ok but it's not "a". I don't have that. (Female, 67 years, moderate TBI)

Participants needed some clarification about inclusion of volunteer activities and they expected volunteering to be included in the question about work situation. One of the participants was not sure what kind of work would be considered as a volunteer activity. Another believed that the measure expected people to participate in volunteer work in addition to their paid work, which was often not achievable due to their limited ability.

No [volunteering]. I know some people do that, do voluntary work, but before I was doing part-time work before my accident, pay is pretty low, minimum sort of thing, and so voluntary work is not feasible

really. I know people who have been making a good income when they've had their accident and they're on benefits and they were getting a really good wage, couldn't earn the money, so they do voluntary work, I know that, but it's not feasible for me. (Male, 60 years, TBI severity unknown)

Some participants suggested if the measure could allow for an aspect of integration in terms of 'how' and not 'how many'. They felt their subjective feeling about their integration and how they achieved that should be recorded in an open field as a part of the measure. They also, suggested to have their integration status compared with the previous one. Additionally, they felt the questions were too specific and did not provided broad overview of the impact of their injury. Participants suggested to have more detailed questions.

I just think the questions need to allow for different stuff to come through. I guess there's a set thing for measuring whether you are this or not, but it actually doesn't allow for anything else that you could be. There's a lot not covered in there, the impacts it has and I've had really good support, which a lot of people haven't from different ones I've talked to. So, where I am now compared to where I was then being totally different. What was the original question? (Female, 39 years, severe TBI)

Need for more examples

Participants had difficulty understanding the term 'leisure', possibly due to limited use of that word in the New Zealand context or the examples listed in the question were not relevant to them. Some participants were not able to engage in movies, restaurants or sports as a result of their injury or personal preferences, instead they would like to be involved in short walks, reading a book, gardening, doing woodwork, attending support groups, or walking a dog. This indicates the need to define the term or add more relevant examples for better understanding of the question.

Well it's a question what you call Leisure? That's me, you know are you saying is leisure reading a book? Is leisure going for a walk? Is leisure going to the movies or some sort of sport Aye, well then, that thing is how you entertain yourself is suppose. (Male, 67 years, severe TBI)

Participants were not clear about what school or training programme would include. Some of the training participants attended were related to art, swimming, computer or iPad, religious study, but they did not consider these when answering the question

about school or training. This indicates that the term needs to be explained and more examples are warranted.

> Please check the answer that best corresponds to your current school or training, it's not applicable. Ah full time, part time, not attending school, not applicable, retired. I am not sure about that term not attending school or training program. What if you are going to university (for exercise training/sports events)? Is that a training program? Its tertiary, you got tertiary? You need something on that one, I think. (Female, 67 years, moderate TBI)

Furthermore, as discussed above under *Difficulty of questions varies* sub-theme, a participant would benefit from specific examples or explanation of the questions 'shopping for groceries', 'shopping outside home' and 'travel outside home'.

Hard to fit into a box

Participants had difficulty selecting one of the response options, in particular for the question inquiring 'When you participate in leisure activities do you usually do this alone or with others?'. Most participants tend to enjoy different activities with different groups of people. Often, they would join the support groups or events for people with disability, sometimes they participate in social gatherings with a combination of family and friends. Participants also enjoyed doing some activities on their own for example, preparing woodwork or online gaming. Participants could not decide which box to tick as they would fit more than one. Additionally, the measure assigns low scores for people who participate in leisure activities, although in some cases, people work alone as a personal preference and not as an outcome of their injury. This question may need revision for better accuracy.

> I think mostly alone. Yeah, I ticked there with a combination of family and friends, well it varies because at [name of the rehabilitation centre] there's usually other people there I'm doing some work with. Well with the gym it's mostly with people that have disabilities. Other times I bought myself a PowerFit down there. Since I did this, so that's mostly alone (laugh). I do everything by myself the majority of the time. (Male, 55 years, mild TBI)

Participants also had difficulty fitting into a box if the tasks addressed in the questions had always been dealt with either alone or with the support or involvement of other people which had no influence of the injury.

Well frequently, because I have got more free time I will do that [organising social gathering]. I will do the chasing, running around. I have also offered to help someone else organise an outing that the Gym does but that's beside the point. So yes, the question is straightforward um except I think the options on that one could be different. I've put myself alone with another A. The option was yourself with and someone else. It's not always and. Hard to know how to how to [choose]. (Female, 67 years, moderate TBI)

Difficulty with quantifying tasks/ Timeframe not always meaningful

Participants reported confusion and difficulty calculating the number of times they would participate in certain tasks. They suggested to have an easier and more meaningful timeframe in the response options.

It could have a 'sometimes'. I mean one to four covers that, but sometimes is a bit better than never. Have never as well but there's not many people that tick never, but I suppose if you have to you have to. If you have sometimes that can cover anything from one to ten, without having to actually think of a number. It's quite hard when you think of a number and you think how many times it was, the same with friends and relatives because you have your favourite ones anyway. But that's quite good. (Female, 62 years, severe TBI)

Participants noted that some questions measured the number of activities per month and some questions focussed on weekly frequency. One participant misread the question and answered as if the activity was measured on a weekly basis. Participants shared their preferences to have their task frequency calculated every week instead of every month.

I don't know whether you need well you know just sort of how many times in a week you go shopping not in a month. (Male, 67 years, severe TBI)

The response options do not allow for variability, as participants may not carry out most tasks regularly. Participants usually planned their visits to supermarkets, their family and friends at times and durations suitable to them to manage their fatigue and other symptoms. At times, they may need to reschedule or cancel due to inadvertent circumstances, illness or other priorities. Their views raised an important question about 'how many times' can be considered good or necessarily better. This finding should be considered in redefining the timeframe that is easily quantifiable and valid.

Interviewer: How many times you go out for shopping?

Participant: Not regularly. Maybe two weeks, three weeks. I'll stock up and so I don't need to go out.

Interviewer: How many times do you visit friends or relatives?

Participant: I don't, it's not regularly, it's not consistently twice a week, three times or one time a week. One week you might see different people and then two or three weeks no one. So, I can't consistently say once a week because it wouldn't be right. (Female, 59 years, mild TBI)

7.4 Discussion

This study presented an analysis of people's perception of the extent to which the CIQ-R captures their level of community integration post-TBI. Participants considered the CIQ-R to offer a very fundamental assessment of integration, although many felt it should also assess their overall recovery. The CIQ-R was viewed as offering good coverage of aspects of life impacted by the injury, while lacking the understanding of broader determinants of successful community integration. For most participants, the measure was feasible to complete in a reasonable timeframe, although some potential modifications to the wording of the items and content of the measure were identified.

While the study aimed to explore how the CIQ-R reflected participants' experiences of community integration, they found it very challenging separating out their TBI recovery and impairments from the impact on community integration. This reaffirms the findings from the previous research reporting ongoing impact of the TBI disrupting peoples' lives and abilities to engage with their communities (Lefebvre et al., 2008; Winkler et al., 2006; Wood et al., 2010). These disruptions were reported to be present across the severity spectrum including varying degrees of physical, cognitive, emotional, and psychosocial impairments. Furthermore, the extracts from participants emphasized how these factors along with social support and external environmental influences had huge impacts on their community integration. Participants highlighted the importance of considering variations in individual experiences and suggested the need to be assessed on a case by case basis. Many felt that the measure was not able to capture their unique experience in its current form. The findings suggest that the measure lacks consideration of variability in individual experiences and meaningful activity. This study also reveals psychological wellbeing as an essential aspect of one's life especially after the injury that involves dealing with loss, coping with ongoing

changes, constructing and accepting new self-identity and making adjustments to fulfil new life roles. This was consistent with the studies explaining the process of successful transition back to the community, yet not covered by the measure (Nalder et al., 2013; O'Neil-Pirozzi et al., 2015; Reistetter & Abreu, 2005; Turner et al., 2007).

The participants described the meaningfulness of independent participation in household activities, social functions as well as employment that clearly align with the literature describing the definitions and understandings of community integration (McColl et al., 1998; Parvaneh & Cocks, 2012; Tate et al., 1989; Willer, Rosenthal, et al., 1993). Participants also endorsed the use of technology that enabled them to virtually engage in social activities contributing to their level of integration as measured by the CIQ-R (Callaway et al., 2016). However, the extracts from participants highlighted one of the most vital components of their independence, was the 'ability to drive' which had an impact on almost all aspects of their lives including shopping, meeting friends and family, and going to work. Studies have identified cessation of driving as detrimental to regaining independence, employment and social mobility after TBI (Kreutzer et al., 2003; McColl et al., 2001; Minnes et al., 2003; Rapport, Bryer, & Hanks, 2006). The CIQ-R does not capture the situation where participants might have the ability to engage in shopping or leisure activities but were unable to drive or take public transport or walk longer distance independently, hence had restricted community integration due to environmental factors.

Some studies have argued for the importance of measuring the change from the preinjury status or baseline to enhance clinical utility of the scale and the findings from this study strengthen this argument (Dijkers, 1997; Karyl M Hall & Johnston, 1994; Tate et al., 1999; Tate et al., 2004). Participants felt that a meaningful reflection of their current level of integration could only be assessed when compared with their functioning prior to their injury or with their expected outcomes. Some of the household tasks were always performed jointly or by someone else pre-injury, yet the CIQ-R does not account for this and may underestimate the level of community integration. In other cases, some of the leisure activities were enjoyed alone, yet not participating in a leisure activity with someone else is reflected as a poor outcome according to the measure. The CIQ-R does not consider contemporary lifestyles where living responsibilities are frequently jointly shared while physically and cognitively

demanding activities including sports, virtual reality, social media are often enjoyable unaccompanied.

Participants identified the issue of community integration being measured by 'how many times' as notated in the measure. They were more concerned that the measure did not capture the modifications and adaptations that they often have to make to enable them to participate in certain activities to accomplish what they set out to achieve. Participants felt 'how' they perform those tasks and whether they were happy with their achievement was more meaningful than knowing *how often* they go shopping. This aligns with the finding from a previous study emphasizing the importance of not only quantifying functions to interpret integration, but capturing subjective aspects of people's feeling and their satisfaction with their level of functioning (Trigg & Wood, 2000; Willer, Linn, et al., 1993). It has also been argued that the concept of community integration should be independent of subjective preferences and that focusing on 'feeling state' could limit the objectivity of the measure (Dijkers, 1997). The current data highlighted that the measure failed to capture intricacy of functioning in people who were at the high end of the spectrum. Participants were considered as being highly functional with full recovery, whereas they had to make multiple adjustments to make things happen and they felt the measure did not accurately reflect their actual picture. The measure was also identified as being aimed at severely impaired people. This finding reinforces the outcome of quantitative studies demonstrating ceiling effects in one or more subscales of the measure (Karyl M Hall et al., 1996; Sander et al., 1999).

The scrutiny of the items from the measure showed that participants had concerns about the wording of some of the items including examples and timeframes. The person could participate in a small gathering but would struggle to cope with larger numbers of people at events such as movies or concerts. Similarly, a person might resume their pre-injury occupation of creating art, but was unable to return to more vigorous activities such as surfing. More comprehensive examples are needed to accommodate varying levels of individual efficiency and task difficulty.

A further difficulty with the wording of the items related to difficulty understanding and relating to terms such as 'leisure' and 'best friend' and participants felt these

terms did not capture their real-life situations e.g. often a spouse was identified as their best friend, but participants were unsure if this was relevant or not. Additionally, sometimes they identified a best friend but might only feel they could only approach them about some things but not others. These findings highlighted the issues with appropriateness of the content of the measure in New Zealand. Again, the concept of quantifying the task frequency with a pre-defined timeframe was not well received.

