

**DEVELOPMENT OF A NEW ZEALAND
VERSION OF THE WORLD HEALTH
ORGANISATION QUALITY OF LIFE
SURVEY INSTRUMENT (WHOQOL)**

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MASTER

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VERSION OF THE WORLD HEALTH
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Primary Supervisor: Rex Billington

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“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 acknowledgement), 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.”

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MEMORANDUM

Auckland University of Technology Ethics Committee (AUTEC)

To: Rex Billington
From: **Madeline Banda** Executive Secretary, AUTEC
Date: 18 November 2008
Subject: Ethics Application Number 08/221 **Development of a New Zealand version of the World Health Organization Quality of Life Survey Instrument (WHOQOL).**

Dear Rex

Thank you for providing written evidence as requested. I am pleased to advise that it satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC) at their meeting on 13 October 2008 and that I have approved your ethics application. This delegated approval is made in accordance with section 5.3.2.3 of AUTEC's *Applying for Ethics Approval: Guidelines and Procedures* and is subject to endorsement at AUTEC's meeting on 8 December 2008.

Your ethics application is approved for a period of three years until 17 November 2011.

I advise that 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/about/ethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 17 November 2011;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/about/ethics>. This report is to be submitted either when the approval expires on 17 November 2011 or on completion of the project, whichever comes sooner;

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 reminded that, as applicant, you are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

Please note that AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this.

When communicating with us about this application, we ask that you use the application number and study title to enable us to provide you with prompt service. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at charles.grinter@aut.ac.nz or by telephone on 921 9999 at extension 8860.

On behalf of the AUTEC and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely



Madeline Banda
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Patricia Hsu hsihsu82@aut.ac.nz, Daniel Shepherd, Jason Landon, Chris Kr loh, Sandra Basset, Carole Wilson

Abstract

Research on health related Quality of Life (QoL) is valuable in developing health policy, assessing medical treatment outcomes and social sciences. Different QoL measurement instruments reflect different facets, and some QoL assessment tools are culturally insensitive. This study examines the existing WHOQOL-BREF (World Health Organisation Quality of Life) 26-item instrument for its suitability for use in New Zealand studies. It focuses on seeking facets of QoL of particular importance to New Zealand culture upon which New Zealand national items may be constructed and included when using the WHOQOL-BREF in studies in New Zealand. In order to achieve this goal, the project involved four sub-studies: verifying the existing WHOQOL response scale descriptors; conducting focus groups to elicit new areas or facets of QoL peculiar and particular to New Zealanders; examining the stability of the WHOQOL-BREF importance scale test-retest reliability; and conducting a national survey to assess what facets of QoL are most important to New Zealanders upon which national items may be developed and the national importance survey.

The verification of response scale showed good correspondence with the standard English WHOQOL version. A total of 46 candidate importance items were generated from 12 focus groups' discussions. Test/retest reliability revealed that the existing WHOQOL-Importance questionnaire items were more stable over a three week period, better than several of the new candidate importance items. Two thousand questionnaires asking what is important to New Zealand were sent out to the NZ general population and 585 returned. Results revealed that what is important varies across age, gender and health states. Twenty-four national items were developed from the national importance data.

The study confirmed that what is considered as important facets of QoL varies within New Zealand and that there are facets that are important to New Zealanders not in the existing WHOQOL-BREF.

INTRODUCTION

Research involving Quality of Life (QoL) assessment has become influential in social policy, human health services, education, and economic development. Health interventions are sometimes described in terms of how the intervention will impact QoL. Quality of Life measurement emerged from the social indicator movement of the 1960s. However, the concept of QoL has no universally acceptable definition. Social scientists and researchers often differ in their definitions of the term. In spite of the difficulties in reaching a consensus definition, it is important that any study purporting to measure or reflect upon QoL should state what it means by the term. Each study should provide an operational definition of the concept. When selecting an established questionnaire, researchers need to closely examine the construct, content and predictive validity of any candidate instruments as well as the reliability and suitability of the instrument for the purposed study. Additionally aspects such as length of the questionnaire and whether objective or subjective questions are used are also important considerations.

This study will review the World Health Organisation Quality of Life (WHOQOL) short form, called the WHOQOL-BREF, for its suitability for use in New Zealand. It will also seek additional areas or facets of QoL that are not covered by the WHO tools. If any are found, then questions will be developed in the WHOQOL format that may be tested later for their suitability for New Zealand. Any new items will be called national items. This research is the first phase in the development of a New Zealand version of the WHOQOL-BREF.

Cultural relevancy and sensitivity are important elements of QoL instrument design. Within different cultures the perception and emphasis of what constitutes QoL vary. What is important to one culture may differ from another. Hence, cultural factors play a significant role in measuring QoL, especially in the twenty-first century when

globalisation has swept the world and cultures have been intermingled. Migration has changed the features of nations in terms of a country's citizen ethnicities. There is no mono-ethnic population in any one nation of the developed world at this time. This significant cultural fact needs to be considered when selecting and/or developing a QoL instrument. Schmidt and Bullinger (2003) suggested that the perception of health and the meaning of QoL must be understood when assessing QoL in cross-national studies. Perhaps the most culturally sensitive instruments are the WHOQOL instruments, which were developed across nations and cultures. The WHOQOL Group recognised the relevance of cultural differences among nations and encouraged development of the national items be developed by each country based on the uniqueness of each country's culture. National items enable the concept of QoL to fully reflect each language and culture (Skevington, Bradshaw, & Saxena, 1999). Therefore, a primary focus of this study is to investigate whether there are national quality of life items particular to New Zealand.

REVIEW OF LITERATURE

Historical Background

Quality of life has become a prominent concept in contemporary society, yet it is rooted in Greek philosophy. The notion of a good life dates back to philosophers such as Plato and Aristotle who believed that achieving happiness, which they argued was derived from virtuous activity of the soul, is the optimal goal of a well-led life (McKeon, 1947). This stream of thought has impacted later Western culture where pursuing happiness is considered by some as the fundamental goal in life. However, philosophers were not the only professionals interested in the issue of QoL; economists were also. The term appeared in USA literature shortly after the Second World War to portray the view that the good life is more than the defeat of deprivation in material resources or being financially secure (Campbell, 1981). In the 1950s and 1960s, the economists Samuel Ordway (1953), Fairfield Osborn (1954) and John Galbraith (1958; 1967) adapted the term while expressing their concerns that the risk of unlimited economic growth may lead to negative ecological development (cited in Frank, 2000). Around the same time, American President Johnson used the phrase “quality of life” in his speech at Madison Square Garden to suggest that financial security does not indicate a good life (Campbell, 1981; McCall, 1975; Noll, 2000). Similarly, in socialist Europe and other developed Western societies during this period, the concept of QoL was used in many fields and especially by social scientists.

There have been many empirical studies using QoL assessments since the 1970s, involving clinicians, social scientists, economists, policy makers and researchers from a variety of disciplines. For example, approximately 200 journal articles published in Index Medicus with “quality of life” as key words appeared between 1996 and 1999 (George, 2000). Over 300 English-language articles exploring the QoL of diabetics had been published by 1999 (Frank, 2000). The *Quality of Life Research* journal was first

published in 1992 and this is not the only publication reporting such research. Among these studies, social scientists focus on the issue of circumstantial, economic and social indicators of life quality (Frank, 2000; Meeberg, 1993). On the other hand, medical and health sciences stress the patient's physical function and subjective well-being. Thus, many different definitions from a variety of disciplines have been used to define QoL.

Happiness, Life Satisfaction, Well-being and Quality of Life

The terms happiness, life satisfaction, well-being, and QoL are sometimes considered equivalent in some research. While some scholars believe that there is some common element and equivalence between these terms, others argue that there are significant differences between each of them. This inconsistency can be considered from both phenomenological and empirical perspectives. For instance, Hörnquist, (1982) suggested that the degree of satisfaction of human needs is the foundations for QoL. Multiple-discrepancies theory, a QoL model proposed by Michalos (1985), used the term life satisfaction to mean happiness and equivalent to well-being and to QoL, in order to evaluate students' life experiences in different domains (Staats, Armstrong-Stassen, & Partilo, 1995; Schulz, 1995). Similar views are found in Andrews (1974) who studied American perceptions of well-being as broadly conceived QoL or the extent to which pleasure and satisfaction have been obtained. Well-being is also defined in some reports as an individual's experience as a whole, but which consists of three interrelated components: life satisfaction, pleasant/affects, and unpleasant/affects (Naess, 1999; Diener & Suh, 1997; Kahn & Juster, 2002). By contrast, Barofsky (2007) argued that QoL is not well-being, but well-being is a quality indicator which refers to feelings a person may have or positive states a person is in; hence it is not a quantitative evaluative statement. Andrews and McKennel (1980) argued that life satisfaction has a more cognitive component that implies evaluation while happiness has a more affective feelings component.

Some researchers focusing on happiness suggested that euphoria is an important construct for assessing life quality (Shin & Johnson, 1978). These authors also believed that human beings are driven by the search for happiness. They proposed the happiness model, that “consists of the possession of resources, the satisfaction of needs, wants and desires, participation in self-actualizing activities and comparisons with others and past experiences” (Shin & Johnson, 1978, p. 479). Ferrans (1990) reviewed a number of categories of definitions of QoL in health care. One of them focused on happiness and satisfaction, where subjective experience of life satisfaction or the degree of satisfaction that a person feels in different domains of life determines an individual’s QoL. McKevitt, Redfern, La-Placa and Wolfe (2003) in their research define QoL from the health professionals’ point of view. They interviewed three different groups of health care professionals who worked with stroke patients, and found ‘happiness’ to be the main component of QoL. The result is consistent with the ‘happiness’ model that Shin and Johnson (1978) proposed nearly three decades earlier. The study also found that other aspects of life that appeared to be significantly associated with QoL were social interaction, good health, physical function, independence and mental well-being (McKevitt, et. al., 2003). Young and Longman (1983) conducted a pilot study on QoL among patients with melanoma. They used the Life Satisfaction Index to conduct the research and defined QoL as the degree of satisfaction with perceived current life circumstances. Although Young and Longman (1983) in their study found that QoL did not equal happiness, in general the terms well-being, QoL, happiness, and life satisfaction had some common characteristics, but the boundaries were very fine. Though the task of distinguishing QoL from other terms is difficult, there is still a need to select one in order to achieve understanding and consistency. It is important therefore to define more clearly what QoL means and as one would expect there is a variety of definitions for it.

The Concept of Quality of Life

Overall, the conceptual framework of QoL is complicated, broad, and variable. No cohesive agreed universal definition exists (Bowling, 2005; Farquhar, 1995; Felce, 1997; Ferrans, 1990; Gill & Feinstein, 1994; Hunt, 1997; McKevitt, et.al., 2003; Nussbaum, & Sen, 1993; Rapley, 2003; Spilker, 1996). Early works on the conception of QoL referred to the life of a certain society, rather than the individual's life within it (McCall, 1975). It was considered more important to know the population level than an individual level. It was proposed that the individual's QoL is based on the material level of living in a country. Thus, if a country has a high GNP (Gross National Product), then its citizens are having a better life. However, in present day use one commentator suggested QoL could best be described "as a characteristic of persons as well as an indication or national prosperity" (Rapley, 2003, p. 4).

Descriptions of the historical development of QoL as a concept in the 1940s and 1950s focus on economic and material perspectives (Crowe, Davidow, & Bothe, 2004; Rapley, 2003). Thus, the political aims of society were the defining forces in this period of time and Western government policies were directed towards large-scale social welfare and socio-economic improvement.

In the 1960s and 1970s the concept shifted to focus more on the individual (Crowe et al., 2004). It appeared that the individual's personal psychological and social needs were recognised for the first time as important components of quality of life, as well as objective impersonal social indicators. This shift beyond the social indicator movement was followed by the public desire to prefer QoL to quantity of possessions (Noll, 2000).

Health is an important component of QoL. In the 1970s health-related QoL assessment tools began to be developed in both Europe and the US. These tools first took the form of health status measures containing both subjective questions of feelings

and objective questions of bodily functions. In clinical settings, QoL stresses patient functions, physical well-being and somatic sensation (Schipper, Clinch, & Olweny, 1996) or used as a patient-reported outcome or patient-assisted outcome measures (Fairclough, 2002). Outcome measures were, and still are, widely used in decision-making in health services regarding resources allocation, intervention, design and chronic disease management. Examples of instruments used for these purposes are those measuring patient's functional ability such as the Stanford Arthritis Centre Health Assessment Questionnaire, The Index of Activities of Daily Living, and the Karnofsky Performance Index (Bowling, 2005). Other examples measuring a patient's health status are the Sickness Impact Profile, the Nottingham Health Profile, and the McMaster Health Index Questionnaire (Bowling, 2005). However, this biomedical model-oriented conception of health status helped lay the foundations for the concept of Health Related Quality of Life (HRQoL).

From 1990, QoL research flourished, especially HRQoL research. More and more components were included in the QoL construct, such as those about the environment, culture and spirituality. For example, Albrecht and Devlieger (1999) conducted qualitative research using semi-structured interviews with 153 participants who had serious disability and found more than 50% reported having good QoL despite their health condition. In this study the key style influence one's QoL was found to be "establishing and maintaining a sense of balance between the body, mind and spirit and with the individual's social context and environment" (Albrecht & Devlieger 1999, p.10).

Despite the lack of consensus in the definition of QoL there is some agreement that it is a multi-dimensional construct that contains various aspects of human life from the micro to the macro system encompassing physical, psychological, social and spiritual domains (Ferrans, 1990; Gillingham, 1982, cited in Beckie & Hayduk, 1997;

Palys & Little, 1980; Schalock, 2000).

Health Related Quality of Life

The boundary of the definition between HRQoL and QoL is somewhat vague. Both encompass a multi-dimensional construct and can be person-centred, or else have a professional or a society orientation. It is quite common to find that HRQoL and QoL are used interchangeably. On the other hand, Sajid, Tonsi and Baig (2008) suggested that a clear distinction between QoL and HRQoL is needed to reduce the confusion in QoL research. Overall, QoL usually applies to all aspects of a person's life, including living conditions, economic state, and spiritual life. HRQoL refers to the individual's perception of physical, psychological and social factors that are associated with health (Rapley, 2003; Staquet, Hays & Fayers, 1998). Although the definition of HRQoL proposed by these authors mainly stresses three dimensions of life, it is important to recognise that living conditions, economic factors and spiritual life also influence one's health.

Health-related quality of life was once the physicians' assessment for the purpose of measuring treatment outcome. Kaplan (1988) defined HRQoL as the impact of disease and treatment on disability and daily function. The patients' subjective judgements about themselves are central to this definition and health is seen as being about disease, disability, and daily functioning. However, the World Health Organisation (WHO) had embraced a broader definition of health in 1948 "as a state of complete physical, mental and social well-being not merely absence of disease or infirmity" (WHOQOL Group, 1997, p.1).

The WHO definition of health conceptualised health as being composed of a number of domains and beyond disease and ill health to include levels and degrees of well-being. It therefore deepened the biomedical model-oriented conception of QoL.

Many HRQoL researchers have embraced this broader concept of health in their HRQoL definition. For example, Bowling (2005) defined HRQoL as no longer limited to physical health and functional status dimensions but also to cover the components of psychological well-being, degree and quality of social interaction and life satisfaction, as well as the level of satisfaction with treatment outcome. Cella (1995) stated “health-related quality of life refers to the extent to which one’s usual or expected physical, emotional, and social well-being are affected by a medical condition or its treatment (cited in Barofsky, 2007, p.428). Five domains derived from the WHO’s health conception are disease state and physical symptoms, functional status, psychological functioning, social functioning, cognitive functioning (De Haes & Van Knippenberg, 1985; Németh, 2006; Spieth & Harris, 1995). Sajid and his colleagues (2008) used the term “all within the skin” (p.366) to illustrate the key dimensions of HRQoL such as sensations, pain/discomfort, self-care/dexterity, cognition, and emotional psychological well-being. The multi-dimensional approach is valuable to physicians to evaluate disease progression and treatment effectiveness as well as providing better understanding of how an illness interferes with their patient’s day-to-day life.

The World Health Organisation Quality Of Life Group (WHOQOL-Group) defined HRQoL:

an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept incorporating in a complex way the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment (WHOQOL-Group, 1995, p. 1405).

