DEVELOPING AND EVALUATING AN ASSESSMENT TO MEASURE THE IMPACT AND OUTCOME AFTER ACQUIRED BRAIN INJURY

by

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ABSTRACT

Acquired brain injury can have devastating effects on the person’s ability to participate in the activities and lifestyle of their choice. “I want *my* life back” is a frequently desired goal after brain injury. Rehabilitation aims to reduce the impact of ensuing impairments and facilitate the person’s return to meaningful activities and roles. Rehabilitation assumes to target those activities relevant to each person that “make life worth living” (1994, p.363). This study describes the development of an assessment instrument to measure the concept of ‘my life’. This has been defined as a person’s lifestyle: the typical way a person lives as expressed by their choice and participation in a wide variety of activities to meet needs in the context of their life (Merriam-Webster Dictionary, 2010; World Health Organisation [WHO], 1946).

There is no consensus regarding which assessment might best address the concept of lifestyle after brain injury (Tate, 2010; Unsworth, 2000). The aim of this research was to complete the initial stages of the development of such an assessment. The research was carried out in three stages. Stage 1 of the study focussed on construction of the Lifestyle Assessment, a 72 item criterion referenced measure which acknowledges people are experts in their own life. The International Classification of Functioning, Disability and Health was selected as an appropriate basis for generating the initial items for the new instrument as it was thought to capture the “lived experience” of individuals after brain injury and provided a ready source of relevant items (Cicerone, 2004; Greenwood, 1999; WHO, 2001, p.229).

In Stage 2 a qualitative review of the first version of the Lifestyle Assessment by a small number of people with brain impairment and clinicians provided an insider’s view of the utility of the new instrument. These processes informed refinement of the items, rating scale, format and administration of the assessment. The views of both groups were accommodated at this stage of the study.

In Stage 3, the Lifestyle Assessment was piloted with 71 people with acquired brain injury. Rasch analysis was used to evaluate the degree to which the assessment was objective, precise and appropriate to measure lifestyle and for people with brain injury. The initial analysis indicated the need for adjustments to the rating scale. After refinement, the data were reanalysed using a modified collapsed rating scale.

This stage of the study provided initial evidence of the reliability and validity of this instrument and identified several issues requiring further exploration. People were able to identify which activities were relevant to their life, and these ranged in number and difficulty. Participation in a chosen lifestyle is a complex phenomenon and appeared to be influenced by each person’s capacity, as well as supportive social environments, internal motivation and talent. People with co-morbid diagnoses had additional influences on their participation and this was found to be different than those with brain injury alone. The findings of the study were supported by literature on the nature of participation after brain injury.

The Lifestyle Assessment offers a person centred assessment that focuses on Lifestyle. It reflects the ideas that individuals are unique and are able to make their own choices about which activities are important to them. It is a collaborative instrument that accommodates the needs of people with brain injury and clinicians who will use it, and displays elements considered essential to effective assessments. With further development this criterion referenced instrument has potential to make contributions to understanding and measuring the change that occurs in people’s life after brain injury.

DECLARATION

I, **HELEN BADGE**, hereby declare that the work contained within this thesis is my own and has not been submitted to any other university or institution as a part of a whole requirement for any higher degree.

I, **HELEN BADGE**, hereby declare that I was the principal researcher of all work included in this thesis, including work published with multiple authors.

Name HELEN BADGE
Signed Helen Badge
Date 28/9/2012

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It is an interesting voyage, to do research. One learns about something new, and also about oneself and what can be achieved with effort and commitment, and a bit of passion.

TABLE OF CONTENTS

CHAPTER ONE

LIST OF TABLES

LIST OF FIGURES

LIST OF PRESENTATIONS

Part of the work in this thesis has been presented in the following forum:

Badge, H., Chapparo, C., and Kupshik, G. (2007). Assessing the concept of ‘my life’ with people with brain injury. Poster presented at *30th Annual Brain Impairment Conference*, The Australian Society for the Study of Brain Impairment. 3-5th May, 2007.

CHAPTER ONE

INTRODUCTION

The main purpose of this research was to develop an instrument to measure changes to a person's lifestyle after brain injury. The research was prompted by my experience working as an occupational therapist and service manager of a regional brain injury service in the United Kingdom, and later in Australia. The service required an assessment tool to measure client outcomes and a review of existing assessment tools highlighted there was a lack of available assessments that reflected the concept of 'my life", when the primary goal identified by people with brain injury is often "I want *my* life back". In this study the concept of 'my life' and how this changes after brain injury has been defined as measurable changes to a person's lifestyle.