The content of the shopping items was also problematic, and the wording caused considerable confusion. It was burdensome and not always meaningful to quantify the number of times a person visited the grocery store or travelled outside home. Participants emphasised the importance of 'quality' of their activity (shopping, travel, work), not 'quantity'. The original CIQ items aiming to capture frequency of tasks were developed by a very small group (n=14) of people in North America who were TBI professionals and consumers (Willer, Rosenthal, et al., 1993). Dijkers (1997) identified the need for a more thorough process of item development, item selection and purification to capture peoples' level of community integration in a meaningful manner. It should be noted that these emerging recommendations from this study should not be considered in isolation from other research evidence and quantitative validation of the CIQ-R.

7.4.1 Limitations

While this study managed to include participants with varying demographic characteristics including age, gender, and TBI severity, the sample included only one ethnic group -NZ European. Hence, the findings are restricted to culture-specific perspectives. Additionally, the study was conducted in a single country (New Zealand) and therefore the generalisability of the findings from this study may have limited representation in the wider TBI population.

In the process of assessing the measure's content validity, it is also important to have the items reviewed by a group of experts to allow for triangulation of outcomes (Lincoln & Guba, 1985). The current study focussed on perspectives of people with TBI on clarity, relevance, grammar, face value, and redundancy of the items. Further research is warranted to investigate experts' opinions on the extent to which these items reflect the construct community integration in New Zealand. Conducting face-to-

face qualitative interviews to investigate acceptability and interpretability of the measure was consistent with the aim of this study. Findings from this study can form a foundation for the future research involving cognitive interviewing technique (Willis, 2004) to further revise and improve the measurement items.

7.4.2 Implications

This study has suggested some future directions for revising or developing a more comprehensive outcome measure of community integration. Moreover, it reinforces the importance of environmental and psychosocial factors which should be acknowledged when measuring community integration. The 'Environment' and 'Personal factors' components of the ICF have been identified as barriers to optimal community integration (Fleming, Tooth, Hassell, & Chan, 1999; M. L. Hawkins, Lewis, & Medeiros, 1996; Ponsford, Olver, Curran, & Ng, 1995; Rapport et al., 2006; Stilwell, Stilwell, Hawley, & Davies, 1998). Further work is needed to explore the impact of these factors in hindering the progress towards integration, in order to inform the adaptation in the infrastructure and clinical practice. This study did not set out to explore the injury related experiences, and yet the findings portrayed a snapshot of how community integration is achieved through ongoing struggle and constant adjustments. This can be very resourceful in establishing professionals' roles in tailoring the interventions to the individual needs.

7.5 Conclusion

This chapter has highlighted vital characteristics of the concept community integration and its measurement as perceived by the people 12 people with TBI. The CIQ-R was generally accepted as capturing some of the important aspects of people's integration post-injury. However, there were a number of issues raised about the content of the measure. The items did not seem to consider the meaningfulness of tasks, task difficulty, quality competence, as well as psychosocial and environmental factors. It is essential to incorporate person-centredness and tailor the content around the issues essential to people's lives and circumstances and acknowledge subjective feelings of people about areas being measured. More developmental, revision and statistical work is required to fine-tune the content and structure of the items in the CIQ-R to enhance its content validity and utility.

Chapter 8: Discussion and conclusion

8.1 Introduction

The primary objective of this doctoral research was to inform the development of a conceptually sound, psychometrically robust, culturally relevant, and contemporary measure of community integration for people with Traumatic Brain Injury. In order to do so, it was necessary to first understand how community integration was conceptualised in the literature and how it was measured in people with brain injury. An initial investigation of community integration explored how community integration was conceptualised in the brain injury and rehabilitation literature (Chapter Two). Another literature-based measurement review evaluated qualities of studies reporting psychometric properties of outcome measures of community integration (Chapter Three).

Following this measurement review, two empirical studies were undertaken. The first was a survey questionnaire-based study which established reliability, concurrent validity, and internal construct validity of a prominent outcome measure of community integration in people with TBI (Chapter Five and Chapter Six). The second, an interview-based study, explored peoples' perceptions of how community integration was captured by the outcome measure (Chapter Seven). The specific findings of each study conducted as a part of this doctoral research, are discussed in detail in the context of existing literature in the discussion sections of individual chapters (Chapters Two, Three, Five, Six, and Seven). Overall, this thesis highlighted that the construct of community integration is much broader than previously conceptualised and the prominent measure CIQ-R displayed generally acceptable validity and reliability, but it needs to be further revised to enhance its psychometric robustness and precision. In this final chapter, key findings from the conceptual review and three empirical studies are drawn together in an integrated discussion. Furthermore, the novel contributions of this doctoral thesis, clinical implications and recommendations for future research are discussed while also highlighting the limitations for this research.

8.2 Summary of key findings

Findings from this study have augmented understanding of community integration and its measurement. The conceptual review highlighted that varying definitions and a lack

of agreement regarding the theoretical underpinnings of the construct community integration, has resulted in problems for both the measurement of community integration and its use when implementing and evaluating rehabilitation interventions aimed at improving community integration outcomes. While some studies have acknowledged the dynamic and evolving nature of the construct, community integration has not been defined and conceptualised in its totality. To address that issue, this study critically examined the existing approaches to defining the construct and introduced a new working definition of community integration: "being independent and having a sense of belonging within the community; having a place to live; being socially connected and psychologically adjusted into the community and involved in meaningful occupational activity". Further to this definition, community integration seemed to be clearly influenced by the injury related, environmental, personal and social factors.

Findings from empirical studies in this doctoral research confirmed the dimensionality of the CIQ-R through various analysis methods including factor analysis, correlational analysis and Rasch analysis, and content analysis (Chapter Five, Chapter Six, and Chapter Seven). The CIQ-R represents four dimensions of the construct 'community integration': home integration, social integration, productivity, and electronic social networking. Comparison of these four dimensions with the proposed definition encompassing components of community integration reveals that the measure does not address the components 'sense of belonging' and 'adjustment' which essentially represent psychological wellbeing of an individual. Aspects of psychological integration are arguably discussed in the community integration literature (McColl et al., 2001; Millis et al., 2014; Tate et al., 1989). However, they have not been operationalised as a part of commonly used community integration measurement tools, including the CIQ-R.

This research demonstrated both strengths and weaknesses of the CIQ-R, based on statistical and content analyses. Findings from both quantitative and qualitative studies pertaining to individual items are integrated in Table 8.1 below. The table includes the acceptability of the items based on content analysis, item-total correlations and loadings on the first principal component based on factor analysis and reliability statistics. Also included are: item difficulty, item fit residual and model fit

statistics based on Rasch analysis. These integrated findings pertaining to each CIQ-R subscale and total scale are summarised below:

Home integration subscale (items 1-6)

All six items included in the home integration subscale of the CIQ-R demonstrated high correlations with the total score providing evidence for homogeneity, which was similar to the findings derived from previous validation studies (Callaway et al., 2016; Sander et al., 1999; Willer et al., 1994) and acceptable fit to the Rasch model. Findings from the qualitative study indicated that most participants supported the content of these items including various household tasks e.g. shopping for necessities, meal preparation, child care, routine housework, social arrangements, finances. However, it was also highlighted that most of these activities had been typically jointly performed prior to the injury, hence it did not capture the actual integration in the absence of pre-injury status. More importantly, the ability to perform these tasks did not guarantee an expected level of quality of those tasks for people, which was considered more important as an indicator for successful integration.

Social integration subscale (items 7-11)

Two (items 10 and 11) out of five items did not display significant correlations with the CIQ-R total score. Arguably, the original validation by Willer et al. (1994) derived low yet significant correlations for these two items in a very small sample (n=47). This was further scrutinised by the Rasch analysis and the current findings suggest that these two items had higher than acceptable fit residuals and significantly high chi square values. Hence, Rasch model fit for these two items was not achieved. These two items were reported by the interview participants as requiring some revision to improve their relevance to the people with TBI. Content and response categories for item 10- 'participation in leisure activities with others' were not considered meaningful as nuances of the task had not been well captured. The question and response options did not seem to consider the intensity of the leisure activity as well as the possibility of some activities being enjoyable when done alone or with others. Item 11 - 'confiding in a best friend' was considered important yet it was deemed necessary to expand its focus from just 'a best friend' to include 'friends and family', as the perceived act of confiding was not limited to one particular friend in most cases. Items 7 to 9

demonstrated good statistical properties, however were regarded as less meaningful as they were focussed on 'frequency' of tasks rather than their 'quality'.

Productivity subscale (items 12-15)

Productivity subscale contained item 12 (frequency of travel outside home) and a composite item 'jobschool' (items 13-15), hence statistical calculations were based on two items only. These resulted in low reliability of the subscale, however both items had statistically significant correlations with the total score. Evaluating the construct validity using Rasch analysis, the 'jobschool' item was found to display disordered thresholds. This finding suggests that the item is not consistently reflecting a higher capacity for construct integration (e.g. productivity), in progressively higher scores on the scale. According to content analysis, items on the productivity subscale were considered important. However as discussed above, variability of tasks and other factors affecting the tasks were not considered. For instance, item 12 only focussed on frequency of travel and did not capture the ability to drive oneself, availability and access to transport, or attention and fatigue interfering with the task. Similarly, hours of work or training in the composite 'jobschool' item did not consider memory, sleep, fatigue and their effect on quality of work.

Electronic social networking (ESN) subscale (item 16-18)

All three ESN items had significant correlations with the total score and the subscale was found to have good internal reliability which is consistent with the previous study examining the validity of the CIQ with its newly added ESN subscale by Callaway et al. (2016). Rasch analysis found acceptable item fit residuals and non-significant chi square values, hence satisfactory fit to the Rasch model was achieved. Interview participants perceived the use of technology to maintain social contact very useful in general. However, the questions were reported to be lacking real-life context including difficulty in cognitive processing and how sound and light, affected integration. To most people, quality of their conversations through calls, texts, or online videos took precedence over frequency as enlisted in these questions. Furthermore, the item contents did not capture the accessibility of technology or internet.

CIQ-R total scale

This doctoral study validated a multidimensional structure for the CIQ-R scale based on the CFA. It was corroborated by Rasch analysis as the initial analysis of the CIQ-R failed

to meet the expectations of the unidimensional Rasch model. The CFA determined four factors representing the four subscales of the CIQ-R which are detailed above. The model fit was achieved after items 7 and 11 had been deleted to enhance fit indices (Chapter Five). Scale analysis findings reported the Cronbach's alpha value of 0.72 for the total CIQ-R scale, which was deemed acceptable according to the cut-off value proposed by Terwee et al. (2007). This study also contributed to establishing evidence for concurrent validity of the CIQ-R based on correlational analysis with the SPRS, which was designed to measure psychosocial integration in people with TBI.

In the Rasch analysis, items of the CIQ-R were combined into six testlets to prevent their local dependency affecting the reliability estimates (Andrich, 1985; Christensen, Makransky, & Horton, 2017; Lundgren Nilsson, Jonsdottir, Ahlborg, & Tennant, 2013; Marais & Andrich, 2008). This approach revealed good model fit supporting the structural validity of the CIQ-R without re-scoring or removing any items. This method of examining the validity of a multidimensional scale has been applied in various measurement validation research studies (Medvedev, Siegert, Kersten, & Krägeloh, 2017; Nilsson & Tennant, 2011). Analysis also confirmed the ability of the CIQ-R items to discriminate between people at different community integration levels (PSI=0.83), hence the CIQ-R can be applied clinically for individual assessment (Streiner et al., 2015). The current Rasch analysis supplied the conversion algorithms for the total CIQ-R and home integration and social integration subscales which will allow researchers to calculate reliable and valid interval-level community integration scores. The additional advantage of the Rasch modified measure is that the data can now be analysed with parametric statistics offering greater precision and statistical power (Brogden, 1977).