This definition reflects the view that QoL is a subjective and not an objective entity; thus its measurement must have subjective not objective items. Objective items

are related to conditions such as mobility, physical and psychological functioning (Cummins, 2000; Schalock, 2000). In other words, objective factors assess a patient's symptoms or functional ability; questions about weight, blood pressure, ability to stand up from an armless chair, and ability to sweep the floor etc. Sometimes the response required is binary, that is a yes/no answer. On the other hand, subjective factors investigate how a person feels about him/herself on a variety of less specific, more general aspects impacting their life. The questions usually focus on feelings, general experiences, and levels of personal satisfaction.

HRQoL and Health Status Measures

Health-related measurement of QoL is also known as health status measurement (Kaplan, 1988). However, Patrick (2003) argued both QoL and HRQoL are more comprehensive than health status and include the environmental dimension that may or may not be affected by health as well as more global evaluations of life (cited in Bowling, 2005). Health status measures reflect functional factors and include objective QoL items, on the other hand, subjective questions of health-related factors that impair or impact one's health. Albrecht (1994) pointed out that traditional evaluation of medical care health assessment has relied upon measuring morbidity and mortality. A good example here is the well-known Karnofsky Scale, a performance scale that is commonly used by physicians to evaluate a cancer patient's daily activity level and performance status. On the other hand, Katz, Akpom, Papsidero and Weiss (1973) disagreed with the idea of evaluating health status from a medical practitioner's point of view and insisted on a population-based reliable measurement of how people perceive their health. Ware (1993) also argued that the patients' self-report survey is the best method of measuring treatment outcome. Likewise, Silver (1990) believed that "an ideal treatment outcome of measurement is a return to the normal or usual QoL for a given

age and medical condition” (cited in Ware, 1993, p. 1429). It is encouraging to know that the HRQoL instruments today are more patient centred. Interestingly, some investigators classify the Medical Outcome Short-Form 36 (SF-36), Nottingham Health Profile (NHP), and Sickness Impact Profile (SIP) as generic HRQoL measurement, whereas they are really health status measurements (see Bowling, 2005; Sajid et al., 2008; Németh, 2006).

Components of HRQoL Scales

The components that are used in HRQoL research are commonly referred to as life dimensions, components or domains. Little consensus exists about the different domains that should be included in a QoL measurement. Bowling (2004) reviewed eight different QoL models and concluded that models of QoL are extremely wide ranging, including potentially everything from Maslow’s (1954) hierarchy of human needs to classic models based solely on psychological well-being, happiness, morale, and life satisfaction. In measuring older people’s QoL, George and Bearon (1980) identified four dimensions, two subjective and two objective. The subjective components are life satisfaction and self-esteem; the objective components are general health/functional status and social-economic status. A study of the same age population by Hughes (1990) suggested eight domains including personal autonomy, satisfaction, physical/mental well-being, social-economic status, environment, purposeful activities, and social interaction and cultural factors.

King and Hinds (1998) as well as Cummins (1996) suggested that the dimensions of physical health, psychological well-being and social well-being have been most common components in health status and QoL measures. Tannock, Gospodarowicz and Meakin (1989) studied the evaluation of pain and QoL among prostatic cancer patients and found that improvement in multiple areas of QoL and in

well-being coincided with reduction in pain associated with bone metastases. The importance of assessing multiple dimensions of HRQoL could be demonstrated in the following areas: evaluate treatment outcomes, implement interventions, understanding individuals' coping strategies, and modify health related programmes. Shumaker, Anderson and Czajkowski (1990) asserted that a multi-dimensional assessment approach is particularly important in HRQoL research to assist clinicians understand the effects of treatment.

In contrast to the multi-dimensional measurement is the uni-dimensional measurement where QoL is defined as a single dimension, index or score. A classic example of a uni-dimensional measurement can be found in preference-based health profile instruments. This type of instrument is usually used in outcome studies for resources allocation to produce a win-win outcome (Németh, 2006). The outcomes obtained from preference-based HRQoL are used for calculating a QALY (Quality Adjusted Life Years) for the evaluation of cost effectiveness. The US National Institute for Health and Clinical Excellence (NICE, 2008) defines the QALY as a “measure of a person’s length of life weighted by a valuation of their HRQL over that period” (p.40). In other words, it measures disease burdens and stresses both quantity and quality of life in a single index (Phillips, 2006). The QALY model believes that “poor health may reduce the quality of a year” (Bowling, 2005, p.17). This type of measure focuses on health-related outcomes of mortality, morbidity, symptoms, and prognosis in assessing an intervention. The value of judgement is highly dependent on age, life context and life responsibility. In other words, this type of measure aims to achieve maximum benefits from limited health resources. Therefore money matters, the highest cost-effective treatment is less encouraged and an individual with low QALY will usually be pushed down to the bottom of the waiting list. This model has been criticised, mainly around the issues of values of human lives and fairness in the allocation of health-care

resources (Phillips, 2006; Harris, 1991). However, it is a favoured definition for health economists who seek and use single indices in describing a health state.

Generic and Disease-Specific QoL Scales

Another distinction in HRQoL measurement refers to whether the instrument is generic or disease specific. Generic HRQoL instruments can be used in a variety of health conditions and situations allowing broad comparisons. They are designed to assess multi-dimensions of health-related issues. They are also useful for comparing treatment options for the same health condition as well as comparing a variety of chronic illnesses (Bowling, 2005; Haberman & Bush, 1998; Spieth, & Harris, 1995). This type of measurement is widely used in health research for comparing projects and programmes, allocating resources, and developing or implementing health policies. Examples of generic HRQoL scales are the WHOQOL-100 and WHOQOL-BREF, and the Quality of Well-Being Scale (QWB).

In contrast to generic HRQoL, disease-specific HRQoL instruments are tailored to a particular disease or programmes that are designed to treat the disease. They study the impact of a specific condition and its treatment on a patient's life. The questionnaires usually contain a list of symptoms relevant to the specific diagnoses and treatment groups and the goal is to monitor the changes in terms of treatment efficacy as well as provide important follow-up information for clinicians (Bowling, 2005; Kaplan, 1988). A growing number of generic as well as disease-specific HRQoL assessment instruments are becoming available (Cieza & Stucki, 2005; Saxena, Carlson, Billington & Orley, 2001).

Both generic and disease specific HRQoL instrument have their strengths and weaknesses. There is wide agreement that generic HRQoL is applicable to any type of disease or person and allows for comparisons between healthy individuals and other

groups of patients (Engel, Wittrock, Crosby, Wonderlich, Mitchell & Kolotkin, 2006; Bowling, 2005; Haberman & Bush, 1998; Speith, & Harris, 1995). Such an assessment approach facilitates the integration of research findings across conditions (Levi & Drotar, 1998). However, the limitations of generic HRQoL tools are their lack of sensitivity to detect specific differences within a specific diseases or condition. In contrast, the disease specific HRQoL has demonstrated a higher sensitivity in measuring the effects of a treatment that relate to specific concerns of the disease (Cohen, 1988). However, it can only be used in patients diagnosed with the particular symptoms related to a specific disease. Hence, it is highly recommended that generic HRQoL measures are supplemented with disease-specific measures in order to obtain comprehensive information of a treatment (Aronson, 1988, cited in Spieth & Harris, 1995; Patrick & Deyo, 1989).

Subjectivity and Objectivity

Social scientists argue whether the judgement of QoL should be left to experts or if it should be an individual's perceptions about themselves. Veenhoven (1996) believes that people have capacity in judging their lived experiences and the citizen's appraisals of life are the true reflection of QoL. Also, Young and Longman (1983) argued that evaluation QoL should take into consideration the perspective of the person who has the chronic or life-threatening disease. Skevington (2002) also stressed that QoL is about subjective perceptions of important aspects of a person's life which may or may not coincide with an accepted consensus about standard-of-living indicators. Schalock (2000) stated "there is good agreement in the quality of life literature about three things: first, quality of life, by its nature, is subjective" (p.118).

However, some analysts are concerned about the limitations of subjective measurement. For instance, if an individual is incapable of providing first-hand

information regarding his or her subjective experiences then measuring is a problem. Commentators also suggest some people do not know what is important to their QoL. For example, one may live in poor environmental conditions to a degree that shortens life expectancy, affecting the immediate future QoL, yet report a high level of subjective QoL (Hagerty, Cummins, Ferriss, Land, Michalos, Perterson et al., 2001). This is not to say that subjective measures are totally unreliable, but they cannot be verified directly. The perception of measuring QoL subjectively or objectively also affects the development of the items themselves. In general, subjective measurement stresses that individuals perform the ratings and objective measurement requires professionals to carry out the rating. At the same time, the subjective items tend to be structured in a more general and intangible way rather than being narrow and specific.

Cultural Relevancy

Culture identifies a group of people as a unique population with a common identity (Hinds & Haase, 1998). Hinds and Haase (1998) also suggested that a group's world views shape individuals' lifestyle, social interaction and attitude towards health. Cultural beliefs and behaviours play an important role in the perceptions of QoL which vary from society to society. For example, Schalock and Verdugo (2001) suggested that the components of QoL and the degree of importance in Latin American families may differ from other countries due to the characteristics of poverty and high rates of unemployment.

It is well accepted that culture is a significant factor when evaluating HRQoL. Culture helps decide the importance of potential areas of QoL to different cultural groups (Chappell, 2007; Buck, Jacoby, Baker, Ley & Steen, 1999). Moriarty and Butt (2004) found that social support is a major component of QoL for ethnic groups in Great Britain. Bajekal, Blane, Grewal, Karlsen and Nazroo (2004) compared the key

influences of QoL between ethnicities and found significance in social networks with the particular factors of family networks and community participation. More and more evidence supports the notion that there is a need for cross-cultural measures to serve evidence-based medicine in the systematic monitoring of outcomes from multi-national clinical trials (Skevington, 2002). For example, a few HRQoL studies have found significant cross-cultural differences in the same subject groups across many Western countries including USA, Canada, Britain, Spain, France, Germany, and New Zealand (Buck, et al., 1999; Collings, 1994; Dodrill, Beier, Kasparick, Tacke, Tacke & Tan, 1984). The global value of many common treatments for chronic diseases (e.g., the use of antidepressants) has only been partially evaluated and often only in a single cultural setting. Cross-cultural QoL data enables comparisons about QoL in different cultural or social groups and between those receiving care in different health-care settings. As stated by Skevington (2002) “this is valuable information for policy-makers and planners at regional, national and international levels” (p136).

Quality of Life in New Zealand

The assessment of QoL is used in New Zealand (NZ) in research, government policy making, and medical treatment analysis. Since the late 1990s there has been rapid immigrant population growth in addition to business development resulting in people shifting from rural communities to urban areas. In response to the growing pressure of urbanisation and its impacts on the well-being of the residents, a QoL assessment project was established in 1999 (City Councils, 2001). It was a conjoint survey covering six cities to begin with, representing 40% of the NZ population, and then expanding to eight cities with 46% of the NZ population, then to 12 cities in 2008 report. The project is aimed at measuring NZ residents’ perceptions of overall QoL. The collected data were distributed to many different government sectors, such as the Long Term Council

Community Plan (LTCCP), Metro Mayors policy programme, the Minister of Urban Development portfolio or central government in order to launch or implement policy and policy programmes (Gatt, 2003; Hastings, Dudding & Dobson, 2009).

The Quality of Life survey that city councils used is not a HRQoL instrument, although there are questions regarding health issues. The survey consisted of 36 questions and was conducted via telephone calls by TNS (a New Zealand custom market research company) employees (TNS, 2007). The questionnaire was designed as open ended questions and a 5-point-Likert rating (TNS, 2007). Most items in the survey focused on the macro level such as crime and safety, city environment (e.g., poor planning, city appearance), connectedness (e.g., community belonging), transportations, (e.g., connivance, affordability), democracy, culture, and community. There were also some individual-based micro questions about lifestyle (e.g., work and study status), leisure time, general health, level of psychical activities that measured by days, well-being, and satisfaction of life in general.

A number of NZ social/policy-related studies in the context of QoL were published in the Social Policy Journal of New Zealand. Grant (2007) focused on evaluating the QoL of a group of former Templeton Centre residents living in the community. These ex-residents are characterised by intellectual disability with limited verbal communication; therefore the participants in the survey were the former service users' mothers. The study investigated the implementation of counterparty disability policies in Christchurch, NZ. Another study using qualitative methodology investigated the QoL of elderly recipients of low-level home support, hoping to provide insight into the Ministry of Social Development, policy of low levels of home support featured in the overall experience of QoL of the elderly, and their capability to remain at home (Hambleton, Keeling & McKenzie, 2008).

Many health sectors used self-reported health measures to obtain information

about a wider spectrum of health outcomes and the level of disability associated with them. These studies explored the QoL in different groups of people, such as tertiary students, using the generic WHOQOL (Hsu, Krageloh, Shepherd, & Billington, 2009), stroke patients (Hambleton, et al., 2008), elderly (Salkeld, Cameron, Cumming, Easter, Seymour, Kurrle et al., 2000; Munro, 2002), heart failure patients (Doughty, Wright, Pearl, Walsh, Muncaster, Whalley et al., 2002), cancer patients (Grierson, Pitts, Whyte, Misson, Hughes, Saxton et al., 2004; Morris, Perez & McNoe, 1997), organ transplant patients (Beilby, Moss-Morris & Painter, 2003), oral health services (Allen, 2003; Chen & Hunter, 1996), pharmaceutical care patients (Emmerton, Shaw & Kheir, 2003) and paramedics services (Eaton, Garrett, Young, Fergusson, Kolbe, Rudkin et al., 2002). Many of these studies presented a coherent factor, namely that general health is a consistent predictor of QoL. These numerous studies reflect the perceived importance of QoL in connection to clinical interventions, policy implementation and research. However, the most important concern is that all these studies were using an overseas-developed instrument and perhaps lack cultural sensitivity and relevancy. The most common instrument in use in NZ to measure HRQoL is the SF36, a short form of the US Medical Outcomes study of the 1990s, but this is a measure of health status that includes both objective and subjective items and is found to have ceiling and floor effects (McDowell, 2006; Obremskey, Brown, Driver & Dirschl, 2007; Unalan, Soyuer, Ozturk, & Mistik, 2008). The cultural relevancy of the items used has not been determined nor has the accuracy of the weighting index scores to New Zealand. The use of the SF36 as a QoL assessment tool is testimony to the confusion with definitions commonplace in QoL assessment.

The Development of the WHOQOL Instruments

With the aim of developing an internationally applicable, reliable, valid, responsive, and cross-culturally psychometric tool for assessing quality of life, the World Health Organisation (WHO) initiated the World Health Organisation Quality of Life (WHOQOL) project in 1991. The team of WHO experts involved in developing the instruments represented diverse health professions and included psychometricians, medical doctors, health psychologists, clinicians, and policy makers. This WHOQOL advisory group was guided by four main principles, 1) comprehensive assessment of QoL; 2) subjective assessment of QoL; 3) equal importance of various facets of QoL; and 4) cultural relevance of the instrument (WHOQOL Group, 1998a).

The first steps in developing the WHOQOL instruments were concept clarification in order to accommodate international comparisons, and the research protocol to develop the WHOQOL. The second stage was a qualitative pilot study that aimed to explore the QoL constructs across cultures and generated questions to satisfy all countries, conducting focus groups to determine the WHOQOL domains and facets. At the end of the focus group work and after a culling of the candidate items for repetition and ambiguities, 235 questions with 29 facets were selected from over 1800 questions to form the WHOQOL pilot instrument. The third stage of development of the WHOQOL was a pilot test leading to the refinement of the WHOQOL structure through examining the construct validity of the domains and facets and selecting the best questions for each facet. The last stage was the field testing of the finalised WHOQOL-100 with six domains and 24 facets to establish the psychometric properties of the WHOQOL-100 including test-retest reliability, and criterion validity (WHOQOL Group, 1995a).

The WHOQOL instrument is composed of items which were drafted on the basis of statements made by healthy people, patients with various diseases and disorders, as

well as health professionals from 15 countries across Europe, Asia, the Americas, and the Middle East (WHOQOL Group, 1997). Since then more national versions have been developed. By the year 2000 more than 40 language versions were available (Skevington, 2002). The last estimate is 56 (personal correspondence by Billington 2009). The WHOQOL instruments focus on individual subjective perceptions. They were designed to be used in medical projects and programmes to assess the effectiveness and relative merits of different treatments, in health services evaluation, in research, and in policy making (WHOQOL Group, 1997). They have been used for individual clinical assessment of patients.