Acquired brain injury (ABI) results in complex and often lifelong disability (Khan, Baguley & Cameron, 2003; Willer & Corrigan, 1994). The nature and extent of disabilities after brain injury varies and can involve varying combinations of physical, cognitive, emotional and behavioural impairments (Greenwood, 1999; Jacobsson, Westerberg, Söderberg & Lexell, 2009; Khan, Baguley & Cameron, 2003; Olver, Ponsford & Curran, 1996; Oppermann, 2004; Willer & Corrigan, 1994). The severity of the brain injury affects the nature and duration of resultant impairments and disabilities. Following mild injuries many people return to independent living with minimal persisting problems (Trevena, Cameron & Porwal, 2004). After more severe injuries, participation restrictions regarding employment, economic self sufficiency and relationships can last many years or be lifelong (Australian Institute of Health & Welfare [AIHW], 200a).

There is growing evidence that multidisciplinary rehabilitation is effective at minimising the impact of brain injury (Cullen, Chundamala, Bayley & Jutai, 2007; Fearnside, Cook, McDougall & Lewis, 1993; Khan, Baguley & Cameron, 2003; Malec, 2009; Powell, Heslin & Greenwood, 2002; Sander et al, 2001; Turner-Stokes, Disler, Nair & Wade, 2005; Wood, McCrea, Wood & Merriman, 1999; Worthington, Matthews, Melia & Oddy, 2006). However up to 54% of people with severe injuries continue to experience reduced participation and community integration despite rehabilitation (Sloan, Winkler & Anson, 2007; Sloan, Winkler & Callaway, 2004; Tate et al, 2007; Trombly, Radomski, Trexel & Burnett-Smith, 2002; Willer & Corrigan, 1994). Associated with this, Tate et al (2007) reported up to 72% of people can have long term care and support needs. Adequately assessing a person’s individual needs and level of functioning is the starting point of goal oriented rehabilitation and could be used to target intervention to address participation more effectively. However there is no consensus regarding what measure of outcome is the most appropriate even though good assessment is considered fundamental to evidence based practice (Skinner & Turner-Stokes, 2006; Tate, 2010).

Fuhrer (1994, p.363) stated that the aim of rehabilitation “is to make life worth living”. In Australia, “the rehabilitation process is different for everyone and rehabilitation programs should be individualised, catering to each person's unique needs” (HealthInsite, October 2010, Online). The elements that make life worthwhile for each individual must be measured to ensure rehabilitation interventions are meaningful and effective (Fuhrer, 1994). Fisher (1992a, 1992b) advised the assessment process needs to be collaborative and allow each person with brain injury to choose what is important to them to achieve this. The majority of outcome measures used in brain injury rehabilitation are not client centred but provide a uniform or ‘normative’ assessment of outcome (Brown, Dijkers, Gordon, Ashman, Charatz & Cheng, 2004; Jenkinson, Ownsworth & Shum, 2007;

Unsworth, 2000). The gap between how the impact of brain injury is assessed using existing measures and the needs of individuals to have their own needs identified is considered problematic (Carpenter, 2004; Doig, Fleming & Tooth, 2001).

This thesis describes the development of an assessment called The Lifestyle Assessment designed to objectively measure changes to participation in the range and nature of activities specific for each individual's lifestyle following brain injury. The construct of lifestyle has been defined, and this provides important criteria for which further assessments were reviewed and to support construction of a tool to effectively measure lifestyle changes after brain injury. The International Classification of Impairment, Disability and Handicap – 2 Beta-2 draft (ICIDH-2), the working draft of the International Classification of Functioning, Disability and Health (ICF) at the time this study commenced, provided the initial impetus to commence planning for tool development (World Health Organisation [WHO], 1999). The ICF was published and used as the initial framework and language to describe the construct of lifestyle and to support construction of an assessment that described the impact of brain injury on a person's functioning (Bilbao et al, 2003; Dahl, 2002; Rentsch et al, 2003; WHO, 2001).

The ICF was considered appropriate for this purpose because it provided a dynamic and interactive model of disability that accommodated the complex nature of disability, and offered significant benefits as a conceptual basis for understanding the impact of brain injury on health and wellbeing (Andresen, 2000; Badley, 1995; Bernabeu et al, 2009, Cohen & Marino, 2000; Greenwood, 1999; Haglund & Henriksson, 2003; WHO, 2001). The application of the ICF to support instrument construction was consistent with recommendations that the classification could be used to develop an assessment tool that captures the ‘lived experience’ of individuals after brain injury (Cicerone, 2004; Greenwood, 1999; Haffey & Johnston, 1990; WHO, 2001, p.123).