Content analysis of the scale and scale items revealed that the overall content of the scale was mostly relatable according to the perspectives of people with TBI. However, the scale still requires significant amendments to enhance its relevance, comprehensiveness and interpretability. The CIQ-R does not have a provision to compare current scores to a previous time-point or pre-injury status, as it gives priority to 'competence' over 'change'. Assessing change over time was more meaningful to people who seek to achieve their pre-injury level functioning as reported in this research. This finding is in accordance with similar measurement research that highlights the need to explicitly measure the impact of the injury on a person, by

comparing it with his/her pre-injury performance (Powell, Beckers, & Greenwood, 1998; Tate et al., 1999). This may also be useful in a more informed clinical decision making and goal-setting process in a patient-centred rehabilitation environment. For example, a person with very limited use of technology prior to injury is less likely to be interested in using or learning to use it after the injury, as compared to the person who is a frequent user of electronic devices for work, school or social contacts. Also, as mentioned above, a focus on the quality not just the frequency of the tasks was found to be vital to participants as the measure in its current state does not capture the variability of day-to-day performance affecting community integration.

Table 8.1. Integrated summary of individual item performance from quantitative and qualitative studies

Item No.	Subscale/item	Content analysis	Item loadings on PC1	Item-total correlation	Item location	Item fit residual	χ^2
Home Integration							
1	Who shops for necessities in the household?	Satisfactory	0.81	0.63	0.19	-1.05	4.61
2	Who prepares meals?	Irrelevant	0.84	0.57	0.23	-0.81	1.70
3	Who does everyday housework?	Satisfactory	0.77	0.61	0.02	-0.18	9.36
4	Who cares for children?	Revision	0.90	0.67	0.02	-1.32	11.59
5	Who plans social arrangements?	Satisfactory	0.63	0.59	0.05	-0.84	6.47
6	Who looks after personal finances?	Satisfactory	0.61	0.50	-0.13	-0.79	2.89
Social Integration							
7	Frequency of shopping	Repetitive	0.03	0.44	-0.93	0.45	3.18
8	Frequency of leisure activities	Revision	-0.65	0.31	-0.11	0.84	3.32
9	Frequency of visiting friends/ relatives	Revision	-0.43	0.43	-0.07	0.29	2.41
10	With whom do you participate in leisure activities?	Irrelevant	-0.57	0.16	0.07	4.54	7.45
11	Do you have a best friend?	Revision	-0.41	0.14	0.48	2.91	20.79
Productivity							
12	Frequency of travel outside the home	Revision	-0.56	0.45	-1.37	0.16	2.11
13	Jobschool	Revision	-0.19	0.61	0.99	0.81	7.84
Electronic Social Networking							
16	Frequency of writing to people using the Internet	Satisfactory	-0.25	0.51	0.29	-0.16	2.72
17	Frequency of talking to people using an online video link	Satisfactory	-0.12	0.37	1.24	0.97	0.29
18	Frequency of talking to people or texting using a phone	Satisfactory	-0.23	0.46	-0.98	-0.27	1.73

8.3 Novel contributions to knowledge

This doctoral research applied a mixed-methods approach to evaluate the reliability and validity of an outcome measure. It also demonstrated the application of advanced methods of Rasch analysis in investigating and improving the reliability and structural validity of the measure. This section focuses on discussing each of these contributions, including how the research findings challenge and/or enhance current knowledge on conceptualisation and measurement of community integration.

8.3.1 Application of mixed-methods approach

The specific 'concurrent nested approach' of a small qualitative study contained within a larger quantitative study as applied in this research, is relatively uncommon in examining validity of an outcome measure in health research. Typically, content validity of a measure is examined during its developmental stage prior to implementation (Creswell, 2014; Morse, 1991). However, many studies rely on statistical analysis in establishing the reliability and validity of a measure and do not discuss content validity despite it being an essential criterion, representing the construct being measured (e.g. see chapter 3). The use of a measure in a different cultural group than the one it was originally developed in, is debatable (Pasick, 1997; Stewart & Napoles-Springer, 2000). This research supports the importance of re-examining the validity of a measure when considering its application in a different clinical and/or cultural group. The study undertook validation of the CIQ-R in the New Zealand TBI population to inform its clinical application by applying a mixed-methods approach. It is consistent with the literature which advocates the usefulness of this method in determining relevancy of the content and identifying any new information not already covered in the measure (Brod et al., 2009). The quantitative study in this research provided evidence for the CIQ-R's statistical validity, while the qualitative study provided new insight into some of the aspects that have not been reported or well-captured by the measure, hence providing evidence of limited conceptual and practical adequacy of the measure in a New Zealand TBI population. This methodological approach can be recommended to inform future outcome measure validation research.

8.3.2 Application of advanced statistical methods

Psychometric analyses of outcome measures are primarily limited to methods based on classical test theory (CTT). A number of commonly used health measures with significant practical implications have been developed using a CTT approach. Advanced psychometric approaches such as the Rasch measurement model are applied to supplement or complement the traditional measurement approach (Medvedev, Siegert, Kersten, & Krägeloh, 2016; Millis et al., 2014; Tennant & Conaghan, 2007). This research contributes novel findings based on the application of state-of-the-art methods of Rasch modelling in evaluating and refining the community integration questionnaire (CIQ), which had been originally developed using CTT methods. This analysis has provided valuable information about the scale and its individual items contributing to their reliability and construct validity. These findings also indicated the modifications required in order to enhance precision and reliability of the scale. The most important contribution of this work includes transformation of ordinal-level responses of the CIQ into linear, interval-level scores. This can now be applied to any future trials or studies involving a similar clinical population. Such a contribution has been acknowledged by other studies for providing enhanced precision and interval-scores that can be used in parametric statistical analyses (Feng et al., 2016; Tennant & Conaghan, 2007).

8.3.3 Conceptualisation and measurement of community integration

Dimensionality and purpose

This research has elucidated a more nuanced definition and conceptualisation of community integration and contributed to a well-rounded understanding of the construct and its multi-dimensional nature. The conceptual framework derived in this research (re-illustrated in Table 8.1) offers a broader, richer perspective on community integration for brain injury rehabilitation.
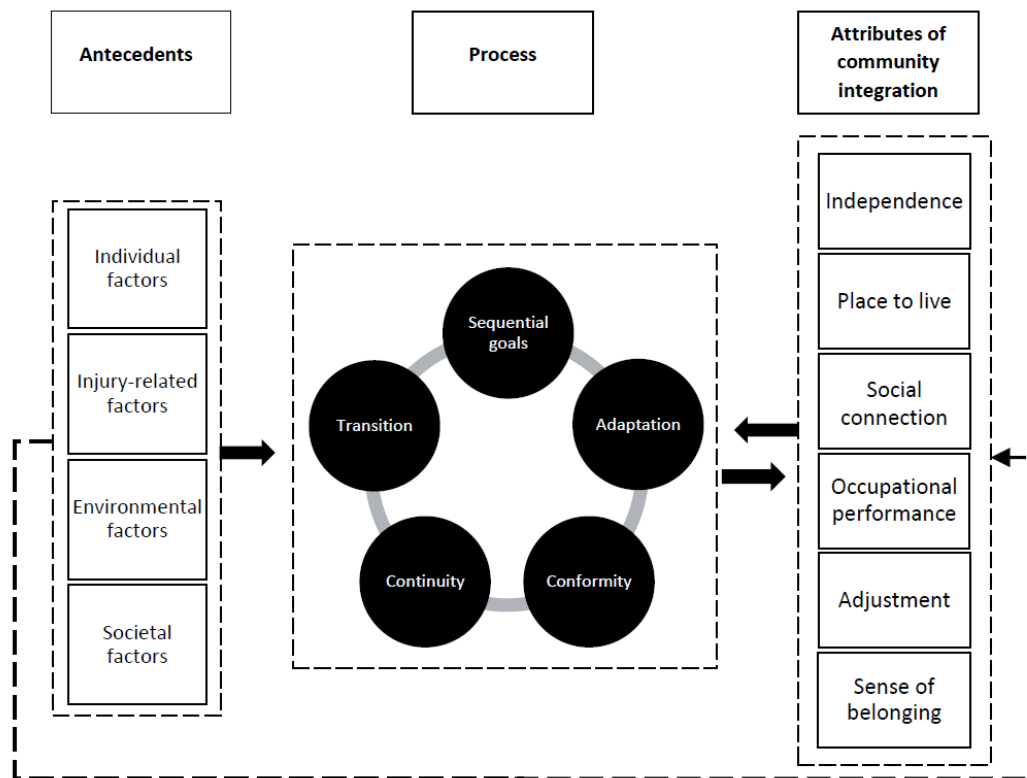
Figure 8.1: Conceptual framework of community integration

Community integration is an outcome-oriented concept and unlike other rehabilitation concepts such as engagement, coping, motivation, it is not often discussed in the wake of a variety of antecedents affecting the outcome. Negative outcome is commonly considered to be associated with severity of injury and residual impairments as well as other demographic, predisposing factors (Andelic et al., 2016; Callaway et al., 2016; Ditchman et al., 2016; Lefebvre et al., 2008; Sander et al., 2010; Sander et al., 2011; Winkler et al., 2006). This ignores the role of personal attributes, social interactions, opportunities to make meaningful contributions to the community, and environmental factors in 'disintegration' (or failure to integrate), which were found to be very influential for integration in the conceptual review findings. The importance of ongoing injury-related symptoms, personal attributes, availability of social support and external environment, was also strongly reflected in the empirical research. Considering these aspects while conceptualising and measuring community integration supports the findings by O'Neil-Pirozzi et al. (2015); Turner et al. (2007), which view integration as a process of on-going transition facilitated by interactions between an individual and his or her social support and environment. This study provides some clarity around the

issue raised in Chapter One about distinction between the concepts of community integration and participation even though this was not specifically explored. From the conceptualisation, it is clear that community integration is a process of assimilation into a meaningful activity where 'sense of belonging' is essential (Shaikh et al., 2018). On the contrary, ICF component of 'participation' (which is defined as *performance*) is based on involvement in daily tasks (WHO, 2001). The current study portrays community integration as a 'state' which may or may not be achieved as a result of 'performance'. For example, a person taking part in domestic, social, occupational, recreational events may not necessarily feel integrated/accepted within his/her community. Moreover, Holsbeeke, Ketelaar, Schoemaker, and Gorter (2009) described performance as an individual's actual function in their own daily environment. ICF's other component 'activity', is defined by WHO (2001) as *capacity*, indicating one's ability to perform a task in a standardised environment. The CIQ-R appears to measure one's ability to do certain tasks without any regards to influences of external environment, hence it represents 'activity' rather than 'participation'. This suggests that it is time to revisit the theoretical framework of the CIQ-R as a measure of community integration to make the distinction as to whether we want to measure capacity, or performance.

Measurement of community integration by the CIQ-R, is limited to the observable and objective aspects of community integration for example, frequency of shopping. Whereas more abstract concepts of belonging and adjustment are pertinent to personal experiences and are commonly measured as subjective performance similar to related health concepts such as quality of life, satisfaction and coping (McDowell, 2006). The focus on objectivity evident in the CIQ-R questions and response options (e.g. 'preparing meals by yourself or with someone else', 'frequency of travel outside home'), was challenged by respondents in the qualitative study (Chapter Seven). People valued the quality of their performance over the frequency of tasks completed and perceived satisfaction was integral to their community integration. Thus, perceived quality and satisfaction are considered as subjective constructs and they are prone to being influenced by personal feelings or opinion (Kayes & McPherson, 2010). This indicates that the outcome measure of community integration should consider

incorporating subjective performance for more meaningful estimation of a subject's level of integration.