THE WHOQOL-100

The WHOQOL-100 is structured in a way that reflects issues important to QoL. It is a self-administered instrument using a 5-point-Likert rating scale. It contains six domains and 24 facets. The 100 items are made up from the 24 facets with four items each. An additional four items ask about overall QoL and general health. Details of domains and facets of the WHOQOL-100 are listed below in Table 1.

Table1.

WHOQOL-100 Domains and Facets

Domains	Facets
	Overall Quality of life and General Health
Physical Health	Energy and fatigue
	Pain and discomfort
	Sleep and rest
Psychological	Bodily image and appearance
	Negative feelings
	Positive feelings
	Self-esteem
	Thinking, learning, memory and concentration
Level of Independence	Mobility
	Activities of daily living
	Dependence on medicinal substances and medical aids
	Work capacity
Social relationship	Personal relationships
	Social support
	Sexual activity
Environment	Financial resources
	Freedom, physical safety and security
	Health and social care: accessibility and quality
	Home environment
	Opportunities for acquiring new information and skills
	Participation in and opportunities for recreation/leisure
	Physical environment (pollution/noise/transport)
Spirituality/Religion/Personal beliefs	Religion / spirituality / personal beliefs

WHOQOL-100 data was collected from more than 4800 people in 15 field centres world-wide. Respondents included both genders. Most participants were female (53.8%) but the participants were from a wide range of ages with a mean age of 43.4 years, and standard deviation of 16 years (Murphy, Herrman, Hawthorne, Pinzone &

Evert, 2000). The global data also showed that 81% of participants were classified as unwell. This indicated that the instrument was patient centred and allowing participants to evaluate what they considered important to their QoL instead of being designed solely by professionals to include what they considered important to their patient's QoL. The global data demonstrated that the WHOQOL-100 has good internal consistency with Cronbach's alphas ranging from 0.66 for physical health domain to 0.93 for working capacity (Murphy et al., 2000).

The WHOQOL-BREF

The WHOQOL-BREF is an abbreviated version of WHOQOL-100. Taking practical utility into account, the WHOQOL-100 may appear to be too long for some people to answer. The WHOQOL-BREF consists of 26 items selected from the WHOQOL-100. One item from each of the 24 facets and organised into four domains: physical health, psychological well-being, social relationship, and environment. The item that was chosen for each facet was the one of the four items that contributed the most common variance for that facet in the WHOQOL-100. (WHOQOL Group, 1998b). In addition, two generic items, general health and overall quality of life, are included.

The component analysis of the WHOQOL-BREF structure revealed the option of a four-or a six-domain structure with a slight preference for a four-domain structure. The spirituality/ religion/ personal beliefs domain was incorporated into the psychological domain. Items from the activities of daily living domain were included in physical and environmental domain. The details of the WHOQOL-BREF four domains model are listed in Table 2.

The WHOQOL-BREF is a widely used international QoL assessment and is available in over 40 different languages. The WHOQOL-BREF has proved to have sound psychometric properties including good test-retest validity, high discriminate

validity, internal consistency and content validity through out the world (WHOQOL Group, 1998b).

Table2.

WHOQOL-BREF Domains and Facets

Domains	Facets
Generic items	Overall Quality of life and General Health
Physical health	Activities of daily living Dependence on medicinal substances and medical aids Energy and fatigue Mobility Pain and discomfort Sleep and rest Work capacity
Psychological	Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality / Religion / Personal beliefs Thinking, learning, memory and concentration
Social relationship	Personal relationships Social support Sexual activity
Environment	Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation / leisure activities Physical environment (pollution / noise / traffic / climate) Transport

Item importance rating Questionnaire

In developing the WHOQOL-100 and WHOQOL-BREF, the WHOQOL Group verified the importance of the generic facets and items across the different ages, genders and diverse international cultures beyond the focus group (Saxena et al., 2001). The study covered the original 15 countries in 12 languages. The questionnaire consisted of 41 original importance items with some facets having more than one importance question. The questions all started with “How important to you is.....” The response for each question was rated on a 5- point-Likert scale with descriptors of (1) not important, (2) a little important, (3) moderately important, (4) very important, and (5) extremely important. The analysis showed most items were rated as high, that is above 4 on the Likert scale. However, some of the importance questions did not score high enough and so were dropped from the original WHOQOL-Importance questionnaire. Hence, the final version of the WHOQOL-Importance questionnaire consists of 32 questions. This questionnaire is presented in Appendix E.

METHODOLOGY

There are four studies involved in this research project. The first, was to verify the descriptors in the 5-point-Likert response scale used in the WHOQOL-100 questionnaire and to examine whether they are appropriate for New Zealanders in general. Second, were conducted focus groups to identify important elements of QoL within the NZ culture that are not in the existing WHOQOL. Third was to examine the Importance questionnaire's test-retest reliability. The fourth study involved mailing the WHOQOL Importance questionnaire, with the new importance items generated from the focus group, to a sample selected at random from the NZ electoral role, and to analysing the responses in order to verify where new national questions for the NZ WHOQOL-BREF are appropriate.

STUDY 1—Verifying the WHOQOL Response Scale

Recruitment/ approach

Following the research protocol of the WHOQOL Group (WHO, 1998), it is necessary that a new national version should review the response scale descriptors in the national language to ensure that each descriptor used at each numerical point on the 5-point-Likert scale is linguistically valid. The visual analogue scale methodology (WHOQOL Group, 1993) was employed to confirm the strength and equivalence of the existing English language descriptors to New Zealand English. In the WHOQOL instruments, the descriptors are catalogued into four different groups; intensity, capacity, frequency and evaluation. A list of 114 descriptors including anchor words (e.g., always, never) which were used in the WHOQOL-100, plus the synonyms of some descriptors from the WHOQOL-100 that are commonly used in New Zealand English (e.g., heaps; good as gold; barely) were created by asking a number of New Zealanders. The words were given to 10 lay subjects (aged 20 to 79) of differing occupations including university

students, health profession workers, labourers, engineers and retired people. They were interviewed individually and asked to mark a place for each of the 114 descriptors on a 10 cm line according to where they thought the descriptor lay. The results showed little consensus among participants on the descriptors. The data are presented in Appendix C. As examples, the descriptor of 'neither satisfied nor dissatisfied' was rated as falling between 0.8 cm and 5.0 cm on the 10 cm line. The term 'very pleased' was rated between 1.1 cm and 9.3cm. The descriptors that showed a good level of consistency were anchor points, such as 'very important' which was rated between 7.9 cm and 9.8 cm, or 'always' which was rated between 7.4 cm and 10 cm. However, this is not always the case, as some anchor points also showed no consensus at all. For instance, 'nil' was rated from 0 - 6.5 cm.

Because of the unsatisfactory results with the visual analogue scale approach, another method was chosen to verify the response scale descriptors. This was to use a percent estimation method. The range started with 0% and ended with 100% with 10 × 10% blocks. Raters placed each descriptor word into one of the 10 percentage blocks. The previous experience suggested the researcher should first consider the existing descriptors that were used in WHOQOL-100 and not test the common terms that were generated for the visual analogue approach. A new word would only be tested if an existing word failed to be rated satisfactorily. It was thought that if the existing English language descriptors were placed into the same percentage block or band as they are found in the WHOQOL instruments, then that would be sufficient verification of their appropriateness for use in NZ. This approach would also avoid the time and complexity of having to test so many words. After all, New Zealand English is not likely to be too different from standard English. Ten lay subjects and representatives of health care users were given the "percent placement" test. The total 32 descriptors including anchor points were included in the test. (See Appendix D.)

Results/discussion

The results from the percentage estimation approach confirmed the suitability of each existing descriptor for use in a WHOQOL for English speakers in New Zealand. The average (*M*) of each descriptor was calculated and showed a good consistency with the WHOQOL-100 response scale. Results are presented in Table 3. As examples of the suitability of items, the left or lower end anchor descriptor (e.g., *not at all; never; very poor*) was located between 11% and 16% which would equate to being between 11 mm and 16 mm if distance units of the 10 cm analogue scale were used. The mean average for the right or upper end anchor descriptor (*an extreme amount; extremely; very satisfied; very good; always*) fell between 77% and 89% which would be equal to being between 77 mm and 89 mm on the visual analogue scale. The matches were not perfect but considered close enough to the WHOQOL-100 response scale. The 25% descriptors in the WHOQOL-10; e.g. *a little; slightly; poor; seldom; unhappy; and dissatisfy*, had similar means falling between 21% and 34%. The 50% descriptors: *moderately; neither poor nor good* were very close to the centre with the mean falling between 49% and 51% which equates to the 45 mm and 55 mm as the WHOQOL Group recommended. The 75% descriptors including (*very often; good; very much; satisfied mostly; and very*) showed a lower mean compared to what was expected from the WHOQOL. The WHOQOL protocol suggested the mean score would fall between 70 mm and 80 mm, but the mean for those descriptors in this study was under 70%, except for the descriptors of ‘very often’ and ‘very much’ which obtained means of 77% and 76 %.

Table 3.

Visual Analogue Descriptors Frequency and Variable

Descriptor	<i>n</i>	<i>M</i>	<i>SD</i>
Not at all	10	16.00	21.70
Very good	10	86.00	9.66
Always	10	89.00	18.52
Very happy	9	86.66	12.24
An extreme amount	10	77.00	19.46
Never	10	11.00	20.78
Satisfied	10	66.00	18.37
Very poor	10	15.00	12.69
A little	10	27.00	17.66
Completely	10	82.00	27.40
Dissatisfied	10	21.00	15.95
Very	10	64.00	18.37
Unhappy	10	22.00	19.88
Neither poor nor good	10	49.00	3.16
Very Satisfied	10	81.00	17.91
Moderately	10	50.00	10.54
Very unhappy	10	14.00	18.37
Neither satisfied nor dissatisfied	10	21.00	7.37
Good	10	67.00	17.66
Moderate amount	10	50.00	14.90
Very Often	10	77.00	20.02
Poor	10	23.00	14.94
Happy	10	67.00	17.66
Quite often	10	63.00	16.36
Neither happy nor unhappy	10	48.00	6.32
Very dissatisfied	10	16.00	17.76
Seldom	10	16.00	11.73
Very much	9	76.66	18.02
Extremely	10	83.00	23.59
Slightly	10	34.00	21.18
Very well	10	72.00	16.86
Mostly	10	69.00	18.52

The first visual analogue test resulted in unacceptable variation that could be attributed to the fact that no anchor points were provided on the 10 cm line. After the test, some participants revealed that in the visual analogue approach they regarded the middle of the line as the starting point then marked the descriptor either towards the right or left end of the line. Also, a long list of more than 100 possible descriptors took more than 20 minutes per participant to complete the task. As a consequence some individuals lost focus and simply marked the descriptor position without thorough consideration. Another factor leading to such variability in rating could be that too many similar words were confusing. Some participants commented on the difficulty of rating the descriptors due to a close association with another on the list. Hence they tried to distinguish these similar descriptors by exaggerating them.

The second approach provided more satisfactory results in terms of corresponding with the standard English WHOQOL version. This finding could be attributed to a shorter number of descriptors being rated, plus a clear and restricted rating range to limit the participant's choice option. However, it is interesting to note that the mean for the 75% descriptors on the WHOQOL-100 in this study showed a lower mean compared to the WHOQOL protocol. A possible explanation could be the association of New Zealand culture and its English language usage. New Zealanders are perhaps conservative in their estimating compared to other English language users. With regard to language usage, New Zealanders may tend to be more modest rather than exaggerate their expressions. A further study regarding this hypothesis is needed.

For the purpose of this study we are comfortable with the existing generic English language version descriptors, because the presentation of the rating scale in the WHOQOL presents the sequential numbers 1 to 5 as well as the verbal descriptors in sequence, and together intuitive meaning.

STUDY 2---Focus Group

Recruitment

According to the WHOQOL study protocol, the purpose of conducting focus groups is to generate potential questions and new facets, to provide preliminary importance ratings for all facets, as well as to assess the validity and comprehensiveness of the existing facet (WHOQOL Group, 1993a). The process of conducting focus groups was guided by the WHOQOL focus group work protocol (WHOQOL Group, 1993b). Focus group recruitment occurred from November 2008 until May 2009. An advertisement was displayed via a newsletter, a website, and noticeboards on the AUT campus and approaches were made to different organisations. Health services and various community groups were contacted or visited (e.g., diabetic support groups, AUT's "Never 2 Old Programme", Age Concern New Zealand) to recruit participants. The advertisement was also distributed through third parties. The focus group participants were approached through word-of-mouth, snowballing, e-mail lists, universities, and health rehabilitation institutes. At the end of the recruitment, 12 focus groups with a total number of 61 participants were recruited. Each group comprised three to eight individuals, demographically representative of New Zealand population in terms of gender, age, marital status, educational background, and ethnic identity. Four groups were outpatients with chronic health conditions and informal care givers, three groups were health professionals and academic health professionals, two groups were members from the general population, two groups were older adults, and one group was immigrants.

Procedure

The procedure of conducting focus groups followed the standard protocol that is recommended in the WHOQOL Focus Group Work (1993). It was the same procedure

for each focus group involving a brief orientation of the research and the purpose of the focus group meeting; the handing out and reading of the participant information sheet (see Appendix A); the signing of consent forms (see Appendix B); and the answering of any procedural questions. The participants were aware that the meeting would be tape recorded and listened to by the research team members of the New Zealand WHOQOL Group based at AUT University, Auckland. They would analyse the audio recorded discussion. Participants were assured of the confidentiality of discussions. The participants were then asked to describe what they thought was important to their QoL and that of New Zealanders and discussed this freely. Next they discussed what they thought were important determinants of the quality of life of people who were not well. Last they were given the WHOQOL 32 items importance questionnaire to rate. Demographic data were gathered with the importance questionnaire. The sessions lasted between 90 and 120 minutes. A detailed protocol underlying the focus group approach used can be found in the WHOQOL Focus Group Work (1993).

The researcher was assisted in the first three focus group sessions and one of the health professional group sessions by her supervisor who had been part of the WHO team who developed the WHOQOL in the 1990s. The researcher was trained in conducting focus group work and moderated the remaining nine focus group sessions. Table 4 presents the size and composition of each focus group.

Table 4.
Participants of the Focus Groups Demographic Characteristics

Focus group	Participants	Group characteristics	Age group
1	5	Disabled and care givers	40-60
2	5	Health professional	50+
3	6	Health researchers	20-50
4	6	Elderly	70+
5	5	Diabetics	50+
6	5	Immigrants	18-50
7	6	University Students	20+
8	11	Elderly	70+
9	6	Diabetics	40+
10	3	Academic health professionals	40+
11	5	Well persons	30+
12	3	Disabled and care givers	40+

Data analysis

Focus group information involved a three person group analysis of each tape, taking notes, discussion during and after the tape had finished, and comparing notes as well as proposing potential facets and items. This was done after all the 12 focus groups interviews were completed. There was no written transcript of the focus group discussion. The purpose of the analysis was to discern possible facets of QoL that could be tested as to their generality later on. Consensus among the research team was not necessary. Sometimes the tape was stopped to permit clarification and discussion of points being made by participants. The new areas that arose from the focus groups' discussion were identified as new themes in this study. A potential theme or later facet could be proposed by an analyst even if the others did not agree. However, this did not occur. Most of the new themes that were proposed in this study were revealed in at least three different focus groups' discussion. The research team then proposed and composed the importance questions, based on the identified themes. A list of more than 50 items was produced from the 12 focus group recordings.

The next step was to have the research team compare the new potential importance items to existing WHOQOL importance questionnaire items and the WHOQOL-100 questions. A new theme or item had to be different from existing domains, facet and questions in the WHOQOL. After removing the questions that were similar to the existing WHOQOL-100 items, the new list of importance items was finalised. The resulting list of new items was then presented to two English language linguistic experts to review the grammar and comprehensibility of the item. Some small changes were made in language structure. Then each question was aligned to an existing facet. However, some new questions were not classifiable and stood alone.