The Lifestyle Assessment enables individuals to select which items are relevant for their own life and measure changes in the nature and range of tasks they participated in prior to, and since their brain injury. The Lifestyle Assessment was developed to fill a gap in current assessments and bridge the requirements for objective measurement with the opportunity for individuals to have their own needs identified during the assessment process. In considering an individual’s preferences and choices, the Lifestyle Assessment should support client centred rehabilitation addressing the client’s aim of ‘wanting to get my life back’ after brain injury.

1.1 AIM OF STUDY

This thesis describes the process to develop an assessment designed to describe the nature of changes to an individual’s participation in activities following brain injury, both in terms of the range of activities and quality of performance. Construction and evaluation of the instrument are described.

1.2 SCOPE OF STUDY

This study is viewed as the beginning of a line of enquiry into this assessment, beginning with the development of the instrument and examination of the initial psychometric properties. The concept of lifestyle, which forms the platform for this instrument, is based on a review of relevant literature including the domain of participation as described in both the ICIDH-2 Beta-2 draft and ICF, the concept of occupation in models of occupational therapy, and the constructs of community integration and quality of life that are commonly used to describe the nature of changes after brain injury (WHO, 2001).

The instrument was constructed based on the ICF and the initial draft revised following feedback from people with brain injury, their carers, and rehabilitation clinicians. A pilot study was completed to enable reliability and validity of the tool to be examined. The analysis of the validity of the Lifestyle Assessment provides initial information about the data the instrument is able to obtain about how a person's lifestyle changes after brain injury. Recommendations for further research are made.

1.3 RESEARCH QUESTIONS

The overall research question guiding this study was:

How can changes to a person's lifestyle after brain injury be assessed?

The study was completed in three stages and the following sub-questions guided specific stages of the study:

1. *How can the ICF be used to guide development of an assessment to measure changes in participation in a person's lifestyle relevant to individuals after brain injury?*

2. *Is the Lifestyle Assessment an adequate and acceptable instrument to measure changes in lifestyle for people with brain injury and their carers and clinicians who will use it?*

   This was addressed in two parts:

   a. *Does the Lifestyle Assessment capture changes to a person's lifestyle considered important by people with brain injury and their carers?*

   b. *Do rehabilitation clinicians think the Lifestyle Assessment is a clinically useful tool to measure changes to a person's lifestyle after brain injury?*

3. *What are the measurement properties of the Lifestyle Assessment?*

   This was addressed in two parts:

   a. *What is evidence of the reliability of the Lifestyle Assessment when measuring lifestyle changes experienced by people after sustaining a brain injury?*

   b. *What is the evidence of the validity of the Lifestyle Assessment in describing changes to a person's lifestyle after brain injury?*

The current research addressed the stated research questions by (a) generating an item bank and constructing a tool based on the ICF that was designed to measure changes to a person's lifestyle after brain injury, (b) gathering feedback from a small number of people with brain injury, carers, and clinicians after a brief pre-test to evaluate the validity and support initial refinement of the tool, and (c) completing a pilot study so that the measurement properties and clinical utility of the new tool could be evaluated.

1.4 DEFINITION OF TERMS

The following definitions provide a conceptual focus to understand the aims of the study and the rationale behind the title for the Lifestyle Assessment.

1.4.1 Lifestyle

Lifestyle is traditionally defined as a pattern of behaviours including diet and exercise that contribute to elevated or reduced health risk (Liddle & McKenna, 2000; McGinnis & Foege, 1993). In the media, lifestyle often has a restricted focus on primarily physical health indicators. In this thesis, a person’s lifestyle is defined as the typical way a person is anchored in the social, physical and community context in which they live. A person’s lifestyle is measured by the typical way a person lives as expressed by their choice in the range and balance of their activities and interests. This reflects their values and preferences and provides interest and vitality and contributes to ‘a better life’ and the experience of physical, social and mental health and wellbeing in the context in which the person lives (Business Dictionary, 2011; 2002; Christiansen & Matuska, 2006; Doig, Fleming & Tooth, 2001; Fuhrer, 1994; Merriam-Webster Online Dictionary, 2010; WHO, 1946).