Recommendations for further refinement of the CIQ-R

Based on the conceptual framework developed here and the empirical findings, a pool of refined, potential items was derived as listed in Table 8.2 below. These proposed items will need to be validated in future research prior to their application in rehabilitation research and clinical practice. In the refined version, items 7 ('frequency' of shopping') and item 10 ('with whom do you participate in leisure activities?') have been removed as these items were identified as ambiguous and did not appear to yield any new information. In addition, items were re-worded to enhance their relevance and the specific timeframe from the CIQ-R responses was modified to a more meaningful Likert-scale ranging from 'always' to 'never'. The proposed items also accommodate the issue of 'competence vs change' by adding a reference to pre-injury status as suggested by Sander et al. (1999). Additionally, subjective performance can be incorporated to capture not only individual's ability to do a task but also how well a person can perform the task considering the adaptations he/she needs to make in order to successfully complete it. The proposed approaches to application of the CIQ-R for more thorough evaluation of one's level of community integration include:

1) Measuring competence: Response categories for 'competence' include a 6-point Likert scale ranging from 'always' to 'never'. For example,
   "Do you participate in shopping for groceries or other necessities in your household?"
   Always (5), Very frequently (4), Occasionally (3), Rarely (2), Very rarely (1), Never (0)

2) Measuring change since injury: All CIQ-R items can be supplemented by a question about 'change since injury'. Rehabilitation outcomes can be compared with pre-injury status by using a version of the CIQ-R using a 5-point Likert scale where 0 indicates 'extreme' change and 4 indicates 'no' change. Higher scores represent a better level of integration. For example,
   "Has your ability to look after your personal finances, such as banking or paying bills changed after the injury?"
   Not at all (4), Slightly (3), Moderately (2), Very (1), Extremely (0)

3) Measuring subjective performance: All CIQ-R items can be supplemented by a question about performance as perceived by an individual. Response categories include a 5-point Likert scale where 0 indicates 'extremely poor' and 4 indicates 'excellent'. For example,

"How do you rate your ability to travel outside the home using a private vehicle or public transport?"

Excellent (4), Above Average (3), Average (2), Below Average (1),

Extremely Poor (0)

Table 8.2. Proposed revised version of the CIQ-R

Subscale/ items	Items[a]
Home Integration	
1	Do you participate in shopping for groceries or other necessities in your household?
2	Do you usually prepare meals in your household?
3	Do you usually do normal everyday housework?
4	Do you usually care for the children/grandchildren in your home?
5	Do you usually plan social arrangements such as get-togethers with family and friends?
6	Do you usually look after your personal finances, such as banking or paying bills?
Social Integration	
7	Do you usually participate in leisure activities that you enjoy such as entertainment, sports, tramping, restaurants/cafes, swimming, gardening etc?
8	Do you usually visit friends or relatives?
9	Do you have a friend or partner in whom you confide?
Productivity	
10	Do you travel outside the home using a private vehicle or public transport?
11[b]	Please check the answer that best corresponds to your current (during the past month) work situation:
12[b]	Please check the answer that best corresponds to your current (during the past month) school or training program situation:
13	Do you engage in volunteer activities?
Electronic Social Networking	
14	Do you write to people for social contact using the Internet (e.g., email, social networking sites such as Facebook)?
15	Do you talk to people for social contact using an online video link (e.g. Skype, FaceTime)?
16	Do you make social contact with people by talking or text messaging using your phone?

[a] All items are to be supplemented by two question: "Has your ability to do this activity changed after the injury?" and "how do you rate your ability to do this activity?".
[b] Same response categories as the CIQ-R for the competence question

Figure 8.2 demonstrates a proposed structure of the scale item incorporating competence, change since injury and quality of an activity.

1a. Do you participate in shopping for groceries or other necessities in your household?

□ Always   □ Very frequently   □ Occasionally   □ Rarely   □ Very rarely   □ Never

1b. Has your ability to participate in shopping for groceries or other necessities in your household changed after the injury?

□ Not at all   □ Slightly   □ Moderately   □ Very   □ Extremely

1c. How do you rate your ability to participate in shopping for groceries or other necessities in your household?

□ Excellent   □ Above Average   □ Average   □ Below Average   □ Extremely Poor

Figure 8.2 Example of a proposed revised version of item 1

8.4 Limitations

Drawing on the findings of the current research, several limitations and recommendations for future research should be considered. The measurement review, conducted to address the second objective of selecting an appropriate outcome measure of community integration, utilised an initial version of quality criteria for psychometric properties (Terwee et al., 2007) . The new and updated version of these criteria provides more sophisticated guidelines for consensus-based taxonomy, terminology, and definitions of psychometric properties of patient-reported outcome measures currently known as the COSMIN checklist. This checklist also includes guidelines for assessing psychometric studies based on item response theory, which were not applied in this research (Mokkink et al., 2010; Terwee et al., 2012). It is recommended to use the COSMIN checklist for any future research or clinical practice scrutinising quality of measurement studies.

This research was conducted in a single country (New Zealand), therefore empirical findings supporting the reliability and validity of the CIQ-R are limited to that geographic location and culture, and further research needs to retest the measure and report the evidence to establish generalisability. Additionally, while this research aimed to recruit a diverse sample, a wider cultural demographic was not accurately captured in the survey data, with relatively low representation of Pasifika, Asian and other ethnic groups. A further limitation of the current research is that the qualitative study lacks cultural-specific perspectives of New Zealand population, in particular ethnic groups other than New Zealand European e.g. Maori, Pasifika, and Asian. Future

research should explore examining more representative groups, as they may offer different perspectives than those captured in this research and also ensure that these community voices are heard appropriately.

It is important to note that the CIQ-R findings of the current empirical research are derived from a wider community-based sample and are not specific to a particular age-group, severity of injury, time since injury, socio-economic status, intensity of rehabilitation received, as well as level of education. These factors are known to affect injury-related outcomes in people with TBI (Andelic et al., 2016; Callaway et al., 2016; Ditchman et al., 2016; Lefebvre et al., 2008; Sander et al., 2010; Sander et al., 2011; Wehman et al., 2009). Therefore, it is recommended that transferability of these findings to the specific rehabilitation or personal contexts should be applied with caution. Moreover, the majority of participants were recruited through community-based rehabilitation providers and support groups, which may limit generalisability of the findings to people who did not receive rehabilitation or support group services. Access to rehabilitation and support group post-injury is believed to enhance outcomes (Gordon et al., 2006; Hibbard et al., 2002; Vandiver & Christofero-Snider, 2000), hence people recruited in this research may differ from people with TBI who did not receive rehabilitation post-discharge from the hospital or were not part of the support group.

This research provides evidence which is limited to dimensionality, internal consistency, internal construct validity, concurrent validity, and content validity of the CIQ-R. However, further evaluation of the measures is required to establish test-retest and inter-rater reliability, responsiveness and discriminant validity to enhance its clinical utility. Furthermore, content validity of the CIQ-R was assessed by consulting only people with TBI. Terwee et al. (2018) recommended that the evaluation of content validity based on relevance, comprehensiveness, and interpretability of the measure should involve both patients and professionals. Further research is required to capture perspectives of researchers and clinicians on the content of the measure items and response options.

The Rasch model offered the conversion to interval level scale data that is considered appropriate for parametric statistical analysis in psychometric research. However

ordinal scores of an individual item or subscale level may sometimes be more useful in interpreting individual functioning and also aid in goal-setting and clinical decision-making. The ordinal scores had been considered to be clinically meaningful for other health-related measures such as the Functional Independence Measure (FIM) (Hobart, Cano, & Thompson, 2010; Lundgren Nilsson et al., 2005). Furthermore, the interval level scores of the CIQ-R display relatively smaller sensitivity (range 14 to 18) in the middle range of the scale in comparison with the ordinal level scores (range 12 to 21) (see Table 6.6 on page 137). Hence, the interval level scores may be less responsive to clinical change in the mid-range and further work is required to investigate the impact and effectiveness of using transformed scores in clinical practice.

8.5 Clinical implications

A number of clinical implications arising from this doctoral research are discussed here. First, quality criteria proposed by Terwee et al. (2007) for studies involving psychometric examination of the measures are applied and these applications have been detailed in this research. These criteria and their application can be adapted to aid selection of outcome measures in clinical settings. It also highlights that various psychometric properties and their quality criteria including standards of content validity, construct validity, reliability, responsiveness, floor and ceiling effects are vital in gauging a measure's robustness prior to its use in practice.

This thesis has extended current knowledge by exploring components of community integration and providing a more comprehensive model. In addition, factors influencing the community integration process and outcomes were highlighted, which need to be addressed during clinical interventions to facilitate successful integration in people with TBI. Furthermore, encompassing these components, including independence, social engagement, return to meaningful occupational activity, and psychological wellbeing informs the focus of the goal-setting process and targeted professional practice.

The CIQ-R is found be subject to some limitations: for example, the ceiling effect for the home integration subscale, low reliability of the productivity subscale and issues with comprehensibility and relevance of the content. However, it appears to be an appropriate measure for use in clinical practice for exploring outcomes of community

integration after rehabilitation, based on its strong statistical properties. The CIQ-R can be used in its original form until further refinement and validation is completed based on recommendations made in this research.

This research raises an overarching issue that self-report measures assessing constructs such as community integration, return to work, psychosocial reintegration may not always provide particularly useful information when measured objectively. The findings from this research suggest that capturing subjective experience of integration and satisfaction with acquired goals along with objective measurement, may be a more valid approach in rehabilitation measurement. Another issue raised in this study is that treatment or measurement without addressing influential environmental and personal factors may not yield expected outcomes. Clinicians must acknowledge that community integration outcomes are not only affected by disability or impairment but also by lack of access, support, resources, and attitudes. This indicates that well-rounded therapeutic intervention, with structural and social support networks, is a more responsible way to shape the healthcare for a person with TBI.

8.6 Conclusion

This research significantly enhanced current understanding of community integration by providing an operational definition for community integration and confirmed that it is a multi-dimensional concept. The study also considered the process of outcome measure selection in research or clinical settings and suggested the advanced methods that can be applied in future practices. Psychometric analysis of the most frequently applied and thoroughly researched measures the CIQ and CIQ-R was the main focus of the research. The findings from this research provide empirical evidence supporting the construct validity, concurrent validity and reliability of the CIQ-R. The Rasch analysis of the CIQ-R contributed to substantial improvement in measurement precision by providing an ordinal-to-interval level score transformation algorithm. Furthermore, these findings offer empirical evidence about the content validity of the measure and elaborate the issues identified by the participants with TBI. Collectively, these findings were applied in refinement of the existing measure's content in an attempt to offer a relevant, appropriate and comprehensive outcome measure of community integration.

By elucidating different components of community integration, this research indicates important advances are still to be made. Further, exploration of effects of antecedents on community integration outcomes may provide better understanding about how community integration is achieved amidst various contexts. The findings may also prompt researchers and practitioners to evaluate and reflect on their knowledge of the complex process of community integration. The operational definition of community integration may be a step forward towards the development of improved operational measures representing each important component of the new definition. The candidate items of the measure proposed in this research can be potentially applied in such a developmental process and further validated through longitudinal research involving different cultural settings to advance the findings of this research.

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Appendices

Appendix A: Ethical approval

AUTEC Secretariat

Auckland University of Technology
D-89, WA505F Level 5 WA Building City Campus
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

7 September 2015

Paula Kersten
Faculty of Health and Environmental Sciences

Dear Paula

Re Ethics Application: 15/237 Community integration: Conceptualisation and measurement.