Results/discussion

All groups participated in an enthusiastic manner and contributed to interesting and rewarding discussions. The exercise produced very useful information. In the context of discussing a definition of QoL, most groups considered it as more than happiness or being content or the absence of disease, but closer to the notion of well-being. All participants accepted the WHO's definition of QoL and saw its relevance to human experience. Table 5 presents the new importance questions arising from the focus group discussion and expert analysis.

Table 5.
New Candidate Importance Items

NEW CANDIDATE IMPORTANCE ITEMS:
D1 Physical – Physical exercise How important to you is physical exercise.
D2 Psychological - Freedom of expression, autonomy, choice How important to you is being able to freely say what you want. How important to you is that others are able to express themselves freely. How important to you is feeling free to do what you want to do. How important is to you is having choices. How important to you is individual freedom. How important is it to you to have government listen to citizen's views. How important to you is being successful in what you choose to do. How important to you is personal success. How important to you is to feel you have control over your life.
D2 Psychological – History, Roots, Memories How important to you is your family roots. How important to you is your memories of the past
D3 Level of Independence – Managing difficulties and disabilities How important to you is being able to manage any disabilities you have. How important to you is being able to manage personal difficulties.
D4 Social Relationships - Identity or belonging How important to you is being accepted for who you are How important to you is a feeling of belonging. How important to you is being part of a group

D4 Social Relationships - Stigma, Respect, Prejudice, Multicultural, Diverse

How important to you is living in a society that accepts differences among people

How important to you is a fair and just society.

How important to you is respect for your culture.

How important to you is that others have a sense of responsibility.

How important to you is being respected by others.

How important to you is living in a multicultural society.

How important to you is having a diverse culture.

How important to you is being a full participant in society

D4 Social Relationships - Family Children

How important to you is having children at some stage of your life

How important to you is your immediate family

How important to you is discipline within the family

D4 Social Relationships -Trust Security Crime

How important to you is being trusted by others

How important to you is being able to trust others.

D5 Environment – Home environment

How important to you is your privacy

How important to you is having practical support at home

D5 Environment - Nature and outdoors

How important to you is to have access to outdoor activities.

How important to you is it to have natural surroundings.

How important to you is New Zealand's natural environment.

How important is it for you to be able to travel overseas.

D5 Environment - Food Diet

How important to you is eating sensibly

How important to you is a proper diet.

How important to you is good healthy food.

D5 Environment - Stability

How important to you is a politically stable environment

D5 Environment - Modern Technology.

How important to you is having access to modern technology. (e.g. computer, cell phone, electrical gadgets)

D5 Environment – Health and social care

How important to you is having access to competent medical personnel.

D5 Environment – Opportunities of acquiring new info

How important to you is having high quality education available.

D6 Spirituality/ Religion/ Personal Beliefs – Purpose, Goals

How important to you is to have purpose to your life

How important to you is being able to meet your expectations.

How important to you is doing things that have social value for others.

D= Domain

In the following discussion, the term related to the WHOQOL domains will be identified with a capital letter such as ‘Physical domain’. The term related to the WHOQOL facets will be identified with italics (e.g., ‘*pain and discomfort*’).

During the focus group work almost all the existing WHOQOL facets and importance questions were rated as important contributors to one’s QoL. A detailed description of the facets discussion from each group is listed in Table 6 at the end of the Results/discussion section.

The four outpatient groups (diabetes groups and disability group) covered all the existing WHOQOL facets in their discussion except facet 2 */energy and fatigue/* and facet 3 ‘*sleep and rest*’. Some discussion of the meaning of some facets and domains was different from the WHOQOL facet definition and questions. For instance, the three facets in the Physical domain were covered but not limited as to contribute to one’s QoL. The issues of general physical well-being, such as food and shelter, and age-related health issues were identified as important new areas for the NZ WHOQOL instrument. The facets in the Psychological domain that are different from the WHOQOL were *memory, self-esteem, positive and negative feelings*. Memory in WHOQOL refers to cognitive learning and capacity to remember things, but in the focus group discussion, memory was referred to as past life experiences. The “good old times past” brings an appreciation of current life circumstances. This group viewed self-esteem as being connected to contributing to a community. Interestingly, when discussing the *body image and appearance* facet, most participants were confident with their own appearance but struggled that others could not accept their appearance if they had a physical impairment which resulted in stigma. Another interesting point made regarding *positive and negative feelings* facet was grieving. Some participants thought feelings of sadness and tearfulness in the context of grieving is actually positive and could contribute to one’s psychological well-being. To “be left alone” was also a

situation that some of the NZ respondents viewed positively, but “depending on one’s personality”. They acknowledged that some people would rather be left alone and feel content than socialising with others.

In the domain of Level of Independence, differences were found in the facet of *dependence on medication or treatments*. The discussion extended from medications to adequate medical personnel. The participants in this study seemed more concerned about the quality they had received or will receive from the health providers as far more important than what kind of medications are available for their current health condition. Also in terms of independence, apart from the existing facets in WHOQOL, the participants also discussed the issue of having control over one’s life as essential to one’s QoL.

In the domain of Social Relationship, the facet *personal relationships*, several participants felt that family is important to them regardless of the level of satisfaction they get from their family as the WHOQOL has defined. Another aspect of this facet considered important is to live in harmony with family members, which was not addressed in the WHOQOL. As for the *practical social support* facet, many referred to support groups with like-minded people (e.g., diabetes support groups) instead of social support being limited to family and friends. Although facet 19 *health and social care* covered the community support, the question used the broader term of social services which was an ambiguous term that confused some respondents.

The facets in the Environmental domain also produced some different views from the WHOQOL. For instance, facet 20 looks at the chance to fulfil a need for information, but some participants raised the issue that language capacity may limit the opportunity to acquire information, especially for people who have physical disability or those from other countries such as the Pacific Islands. The facet 21 *participation in and opportunities for recreation/leisure* was linked by some participants to culture. This

was not specified in the WHOQOL. Also in the facet of *physical environment*, many regarded peaceful in terms of no war as priority above other perspectives that are listed in the WHOQOL. The majority of participants agreed that spirituality and personal beliefs played a significant part in contributing to one's QoL. Some additional themes which emerged in the discussion were technology, the sense of freedom, having choices, and living in a justice and equitable society.

To summarise, 12 new themes identified as important contributions to one's QoL from these outpatient group discussions are listed below:

- | | |
|----------------------------------------|-------------------------|
| 1. Food | 2. Adequate shelter |
| 3. Manage health-related health issues | 4. Memories of the past |
| 5. Contribute to a community | 6. Be left alone |
| 7. Free from being stigmatised | 8. Immediate family |
| 9. Adequate medical personnel | 10. Technology |
| 11. A member of a support group | 12. Language barrier |

The view of the health and academic health professional participants showed considerable similarity to the outpatients with chronic health condition and informal care givers groups. The health experts group did not discuss facet 2 */energy and fatigue/* nor facet 15 */sexual activities/*. However, in the Physical domain, the NZ sample valued exercise and being physical fit important to one's QoL. The facets in the Psychological domain were not extensively discussed. Most of the issues were related to personal development, and the sense of belonging. The *self-esteem* and *bodily image and appearance* discussion was similar to the outpatients groups' and being free from stress caused by stigma and discrimination. The group of health experts emphasised positive thinking rather than *positive feelings*. When discussing the facet of *medication or treatments*, the focus seemed to be on informed consent and autonomous choices

including the choice of euthanasia. The freedom and rights to make choices were discussed intensely.

In the domain of Level of Independence the facet of *mobility* was discussed in the context of accessibility such as access to nature. The facet of *working capacity* was discussed in the context of having meaningful occupation and appropriate workload rather than a person's ability to perform work as was proposed by the WHOQOL. The facet of *participation in and opportunities for recreation/leisure* discussion focused on outdoor activities rather than other forms of recreation. Two aspects raised in the facet of *physical safety and security* discussion were respect and trust. Participants from the health experts groups believed that in order to have a good quality of living in the community, people need to respect others and be trustworthy. About the facet of *physical environment*, the groups also referred to peaceful environment without war and conflict as well as consideration of noise and climate.

Major themes that were proposed by the health experts and outpatients groups in addition to the WHOQOL existing facets are listed below but not in any order:

- | | |
|---------------------------------------|--------------------------------|
| 1. Freedom to make choices | 2. Autonomy and responsibility |
| 3. Living in a multi-cultural society | 4. Connection to the land |
| 5. Food | 6. Sustainability |
| 7. Physical exercise | 8. Memories of the past |
| 9. Managing difficulties/disabilities | 10. Stigma, respect, prejudice |
| 11. Trust, security, crime | 12. Health and social care |
| 13. Home environment | 14. Family members, children |
| 15. Stability | |

The results from the older adult groups' discussion produced a significant content

validation of the WHOQOL-Old. Participants perceived that having good sensory function is an important factor to QoL. They also considered the quality of present life in comparison to the past experiences. With regard to the existing WHOQOL facets and domains, these two groups of elderly people were consistent in what they considered as important to their QoL were similar to previous groups, in terms of extending their discussion beyond the existing WHOQOL facet definition. For instance, in the Physical domain, good health was not limited to freedom from pain, having energy and being able to sleep well, but included having their basic needs met, as well as being fit and able to exercise. The discussion of the elderly regarding the facets in Psychological domain did not focus only on the existing WHOQOL facets. For instance, the participants said they preferred having a positive attitude towards life and to issues that arise in life rather than having positive feelings. Additionally the memory issue was related to past life experience and how these experiences relate to and affect the present. When discussing negative feelings, and similar to the outpatients groups, the elderly participants also acknowledged that what could be regarded as negative factors could also contribute positively to QoL. For example, some people prefer being left alone with limited or no social connections and having their own privacy.

For the facet *personal relationship*, the participants confirmed the importance of having families or being with family members. The participants discussed the facet of *social support* in the context of social connection. Interestingly, when discussing the facet of *sexual activity*, most participants believed that with increasing age sexual activity is not the usual way of expressing their intimate needs, but rather it is replaced with affection, hugging and touching. It is also interesting to note that when discussing the facet of health and social care, the participants focused on affordability rather availability. Also as with other groups, apart from the existing facets in WHOQOL-100, the group confirmed a few new areas that are important to one's QoL. The new themes

that could be generated from the elderly groups' discussion are listed below:

1. Technology
2. Freedom to make choice
3. A sense of humour
4. Having justice
5. Food
6. Able to be in charge
7. Live in a diversified culture society
8. Physical exercise
9. Memories of the past
10. Health and social care
11. Family history, roots

The /general population group/ University students and well persons- covered most facets in their discussion except those facets of *pain and discomfort*, *sleep and rest* and *transport*. The facet of */body-image and appearance/* it was linked with the concept of being confident in oneself, and the idea of being understood was considered more important than the person's appearance being accepted. In regard to *negative feelings*, the focus was on the opportunities to express the negative emotions rather than just experiencing them. The facet of *working capacity* was linked to the concept of being successful. In the discussion about *personal relationships*, the general population groups emphasised being accepted by the group more than the concept of fitting in. Another interesting point in this discussion was that the QoL of family members and close friends impacts on one's own QoL. For example, if a child is sick then the mother's QoL would be impacted. In relation to *participation in and opportunities for recreation/leisure*, the discussion stressed the importance of access to nature and the natural environment. Interestingly, the facet of *physical environment* was discussed in the context of not being crowded and not having environmental barriers to contend with. The additional themes that came up from the discussions of these groups are listed below:

- | | |
|------------------------|---------------------------------------|
| 1. Having choices | 4. Family / Children |
| 3. Purpose / Goal | 5. Basic needs to be met (e.g., food) |
| 2. Stability | 6. Stress free |
| 7. Identity/ Belonging | |

The results from the new immigrants group were somewhat different than other groups in terms of the discussion. A large amount of discussion was dedicated to comparing their country of origin and New Zealand. This was to be expected. For example, they compared the differences of the medical system and the quality of education between the two countries. Not many new facets were discussed by this group. They were very similar to the WHOQOL facets definition. One issue arose in the facet of *working capacity*, which was long working hours rather than one's ability to perform work. Two additional issues that emerged from this group were culture acceptance and having freedom to do things.

After generating themes from the focus groups discussion, the research team then compared these themes with existing WHOQOL domains and facets. For example, physical fitness went into the Physical domain. The questions from new themes assigned to the Psychological domain included importance questions concerning: freedom of expression, autonomy/making choices, and history/ roots/ memories of the past. Only one new theme related to the Level of Independence domain was generated, which was to manage difficulties and disabilities. Four themes assigned to the Social Relationship domain included importance questions about identity and belonging; stigma, respect, prejudice, and multicultural diversity; family and children; trust security and crime. The Environmental domain also had some new questions covering nature and outdoors; food and diet; stability; and modern technology. Apart from the new themes, some generated items could be assigned to the existing facets. For example, a new item asking about one's privacy was grouped under the facet of *home*

environment.

In summary, the discussion from all focus groups has confirmed that the existing WHOQOL domains thoroughly evaluate one's HRQoL. The existing WHOQOL facets that were answered in the focus groups are presented in Table 6. The focus groups proposed 16 new themes (see Table 7). Again, a summary of the themes and questions that emerged or were considered to be important was presented earlier in Table 5. Altogether 16 new themes and forty-six (46) new importance items were developed by the research team from the 12 focus group sessions. These new items have been sorted into the table where they may possibly fit into the existing WHOQOL domain and facet structures (see Table 5). Some items are not clearly classifiable into facets and so are left unnumbered within a possible domain. While no new domains have been created some new facets appeared possible. The next step is to get them rated as to their importance to QoL on a national sample.

Table 6.
Summary of focus groups' discussion—facets that were viewed as important to contribute to QoL

FACETS	F.G.1	F.G.2	F.G.3	F.G.4	F.G.5	F.G.6	F.G.7	F.G.8	F.G.9	F.G.10	F.G.11	F.G.12
F1			√	√	√		√	√				
F2												
F3						√				√		
F4		√					√			√	√	
F5		√				√			√			
F6	√									√	√	
F7	√									√	√	
F8		√						√		√		
F9	√			√	√		√	√	√	√		
F10		√			√			√	√		√	
F11		√	√		√			√	√	√	√	√
F12				√	√	√	√	√	√	√	√	√
F13	√	√	√		√	√		√	√	√	√	√
F14		√		√	√	√		√	√	√	√	
F15	√							√		√	√	
F16	√			√	√	√	√	√	√		√	√
F17	√	√	√	√	√	√	√	√	√		√	√
F18	√	√	√	√	√	√	√	√	√	√		√
F19	√			√	√		√	√	√	√		√
F20	√				√	√	√	√	√	√		√
F21	√					√	√	√	√	√	√	
F22			√		√	√	√	√	√	√	√	√
F23	√	√		√	√	√		√	√			√
F24	√		√		√	√	√	√		√		

Note. F.G. = focus group F.G.1-4 outpatients F.G. 5-7 health professionals; F.G. 8-9 older adults; F.G.10- 11 general populations F.G. 12 Immigrants
F1= Pain and discomfort; F2=Energy and fatigue; F3= Sleep and rest; F4= Positive feelings; F5= Thinking, learning, memory and concentration; F6= Self-esteem; F7= Bodily image and appearance; F8=Negative feelings; F9= Mobility; F10= Activities of daily living; F11 Dependence on medication or treatments; F12= Working capacity; F13= Personal relationships; F14= Social support; F15= Sexual activity; F16= Physical safety and security; F17=Home environment; F18=Financial resources; F19= Health and social care: availability and information and skills; F20= Opportunity for acquiring new information and skills; F21= Participation in and opportunities for recreation/leisure; F22= Physical environment: (pollution/noise/traffic/climate); F23= Transport; F24= Spirituality/ religion/ personal beliefs

Table 7.