The definition of lifestyle defined in this thesis challenges the current narrow focus on health promotion activities. In public health, "lifestyle" generally means a pattern of individual practices and personal behavioural choices that are related to elevated or reduced health risk, such as diet and exercise (Liddle & McKenna, 2000; McGinnis & Foege, 1993). This is contrary to the definition of health in the ICF, which reflects both the absence of disease and the attainment of wellbeing through participation in a range of meaningful and varied activities (World Health Organisation, 2001).

1.4.2 The International Classification of Functioning, Disability and Health

The International Classification of Functioning, Disability and Health (ICF) is an international classification designed to “provide a unified and standard language and framework for the description of health and health related states” and includes some health related components of wellbeing (WHO, 2001, p.3). The ICF includes specific items with operational definitions that enable categorization of all body functions, activities and participation that are relevant to human functioning (WHO, 2001).

1.4.3 Activity and Participation

Activity is defined by the ICF as is the execution of a task or action by an individual and represents the individual perspective on functioning (WHO, 2001). The societal aspect of functioning is considered in Participation, which is defined by the ICF as a person's involvement in a life situation (WHO, 2001). In this study, individual activities that were thought to be relevant to a person after brain injury were selected for inclusion in the item pool. All activities identified for the item pool are thought to reflect participation as they are included to represent each person's life situation. The term participation is used to describe when a person engages in an activity.

In this thesis the concept of activities and participation also reflect that people decide what, when and how they will do things, for a variety of different reasons and needs (Fisher, 2003; Kielhofner, Henry & Walens, 1991; Wilcock, 1999; Yerxa, 1991).

1.4.4 Disability, Activity Limitations and Participation Restrictions

Activity limitations are experienced when people have difficulty completing activities. Participation restrictions are problems a person may experience in involvement in life situations (WHO, 2001). In the ICF, the term disability is an umbrella term for impairments, activity limitations and participation restrictions, whereas functioning describes the more positive aspects (WHO, 2001, p.3). Disability is defined as "a multidimensional phenomenon resulting from the interaction between people and their physical and social environment" (WHO, 2001, p.242).

In this thesis the term disability is used to describe any negative changes to a person's participation in activities. This term was thought appropriate as it is commonly used and understood and avoids confusion given the lack of distinction between activities and participation, both in the ICF and items selected for the Lifestyle Assessment.

1.4.5 Acquired Brain Injury

Acquired Brain Injury (ABI) is an umbrella term that involves “brain damage caused by traumatic and non traumatic causes, that occurs after birth and which is not related to congenital disorders, developmental disabilities, or processes that progressively damage the brain” (Teasell et al, 2007, p.108). In this study participants were included with any diagnosis of non progressive acquired brain injury, regardless of cause or type, or time that had elapsed since injury.

1.4.6 Assessment

The assessment process is a vital part of the rehabilitation process. Assessments provide a systematic approach to gathering and measuring clinical observations (Streiner & Norman, 2003). Criterion referenced assessments measure each person’s performance regarding mastery of specific behaviours that are assumed to have been learned, as opposed to norm referenced tests, which compare a person’s performance to performance of a specified group (Glaser, 1963; Griffin, 2007). The purpose of criterion referencing is to describe a coherent set of items to describe a person’s proficiency and "encourage the development of procedures whereby assessments of proficiency could be referred to stages along progressions of increasing competence" (Glaser, 1981, p. 935).

1.5 RESEARCH DESIGN AND OVERVIEW OF THE STUDY

The study describes the development of a new assessment tool designed to measure changes to a person’s lifestyle after brain injury. The research employed mixed methodology, which involved use of complementary qualitative and quantitative approaches to clarify and increase the meaningfulness of results and test the utility, structure, reliability and content validity of the assessment (Bernabeu et al, 2009; Gray, 2000; Jones & Nicol, 1998; Streiner & Norman, 2003). Test developers advise that mixed methods can improve the reliability and validity of results "while preserving the richness of information derived from talking with a client in a more conversational manner" (Jones & Nicol, 1998; Streiner & Norman, 2003; Teddie & Tashakkori, 2009, p.138).

The study was completed in three stages which are summarized in Figure 1.1. Each stage of the study had different aims and used different methodology. For clarity, the separate stages are reported in separate chapters.