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 7 September 2018.

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 7 September 2018;

- 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 7 September 2018 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.

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: Nusratnaaz Shaikh nshaikh@aut.ac.nz, Richard Siegert

AUTEC Secretariat

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25 February 2016

Richard Siegert
Faculty of Health and Environmental Sciences

Dear Richard

Re: Ethics Application: 15/237 Community integration: Conceptualisation and measurement.

Thank you for your request for approval of amendments to your ethics application.

I have approved minor amendments to your ethics application allowing the changes to the data collection instrument.

I remind you that as part of the ethics approval process, you are required to submit the following to the Auckland University of Technology Ethics Committee (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 7 September 2018;

- 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 7 September 2018 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.

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: Nusratnaaz Shaikh nshaikh@aut.ac.nz, Alice Theadom

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Appendix B: Search Strategy for Concept Analysis

1. Community integration
2. Community reintegration
3. Community participation
4. Community re-entry
5. Social integration
6. Socialization
7. Social participation
8. Return to work
9. Work participation
10. Transition home
11. OR/1-10
12. Brain injury
13. TBI
14. Traumatic brain injury
15. ABI
16. Acquired brain injury
17. CVA
18. Cerebrovascular brain injury
19. Stroke
20. Cerebrovascular disease
21. Hemiplegia
22. OR/12-21
23. 11 AND 22
24. Review
25. Concept
26. Measure
27. Assessment
28. Perception
29. Experience
30. Model
31. Construct
32. OR/24-31
33. 23 AND 32

In addition, citation lists of relevant articles were searched for articles not found in database search were identified.

Appendix C: Search Strategy for Measurement Review

1. Community integration
2. Socialization
3. Community reintegration
4. Community participation
5. OR/1-4
6. Brain injury
7. TBI
8. Traumatic brain injury
9. ABI
10. Acquired brain injury
11. CVA
12. Cerebrovascular brain injury
13. Stroke
14. Cerebrovascular disease
15. Hemiplegia
16. OR/6-15
17. 5 AND 16
18. Outcome measure
19. Outcome assessment
20. 17 AND 18-19
21. Community integration questionnaire
22. Craig Handicap Assessment and Reporting Technique
23. Reintegration to normal living index
24. Community integration measure
25. Sydney psychosocial reintegration scale
26. 17 AND 21
27. 17 AND 22
28. 17 AND 23
29. 17 AND 24
30. 17 AND 25

In addition, reference lists of relevant articles were searched, and additional searches for specific psychometric properties were conducted for each outcome measure.

Appendix D: Cover Letter from Recruitment Localities

AUT

Date

Xxxxx

Xxxxx

Xxxxx

Xxxxx

Dear XXXXXX

Our organisation is currently working with researchers at the Auckland University of Technology (AUT) on some research looking at community integration in people with Traumatic Brain Injury (TBI) and stroke.

Enclosed is some information about a small study that we would like to give you the opportunity to participate in. Also enclosed is a consent form and a stamped self-addressed envelope. If you would like to take part in this study, then please complete the consent form and post it to the researchers at the AUT in the envelope provided.

In order to protect your Privacy, we have mailed this letter to you directly from our office. Please post your reply, using the envelope provided, directly to the researchers at AUT.

Please note that:

• We have not divulged your name and address to AUT or the researchers

• Your reply goes directly to the Researchers and we are not informed of the names and addresses of those that choose to participate

Yours sincerely

GENERAL MANAGER

Participant Information Sheet

Exploring community integration in people with acquired brain injury (ABI)

Invitation

| **Principal Researcher:** | Nusrat Shaikh | nshaikh@aut.ac.nz |
| | | Free phone: 0508 224737 |

Tēnākoe, talofa lava and hello. You are invited to take part in a study exploring community integration/engagement in people with ABI. The study is being carried out by a PhD candidate based in the Person Centred Research Centre at AUT University.

This information sheet will explain the research study. We appreciate your time reading this material. Please consider:

- Your participation in this study is entirely voluntary (your choice). You do not have to take part in this study and, whether you take part or not, will not result in any disadvantage to you.
- If you do agree to take part, you are free to withdraw at any time without having to give a reason.
- If you would like to go through this information sheet with someone in person or if you have any questions about anything you do not understand please feel free to contact the researcher on **0508 224737**.

What is the purpose of the study?

We are trying to develop a valid and reliable questionnaire tool to measure community integration in people with Acquired Brain Injury. There are two parts to this research:

> **Part One** aims to investigate the suitability of the existing measures of community integration in people with ABI
>
> **Part Two** aims to explore the perspectives of people with ABI with regards to the suitability of these measures and to also explore the important aspects of community integration that are important to them.

How will this study help?

This study will help investigate the appropriateness of the measurement tools that we currently use to measure how well people re-integrate into their community after their injury. Your views and experiences will help us understand the most important aspects of community integration and the best ways that we can measure them. The findings of this study will help us form the model of community integration and based on that we will be able to develop a valid and reliable tool to measure community integration in ABI population, thereby contributing towards enhanced health outcomes for this population. This research is expected to increase awareness of community integration post acquired brain injury in wider community.

How are people chosen to be asked to be part of the study?

Anyone who has sustained a stroke or traumatic brain injury and who has accessed the services of THINK-NZ, Stroke Foundation, Brain injury Association, or ABI Rehabilitation have been sent an information pack about this study. Rehabilitation representatives at these agencies then sent this invitation to take part on our behalf. Furthermore, the study will be advertised on social media such as local newspaper or magazine as well as Facebook page to invite people to be part of the study. Potential participants will be selected based on the eligibility criteria described below.

Who is eligible to participate?

You are eligible to participate if you are aged 18 or older and have been diagnosed with either stroke or traumatic brain injury. You must have been living in a community setting for at least 6 months after your injury and be able to complete this online questionnaire.

What happens in the study?

If you would like to participate in this study, there are two ways you can do this:

Part One: You can complete the questionnaire by clicking on the survey link provided to you, the questionnaire asks you questions about your current level of integration/engagement in to community.

Part Two: You can also take part in an in-depth interview to share your experience of filling out the questionnaire and also discuss more about your injury experiences and future expectations with regards to your involvement or active participation in the community.

1. **If you want to complete the questionnaire:**
You can complete the questionnaire online or by telephone interview
Use the link and complete the online survey or phone/email the researcher and arrange for a convenient time for you to complete the questionnaire over the phone.

2. **If you also wish to be considered to take part in a more in-depth interview**
You may indicate on the consent form if you are happy to be contacted to take part in an in-depth interview, exploring the validity of the questionnaire and aspects of community integration in more detail. We will select only 20 consenting participants, with a range of diagnosis, age, severity and ethnicity, to take part in these interviews. We will arrange a time and place that is convenient to you to conduct the interviews. These interviews will be audio-taped and transcribed.

What are the risks of this study?

There are no known risks to you from this study. However, you could find answering some of the questions difficult or distressing. If such issues do arise and you would like to discuss this with someone, then please phone the researcher so we are able to refer you to stroke or brain injury support services or Health and disability board as appropriate. It is also possible that you may find the interview session tiring, but we will try to minimise this for you by going at your own pace and giving you the opportunity to take a break at any time if you desire.

How will my privacy be protected?

All of the information you provide us with and the interview recordings will remain strictly confidential. All computer records will be password protected and the password will not be known to anyone but the researcher. Your questionnaire will be given a code and the answers you give in the questionnaire

will not be able to be tracked back to you. We will keep the consent forms and questionnaires locked in a cabinet, in separate locations. No material that could personally identify you will be used in any reports from this study.

The researchers are independent of THINK-NZ, ABI rehabilitation, Brain Injury Association, and Stroke Foundation and so we have no access to their records. Likewise, these Rehabilitation service providers will have no access to individual data collected for the purposes of this study. Upon completion of the study your records will be stored for at least 10 years in a secure, locked cabinet at Auckland University of Technology. All future use of the information collected will be strictly controlled in accordance with the Privacy Act.

What are the costs of participating in the project?

The cost to you is the time and effort you choose to contribute. The questionnaire should take approximately 15-20 minutes to complete. If you participate in the interview it will last for approximately one hour.

What will happen with the results?

The findings from this study will help us to develop improved measurement tools for rehabilitation practitioners. In addition, the findings will be made available to rehabilitation service providers and may be used to inform their service developments. Findings will also be presented to health practitioners and academics at conferences or through publication in peer-reviewed journals. No individuals will be able to be identified in these publications or presentations.

Will I be able to have a copy of the results?

If you would like to receive a plain English summary of results you can say so on the consent form and it will be sent to you at the end of the study. The findings should be available approximately 6 months after you take part.

What do I do if I have concerns about this research?

If you have any questions or want more information about this study, please feel free to contact the primary researcher or her supervisors:

	Nusrat Shaikh	0508 224737	nshaikh@aut.ac.nz
	Prof. Richard Siegert	(09) 921 9999 ext 7885	rsiegert@aut.ac.nz
	Dr. Alice Theadom	(09) 921 9999 ext 7805	atheadom@aut.ac.nz

Concerns regarding the conduct of the research should be notified to the executive Secretary, AUTEC, Kate O'Connor at (064) 9 921 9999 Extn: 6038

Statement of Approval

Approved by the Auckland University of Technology Ethics Committee on 7th September 2015. AUTEC Reference number: 15/237

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Consent Form
Exploring community integration/engagement in people with acquired brain injury (ABI)

Principal Researcher:	Nusrat Shaikh	nshaikh@aut.ac.nz 022 303 6995

Please tick to indicate you consent to the following:

	Yes	No
• I have read or had read to me, and I understand, the participant information sheet dated 25/06/15	☐ Yes	☐ No
• I have had sufficient time to consider whether to take part or not and I know who to contact if I have any questions about the study	☐ Yes	☐ No
• I have had the opportunity to ask questions. I am satisfied with the answers I have been given	☐ Yes	☐ No
• I have had the opportunity to use family/whanau support or a friend to help me ask questions and understand the study	☐ Yes	☐ No
• I understand that taking part in this study is entirely voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in anyway.	☐ Yes	☐ No
• I understand that my participation in this study is confidential and no material which could identify me will be used in any reports on this study.	☐ Yes	☐ No

• I consent to taking part in this research and have enclosed a completed questionnaire.	☐ Yes	☐ No
• I wish to receive the summary of the results	☐ Yes	☐ No
• I consent to be contacted to participate in an in-depth interview (**If YES:** Please provide a telephone number below or contact us on 022 303 6995)	☐ Yes	☐ No
• If I participate in an in-depth interview, I consent to my interview being audio-taped and transcribed. **If YES:**	☐ Yes	☐ No
• I wish to have the audio tape returned to me on completion of study (**If NO:** Please note that audio tape will be destroyed)	☐ Yes	☐ No
• I would be willing to be contacted in the future for related research.	☐ Yes	☐ No

Full Name:		
Address:		
Phone:	(Home)	(Mobile)
Signature:		Date:

Appendix G: Demographic Information Sheet

Participant ID			
Today's Date			

dd   mm   yyyy

AUT

Demographic information Sheet

Thank you for agreeing to take part in this study.
Please remember that all information collected about you as part of this study will not be shared with anyone except the research team.