Summary of the New Themes that was generated from the focus group discussion--

Physical fitness
 Freedom of expression, autonomy, choice
 History, Roots, Memories
 Managing difficulties and disabilities
 Identity or belonging
 Stigma, Respect, Prejudice, Multicultural, Diversity
 Family Children
 Trust, Security, Crime
 Home environment
 Nature and outdoors
 Food Diet
 Stability
 Modern technology.
 Health and social care
 Opportunities of acquiring new information
 Purpose, Goals

The results presented from the focus group work analysis suggest strongly that QoL is a multi-dimensional concept. Further testing of the existing WHOQOL items and any new generated items and subsequent structural analysis will examine this theory more fully. Quality of life comprises many areas of human life including both macro and micro components. Participants in this study discussed QoL as having both subjective and objective components. However, in order to keep the definition of QoL consistent with the WHOQOL definition, examples of themes that were described in objective terms in the focus groups will later be written and expressed in a subjective format asking the respondent about his /her feelings of satisfaction with a general facet of QoL and not their functional ability to complete a specific activity as one finds in measures of health status. One of the important themes that emerged a number of times in focus groups' discussions was around basic human needs. It seemed to echo Hörnquist's (1982) idea of QoL, which considered the degree of satisfaction of human needs. Interestingly, the WHOQOL instruments do not have an item that asks about

food. In contrast, Hong Kong includes eating and appetite in their Chinese Mandarin (Hong-Kong) WHOQOL as a national item.

The limitations in the focus group work are first, the focus group interview was loosely structured and the researcher was encouraged to make minimum interventions during the group's conversation. This could be interpreted in both positive and negative ways. For the positive side, participants could freely express their thoughts and hence increase the likelihood of obtaining authentic data. On the other hand, participants could drift from the research topic and have side-track conversations. For instance, one group when talking about family members shifted the conversation to debating whether the New Zealand anti-smacking bill should be legalised as anti-smacking law. This could be considered a waste of time. From a positive viewpoint, however, this could be interpreted as discussion around discipline of children which could be considered an issue affecting the lives of some people. This discussion about smacking children may also be interpreted as an example of how the media influences public conceptions of QoL.

Another example of this possible limitation to the focus group phase was that while discussing the definition of QoL, one group shifted to reflect upon the measurement of QoL as well as the theories and methodology of the current study. Another group spent time comparing the QoL in NZ and other countries. These digressions do waste time and intellectual energy. However, such tangents can also be enriching to the study because they identify different ways of viewing and embellishing an existing facet by way of a current event.

Second, there were limitations to the focus group work due to the difficulties of assembling everyone at the designated meeting place and agreed time, plus the unexpected illness or accident on the meeting date. Hence, 2 of the 12 groups had 3 participants compared to the preferred number of 5 to 10 people. With few participants

in the meeting, the conversation was less stimulating and reduced the richness in discussion.

Third, there were perhaps limitations to the focus group work because the majority of the participants were female (67.2%). The gender difference could lead to different direction of discussion. Male participants may contribute a different view on a specific issue from to female participants. The research literature confirms that there are gender differences in QoL, although most of the studies were examining the different outcome of QoL that associated with physical or mental health (Avis, Smith, Mayer & Swislow, 1997; Gray, Sprigg, Bath, Boysen, De Deyn, Leys et al., 2007). However, the differences occurred in the QoL ratings rather than the importance ratings. There is possibility that what people perceive as important in their lives may not have any gender differences. Whether the assumption is accurate can be examined by conducting further importance rating research in different people groups.

STUDY 3- WHOQOL Importance Questionnaire Reliability

Recruitment

Test-retest reliability and internal consistency were examined for the existing WHOQOL importance scale and for the new importance items generated from the focus group work. The questionnaires were given to a class of Auckland University of Technology students. The test-retest interval was three weeks. Forty-two students completed the two testing sessions.

Procedure

At the first session, the researcher explained to students about the project and answered all their questions. The participants were requested to write or draw a unique symbol on the front page of the questionnaire before completing the questionnaire and were asked to remember their symbol for the second test. This procedure was used to ensure confidentiality of the respondents' answers and permit comparison between the two testing sessions. The students were given the opportunity to ask any questions at the start of the second testing session. Students were asked to use the same identification symbol as they did for the first session. Each testing session lasted approximately 20 minutes. There were fewer students at the second session, but this was not in anyway connected to the WHOQOL questionnaire task.

Data analysis

Four questionnaires had more than three missing items. These questionnaires were dropped from the reliability calculations, resulting in a sample of 38 students. Data was analysed using the Statistical Package for the Social Sciences (SPSS, v.16.0). Means

and standard deviations were calculated. Pearson product-moment correlation coefficients (r) were calculated for both of the original WHOQOL-importance items and for the new importance items. Cronbach's alpha was applied to examine the internal consistency of the original 32 importance questions as well as the analysis for each of the four domains.

Results/ Discussion

The respondents in this study were 84.2% female students compared to 15.8% male students. The mean age of the students was 27. The age ranged between 18 to 49 years. Nine students were under 20, 19 students were between 21 and 31, four students were between 31 and 40, and six students were above 41 years of age.

Six domain scores were calculated from the existing WHOQOL-Importance items: physical, psychological, level of independence, social, environmental, and spiritual. Domain means and standard deviations are listed in Table 10 along with Cronbach's alpha statistics. The Cronbach's alpha for all the domains except the Spiritual domain were lower than the conventionally accepted cut off (i.e., 0.70) at the first test session, but all above 0.70 for the second session except the Psychological domain.

Table 8
Descriptive and Reliability Statistics for the WHOQOL Domains

Domain	# of items	First test			Second test		
		M	SD	α_c	M	SD	α_c
Physical	3	4.28	0.49	.66	4.21	0.51	.74
Psychological	9	4.04	0.47	.63	4.15	0.46	.68
Level of Independence	4	3.81	0.51	.63	4.08	0.53	.74
Social	3	3.81	0.51	.63	3.79	0.47	.72
Environmental	10	3.95	0.38	.63	4.00	0.43	.74
Spiritual	1	4.02	0.78	.81	4.18	0.83	.77

The rating of the new candidate importance items at the first test was lower than the second test, but the means were similar in most items. A few items had more than 0.30 mean differences between first and second test. Item 33.2, asking the importance of being trusted by others ($M = 3.78$ vs $M = 4.26$), had 0.48 difference between the two tests. Item 36.1, asking the importance of living in a politically stable society ($M = 3.71$ vs $M = 4.10$), had 0.39 differences in the mean. The two items listed above were rated lower at the first test and higher at second test. On the other hand, Item 40.3, asking about ‘doing things with social values to other; was rated higher at the first test ($M = 4.07$) and lower at the second test ($M = 3.78$).

The test-retest reliability for the whole questionnaire (32 existing and 46 new items) showed a satisfactory reliability coefficient ($r = .79$). Table 9 displays correlations between the first and second test of each WHOQOL–Importance existing item. The results indicated high reliability among all the items except item 19.1, asking the importance of getting adequate health care ($r = .12$).

Table 9.
Test-Retest Reliability of the existing WHOQOL-Importance Items

Items	Pearson Correlation	Items	Pearson Correlation
overall QoL	.48**	dependence on meds	.71**
general health	.37*	able to work	.63**
free of any pain	.35*	relationships with others	.58**
having energy	.36*	support from others	.60**
restful sleep	.68**	sexual life	.75**
feel happiness	.66**	feeling physically safe	.44**
feel content	.48**	home environment	.39*
feel hopeful	.63**	financial resources	.40*
learn/remember import. Info.	.48**	get adequate health care	.12
able to think through everyday problems + make decisions	.64**	able to get adequate social support	.36*
able to concentrate	.54**	getting new information	.48**
feeling positive about yourself	.72**	learn new skills	.30
body image/appearance	.50**	relaxation/leisure	.58**
free of negative feelings	.68**	environment	.69**
able to move around	.44**	adequate transport	.44**
Take care of daily living activities	.53**	Personal belief	.61**

*. Correlation is significant at $p < .05$ level (2-tailed).

**. Correlation is significant at $p < .01$ level (2-tailed).

Table 10 presents the WHOQOL domains' reliability. The results showed a satisfactory correlation in all domains except the 'level of independence' domain.

Table 10
Test-Retest Reliability of the existing WHOQOL Domains

Domain	<i>r</i>
Physical	.55**
Psychological	.82**
Level of Independence	.26
Social	.64**
Environmental	.47**
Spiritual	.61**

*. Correlation is significant at $p < .05$ level (2-tailed).

**. Correlation is significant at $p < 0.01$ level (2-tailed).

Table 11 presents the results of test-retest reliability on the new candidate importance items. The results in this set of items presented a lower test-retest reliability overall compared to the existing WHOQOL-Importance items. The Pearson Correlation ranged from 0.18 to 0.80. The items that obtained a low correlation were *living in a multicultural society* ($r=0.18$), *free to do things* ($r=0.19$); and being successful ($r=0.20$). There are other low consistency items ($r < 0.4$), but some of them showed a significant coefficient such as the item about having diverse culture ($r=.34$, $p < .05$), a full participant in society ($r=.38$, $p < .05$), importance of a political stable environment ($r=.39$, $p < .05$).

Table 11.
Test-Retest Reliability of the New Candidate Items

Items	Pearson Correlation	Items	Pearson Correlation
physical exercise	.79**	having diverse culture	.34*
free to say what you want	.68**	being a full participant in society	.38*
other able to express freely	.47**	having children at some stage of your life	.55**
free to do what you want	.19	immediate family	.57**
having choices	.49**	discipline within the family	.46**
individual freedom	.49**	being trusted by others	.44**
government listens to citizen's views	.63**	being able to trust others	.47**
being successful in what you choose to do	.20	your privacy	.29
personal success	.63**	having practical support at home	.61**
have control over your life	.47**	have access to outdoor activities	.65**
family roots	.62**	natural surroundings	.80**
memories of the past	.46**	NZ natural environment	.69**
manage any disabilities you have	.60**	travel overseas	.77**
manage personal difficulties	.43**	eating sensibly	.76**
being accepted for who you are	.51**	proper diet	.76**
feeling of belonging	.28	good healthy food	.73**
being part of group	.31	politically stable environment	.39*
living in a society that accepts differences among people	.51**	having access to modern technology	.66**
fair and just society	.25	access to competent medical personnel	.61**
respect for your culture	.68**	high quality education available	.47**
others have a sense of responsibility	.64**	having a purpose to your life	.28
being respected by others	.50**	able to meet your expectations	.46**
living in a multicultural society	.18	doing things that have social values for others	.23

* Correlation is significant at $p < .05$ level (2-tailed).

** Correlation is significant at $p < .01$ level (2-tailed).

In general, the test-retest exercise has showed satisfactory results for the whole importance questionnaire for the existing WHOQOL importance items as a group and for the new importance items. However, there are some discrepancies. First of all, the

data were obtained from a convenience sample of students with a relatively small number of participants and most of them females. However, the means and the variability scores indicate that most of the items that are listed in the WHOQOL-Importance questionnaire are perceived as significant to one's QoL by New Zealand higher education student representatives. The low correlation on the item *getting adequate health care* indicates item instability that could be attributed to the characteristic of young age and good health of this sample. The similar results in the domain of the Level of Independence with a relatively low correlation score could also be due to the good health state that most students are in. Therefore, this domain does not appear to be significant to young people.

The mean values and the reliability results of the new candidate items showed potential value for the new items. These results confirmed that most of the new questions are important when measuring New Zealanders' QoL and that most are stable over a short time period. Those few new items that have low test-retest reliability should ideally be retested again on a more heterogeneous population to examine their stability. The current decision is to keep them as potential new facets for the next stage of the larger research programme. If they continue to show instability in a later study they will be dropped from the NZ WHOQOL.

The WHOQOL Group acknowledges that over a longer time period there will likely be changes in importance for some facets too (WHOQOL-Group,1995). This change is reflected in the rationale for the WHOQOL-OLD. The WHOQOL instruments ask participants when responding to the questionnaire to rate any item according to two weeks period of time if they are unsure.

Research has suggested that one's QoL can be impacted by many immediate factors such as health, emotions, stress, family, work, and environment (Scott, Nolan & Plagnol, 2009). Taking into account the condition of the university students and the first

test session occurring in the beginning of a new semester, there might be some anxiety in their life. They also would have been in the university for only a month. These factors could potentially impact on the stability of their ratings. Some items they perceived as important at the first test may not hold the same weight at the second test and vice versa. For example, Item Imp 22.1 regarding environment the students might not consider that the environment was an important factor at the first test, but after a few weeks settled down in the university, it became more important for them to know their surroundings.

STUDY 4- Testing for Importance among the General Population

This is the final step of the research for the thesis. The purpose is to examine whether the new candidate importance items derived from the focus groups' discussions reflect New Zealanders' perception of what is important to their QoL. These results will reveal what is most important to the QoL of New Zealanders and then potential New Zealand national items will be developed.

Recruitment

Two thousand participants were randomly selected from the New Zealand electoral roll using the research randomizer online version (Urbaniak & Plou, 1997). The importance questionnaire is presented in full in Appendix E. A participant information sheet and a covering letter explaining the survey and questionnaire were posted to the sample with a stamped addressed return envelope included. By the cut-off day for data analysis, which was one month after posting, there were 585 questionnaires returned. The response rate was 29%.

Data analysis

The data were entered into a computerised spreadsheet. Statistical analysis was undertaken using the SPSS V.16.0. Following the WHOQOL Group instructions, the data from the existing WHOQOL-Importance were prepared using the WHOQOL-100 manual's domain items (WHOQOL Group, 1995). There were neither reversed items nor negatively worded items in the existing WHOQOL-Importance questionnaire or in the new candidate importance items. The focus of analysis was on descriptive statistics and internal consistency/reliability. The selection criteria for any item were of a mean of 4 or greater on the 5-point scale, or a mean marginally below 4 but with a median value

above 4. Inferential statistics were used to examine the relationship between gender, age, self-reported health state, and between the WHOQOL domains.

Results

Missing data analysis

The 78- item questionnaire included both the 32 existing WHOQOL-Importance items and the 46 new candidate items. Overall, 61 items were not answered out of 45,630 possible items (585 participants \times 78 items). Thus there was 0.001 percent missing data.

Demographic Profile

A total number of 585 participants responded to the study consisting of 213 males (36.4%) and 362 females (61.9%). Ten people (1.7%) did not indicate their gender. The ages ranged from 18 to 94 years old with a mean age of 53 years and a standard deviation of 16 years. Five people did not disclose their ages. Among the 585 participants there were 223 people who identified themselves as healthy without any disease diagnosis given or being currently in ill health. Three hundred and sixty two reported that they are either currently ill or have received a medical diagnosis. Detailed demographic information is displayed in Table 12. Some participants disclosed that they have multiple illnesses. No geographical data was requested; for example, town or city of residence.

Table12.
Demographic profile of the sample

Variables	<i>n</i>	Percentage of valid response
Ages		
-under 20	12	2.1
-21-30	39	6.7
-31-40	84	14.5
-41-50	108	18.6
-51-60	139	24.0
-61-70	114	19.7
-71-80	63	10.9
-81-90	16	2.8
-above 91	5	0.9
Illness status		
-heart trouble	42	
-arthritis or rheumatism	106	
-emphysema or chronic bronchitis	13	
-diabetes	33	
-stroke	6	
-chronic nervous disorder	7	
-chronic emotional problem	9	
-high blood pressure	99	
-cancer	13	
-poor eyesight	101	
-skin infection	30	
-physical disability	28	
-hearing disability	58	
-Others	77	

The Existing WHOQOL-Importance

The mean importance rating of the whole questionnaire (78 items) is 4.03 with a standard deviation of 0.40. The existing WHOQOL-Importance item means ranged from 3.09 to 4.50 (*SD*= 0.59 to 1.22). The internal consistency was high with a Cronbach's alpha of = .92. The data also showed high item-total correlations (i.e., greater than 0.3). Item total correlations are the correlations between an individual item and the total scores of other items. This indicates that the most questions in the questionnaire were tapping the same underlying dimension. Table 13 presents the descriptive statistics and Cronbach's alpha for two global items and six domains. However, due to there being only one item in the spiritual domain Cronbach's alpha could not be calculated.

Table 13.