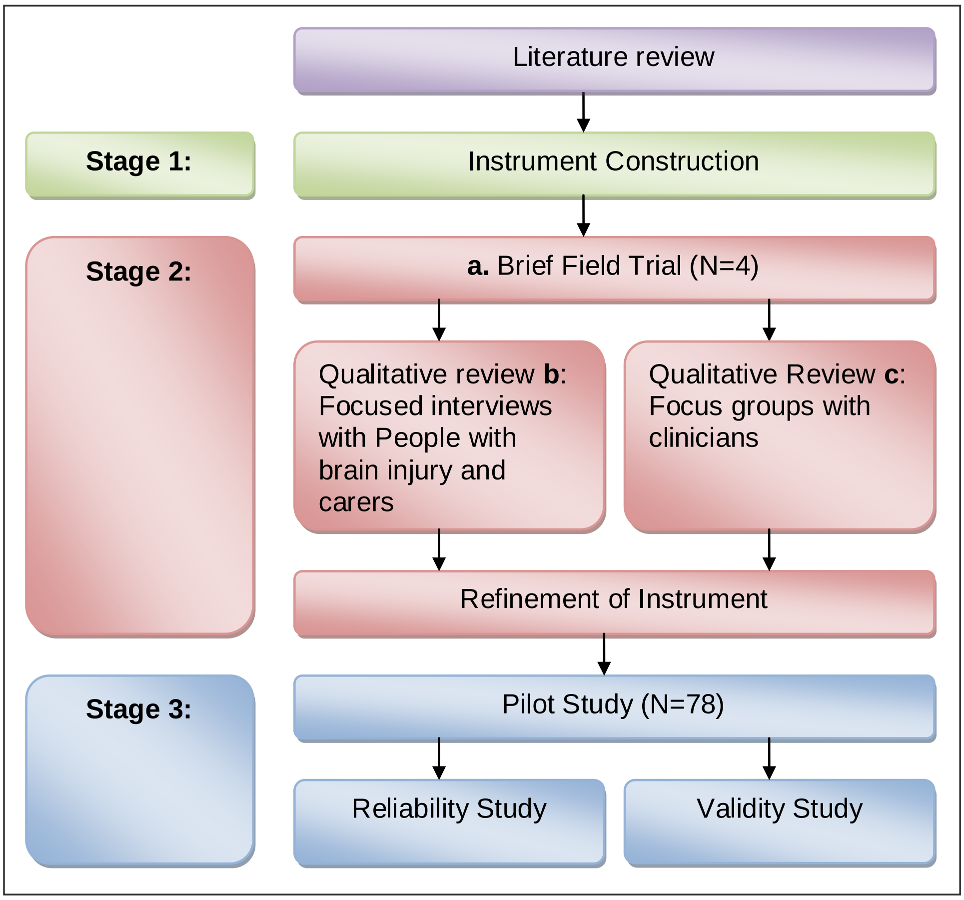


Figure 1.1: Stages of the Study

1.5.1 Stage 1: Instrument Construction: Development of an Assessment Instrument Based on the ICF to Measure Changes to a Person’s Lifestyle

Stage one of the study (Chapter Three) focused on the construction of the instrument by selecting items and adapting the rating scale from the International Classification of Functioning, Disability and Health (WHO, 2001). The construct of lifestyle was described and the ICF had been identified as an appropriate source of items to support development of the instrument (See Chapter Two). The ICF was reviewed and 58 items considered relevant to measuring lifestyle changes after brain injury were identified (See Chapter Three). Item selection was based on clinical experience and brain injury literature (Streiner & Norman, 2003). The rating scale was drawn from the ICF and issues such as language and format were considered during the design phase. Administration guidelines were developed that enabled the person with brain injury to choose which activities were relevant to their life. This approach was thought to support clinical utility of the new instrument that was evaluated using qualitative and quantitative methods (Chapters Four and Five).

1.5.2 Stage 2: Initial Testing, Qualitative Review and Refinement of Instrument

The second stage of the study involved trial and evaluation of the first draft of the instrument (Chapter Four). The nascent version of the Lifestyle Assessment was administered to a small sample of people with acquired brain injury who were participating in community based brain injury rehabilitation. This field trial informed brief focused interviews completed with the participants to gain feedback on the adequacy of the item content to reflect real life experience of brain injury and the acceptability of the assessment (Streiner & Norman, 2003). Carers were involved in the field trial and interviews when the person’s cognitive or language deficits limited their ability to participate (Streiner & Norman, 2003). Qualitative feedback was also obtained from a focus group of clinicians regarding the purpose and clinical utility of the assessment.

All feedback was used to refine the Lifestyle Assessment to increase the relevance of the tool for people with brain injury. Changes were made to the items, rating scale, format and administration guidelines. To increase the meaningfulness of the information derived from the instrument, daily and weekly timetables were added to the assessment form and an Excel programme was developed to produce charts to visually display the nature and magnitude of changes in a person's lifestyle captured by the assessment. The primary outcome of this stage was the development of the Lifestyle Assessment, a 73 item scale with a six point Likert rating scale designed to measure changes in the range and quality of participation in activities relevant to each person's lifestyle after brain injury.