1	**Age:**	_____ Years		
2	**Date of birth:**	__ / __ / ____ (dd / mm/ yyyy)		
3	**Gender:**	☐ Male	☐ Female	☐ Other

4	**Which ethnic group, or groups do you identify with (choose as many as apply):**
	☐ Māori ☐ Tongan ☐ Cook Island Māori ☐ Niuean
	☐ NZ European ☐ Chinese ☐ Indian ☐ Samoan
	☐ Other, Please specify _____

5	**What is your diagnosis?**	
	☐ Stroke	☐ Traumatic Brain Injury
	☐ Others, Please specify _____	

6	**How long ago was a diagnosis of Traumatic Brain Injury or Stroke confirmed?**
	_____ Years _____ Months

7	**What is/was your funding status after your injury?**
	☐ ACC
	☐ Ministry of Health
	☐ Other, Please specify _____

8	Are you currently having rehabilitation (e.g. physiotherapy, occupational therapy, speech language therapy, or counselling) for this condition?
	☐ Yes, Please specify _____
	☐ No
9	Which of the following best describe your relationship status at the time of injury?
	☐ Partnered (e.g. spouse, civil union, de facto)
	☐ Non-partnered (e.g. single, never married, separated, divorced, widowed)
10	What was your work situation at the time of injury?
	☐ Full-time (paid)
	☐ Part-time (paid)
	☐ Other (please specify) (e.g. student, homemaker, volunteer, retired) _____

CIQ-R

Participant ID: _____ **Date of Birth:** __/___/_____ **Today's Date:** __/__/_____

Instructions:

There are 18 items in this questionnaire- **please complete all 18 items.** For each item please tick the box that best describe your situation.

1	Who usually does the shopping for groceries or other necessities in your household?

☐ Yourself alone ☐ Yourself and someone else ☐ Someone else

2	Who usually prepares meals in your household?

☐ Yourself alone ☐ Yourself and someone else ☐ Someone else

3	In your home who usually does normal everyday housework?

☐ Yourself alone ☐ Yourself and someone else ☐ Someone else

4	Who usually cares for the children in your home?

☐ Yourself alone ☐ Yourself and someone else ☐ Someone else

☐ Not applicable (no children under 17 yrs in the home)

5	Who usually plans social arrangements such as get-togethers with family and friends?

☐ Yourself alone ☐ Yourself and someone else ☐ Someone else

6	Who usually looks after your personal finances, such as banking or paying bills?

☐ Yourself alone ☐ Yourself and someone else ☐ Someone else

7 Approximately how many times a month do you usually participate in shopping outside your home?

☐ 5 or more   ☐ 1-4 times   ☐ Never

8 Approximately how many times a month do you usually participate in leisure activities such as movies, sports, restaurants, etc?

☐ 5 or more   ☐ 1-4 times   ☐ Never

9 Approximately how many times a month do you usually visit friends or relatives?

☐ 5 or more   ☐ 1-4 times   ☐ Never

10 When you participate in leisure activities do you usually do this alone or with others?

☐ Mostly alone

☐ Mostly with family members

☐ Mostly with friends who have a disability

☐ Mostly with friends who do not have a disability

☐ With a combination of family and friends

11 Do you have a best friend in whom you confide?

☐ Yes   ☐ No

12 How often do you travel outside the home?

☐ Almost every day

☐ Almost every week

☐ Seldom / never (less than once per week)

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13 Please check the answer that best corresponds to your current (during the past month) work situation:

    ☐ Full-time (more than 20 hours per week)

    ☐ Part-time (less than or equal to 20 hours per week)

    ☐ Not working, but actively looking for work

    ☐ Not working, not looking for work

    ☐ Not applicable, retired due to age

14 Please check the answer that best corresponds to your current (during the past month) school or training program situation:

    ☐ Full-time

    ☐ Part-time

    ☐ Not attending school or training program

    ☐ Not applicable, retired due to age

15 In the past month, how often did you engage in volunteer activities?

    ☐ 5 or more   ☐ 1-4 times   ☐ Never

16 How often do you write to people for social contact using the Internet (e.g., email, social networking sites such as Facebook)?

    ☐ Every day / most days

    ☐ Almost every week

    ☐ Seldom / never

17 How often do you talk to people for social contact using an online video link (e.g. Skype, FaceTime)?

    ☐ Every day / most days

    ☐ Almost every week

    ☐ Seldom / never

18 How often do you make social contact with people by talking or text messaging using your phone?

    ☐ Every day / most days

    ☐ Almost every week

    ☐ Seldom / never

SPRS- Form B

Participant ID: _____   Date of Birth: __/___/_____   Today's Date: __/__/____

Instructions:

There are 12 items in this questionnaire- please complete all 12 items. For each item please tick the box that best describe your situation.

WORK AND LEISURE

1.	Current work: HOW DO YOU RATE YOUR HOURS OF WORK/STUDY, OR THE TYPE OF WORK/STUDY?

(If a student, answer the question in this section in terms of your studies)

☐ Very good:

☐ A little difficulty: I work (study) less than average hours per week, OR work duties (studies) are easy/light one

☐ Definite difficulty: I work casually, OR have some help from others in doing some work (study)

☐ A lot of difficulty: I am unemployed, OR in rehabilitation, OR in a supported work program, OR do volunteer work, OR receive remedial assistance in studies

☐ Extremely poor: I am unable to work (study) at present

2.	Work skills: HOW DO YOU RATE YOUR WORK (STUDY) SKILLS?

☐ Very good:

☐ A little difficulty: For example, I have to put in a lot of effort to get good results, get tired easily, lose concentration

☐ Definite difficulty: For example, I sometimes make mistakes

☐ A lot of difficulty: For example, I am slow, my work is of poor quality

☐ Extremely poor: For example, I need constant supervision and/or reminders

3. Leisure: HOW DO YOU RATE YOUR NUMBER OR TYPE OF LEISURE ACTIVITIES OR INTERESTS?

☐ **Very good:**

☐ **A little difficulty:** I have leisure activities and interests, but I do not do them often

☐ **Definite difficulty:** I have definite difficulties in developing and doing leisure activities of interests

☐ **A lot of difficulty:** I have a lot of difficulty developing and doing leisure activities and interests

☐ **Extremely poor:** I do not have any leisure activities or interests at present

4. Organising activities: HOW DO YOU RATE THE WAY YOU ORGANISE WORK AND LEISURE ACTIVITIES?

☐ **Very good:**

☐ **A little difficulty:** For example, I need prompts or support from others

☐ **Definite difficulty:** I am fairly dependent on other people to organise activities, e.g. others suggest what to do and how to go about it

☐ **A lot of difficulty:** I need other people to do the organising, e.g. making arrangements, providing transport

☐ **Extremely poor:** I am dependent on other people to suggest and organise activities at present

RELATIONSHIPS

5. **Spouse or partner: DO YOU HAVE A PARTNER OR SPOUSE?**
a) **IF YES, HOW DO YOU RATE YOUR RELATIONSHIP?**

☐ **Very good:**

☐ **A little difficulty:** Not good, but still able to get along together, and if it broke down I have the skills to form new relationship

☐ **Definite difficulty:** Definite difficulties, but I have the skills to form and also probably maintain a new relationship

☐ **A lot of difficulty:** I might have the skills to form a new relationship

☐ **Extremely poor:** Relationship is extremely limited (e.g. partner is a primary caretaker) and I do not have the skills to form a new relationship

b) **IF NO, HOW DO YOU RATE YOUR ABILITY TO FORM AND MAINTAIN SUCH A RELATIONSHIP?**

☐ **Very good:**

☐ **A little difficulty:** I have the skills to form and maintain a new relationship

☐ **Definite difficulty:** I have the skills to form and also probably maintain a new relationship

☐ **A lot of difficulty:** I might have the skills to form a new relationship

☐ **Extremely poor:** I do not have the skills to form a new relationship

6. **Family: HOW DO YOU RATE YOUR RELATION WITH OTHER FAMILY MEMBERS?**

☐ **Very good:**

☐ **A little difficulty:** Not good, but I am still able to get along together with family members

☐ **Definite difficulty:** Definite difficulties, but I still see family

☐ **A lot of difficulty:** I have a lot of difficulties getting along with some family members

☐ **Extremely poor:** Relationship is extremely limited and there has been breakdown

7. **Friend and other people: HOW DO YOU RATE YOUR RELATIONSHIP WITH OTHER PEOPLE OURSIDE FAMILY (SUCH AS CLOSE FRIENDS, WORK MATES, NEIGHBOURS)?**

☐ Very good:

☐ A little difficulty: Not good, but I have close friends, can make new friends, and get along with work mates and neighbours

☐ Definite difficulty: Definite difficulties, but I still see some friends once a month or more and can make new friends

☐ A lot of difficulty: I only see a few friends (or other people outside family), and do not make new friends easily

☐ Extremely poor: I do not see any friends (or other people outside the family)

8. **Communication: HOW DO YOU RATE YOUR COMMUNICATION SKILLS (THAT IS, TALKING WITH OTHER PEOPLE AND UNDERSTANDING WHAT OTHERS SAY)?**

☐ Very good:

☐ A little difficulty: For example, I ramble and get off the point, my talk is sometimes inappropriate, I have some trouble finding the words to express myself

☐ Definite difficulty: For example, I have difficulties thinking of things to say, joining in talk with group of people, I only talk about myself

☐ A lot of difficulty: For example, I have trouble understanding what people say

☐ Extremely poor: Communication is almost impossible

LIVING SKILLS

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9. **Social skills: HOW DO YOU RATE YOUR SOCIAL SKILLS AND BEHAVIOUR IN PUBLIC?**

☐ **Very good:**

☐ **A little difficulty:** For example, I am awkward with other people, I do not worry about what other people think or want

☐ **Definite difficulty:** For example, I can act in a silly way, am not tactful or sensitive to other people's needs

☐ **A lot of difficulty:** For example, I am dependent on other people, I am socially withdrawn, I have difficulty interacting appropriately with others

☐ **Extremely poor:** For example, I have temper outburst in public, require supervision when with other people

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10. **Personal habits: HOW DO YOU RATE YOUR PERSONAL HABITS (E.G. YOUR CARE IN CLEANLINESS, DRESSING AND TIDINESS)?**

☐ **Very good:**

☐ **A little difficulty:** For example, I do not take much care

☐ **Definite difficulty:** I attend to own hygiene, dress and tidiness, but I have definite difficulties in this area; OR I need supervision

☐ **A lot of difficulty:** I need prompts, reminder or advise from others, but I respond to these; OR I need stand-by assistance

☐ **Extremely poor:** I need prompts, reminders or advise from others, but I am unwilling to respond to this; OR I need hand-on assistance

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11. Community travel: HOW DO YOU RATE YOUR USE OF TRANSPORT AND TRAVEL AROUND THE COMMUNITY?

NOTE: Do not include the driver of transport, or other passengers using such transport, in rating whether you can travel "on my own".