Item Analysis for the Existing WHOQOL-Importance. Both Descriptive and Reliability

Domain	Item	<i>M</i>	<i>SD</i>	Item-Total Correlation	α_c if item deleted
Global item	Overall QoL	4.42	0.59	-	-
Global item	General health	4.48	0.60	-	-
Physical	Free of any pain	4.24	0.77	.469	.606
	Having energy	4.32	0.60	.540	.528
	Restful sleep	4.20	0.73	.464	.605
Psychological	Feel happiness and enjoyment of life	4.42	0.59	.588	.836
	Feel content	4.22	0.68	.628	.832
	Feel hopeful	3.99	0.80	.589	.835
	Able to learn and remember	4.08	0.70	.588	.835
	Able to think through everyday problems	4.26	0.65	.501	.843
	Able to concentrate	4.20	0.65	.577	.837
	Feeling positive about yourself	4.14	0.74	.648	.829
	Body image and appearance	3.54	0.83	.508	.845
	Free of negative feelings	4.05	0.84	.560	.839
Level of Independence	Able to move around	4.50	0.62	.487	.495
	Able to take care of daily living activities	4.50	0.64	.411	.536
	Free of dependence on medicines	3.91	0.95	.396	.539
	Able to work	3.96	0.99	.342	.594
Social	Relationship with others	4.09	0.76	.464	.292
	Support from others	3.50	0.90	.393	.348
	Sexual life	3.09	1.22	.233	.685
Environmental	Feeling physically safe and secure	4.28	0.68	.463	.792
	Home environment	4.31	0.65	.482	.791
	Financial resources	4.10	0.76	.510	.787
	Able to get adequate health care	4.37	0.67	.513	.788
	Able to get adequate social support	3.34	0.99	.492	.790
	Getting new information or knowledge	3.61	0.83	.592	.777
	Chances to learn new skills	3.34	0.93	.454	.794
	Relaxation/leisure	3.90	0.81	.464	.792
	Environment (pollution, climate, noise...)	4.04	0.82	.426	.796
	Adequate transport in everyday life	3.98	0.83	.481	.790
Spiritual	Personal belief	39.7	0.90	-	-

Analysis of domains

The physical domain was rated as the most important. The social domain had the lowest mean score and was not above four which was unexpected. It infers that this New Zealand sample did not consider the social domain as important as the other domains. Whether this is reflective of a global change since the WHOQOL was first constructed or a New Zealand characteristic is not known. The spiritual domain appeared to have a wider spread of scores compared to other domains. This domain is part of the psychological domain when the four domain structure is used. Interestingly, the environmental domain which contains the most items did not obtain the highest importance rating, but produced the least variation (see Table 14).

Table 14.
Descriptive and Reliability Statistics for the WHOQOL-Importance Domains

Domain	# of items	<i>M</i>	<i>SD</i>	α_c
Physical	3	4.26	0.55	.75
Psychological	9	4.10	0.50	.73
Level of independence	4	4.22	0.55	.76
Social	3	3.56	0.70	.78
Environmental	10	3.93	0.48	.74
Spiritual	1	3.97	0.90	.83

Three of the six domains had a mean rating lower than four. An analysis of mean values between demographic and health/ illness groups will help to clarify the results.

The results of *t*-tests on gender showed that males rated importance significantly lower in overall QoL ($t(573)=-3.849$, $p<.001$), general health ($t(573)=-3.274$, $p=.001$), and four domains: physical ($t(573)=-5.504$, $p<.001$), psychological ($t(573)=-4.65$, $p<.001$), environmental ($t(573)=-4.536$, $p<.001$), and spiritual ($t(572)=-2.865$, $p=.004$). compared to females.

Age was categorised into three groups (Group1 = below 30, Group2 = 30-60, Group3 = 60+). A One-way Analysis of Variance (ANOVA) was calculated to compare the mean of importance values between the three groups. Significance was found in two global items and three domains (see Table 15). The results also showed that Group 3 had lower scores when compared with other age groups in those significant items and domains. Group 2 rated significantly lower in general health than group 1, but higher in social domain.

Table 15
Means of Each Age Group

Items/ Domain	Age below 30	31-60	60+
Overall QoL	4.33 ^{a,b}	4.49 ^a	4.32 ^b
General health	4.24 ^a	4.54 ^b	4.44 ^{a,b}
Physical	4.24 ^{a,b}	4.32 ^a	4.15 ^b
Psychological	4.07 ^a	4.12 ^a	4.08 ^a
Level of Independence	4.28 ^{a,b}	4.31 ^a	4.06 ^b
Social	3.82 ^{a,b}	3.67 ^a	3.30 ^b
Environmental	3.89 ^a	3.96 ^a	3.89 ^a
Spiritual	3.82 ^a	3.99 ^a	3.95 ^a

Letter indicates if the mean are significantly different

Analysis based on the health status was also carried out. Interestingly, the healthy group rated higher in three domains: Physical (4.27 vs 4.25), Level of Independence (4.30 vs 4.17), and Social (3.66 vs 3.94) than the ill-health group. On the other hand, the ill-health group rated Psychological (4.12 vs 4.07), Environmental (3.94 vs 3.90) and Spiritual (4.03 vs 3.87) domains more important to their QoL compared to the healthy group. A battery of independent samples *t*-tests revealed that the means between the two groups differed significantly on the Level of Independence ($t(583)=2.889$, $p=.004$), social ($t(583)=2.87$, $p=.006$), and Spiritual ($t(582)=-2.072$, $p=.039$) domains.

New Candidate Importance Items

The means of the new candidate items ranged from 3.07 ($SD = 0.654$) to 4.61 ($SD = 1.256$). Table 16 displays which items obtained the mean value lower than four, and Table 17 displays which items' mean values are higher than four. The median value was also calculated in order to assist in selecting areas for developing national items.

Table16
New Item's Means Below 4.00

Items	<i>M</i>	Median	<i>SD</i>
25.1 physical exercise	3.67	4.00	0.86
26.2 others are able to express themselves freely	3.89	4.00	0.76
26.8 personal success	3.86	4.00	0.84
27.2 memories of the past	3.72	4.00	0.93
29.1 being accepted for who you are	3.96	4.00	0.86
29.2 feeling of belonging	3.83	4.00	0.91
29.3 being part of group	3.22	3.00	0.95
30.1 living in a society that accepts differences among people	3.96	4.00	0.85
30.3 respect for your culture	3.76	4.00	0.99
30.5 being respected by others	3.91	4.00	0.79
30.6 living in a multicultural society	3.18	3.00	1.06
30.7 having diverse culture	3.07	3.00	1.05
30.8 being a full participants in society	3.32	3.00	0.95
31.1 having children at some stage of your life	3.93	4.00	1.25
33.2 having practical support at home	3.54	4.00	1.03
34.1 have access to outdoor activities	3.79	4.00	0.91
34.4 able to travel overseas	3.44	4.00	1.19
35.1 eating sensibly	3.91	4.00	1.19
35.2 proper diet	3.89	4.00	0.87
37.1 having access to modern technology (e.g. computer, cell phone, electrical gadgets)	3.60	4.00	0.99
40.3 doing things that have social value for others	3.72	4.00	0.84

Table 17
The New Items with Means Above 4.00

Items	<i>M</i>	Median	<i>SD</i>
26.1 being able to freely say what you want	4.06	4.00	0.76
26.3 feeling free to do what you want to do	4.12	4.00	0.72
26.4 having choices	4.17	4.00	0.70
26.5 individual freedom	4.32	4.00	0.84
26.6 have government listen to citizens' views	4.18	4.00	0.84
26.7 being successful in what you choose to do	4.08	4.00	0.74
26.9 feeling you have control over your life	4.30	4.00	0.68
27.1 your family roots	4.04	4.00	1.00
28.1 being able to manage any disability you have	4.03	4.00	0.90
28.2 being able to manage personal difficulties	4.13	4.00	0.70
30.2 a fair and just society	4.30	4.00	0.73
30.4 others have a sense of responsibility	4.06	4.00	0.71
31.2 your immediate family	4.61	5.00	0.69
31.3 discipline within the family	4.03	4.00	0.84
32.1 being trusted by others	4.40	4.00	0.66
32.2 being able to trust others	4.26	4.00	0.67
33.1 your privacy	4.21	4.00	0.77
34.2 have natural surroundings	4.02	4.00	0.81
34.3 New Zealand natural environment	4.25	4.00	0.79
35.3 good healthy food	4.08	4.00	0.79
36.1 a politically stable environment	4.02	4.00	0.80
38.1 having access to competent medical personnel	4.37	4.00	0.73
39.1 having high quality education available	4.19	4.00	0.85
40.1 having purpose to your life	4.28	4.00	0.75
40.2 being able to meet your expectations	4.03	4.00	0.72

The comparison between groups was also conducted for the new candidate importance items to examine whether there were different ratings between different groups of respondents. Although Type I errors are likely to occur in omnibus single item comparison, the test can still provide valuable information about group differences. For example, the gender group comparison had 10 out of 46 new candidate importance items without any significance. Also, males rated less importance on all the significantly different items than females did. Table 18 presents the new candidate importance items that obtained significant differences when gender was selected as the grouping variable.

Table 18

Probability Values of the New Candidate Items with Significance between Genders

Items	p-value
having choices	.05
individual freedom	.03
have government listen to citizens' views	.04
being successful in what you choose to do	.03
your family roots	<.01
memories of the past	<.01
able to manage any disability you have	<.01
able to manage personal difficulties	<.01
being accepted for who you are	<.01
feeling of belonging	<.01
being part of group	<.01
living in a society that accepts differences among people	<.01
a fair and just society	<.01
respect for your culture	<.01
others have a sense of responsibility	<.01
being respected by others	<.01
living in a multicultural society	<.01
having diverse culture	<.01
being a full participant in society	.01
having children at some stage of your life	<.01
your immediate family	<.01
discipline within the family	.01
being trusted by others	<.01
being able to trust others	<.01
your privacy	<.01
have natural surroundings	.01
New Zealand natural environment	<.01
eating sensibly	<.01
proper diet	<.01
good healthy food	<.01
a politically stable environment	.01
having access to competent medical personnel	.01
having high quality education available	.01
having purpose to your life	.03
being able to meet your expectations	.02
doing things that have social value for others	<.01

There were only 19 new candidate importance items that were rated significantly different between the three age groups. The means of each group are presented under the column of Group 1, Group 2, and Group 3. The significance between groups is presented under the pair column, and the significant level followed (Table 19). The results showed that the above 60s age group rated many factors were more important than the other two younger age groups. However, when the factors were related to

successfulness, being respected, technologies, and doing things that have social value for others, the younger group had rated them more important than other older groups. The middle-aged group appeared to rate as highly important as the natural environment and outdoor activities factors.

Table 19
Significance Between the Age Groups (Group1:18-30, Group 2:31-60, Group 3:60+) on the New Candidate Importance Items

Items	Group1 n=51	Group2 n=331	Group3 n=198	pair	P-value
successful in what you choose to do	4.25	4.07	3.96	1 vs 3	.03
personal success	4.24	3.85	3.65	1 vs 2	.01
				2 vs 3	.02
your family roots	3.82	3.91	4.23	1 vs 2	.03
				2 vs 3	<.01
being able to manage any disability you have	3.92	3.96	4.19	2 vs 3	.02
fair and just society	4.08	4.29	4.38	1 vs 3	.03
being respected by others	4.16	3.84	3.91	1 vs 2	.02
discipline within the family	3.69	4.00	4.17	1 vs 2	.04
				2 vs 3	<.01
having practical support at home	3.61	3.42	3.64	2 vs 3	.05
have access to outdoor activities	3.73	3.87	3.65	2 vs 3	.02
have natural surroundings	3.69	4.11	4.03	1 vs 2	<.01
				1 vs 3	.02
New Zealand natural environment	4.00	4.34	4.29	1 vs 2	.01
				2 vs 3	.05
eating sensibly	3.67	3.85	4.11	1 vs 3	<.01
				2 vs 3	<.01
proper diet	3.75	3.83	4.04	2 vs 3	.02
good healthy food	3.80	4.04	4.22	1 vs 3	<.01
				2 vs 3	.04
a politically stable environment	3.67	4.02	4.19	1 vs 2	.01
				1 vs 3	<.01
having access to modern technology (e.g. computer, cell phone, electrical gadgets)	3.82	3.61	3.38	1 vs 3	.01
				2 vs 3	.02
having access to competent medical personnel	4.18	4.32	4.51	1 vs 3	.01
				2 vs 3	.01
doing things that have social value for others	3.86	3.60	3.68	2 vs 3	.05

There were only ten items that have been rated significantly different between the healthy and ill-health groups in the new candidate importance items. Table 20 presents the ten items.

Table20
Probability Values of the New Candidate Items with Significance between Healthy and Illness Groups

Items	Healthy n=223	Illness n=362	P-value
individual freedom	4.22	4.37	.01
have government listen to citizens' views	4.10	4.25	.05
able to manage any disability you have	3.81	4.17	<.01
able to manage personal difficulties	4.00	4.22	<.01
feeling of belonging	3.67	3.88	.01
your privacy	4.11	4.24	.05
having practical support at home	3.38	3.59	.02
have access to outdoor activities	3.92	3.70	<.01
travel overseas	3.65	3.25	<.01
doing things that have social value for others	3.59	3.75	.02

Reduction of the items

Based on the general population's responses to the importance questionnaire and with the statistics employed to examine them, importance items were selected to be written as questions in the WHOQOL format. For the national survey, any importance item with a mean greater than 3.6 and a median value greater than 4 was included. The unstable items revealed in the analysis of the student test-retest reliability (Study 3) were not used due to the limited and homogenous nature of the sample.

One new item, or often more than one new item, was written in the WHOQOL formats for each importance item that had been selected (see Table 21). The question was written in one of the original WHOQOL four formats; intensity, frequency, capacity and evaluation. This writing was done by one of the researchers and edited by an independent lawyer and journalist. The WHOQOL research team then examined the written questions and chose the best format for each item. Some items that closely related to a particular cultural issue in New Zealand were altered slightly in order to accentuate the culture dimension. For example, the item asking about the importance of one's immediate family was reformatted into "the support you get from your family/whanu". One item was edited to achieve greater generalisability to all people through out their life span and not just a particular time in their life. For example, the importance item asking "How important to you is having high quality education available", which could be interpreted as only applying to an individual's personal education needs, was rephrased to "How satisfied are you that high quality education is available" which could apply to others the individual is involved with. However, most potential national items maintained the authentic content wording of their related

importance questions. If there were a few items similar in meaning then they were combined into one item. For example, items measuring the importance of (free to say what you want), (free to do what you want) and (individual freedom) were combined into an item that referred to an individual's freedom. Some items that appeared to be duplicated within the existing WHOQOL-BREF were discarded. The discussion of the research team was constructive, thorough, and supported where available by the statistical data. The procedure produced 24 new candidate national questions for the next phase of the research which was to give all the existing WHOQOL-BREF questions with the new candidate items to a national random sample of 3000 people aged over 18 years.

Table 21

The New Candidate national items and their matching importance items

Original Candidate Importance items	Candidate National Items
How important to you is individual freedom	To what extent do you feel you have individual freedom?
How important is it to you to have government listen to citizens' views?	How satisfied are you that the government listens to citizens' views?
How important to you is being successful in what you choose to do?	To what extent do you feel successful in the things you choose to do?
How important to you is feeling you have control over your life?	To what extent do you feel you have control over your life?
How important to you are your family roots?	How much do you value your family roots?
How important to you is being able to manage personal difficulties?	To what extent are you able to manage personal difficulties?
How important to you is a fair and just society?	To what extent do you feel you live in a fair and just society?
How important to you is it that others have a sense of responsibility?	To what extent do you feel others have a sense of responsibility?
How important to you is your immediate family?	How satisfied are you with the support you get from your family/whanau?
How important to you is being trusted by others?	To what extent do you feel trusted by others?
How important to you is being able to trust others?	To what extent do you feel you can trust others?
How important to you is your privacy?	To what extent do you feel you have enough privacy?
How important to you is New Zealand's natural environment?	To what extent do you enjoy New Zealand's natural environment?
How important to you is good healthy food?	How satisfied are you that you eat healthily?
How important to you is having access to competent medical personnel?	To what extent do you feel you have access to competent medical personnel?
How important to you is having high quality education available?	How satisfied are you with the quality of education that is available?
How important to you is being able to meet the expectations of others?	How satisfied are you that you are able to meet the expectations placed on you?
How important to you is physical exercise?	How satisfied are you that you get enough physical exercise?
How important to you is being accepted for who you are?	To what extent do you feel accepted for who you are?
How important to you is a feeling of belonging?	To what extent do you have feelings of belonging?
How important to you is living in a society that accepts differences among people?	How satisfied are you that you live in a society that accepts differences among people?
How important to you is respect for your culture?	To what extent do you feel your culture is respected?
How important to you is being respected by others?	To what extent do you feel respected by others?
How important to you is having access to	How satisfied are you with your access to

DISCUSSION

The age distribution was not reflective of the New Zealand population. Young people were under represented in the sample probably because they have greater mobility and tend to travel or relocate more often compared to middle and late adulthood aged groups. According to the NZ Census of Population and Dwellings data, economics and employment are the two main factors why young people change their place of residence (Statistics New Zealand, 2006). A possible solution to increase representation in this age group is to recruit from education institutions or employment workplaces. Alternatively another sample of under 30-year-olds could have been conducted in order to approach the national demographic proportion, but the time and cost to do this precluded this option.