1.5.3 Stage 3: Pilot Study and Quantitative Analysis of Instrument

A pilot of The Lifestyle Assessment was completed in Stage Three with a larger cohort of people with acquired brain injury (See Chapter Five). Data analysis evaluated the measurement properties of the Lifestyle Assessment including reliability and validity and indicated areas requiring further revision. The objective of this study was to provide the evidence required to facilitate its application in clinical practice (Domholdt, 2005).

To address the research questions several analyses were completed. The success and extent to which the Lifestyle Assessment enables measurement of a person's level and nature of participation in a range of activities were investigated. Rasch Analysis was completed using Winsteps (Linacre, 2010a, 2004) to evaluate reliability at a scale and item level, uni-dimensionality, construct and content validity. Data were also analysed using the Statistical Package for the Social Sciences version 17.0 (SPSS, 2008) to calculate descriptive statistics. These analyses provided information regarding the appropriateness and effectiveness of the assessment for people with brain injury. Recommendations for revision and further research using the Lifestyle Assessment based on the results are included in the discussion. Table 1.1 provides an outline of the structure of this thesis.

Table 1.1: Outline of Thesis

Chapter		Description
1	Introduction	Introduction to Study
2	Literature review	Describes relevant literature that informed the study methodology and tool development for use with people following brain injury.
3	Construction of the Instrument	Describes Stage 1 of the Study including development of an item bank based on the ICF and a description of the new tool named the Lifestyle Assessment.
4	Qualitative Analysis of The Lifestyle Assessment	Describes Stage 2 involving the initial pre-test pilot and qualitative review of the new instrument through interviews with people with brain injury and carers and a focus group with rehabilitation clinicians. Information supported refinement of the Lifestyle Assessment.
5	Quantitative Analysis of Measurement Properties of the Lifestyle Assessment	Describes Stage 3 of the Study which includes analyses of the psychometric properties of the Lifestyle Assessment using Rasch Analysis and classic test methodology.
6	Discussion	A discussion on the significance and limitations of the study and recommendations for further research.

CHAPTER TWO

LITERATURE REVIEW

The purpose of this chapter is to present the relationships between the key constructs under study: common consequences of brain injury on activities and lifestyle, elements of a satisfying lifestyle, and the assessment of these issues in rehabilitation (Figure 2.1). This chapter is divided into several parts. First, the nature and prevalence of brain injury are described to set the context for the study. Second, the concept of lifestyle as a multifaceted phenomenon is explored. Common changes to lifestyle experienced after brain injury are described using the structure of the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation [WHO], 2001). The third section focuses on the assessment of lifestyle changes after brain injury including the elements considered essential to effectively measure lifestyle changes, a review of existing assessments, and the limitations of existing assessments. The fourth section reviews the benefits and limitations of the ICF as the basis for instrument construction of an assessment of a person’s lifestyle.