☐ **Very good:**

☐ **A little difficulty:** I am unable to use some forms of transport (e.g. driving a car) but I can still get around in the community by using other forms of transport without help

☐ **Definite difficulty:** Definite difficulty using transport, but after training I can travel around the community my own

☐ **A lot of difficulty:** I need assistance to plan use transport, but with such help I can travel around the community on my own

☐ **Extremely poor:** I am unable to go out into the community on my own

12. Accommodation: HOW DO YOU RATE YOUR LIVING SITUATION?

☐ **Very good:**

☐ **A little difficulty:** I live in the community, but with emotional or social supports provided by other people, such as family, friends or neighbours.
I could not be left alone without supports for two-week period

☐ **Definite difficulty:** I live in the community, but could not be left alone for a weekend unless someone checked that everything was OK

☐ **A lot of difficulty:** I live in the community but in supported accommodation, such as a group home, boarding house, transitional living unit, in a family home but I require daily supervision or assistance

☐ **Extremely poor:** I need care, which may be at home requiring extensive, daily supervision or other care OR in a facility, e.g. a nursing home, residential service, rehabilitation unit

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Appendix J: Summary of included articles (Chapter 3)

Author	Outcome Measure	Purpose of Study	Participant Information	Mode of administration	Main findings
1993 Willer, Rosenthal, Kreutzer, Gordon, & Rempel	Community Integration Questionnaire; Craig Handicap Assessment and Reporting Technique (CHART)	Development & Initial Validation of the CIQ	(1) N=14 Professionals (2) N=49(pilot-1) moderate to severe brain injury pts; (3) N=16 (pilot-2) Moderate to severe brain injury patient (4) N=94(model system sample); N=352 (community samples with TBI); N=237 non-disabled samples U.S. Population	Focus group for development Not specified for pilot testing	For CIQ: α=0.76. Younger individuals had significantly higher total integration scores than older adults. Females had significantly higher scores on integration into the home, and males had significantly higher scores on integration into productive activities. Agreement: 0.89 Total integration; Test-retest reliability: 0.91; Evidence for construct validity of the CIQ and the CHART
1994 Willer, Ottenbacher, & Coad	Community Integration Questionnaire	Exploratory Comparative analysis of an outcome measure	N=341 TBI N=210 Nondisabled U.S. Population	Self-report, Mail administration	The productivity subscale correlated poorly with the total CIQ score (r = 0.27) and with the subscale scores of home integration (r = -0.27) and social integration (r = 0.15). The social integration and home integration subscales correlated well with the total CIQ score, 0.66 or 0.70, respectively, but correlated poorly with each other (r = 0.07).
1995 Corrigan & Deming	Community Integration Questionnaire	Replication & extension of existing study, exploring psychometrics of the CIQ	Premorbid: N=104 TBI; N=357 other injuries Follow-up: N=46 TBI; N=171 Other injuries U.S. Population	Telephonic interview	α= 0.791(pre-morbid) & α= 0.841 (follow-up); results supported the utility of the CIQ as a measure of handicap following TBI. Problems In the distribution of the productivity subscale suggested that it should not be used independently of the total score; premorbid scores showed a slight negative skew.
1996 Hall, Mann, High, Wright, Kreutzer, & Wood	Community Integration Questionnaire	To examine ceiling effects of Functional Measures such as FIM, FIM+FAM, DRS, and CIQ after TBI	N= 312 TBI (9.7% mild) U.S. Population	In person interview (53%), telephone interview (23%), mail (5%)	33-48% Ceiling effects at 1-year post-discharge
1997 Sander, Seel, Kreutzer, Hall, High, & Rosenthal	Community Integration Questionnaire	Examine agreement between persons with Traumatic Brain Injury and their relatives using the CIQ	N= 122 TBI 1-year post-injury (23%-mild; 18%- Moderate; 59% Severe injury)	Telephonic Interview	Moderate to substantial correlations amongst TBI samples and family members for Home and social integration ranging from 0.42 to 0.70 and Strong agreement (0.69-.94) for the productive activity subscale

Author	Outcome Measure	Purpose of Study	Participant Information	Mode of administration	Main findings
Burleigh 1998	Community Integration Questionnaire	To examine the relationship of the degree of community integration to the life satisfaction of persons with traumatic brain injury (TBI)	N= 30 TBI between 26 and 60 years of age	Self-report face to face questionnaire completion	A significant relationship (rho = .31, p < .05) was found between life satisfaction and social integration (a component of community integration). No significant association was found between the total community integration score and life satisfaction.
1999 Sander, Fuchs, High, Hall, Kreutzer, & Rosenthal	Community Integration Questionnaire	1) to examine the factor structure of the CIQ in a large sample of individuals with TBI 2) To examine the CQI's concurrent validity by comparing CIQ scores to the FAM and the DRS.	N= 312 TBI (Maximum numbers with severe injury) African American patient > General population. U.S. population	Face-to-face Interview, Telephonic Interview	Moderate correlations with DRS and FAM, confirming construct validity for the CIQ
2001 Kaplan	Community Integration Questionnaire	To investigate concurrent validity of the CIQ and influence of demographic variables when used with new scoring guidelines.	N=33 biopsy confirmed malignant brain tumour U.S. Population	Not stated	Women scored significantly higher on Home Integration (r =0.40; p <0:05). Older subjects had lower CIQ scores: CIQ total (r =0.54; p <0:005); Home Integration (r = 0.42; p <0:01); Social Integration (r =0.44; p <0:005); and Productivity (r=0.45; p <0:005). More education was related to higher CIQ total (r =0.31; p <0:05); Social Integration (r=0.30; p <0:05); and Productivity (r =0.35; p <0:05). Significant relationships between CIQ scores and both the Social Activity and Inactivity subscales of the Chronic Illness Problem Inventory (r =0.43; p <0:005 and r =0.68; p <0:005, respectively
2004 Kuipers, Kendall, Fleming, & Tate	Sydney Psychological Reintegration Scale, Community Integration Questionnaire	To examine psychometric properties (Suitability of mail-out administration, Client and proxy responses, correlation b/w the two scales, Theoretical structure of the two scales) of SPRS and CIQ in ABI population	n= 96 ABI n= 121 nominated proxies	Mail-out administration	The SPRS had greater internal consistency and more normal distributions than the CIQ. Correlations between the three pairs of theoretically parallel sub-scales were modest (0.41–0.60). Multi-dimensional scaling did not support the theoretical structure of the sub-scales but found two dimensions underpinning the measurement of community integration.

Author	Outcome Measure	Purpose of Study	Participant Information	Mode of administration	Main findings
Dalesman 2010	Community Integration Questionnaire (adjusted for aphasia)	To describe the feasibility of the Community Integration Questionnaire (CIQ) adjusted for use in people with aphasia and to report its psychometric properties in people with aphasia (internal consistency, factor analysis, test-retest reliability, convergent validity)	N= 150 Stroke with aphasia	Structured interview administration	The CIQ adjusted for people with aphasia was found to be a feasible instrument. Results showed good internal consistency for the CIQ total (standardized Cronbach α= .75), excellent test-retest reliability (intraclass correlation coefficient= .96), moderate correlations with the Barthel Index, the COOP-WONCA, and the Life Satisfaction Questionnaire with regard to construct validity.
Andelic 2016	Community Integration Questionnaire	To assess the trajectories of community integration in individuals with TBI through one, two, and five years post-injury and to examine whether those trajectories could be predicted by demographic and injury characteristics	N= 105 with moderate-severe TBI	Face-to-face interviews	CIQ scores improved across the three time-points (p < 0.001). Additionally, higher trajectories of community integration were predicted by being single at the time of injury (p < .001), higher level of education (p = 0.006), employment (p < 0.001), and a shorter length of PTA (p < 0.001). The longitudinal course of community integration described in this study may help rehabilitation professionals to plan more extensive follow-ups and targeted rehabilitation programs in the early stage of recovery for patients with specific demographic and injury characteristics.
Lequerica, Chiaravalloti, Sander, Pappadis, Arango-Lasprilla, Hart et al., 2013	Community Integration Questionnaire	To examine the factor structure and construct validity of the Community Integration Questionnaire, a widely used measure of community participation among individuals with TBI, among 3 racial/ethnic groups	N=1756 with TBI (n=1192 whites; n=450 blacks; n=114 Hispanics) U.S. population	Face-to-face Interview, Telephonic Interview	The goodness of fit for the factor structure of the Community Integration Questionnaire, separating items into Home Competency, Social Integration, and Productive Activity, was satisfactory for whites but not for blacks or Hispanics. Clinicians and researchers should take race/ethnicity into account when utilising measures of community integration.

Author	Outcome Measure	Purpose of Study	Participant Information	Mode of administration	Main findings
Rintala, Novy, Garza, Young, High Jr et al. 2002	Community Integration Questionnaire	To develop and test the psychometric properties of a Spanish version of the Community Integration Questionnaire (CIQ)	N=70 with SCI N=29 with TBI U.S. Population	Questionnaire completion in a structured interview by research assistant	Total score correlations between Spanish and English version of the CIQ= .83; test–retest reliability=85; internal consistency= .70. The Social Integration subscale was the most problematic and further refinement is recommended.
Seale 2002	Community Integration Questionnaire	To evaluate changes in community integration using the Community Integration Questionnaire (CIQ) for survivors of traumatic brain injury (TBI) who participated in a post-acute rehabilitation programme.	N= 71 with TBI divided into two groups: L1Y-presenting for post-acute rehabilitation less than 1-year post-injury and G1Y-presenting for post-acute rehabilitation between 1±5 years post-injury	Interview administration	Both groups showed significant improvements from admission to follow-up; however, some CIQ findings were more pronounced for the L1Y group. These findings cannot simply be attributed to neurological recovery and individual factors are important to examine when assessing change.
2002 Zhang, Abreu, Gonzales, Seale, Masel, & Otttenbacher	Community Integration Questionnaire; Craig Handicap Assessment and Reporting Technique (CHART)	To compare performance of CIQ, CHART, and DRS in patients with TBI and examine the concurrent validity of the CIQ.	N=70 with a medical diagnosis of TBI. U.S. Population	Structured interview by trained interviewers	Correlation between CIQ and CHART is stronger than that between CIQ and DRS or between CHART and DRS, and the correlation between CHART and DRS is stronger than that between CIQ and DRS. The CIQ appears to be the most appropriate instrument in quantifying rehabilitation outcome in patients with TBI at the participatory (handicap) level.
Whiteneck 1992	Craig Handicap Assessment and Reporting Technique (CHART)	To describe the design and development of the CHART, using the WHO model and examine psychometric properties of the CHART by pilot testing the instrument in individuals with SCI	N= 135 with SCI with 2 to 35 years postinjury aged between 16 and 74 N=135 family members as proxy; (n=41 complete quadriplegia; n=38 incomplete quadriplegia; n=42 complete paraplegia; n=13 incomplete paraplegia)	Face-to-face interview	The test-retest reliability coefficient for the overall CHART score was .93. For individual dimensions, the coefficients were .92 for physical independence, .95 for mobility, .89 for occupation .80 for economic self-sufficiency, and .8 1 for social integration. For the social integration dimension, the subject-proxy correlation was low at .28. Rasch analysis showed that the item separation reliability was .99 which indicated that the CHART is a well-calibrated scale.

Author	Outcome Measure	Purpose of Study	Participant Information	Mode of administration	Main findings
1995 Segal & Schall	Craig Handicap Assessment and Reporting Technique (CHART)	1. To document proxy agreement for the CHART of stroke survivors. 2. To establish the internal structure of the scales of the CHART for Stroke Survivors. 3. To identify the relationships among the survivors' CHART total, scale scores, and Functional Independent Measure (FIM) ratings.	N= 40 Dyads (Stroke survivors and their caregivers/significant others)	In-person interview	Proxy agreement ICC= 0.77; Significant correlation with the FIM (0.53-0.68)
2001 Cusick, Brooks, & Whiteneck	Craig Handicap Assessment and Reporting Technique (CHART)	To assess the level of agreement b/w persons with various disabilities and their proxies in reporting community integration outcomes using the CHART	N = 983 (n=83 amputation; n=65 burns; n=235 MS; n=224 SCI; n = 177 strokes; n=199 TBI) U.S. population	Telephonic interview	Strong agreement Kappa= 0.61-0.80
2001 Hall, Bushnic, Lakisic-Kazazic, Wright, & Cantagallo	Craig Handicap Assessment and Reporting Technique (CHART)	To determine which outcome measures are best and least suited for assessing long-term functional outcome of individuals with traumatic brain injury (TBI) in the community	N = 48 moderate to severe TBI, U.S. population	Administration by mail and telephone conducted by a trained interviewer	Measures that showed a range of deficits across participants were DRS employability, the NFI, PCRS, and the R-CHART cognition subscale. A positive correlation was found between NFI and PCRS and the R-CHART cognition subscale.