The illnesses that participants in this study reported were primarily physical. A fair number of respondents reported chronic diseases such as arthritis, high blood pressure, heart disorders and diabetes. There were two illness categories related to mental health problems. However several of these physical disorders could be psychosomatic. Compared to statistics published by the Ministry of Health (2000) nearly one out of five New Zealanders will experience mental illness at some stage in their life. However, it is difficult to design and get valid responses to demographic questions regarding mental state in a questionnaire of this kind. Another problem in classifying disorders in the questionnaire is exemplified by the term 'poor eyesight'. It is rather ambiguous. Poor eyesight could mean many things to different people. For example, people who have lost their eyesight completely or partially or who wear reading glasses could tick this box. A few participants provided fuller information on

their 'poor eyesight' that suggested this variety of interpretations. Some reported that they wear glasses while at the same time reported having cataracts, blurred vision, or a blind spot. This resulted in more than 100 participants confirming they had poor eyesight.

Comparison between different groups revealed some facets did not show differences in ratings of importance across genders, ages, and health conditions, such as the importance of one's QoL. At the same time, some domains were only seen as important to some groups. The physical domain was different for each age group as it was between genders. Also different health conditions had different importance values. Different perceptions of importance appeared among the new candidate items as well, especially within age groups. What young people perceived as important did not hold the same values as for the older people groups. This again confirms that people's values changed over time.

Is the perception of what is important in ones QoL based on wants, needs or desire planted in people's mind? How do they originate or have their foundation? A three-year longitudinal study examining the predicates of QoL among cardiovascular disease patients and Type 2 diabetes patients found that patients with cardio disease had poor QoL in respect of physical function, vitality, social function and the mental component compared to diabetics without cardiovascular disease (de Visser, Bilo, Groenier, de Visser & Meyboom-de Jong, 2002). What this report implies for the current study is that what people perceive as important to their QoL could be grounded in their adaptation to their health problems. Once a person accepts the limitation of activities resulting from a specific disorder then the importance of that limitation factor might be reduced.

Another study investigated the perceptions of multiple sclerosis patients on the importance of meeting their own needs (Forbes, While & Taylor, 2006). The findings

identified several important dimensions for MS patients to meet their needs such as socio-environmental support (i.e., housing, mobility) and psychological support. This suggests that what was important to multiple sclerosis patients was to meet the needs that they could not easily accomplish because of their disease.

A conclusion then can be drawn the current study and other previous studies that people with ‘heart trouble’ or who are elderly feel that having energy, being free of any pain, being able to have restful sleep, and feeling hopeful are less important facets to them when they are in poor health or are older. A study to explore what underlies the perceived importance of HRQoL facets would provide more understanding of the origins of QoL values.

More than half of the total new candidate importance items produced a mean value above 4. This indicates that the random sample of New Zealanders in this study endorse many of the facets that the focus groups’ participants generated through their discussions as one would expect. It is interesting to observe that some of the new items that on the surface appear to be similar were rated differently by the national sample respondents. For example, the new theme of food and diet has three items asking about eating sensibly (35.1), proper diet (35.2), and healthy food (35.3). The first two questions were rated lower in importance than the last. This could be due to semantics. However, the word ‘diet’ is also easily associated with weight management or food control that in turn could produce a negative attitude to it (Hill, 2002; Heartya, McCarthy, Kearneyb & Gibney, 2007). Another example of the relevance of semantic considerations in questioning is found in the new candidate importance questions which is ‘having children at some stage of your life’. The comments of some respondents indicated some confusion in answering the question. Comments such as “already have four children”, “cannot have any more children with my age”, “don’t want any more” are comments that show the question was not interpreted the same by all respondents.

The results from both focus groups and the national sample support the findings emerging from the literature review, which indicated that culture is a significant factor when measuring QoL. Quality of life is culture bound and affects different values and the degree of importance in what is important to QoL. A few items that reflect on New Zealand's culture, such as family roots, NZ natural environment, meeting the expectation placed on you, and your immediate family, are linked to New Zealand Pakeha culture, Maori culture and Polynesian cultures. Most New Zealanders appeared to be proud of the country's green and clean landscape so that it has become part of the collective psychological well-being of New Zealanders (Egoz, 2000). Some Maori culture research has concluded that cultural practice and whakapapa (Maori genealogy) play a significant role in the development of Maori identity (Durie, 2003; Moeke-Pickering, 1996). In Maori culture, parents, family, and peers have an important role in shaping one's identity. Family and obedience are two of the major issues in Polynesian culture. Research has found that Polynesian culture is a family-orientated culture, where family members are expected to live up to parents' expectation. This expectation is common in raising children and teenagers (Capstick, Norris, Sopoag, & Tobata, 2009; Ritchie & Ritchie, 1983). The cultural perspective is also a strong consideration when adapting the importance questions into the WHOQOL format therefore; family/whanau was used in one question.

LIMITATIONS/ FUTURE STUDIES

There are a number of limitations inherent in the research. The current study was subject to other sampling limitations as described earlier. The descriptor verification exercise using the visual analogue response scale could have provided anchor points to avoid confusion and obtain more consensus data. Too many descriptor options were given to the ten participants. The gender imbalance in the student test-retest reliability exercise is an issue. However, this can be justified by reflection on the New Zealand gender population as well as there being more female students studying in health majors. The current project had more female participants in all sub-studies (response scale verification, focus groups, test-retest reliability, and the national importance survey). Thus an insufficient number of male representatives may not fully capture New Zealand males' perception of QoL.

Age is also one of the weaknesses in this project, especially in the focus groups and the national importance survey. Less than 9% of the young adults in this study were below 30 years old, which does not represent this age group's population ratio. With more young adults participating the variability and strength of the perception of what is important to QoL of young people would have been better represented.

The response rate of 29% of the sample was somewhat disappointing but not unexpected. National surveys often suffer from similar response rates. Confidentiality of responses is important in studies such as these but it makes follow-up difficult. Preparatory letters to potential respondents and follow up letters have been known in some studies to improve the response rates to postal questionnaires but cost and time

did not permit these options.

The length of the questionnaire is another considerable factor that might have impacted on the research results, especially when the new candidate importance items were placed at the end of the questionnaire. To answer a 78-items questionnaire can be time consuming and bore some people. Lack of thoughtful consideration in answering towards the end of the questionnaire can be attributed to loss of patience. The size and the font of the questionnaire on top of the questionnaire length issue could also cause some difficulties to older people or people with poor eyesight.

Conclusion

Quality of life is a complex concept and there is no consensus definition at the current time. Quality of Life research requires well-designed and thorough studies in order to comprehend its content and meaning. There are various QoL research measuring tools available, but most of them do not suit all study populations. The ambiguous context in measurements, such as measuring health status rather than QoL, and a lack of culture sensitivity, are the major weakness in those existing measurement. Additionally many measurements were designed from a professional's perception of QoL rather than ordinary people's view. However, research on QoL has significant implication in different professions and valuable scientific evidence to improve human life experiences in our generations.

This project is complex and involved four studies. Every study was carefully designed and examined, critiqued, and altered if necessary. In order to obtain the goal of generalisation the study maximises participant number with the limited resources available. The outcome of meeting this goal was not perfect but satisfactory. The data had produced wealthy and valuable results in all studies.

This research is part of a bigger study to develop a New Zealand version of the WHOQOL-BREF. This study has had the vital role of generating and verifying what facets of QoL, which are not in the existing WHOQOL-BREF, but important to New Zealanders. National items will be developed on the basis of this study for a broad New Zealand version. However, this study also reinforces that what is important to the QoL of one age group may not be important to others. New Zealand is a multicultural society. With its cultural diversity it is likely that there will be variation in what various ethnic groups consider as important to themselves and which could be different from

others. This suggests that there should not be one NZ WHOQOL but a number of NZ WHOQOL versions to fit the cultural realities and languages of our diverse groups of citizens. It is also suggested that QoL studies should consider assessing both the importance of each facet of QoL and the level of satisfaction with each facet in the same study and comparing results.

To summarise, it is adequate to suggest that this study should best be regarded as one that ‘attacks the average’ by showing that diversity really exists in the perceptions of what is important to the quality of life of different folks, so be wary of QoL statistics that claim to speak for all.

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Appendices

Appendix A

Participant Information Sheet (Focus group)



Date Information Sheet Produced:

25th of October, 2008

Project Title

Developing a New Zealand version of WHO Quality of Life scale

An Invitation

We are undertaking a study about the quality of life of New Zealanders. This study forms the basis of a Master of Health Sciences thesis at AUT University. We invite you to participate in this research. Your participation is voluntary. You can choose not to participate if you wish. Please read this form and then ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Patricia Hsu and supervised by Prof. Rex Billington, Department of Psychology, AUT University.

What is the purpose of this research?

The purpose of this study is to develop a questionnaire that can be used to survey the quality of life of New Zealanders. By quality of life we mean the things that matter most to New Zealanders and which ultimately affect their health. The questionnaire includes aspects of living that relate particularly to New Zealanders, our culture and our values. An original questionnaire, called the WHO Quality of Life assessment instrument, the WHOQOL, was developed by the World Health Organization in collaboration with 14 countries in the 1990s. Unfortunately New Zealand was not one of these countries. Many more countries in the world have since developed their own version of the WHOQOL in their national language(s). Currently there is an Australian version, a Chinese version, a Thai version, a Russian version and many others. We intend to develop a New Zealand version and request your help to do this well. So far, quality of life studies conducted in NZ have been using the Australian version of the WHOQOL and other questionnaires developed in other countries. Although Australia and New Zealand societies are considered similar, clearly they are not the same. There may be some different perceptions of quality of life between these two countries.

This study will help us establish our own version by asking you to consider what is important to the quality of your life, so that when the health of the nation is being assessed we will be able to include not just sickness and disability statistics, but also such things as our social, environmental, daily living conditions and our physical, mental and spiritual well beings which in some way affect how healthy we are. We want to find out from you what you think is important when measuring quality of life of New Zealanders.

How were you chosen for this study?

You were selected as a possible participant simply because you are a New Zealander, currently in Auckland and accessible to the researcher. No personal information has been collected or known about you and others in the study.

What will happen in this research?

If you agree to be in this study, you will be asked to do the following things:

(1) Discuss with a group of about 10 others, what is important to the quality of life of New Zealanders.

(2) You will be asked to read and rate the importance of some of the questions in the existing WHOQOL . There are 34 questions for you to answer here.

(3) You will be asked to suggest and discuss any other areas that you consider are not in the WHOQOL instrument which would be important in a New Zealand version.

Discussions will be audio recorded and with the questionnaire you have answered used for later analyses by the research team. But, neither your completed questionnaire nor your recorded comments will be identifiable or traceable back to you.

What are the discomforts and risks?

Some of the questions on the WHOQOL may be remind you of a distressing event in your life. If such a question causes you any discomfort you do not need to answer it. From past experience and because of the generality of the questions and because you will just not have time to ponder each question discomfort to you is very unlikely.

How will these discomforts and risks be alleviated?

You are free to decline to answer any question or to withdraw from the research at any time prior to the completion of the data collection session. You will not have to provide any neither explanation nor justification if you decide to withdraw.

What are the benefits?

The direct benefits for participating in the study is the opportunity of reviewing what is important to your own quality of life and learning what others think is important to them. There are no rights or wrongs. There will be no score given. Remember, you are advising us of what you consider is important when assessing the quality of life of New Zealanders. The exercise does not involve assessing your quality of life, or comparing you with others.

How will my privacy be protected?

As mentioned above, the records of this study will be kept confidential. You will not be identified either during the discussion or in answering the importance questionnaire. Though we will record basic information on your age, your gender and your perceived state of your health etc. your name and address will not be identifiable. In any report we publish, we will not include information that will make it possible to identify you in any way. Research data will be kept in a locked file; the researchers will be the only people who will have access to the data.

What are the costs of participating in this research?

From past experience we expect the focus group discussion and answering the importance questionnaire will take about 105 minutes of your time; 90 minutes for discussion and another 15 minutes to answer the questionnaire.

How do I agree to participate in this research?

Your participation in this study is entirely voluntary. If you decide to participate, please sign the consent form that is attached with the participant information sheet.

Will I receive feedback on the results of this research?

No personal response or feedback will be given because there are no rights or wrongs to answers. Furthermore your questionnaire is unidentifiable. However, you can obtain the general study result by contacting the researchers about 3 months after the focus group session is completed.

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

Immediate researcher contact details to Patricia Hsu at hsihsu82@aut.ac.nz.

Notification of any concerns regarding the nature of this project should be addressed in the first instance to the Project Supervisor; Prof. Rex Billington at [<rbilling@aut.ac.nz>](mailto:rbilling@aut.ac.nz), or phone (09) 921-9999 extension 7586.

For further information about this research, you could also contact Dr. Daniel Shepherd, the second supervisor, [<daniel.shepherd@aut.ac.nz>](mailto:daniel.shepherd@aut.ac.nz) or phone (09) 921-9999 extension 7238.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of the AUT Ethics Committee, ATEC, Madeline Banda, [<madeline.banda@aut.ac.nz>](mailto:madeline.banda@aut.ac.nz) or phone (09) 921 9999 ext 8044.

Approved by the Auckland University of Technology Ethics Committee on 18 November 2008, ATEC Reference number 08/221.

Consent Form

Project title: **Developing a New Zealand version of WHOQOL**

Project Supervisor: **Prof. Rex Billington**

Researcher: **Patricia Hsu**

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 25th of October, 2008
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand that identity of my fellow participants and our discussions in the focus group is confidential to the group and I agree to keep this information confidential and secure.
- ☐ I understand that notes will be taken during the focus group and that it will also be audio-taped and listened too, later in confidence only by the research team.
- ☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- ☐ If I withdraw, I understand that while it will not be possible to destroy the audio tape of the focus group discussion of which I was part, the relevant information from myself including that which is taped or parts thereof, will not be used and the questionnaire which may be completed will be destroyed.
- ☐ I agree to take part in this research.
- ☐ I wish to receive a copy of the report from the research
- (please tick one): Yes ☐ No ☐

Participant's signature :

Participant's name:

Participant's contact details (if appropriate):

.....

.....

.....

.....

Date:

Approved by the Auckland University of Technology Ethics Committee on 18 November 2008, AUTEK Reference number 08/221.