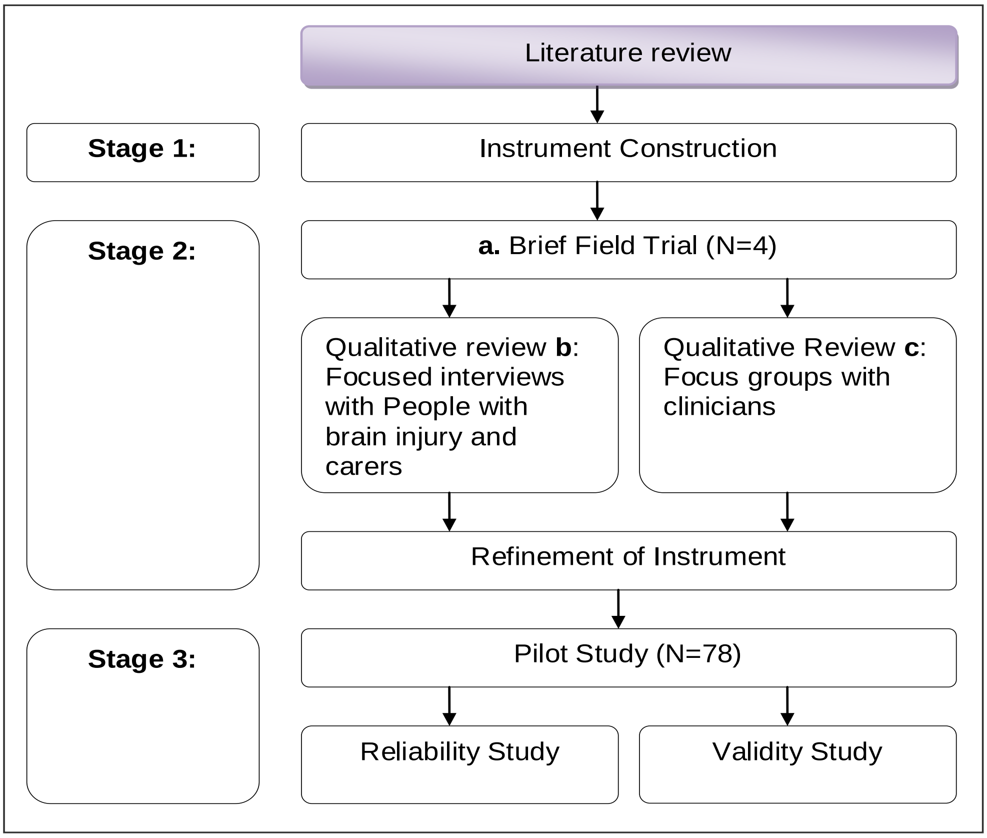


Figure 2.1: Flowchart of Stages of the Study: Literature Review

2.1 BRAIN INJURY

Acquired brain injury is one of the major causes of significant disability and death in Australia (Australian Institute of Health & Welfare [AIHW], 2003a; Fortune & Wen, 1999). The incidence of acquired brain injury is estimated at 57—377 people per 100,000 (AIHW, 2003a). About 432,700 Australians, representing 2.25% of the population experienced some level of disability after ABI with 157,500 of these experiencing severe disabilities (AIHW, 2003a). A large proportion of both groups were under 65 years of age, with 311,800 people of this age group experiencing some disability including almost 99,900 people with severe disabilities (AIHW, 2003a). Disability after brain injury is twice as high for people over 65 years, and all prevalence rates were higher for males. Brain injury affects people of all ages, but the incidence peaks for males aged 15-19 and for females over 65 years of age (AIHW, 2003a).

Many people with brain injury report multiple types of disabilities, and ABI was the main disabling condition reported by about 27,300 people aged under 65 years. A traffic injury was the main cause for more than half (55%) of these people and around 65% of people sustained their injury under the age of 25 years, suggesting that they will experience the consequences for decades. Of this group, over 90% sustained traumatic brain injury (AIHW, 2003a).

The severity of the brain injury and age at which the injury was sustained influences the short and long term outcomes including the level of disability, personal and social costs (Hukkelhoven et al, 2003; Testa, Malec, Moessner, & Brown, 2005). Most people with brain injury will sustain mild brain injuries and make a near or full recovery (Koch, Narayan & Timmons, 2010). While only around 10% sustain severe brain injury, this group has a much greater likelihood of mortality, lifelong disability and associated higher costs for care, rehabilitation and support (Brooks, 1990; Gray, 2000; Haslam et al, 1994; Koch, Narayan & Timmons, 2010; Wood & Rutterford, 2006; Willer & Corrigan, 1994; Ylvisaker & Feeney, 1998). The personal and financial cost of brain injury for the person, their family and society is enormous (Ragnarsson, 2002).

The mechanism of injury is thought to be associated with specific damage to the brain (Eisenberg & Weiner, 1987; Ylvisaker & Feeney, 1998). The specific structural changes to the brain relate to the type of impairments experienced, which have the primary impact in the participation restrictions and disability experienced by each person (Khan, Baguley & Cameron, 2003). The location and extent of damage to the brain results in a complex mix of impairments, disabilities and participation restrictions regardless of the aetiology of their injury (Doig, Fleming & Tooth, 2001; Greenwood, 1999; Jacobsson, Westerberg, Söderberg & Lexell, 2009; Khan, Baguley, & Cameron, 2003; Ragnarsson, 2002;

Reistetter & Abreu, 2005). However, there is extreme individual variability in outcomes over time even when injuries are severe (Tate et al, 1989). Each person with brain injury has a unique set of premorbid abilities, interests and roles and different psychosocial circumstances, which also affect how brain injury impacts their day to day functioning and outcome (Khan, Baguley & Cameron, 2003; Willer & Corrigan, 1994). Due to the complex nature of mechanisms, personal circumstances and the recovery process, no two people have the same experience of brain injury (Ragnarsson, 2002; Willer & Corrigan, 1994).