Author	Outcome Measure	Purpose of Study	Participant Information	Mode of administration	Main findings
2003 Walker, Mellick, Brooks, & Whiteneck	Craig Handicap Assessment and Reporting Technique (CHART)	To assess test-retest reliability, across a range of disability groups, of the chart	N = 1110 community-based participants (n = 236 SCI, n = 242 TBI, n = 248 MS, n = 223 Stroke, n = 91 Amputation, n=70 Burns) U.S. population	Administration by telephone	Overall, the ICC for the CHART and its subscales range from 0.81 (Social Integration, Occupation, and Economic Self-Sufficiency) to an overall high of 0.93 (total CHART). The CHART offers an opportunity to measure societal participation and is able to differentiate group characteristics across a range of impairments.
2001 McColl, Davies, Carlson, Johnston, & Minnes	Community Integration Measure	To develop and perform preliminary validation of the community Integration measure	N=92; n=41Moderate to severe ABI, n=36 community college students(volunteers), n=15 family members of ABI samples		α=0.87. Content validity was assured by the development procedure, correspondence with the theoretical model, and direct use of consumer language. Discriminant validity was supported by the CIM's ability to differentiate between subsamples. Criterion validity was supported by using correlations with the Community Integration Questionnaire. Construct validity was supported by correlations with the Interpersonal Support Evaluation List.
Minnes 2003	Community Integration Measure	To contribute to a clearer understanding of the construct of community integration in relation to three measures of community integration: the AIMS Interview, Community Integration Measure and Community Integration Questionnaire	N=64 adults with ABI	Face-to-face interview	Significant correlations were not found between total scores on the three measures and problem behaviour or quality of life. However, significant correlation between the first item on the Community Integration Measure (i.e. sense of belonging) and quality of life.
2005 Reistetter, Spencer, Trujillo, & Abreu	Community Integration Measure	To examine reliability and validity of the community integration measure	N= 51 Severe to mild ABI, N=40 Non-brain Injury samples	Telephonic Survey	α= 0.72 to 0.83, Significant positive correlations were found among the CIM and both the CIQ-R and SWLS; The CIM discriminated between subject samples as well as by living arrangement. The factor loading solution revealed a three-factor model that explained 63.72 percent of the variance.

Author	Outcome Measure	Purpose of Study	Participant Information	Mode of administration	Main findings
2010 Griffen, Hanks, & Meachen	Community Integration Measure	To investigate the reliability, validity, and utility of the CIM among a large sample of participants with a history of Mild-complicated TBI	N=279 mild-complicated TBI Completed TBI at 1-year post-injury n=77, 2 years n=78, 5 years n=69, 10 years n=62, 15 years n=52 U.S.A population	Self-report at follow-up appointments	α=0.87; The CIM was most strongly correlated with the SPS, a measure of social support (r =0 .51, p < .01)., the BSI-18 (rs from –.23 to –.37, p < .01), the SF-12 mental composite score (r =0 .37, p <.01), and the SWLS (r =0 .32, p < .01). The CIM was not significantly correlated with the Physical independence subscale of the CHART (r = .04, p <.49). The utility of the CIM was evident in its prediction of perceived social support.
2014 Millis, Meachen, Griffen, Hanks, & Rapport	Community Integration Measure	To evaluate measurement properties and conformity or fit for the CIM using Rasch Analysis in persons with TBI.	N= 279 for 1 to 15 years post injury	Archival data (Collected using self-report at different times	The CIM met Rasch expectations of unidimensionality and reliability (person separation ratio=2.01, item separation ratio=4.52). The CIM is a relatively reliable and unidimensional scale.
1999 Tate, Hodgkinson, Veerabangsa, & Maggiotoo	Sydney Psychosocial Reintegration Scale	To examine psychometric properties (Reliability, Validity, and Responsiveness) of SPRS in persons with Traumatic Brain Injury	Sample 1: Long-term TBI (sufficiently Severe, Almost 2 years post-trauma) n= 40 Time 1: First administration post-discharge from inpatient rehabilitation Time 2: One month following the first administration Sample 2: Subacute n= 20 Australian Population Time 1: At admission to the unit Time 2: either at discharge or three months after study commencement date, whichever occurred first.	Semi-structured interview by Professional & Trained Interviewers (Physician/ Clinician/ Clinical Psychologist)	α=0.90; Agreement between ratters and stability over a one-month period (ri =0.95 and 0.90, respectively). Reliability and stability coefficients for the three domains of the scale were also high, ranging from .86 to .94 for reliability and .77 to .93 for stability. Preliminary evidence for construct validity was established with a number of standard instruments, with evidence of both convergent and discriminant construct validity from the Sickness Impact Profile (SIP). The SPRS was sensitive to group differences on the Glasgow Outcome Scale (GOS) and to changes occurring during the period of active recovery.

Author	Outcome Measure	Purpose of Study	Participant Information	Mode of administration	Main findings
2004 Tate, Pfaff, Veerabangsa, & Hodgkinson	Sydney Psychosocial Reintegration Scale Form A: Original SPRS that measures changes from premorbid level Form B: new version that measured current level of competency without reference to premorbid level of functioning	To assess the psychometric properties of Form B of the SPRS and comparability between Form A and Form B. To compare scores of clinicians and those of close relatives of people undergoing inpatient rehabilitation for brain injury.	N=66 total TBI sample N=46 subset of total sample assessed one week later the first administration of Form A and B. N=25 close relatives of the inpatient	Completion by clinician and relatives of the inpatients	The internal consistency of Form B was high (α=0.90), as was stability (intraclass correlation coefficient [ICC=0.90) and interrater agreement (ICC=0.84). Comparability between forms was excellent (ICC=0.97), and correspondence between ratings of the clinician and close relatives on Forms A and B was fair to good (ICC=0.57, ICC=0.67, respectively

Author	Outcome Measure	Purpose of Study	Participant Information	Mode of administration	Main findings
2011 Tate, Simpson, Soo, & Lane-Brown	Sydney Psychosocial Reintegration Scale Form A: Original SPRS that measures changes from premorbid level Form B: new version that measured current level of competency without reference to premorbid level of functioning SPRS-2: Revised 5-point rating scale	1) To determine equivalence of both versions (7-points & 5-points) of the SPRS and compete for their psychometric properties. 2) To further examine the construct validity of the SPRS using Rasch Analysis. 3) To present normative and TBI comparison data for SPRS-2. 4) To derive reliable change index data for the SPRS-2 to interpreted changes in scores at different respondent level.	Aim 1: Sample A: Long-term TBI (sufficiently Severe, almost 2 years post-trauma) n= 40 Time 1: First administration post-discharge from inpatient rehabilitation Time 2: One month following the first administration Sample B: Subacute n= 20 Australian Population Time 1: At admission to the unit Time 2: either at discharge or three months after study commencement date, whichever occurred first. Aim 2-4: Control Group (Healthy Volunteers) n= 105; People with TBI n=510; assessed at the point of discharge (n-form A=104, n-Form B= 55) and more than 12 months post-trauma (n-Form A=201, n-Form B= 150) Australian Population	Clinical Rating for TBI samples, Self for control group	Patterns of psychometric properties for the 5- and 7-point versions were almost identical (e.g. total scores rs = 0.98). Rasch analyses on Forms A and B found a good fit to the model; Reliability coefficients were high (all ≥ 0.90). No floor/ceiling effects were detected. The 5-point version of the SPRS demonstrates strong psychometric qualities as a measure of participation after traumatic brain injury.

Author	Outcome Measure	Purpose of Study	Participant Information	Mode of administration	Main findings
Tate 2012	Sydney Psychosocial Reintegration Scale	To review the construct of participation and provide an overview of the revised 12-item Sydney Psychosocial Reintegration Scale (SPRS-2) as a measure of participation and its application in different neurological groups.	N=130 with TBI N= PBT N=50 SCI	Rating by clinician	There was a significant difference among the samples on all SPRS total and domain scores. Post-hoc investigation demonstrated that the TBI sample had lower levels of psychosocial reintegration (total, OA, and IR scores) than the PBT and SCI populations, who did not differ significantly. For the LS domain, the PBT group performed significantly better than the TBI group, and there was no significant difference between TBI and SCI groups. There was no effect of age or sex on the SPRS scores for any of the neurological populations, although participants with the more severe TBI demonstrated poorer SPRS total and domain scores.
1987 Wood-Dauphinee & Williams	Reintegration to normal living index	To introduce a new outcome, "reintegration to normal living index" and compare it to the quality of life measure	Group 1 N=109, patients with cancer, myocardial infarction, central nervous system and orthopedic disorders. Group 2 N=70 newly diagnosed, (n=25) myocardial infarction, (n=45) carcinoma	Administration by trained interviewers	α=0.90; interrater reliability= 0.39(patients and healthcare professionals) to 0.62 (Patients and significant others); The RNLI subscale Daily Functioning, correlates significantly with the combined QLI items, activity and daily living (0.67, p=0.00).
2003 Daneski, Coshall, Tilling, & Wolfe	Reintegration to normal living index, an agree/disagree response format was chosen. Responses were scored 0 for disagree or 1 for agree.	To assess reliability and validity of a post version of the RNLI for stroke patients.	Group-1 N= 26 (Reliability study) Group-2 N= 76 (Validity Study)	Administration by post	α=0.84; Test-retest reliability >0.61; Correlations between the RNLI-P and the BI, FAI, and SF36 indicated strong positive linear relationships

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Author	Outcome Measure	Purpose of Study	Participant Information	Mode of administration	Main findings
2005 Stark, Edwards, Hollingsworth, & Gray	Reintegration to normal living index	To validate the RNLI in a population of community-dwelling adults with mobility limitations	N = 604 people with mobility limitations (n = 141 SCI; n = 126 MS; n = 80 stroke; n = 88 cerebral palsy; n = 169 polio survivors)	Administration via mail (n = 471 & personal interview in the participants home n = 133)	α=0.91; 2- factor structure with 65.3% of the variance; The RNLI is a reliable and valid measure for studies of community integration among people living with long-term consequences of a chronic health condition.
Miller 2011	Reintegration to normal living index	To examine the validity and reliability of a modified Reintegration to Normal Living Index (mRNL Index) with a sample of community-dwelling adults with mixed diagnoses.	N=46 (time-point 1) N=28 (time-point 2) With Brain injury, Stroke, Fractured neck of femurs, Multiple sclerosis, Spinal injuries, Heart disease, Parkinson's Disease and Guillain-Barre´ Syndrome	Self-report questionnaire survey	The mRNL Index demonstrated good construct validity and acceptable internal consistency (Cronbach's α=0.80). Test-retest reliability was also acceptable (ICC= 0.83, p= .0001). As hypothesised, the Life Space Assessment (LSA) did not correlate with the Personal Integration subscale and moderately correlated to the Daily Functioning subscale. The CIM was moderately correlated with the Personal Integration subscales and the Daily Functioning subscale.
Tooth 2003	Reintegration to normal living index	To measure reliability between stroke patients' and significant others' scores on items on the Reintegration to Normal Living (RNL) Index and investigate for any scoring biases.	N=57 pairs of patients with stroke and their significant other	Verbal administration through interview	Overall poor reliability was found for the RNL Index total score (ICC=.36, 95% CI .07 to .59) and the daily functioning subscale (ICC=.24, 95% CI -.003 to .46) and moderate reliability was found for the perception of self-subscale (ICC=.55, 95% CI .28 to .73). There was a moderate bias for patients to rate themselves as achieving better reintegration than was indicated by significant others, although no demographic or clinical factors were associated with this bias. Exact match agreement was best for the subjective items and worse for items reflecting mobility around the community and participation in a work activity.