Appendix C

Results of the Words for Visual Analogue Scale

Visual analogue scale	Participants									
INTENSITY	1	2	3	4	5	6	7	8	9	10
absolutely	9.8	9.2	10	9.4	10	9.9	10	9.2	6.9	9.5
a bit	1.1	1.4	3.5	1.4	3	8.4	5.5	0.7	5.5	2.7
an ample amount	7.1	7.5	7.3	5.8	7.8	7.5	7.9	7.5	5.5	8.9
An extreme amount	10	8.9	9.8	9.3	9.6	9.5	10	9.9	10	10
a great amount	9.6	7.4	8.1	7.6	8	6.2	8.8	9.5	6.7	9.4
all the time	10	8.9	10	8.9	10	9.2	10	9.6	7.2	10
Almost all the time	8.5	7.4	8.9	8	9	9.7	9.4	7.9	9.4	9.7
A little	1	1.3	1.8	3.4	0.8	9.2	6	0	2.9	1.2
a little bit	1.3	1.9	4.7	1	0.9	9.8	6	0.4	3.2	0.4
a lot	9.9	8.1	8.5	8.6	8.8	9.6	9	9.8	7	9.5
a moderate amount	2.8	4.2	6.3	2.8	4.7	0.6	4.9	1.4	4.7	6
a small amount	1.4	1.8	3.5	2.1	0.9	9.4	5.5	0	3.4	3
barely	0.9	1.1	1.5	1.3	0.6	2	5.5	0.8	3.1	0.6
completely	10	9.0	10	9.5	10	8.6	10	9.6	9.5	9.8
constantly	9.9	7.0	9.4	8.1	10	6	8.5	8.9	5	9.6
exaggerate amount	10	0.4	6	6.7	3.1	8.5	9.1	9.6	6.7	9.5
extremely	10	9.5	8.9	9.1	10	6.7	10	9.6	10	9.8
far fetched	10	0.7	7.3	3.3	0	1	3.1	9.4	1.8	3.1
fraction	1.3	0.9	5.2	1.5	1.9	9.3	5.3	0.7	4.5	1
inevitable	10	5.0	0.4	9.3	10	1.8	9.3	5.8	7.8	9.7
moderately	1.4	3.1	7.2	3.8	7.1	9.6	7.5	2	4.8	5
mostly	8	6.9	7.9	7.4	7.7	9.3	9.5	9.4	8.5	9.4
more often than not	7	7.3	7.8	6.2	7.8	6.1	9.5	7.7	5.2	8.5
most certainly not	10	1.3	0.1	0.7	0	1.1	1	0.1	1.2	0
Not at all	0	0.6	0	0.8	0	9.6	0.1	0.2	0	0
nil	0	0.3	0.3	0.9	0	6.5	0	0	0	0
not very much	0.7	1.9	2.2	2.4	0.3	9.3	5.7	1.5	3.1	1
plenty	8.9	7.2	8.6	8	8.5	9.5	8.6	9.1	6.8	9.5
slightly	0.8	1.5	2	2.2	0.6	1.1	5.2	0.8	4.9	1.1
some	2.8	1.7	4.8	2.3	4.7	9.3	6	0.8	4.9	5.5
somewhat	2.9	1.7	6.7	2.8	6.2	7.3	6.7	1.9	4.2	4.8
totally	10	9.3	9.9	8.7	10	9.5	10	9.4	6.9	10
very much	9	7.3	7.7	9.3	8.8	9.5	9.5	9.4	8.3	9.3
very	7.8	7.5	9.4	8.7	8.4	5.2	1.4	8	6.9	8.9
very important	7.9	9.7	9.5	8.4	9.8	9.8	9.2	9.4	8.4	9.5
EVALUATION										
above average	9.8	6.5	7.1	5.8	6.5	5.9	6.5	9.5	6	5.9
average	3	4.5	4.9	5.2	4.5	5.1	4.9	5.4	5	4.7

annoyed	1.5	0.8	3.4	1.6	0	1.7	3.8	0.6	3.9	2.4
completely unsatisfied	0.1	0.2	0.1	0	0	2	0.2	0	1.2	0.8
choice	7.2	8.2	6.8	8.7	9.2	9.3	8.3	4.6	6	8.7
content	7.5	6.7	6.7	4.2	8.9	3.7	9	9.5	5.8	7.8
dissatisfied	1.6	1.6	2.9	2.6	0.7	1.8	1.9	0	4.9	1.5
disappointed	1.4	0.7	4.1	2.2	0	9.1	3.4	0.4	4.2	2.4
displeased	1.2	0.3	3.8	2.2	1.2	5.3	3.7	0.3	4.1	3.2
dismal	1.3	0.5	3.3	0.9	0	1.5	0.8	0	3.2	1
excellent	10	8.3	9.2	8.6	10	8.7	9.6	9.6	10	9.6
exceedingly poor	0.1	0.5	0.8	0.5	0	1.2	0.3	0.2	2	1.2
extremely poor	0	0.1	0.7	1.2	0	1.2	0	0.1	0.7	0.8
fantastic	9.3	8.6	8.2	9	10	7.8	10	9.7	8.2	9.8
great	9.1	8.2	7.9	8	9.3	9.7	8.6	9.9	9.5	9.7
good	3.5	4.2	7.8	6.4	8.2	9.5	6.7	9.9	6.5	7.6
good as gold	8.5	8.8	8.8	9.4	10	9.8	9.7	9.6	6.8	8.5
happy with	5.1	8.6	7.1	8.7	9	8.9	7.1	8.4	6.6	4.5
hellish	0.5	0.5	1.1	0.9	0	2.9	1.6	0.8	0.6	0.5
middle	5.1	3.9	4.8	5.6	4.9	3.8	4.8	4.8	4.8	4.9
neither satisfied nor dissatisfied	5	0.8	4.5	3.1	4.8	2.1	4.7	4.9	5	4.6
neither poor nor good	5.3	0.6	4.9	4.4	4.9	0.2	5.1	4.8	5.2	3.9
neither happy nor unhappy	5.5	1.2	5.1	4.4	4.9	3.5	5.6	5.2	5.2	4
not at all satisfied	3.6	0.3	1	1.5	0	0.6	0.7	0.5	2.4	3.4
not ok	0.3	0.9	3.8	3	1.1	4.2	3.3	0	4.2	4.8
neutral	5.1	2.3	4.9	4.7	4.7	5.5	5.3	5	4.8	4.8
ok	3.1	2.5	6	4.7	6.8	4	6.9	7.8	7.1	5.8
pleased	7.2	8	6.8	4.8	9.1	7.9	7.2	9.4	5.9	8.2
putrid	0.1	0.3	2.5	1.1	0	2.6	0	0.1	0.2	1.6
real poor	0.1	0.5	2.9	1.8	0	1.9	2	0.3	3.3	2.1
satisfied	3.2	5.6	8	3.8	8.7	9.5	7.8	9.6	6.3	6.1
super	7.8		8.7	8.8	10	5.5	9.3	9.2	8.3	7.8
top class	9.9	8.5	9.6	9.8	9.3	5.8	9.8	9.7	7.7	9.8
unsatisfied	1.1	1.0	3.2	1.9	0.3	3.1	1.6	0.3	3.2	3.1
unhappy	1.9	0.5	3.4	1.8	0.9	0.4	3	0	2.8	1.3
very unhappy	1.3	0.2	1.4	1.6	0	0.2	1.6	0.2	0	1.6
very dissatisfied	0		1.7	1.2	8.6	1.1	0.5	0.1	0.6	1.1
very displeased	0	0.4	1.4	0.2	0	1.9	1.2	0.1	3.2	1.1
very poor	1	0.4	1.1	1.5	0	3.5	1.6	0.2	2.2	0.9
very good	5.2	6.3	8.8	8.9	10	7.8	7.6	10	8.8	9
very satisfied	8.4	9.2	9	6.2	8.9	9.3	8.5	9.6	8	7.6
very pleased	9.1	8.9	9.1	8.4	10	1.1	8.6	9.3	6.8	8.6

CAPACITY										
a little	1.1	0.8	6.1	1.8	0.6	7.7	6	0.4	4.1	
completely	10	9.7	10	9.2	10	6.4	10	9.8	8.7	
Fatally	9.2	0.4	0.8	8.9	10	6.8	0	0	2	
fully	9.9	9.5	8.6	9.2	10	3.3	10	9.8	9.1	
unquestionably	9.3	7.6	2.4	9.3	10	3	9.5	4.8	3	
mostly	7.5	6.6	8.5	8.1	8	9.4	9.4	8.1	8.2	
moderately	2.6	4.0	5.5	3.2	4.8	9	6	4.8	3.6	
not at all	0	0.3	0.1	0.3	0	9.4	0.5	0.3	0	
some	2.9	2.4	5.8	4	3.5	5.7	6.2	2.1	5	
somewhat	2.9	1.8	6	2.7	3.9	8.7	5.9	4.8	4.8	
totally	10	9.6	10	9.5	10	9.8	10	9.8	7.1	
FREQUENCY										
always	10	8.4	9.2	9.3	9.8	9.7	10	9.6	7.4	10
at all time	10	8.7	10	8.9	10	9.7	10	5.3	8.5	10
certainly not	0.1	0.8	0.6	1.5	0.1	2.6	0.8	2.4	1.2	1
continually	9.9	8.6	9.2	8.7	10	2.8	8.6	5	6.6	9.3
for no reason	5.4	0.4	3.4	2.5	1.5	0.8	5.2	3.4	3.9	2.9
frequent	8.2	8.2	7.7	7	8.5	7.1	6.5	4.4	7.2	8.9
hardly ever	1.2	1.9	2.7	1.7	0.8	1.8	0.5	0.9	1.7	0.4
generally	5.5	5.0	6.7	4.8	7.8	9.3	8	8.5	6.6	8.3
infrequently	1.2	2.4	2.2	2.8	0.8	0.4	0.9	0.2	3.5	3.1
more often than not	7	6.2	6.8	6.5	8.5	2.3	9.5	7.9	5.7	8.8
most often	8.7	6.4	7.6	7	8	4.4	9.8	5.7	7.1	8.2
never	0	0.5	2.4	0.4	0	0.5	0	0	0	0
nil	0	0.3	0	0.1	0	0.2	0	0	0	0
not often	1.1	1.3	2.6	1.2	2.4	4.8	2.9	4.5	3.6	2.4
now and again	5.3	2.3	5.4	3.4	7.7	5.2	4.8	2.9	4.7	6.2
nearly	7.5	0.8	3.5	6.8	7.3	5.7	9.5	8.8	5.2	4.7
occasionally	1.3	2.6	2.9	3.1	1.5	1.7	5.4	2.2	5.1	2.8
quite often	7.2	6.3	6.5	7.3	8.5	0.4	6	7.2	7.8	8.7
rarely	1.8	1.4	1.5	2.8	1.1	0.6	0.9	0.2	3.4	0.5
repeatedly	9.1	0.3	8.4	3.7	8.5	9.2	7.2	6.7	6	8.4
seldom	0.5	1.7	2.8	1.8	0.7	0.5	0.8	1.9	3	1.9
somewhat	3.2	1.6	3.5	2.8	8.5	3.8	6.4	5.6	4.7	2.1
usually	8.8	5.4	6.3	6.8	8.3	9.3	7.8	9.8	5.8	9.2
under no circumstances	0	2.5	0.7	0.7	0	9.7	0	1.2	0	0
very frequently	9.5	7.5	8.7	9	9.2	1.2	8.1	6	7.5	8.8
very much so	9.6	9.2	8.2	7.2	9	2.8	9.7	7.7	8.2	9.3
very often	9.1	8.8	8.5	8	9	6.3	8.7	8.8	8.7	9.4

Appendix D

The words list below represents a measure unit. Please rate accordingly from negative to positive. The starting point is 0%

Not at all

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Very good

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Always

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Very happy

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

An extreme amount

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Satisfied

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Very Poor

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

A little

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Completely

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Dissatisfied

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Very

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Unhappy

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Neither poor nor good

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Very satisfied

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Moderately

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Very unhappy

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Neither satisfied nor dissatisfied

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Good

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

A moderate amount

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Very often

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Poor

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Happy

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Quite often

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Neither happy nor unhappy

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Very dissatisfied

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Seldom

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Very much

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Extremely

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Slightly

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Very well

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Mostly

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Field Trial

WHOQOL New Zealand

IMPORTANCE QUESTIONS



ABOUT YOU

What is your gender (Circle the correct answer) Male Female

What is your age? _____ years

How is your health?

Very poor | Poor | Neither poor nor good | Good | Very good

Are you currently ill? ☐ Yes ☐ No

If yes, what is your illness? _____

Do you have any of the following health problems at the moment? (TICK NEXT TO THOSE THAT APPLY TO YOU)

☐ Heart trouble

☐ High blood pressure

☐ Arthritis or Rheumatism

☐ Cancer

☐ Emphysema or chronic bronchitis

☐ Diabetes

☐ Poor eyesight

☐ Stroke

☐ Skin infection

☐ Chronic nervous disorder

☐ Physical disability

☐ Chronic emotional problem

☐ Hearing disability

Other (please describe) _____

Importance Questions

The following questions ask about **how important** various aspects of your life are to you. We ask that you think about how much these affect your quality of life. For example on question asks about how important sleep is to you. If sleep is not important to you, circle the number below “not important”. If sleeps is “very important” to you, but not “extremely important”, you should circle the number below “very important”. **Please answer all questions.** If you are unsure please choose one that appears the most appropriate. This can often be your first response. **Thanks for your help.**

G.1 How important to you is your overall quality of life?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

G.2 How important to you is your health?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

1.1 How important to you is it to be free of any pain?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

2.1 How important to you is having energy?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

3.1 How important to you is restful sleep?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

4.1 How important to you is it to feel happiness and enjoyment of life?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

4.2 How important to you is it to feel content?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

4.3 How important to you is it to feel hopeful?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

5.1 How important to you is being able to learn and remember important information?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

5.2 How important to you is being able to think through everyday problems and make decisions?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

5.3 How important to you is it to be able to concentrate?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

6.1 How important to you is feeling positive about yourself?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

7.1 How important to you is your body image and appearance?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

8.1 How important to you is it to be free of negative feelings (sadness, depression, anxiety, worry...)?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

9.1 How important to you is it to be able to move around?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

10.1 How important to you is being able to take care of your daily living activities (e.g. washing, eating, dressing)?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

11.1 How important to you is it to be free of dependence in medications or treatments?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

12.1 How important to you is being able to work?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

13.1 How important to you are relationships with other people?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

14.1 How important to you is it to support others?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

15.1 How important to you is your sexual life?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

16.1 How important to you is feeling physically safe and secure?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

17.1 How important to you is your home environment?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

18.1 How important to you are your financial resources?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

19.1 How important to you is it being able to get adequate health care?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

19.2 How important to you is it being able to get adequate social help?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

20.1 How important to you are chances for getting new information or knowledge?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

20.2 How important to you are chances to learn new skills?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

21.1 How important to you is relaxation/leisure?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

22.1 How important to you is your environment? (e.g. pollution, climate, noise, attractiveness)?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

23.1 How important to you is adequate transport in your everyday life?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

24.1 How important to you are your personal beliefs?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

25.1 How important to you is physical exercise?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

26.1 How important to you is being able to freely say what you want?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

26.2 How important to you is that other are able to express themselves freely?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

26.3 How important to you is feeling free to do what you want to do?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

26.4 How important to you is having choice?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

26.5 How important to you is individual freedom?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

26.6 How important is it to you to have government listen to citizen's views?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

26.7 How important to you is being successful in what you choose to do?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

26.8 How important to you is personal success?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

26.9 How important to you is feeling you have control over your life?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

27.1 How important to you are your family roots?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

27.2 How important to you are your memories of the past?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

28.1 How important you is being able to manage any disabilities you have?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

28.2 How important to you is being able to manage personal difficulties?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

29.1 How important to you is being accepted for who you are?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

29.2 How important to you is feeling of belonging?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

29.3 How important to you is being part of group?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

30.1 How important to you is living in a society that accepts differences among people?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

30.2 How important to you is a fair and just society ?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

30.3 How important to you is respect your culture?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

30.4 How important to you is that others have a sense of responsibility?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

30.5 How important to you is being respected by others?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

30.6 How important to you is living in a multicultural society?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

30.8 How important to you is being a full participant in society?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

31.1 How important to you is having children at some stage of your life?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

31.2 How important to you is your immediate family?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

31.3 How important to you is discipline within the family?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

32.1 How important to you is being trusted by others?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

32.2 How important to you is being able to trust others?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

33.1 How important to you is your privacy?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

33.2 How important to you is having practical support at home?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

34.1 How important to you is to have access to outdoor activities?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

34.2 How important to you is to have natural surroundings?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

34.3 How important to you is New Zealand natural environment?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

34.4 How important it is for you to be able to travel overseas?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

35.1 How important to you is eating sensibly?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

35.2 How important to you is a proper diet?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

35.3 How important to you is good healthy food?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

36.1 How important to you is a politically stable environment?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

37.1 How important to you is having access to modern technology? (e.g. computer, cell phone, electrical gadgets)

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

38.1 How important to you is having access to competent medical personnel?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

39.1 How important to you is having high quality education available?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

40.1 How important to you is having a purpose to your life?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

40.2 How important to you is being able to meet your expectations?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

40.3 How important you to is doing things that have social value for others?

Not important	A little important	Moderately important	Very important	Extremely important
1	2	3	4	5

THANK YOU FOR YOUR HELP