2.2 LIFESTYLE

Lifestyle is described in this thesis as how a person's participation in a range of activities provides structure to, and assists in, making sense of his/her life. The following definition of lifestyle is integral to this thesis.

Lifestyle is the typical way people live as expressed by their choice in the range and balance of their activities and interests, including the pattern of activities, which reflects their opinions and values and preferences and provides interest, and vitality and contributes to the experience of physical, social and mental wellbeing. A person's lifestyle is anchored in the social, physical and community context in which (s)he lives (Business Dictionary, 2011; Merriam-Webster Dictionary, 2010; WHO, 1946).

To attain a satisfying lifestyle people need autonomy in their choice of activities and control over their ability to complete them. In this thesis, a balanced and satisfying lifestyle is thought to incorporate satisfying relationships and the opportunity to choose and successfully complete a pattern of meaningful regular activities that is sustainable, and contributes to health and wellbeing within the context of current life circumstances (Business Dictionary, 2011; Chapparo & Ranka, 1997; Christiansen & Baum, 2005;

Christiansen & Matuska, 2006; Doig, Fleming & Tooth, 2001; Yerxa, 1998). In contrast, an unsatisfying lifestyle is characterised by an insufficiency or absence of engagement in activities that has been associated with disempowerment, social isolation, dissatisfaction, increased stress, depression and other chronic health problems (Csikszentmihalyi, 1990; Fisher, 2003; Wilcock, 1998, 1999, 2005).

After brain injury, many people have difficulty with, or are unable to perform activities and their control and opportunity to resume activities may be restricted (Willer & Corrigan, 1994). Many spend the majority of their time engaged in passive or solitary activities, resulting in uninvolved and unsatisfactory lifestyles (Farnworth, 2003; Melamedt, Groswassers & Stern, 1992; Yerxa & Locker, 1990). During his recovery from brain injury, Jason Lewin (Ylvisaker & Feeney, 1998) summarised the key issue thus: “Creating a satisfying lifestyle after brain injury does not simply mean recovering functions. It must include becoming successfully engaged in activities that are meaningful to the person” (p.267).

2.3 ELEMENTS OF A SATISFYING LIFESTYLE

The key elements of a satisfying lifestyle include choice in activities and finding the meaning and value of participation in a balanced range of activities for each person. These elements are reviewed in more detail, and in doing so, the common lifestyle changes experienced after brain injury are identified.

2.3.1 Individual Choice

The freedom and opportunity to choose one’s activities, and when and with whom they are completed is a key aspect of a satisfying lifestyle. Individuals make active choices about the range of activities they need to complete, which are influenced by a complex myriad of both intrinsic and external factors that support or hinder participation (Chapparo & Ranka, 1997; Yerxa, 1991). The type of activities people choose are dependent on the social and cultural context in which they live and their need to fulfil social roles, meet personal and environmental demands and accommodate personal preferences (Chapparo & Ranka, 1997; Minnes et al, 2003; Wilcock, 1999; WHO, 2001). This is a dynamic process which, when successful, accommodates to ongoing changes in a person's roles and circumstances (Townsend et al, 1997). Other factors that influence the activities a person chooses and needs to perform include their experience and skills, roles, face and culture, time and money and the availability and nature of supports, facilities and services (Chapparo & Ranka, 1987; Law, 2001; Townsend et al, 1997; WHO, 2001). However, after brain injury, people may not always be able to discern the combination of factors that contribute to desired and necessary activities. Focusing on each person's chosen activities may be more helpful than addressing the broader issue of social roles (Jones & Nicol, 1998; Sloan et al, 2009).

After brain injury many people have less choice and fewer opportunities to participate in a balanced range of meaningful activities as a consequence of reduction in their ability and associated environmental restrictions (Khan, Baguley & Cameron, 2003; McCabe et al, 2007; McColl et al, 1998; Willer & Corrigan, 1994; Yerxa et al, 1990). Personal control over activity choice is often intentionally restricted for safety purposes if people lack sufficient awareness of the nature, severity or consequences of their impairments or disabilities (Durgin, 2000; Fleming & Strong, 1995; Sherer et al, 1998; Trevena, Cameron & Porwal, 2004; Williams & Evans, 2001).

2.3.2 Meaning and Value of Participating in Activities

Activities are meaningful and valued only when they are chosen and carried out with a clear purpose by a person, and within the context of their life (Persson, Erlandsson, Eklund & Iwarsson, 2001). Activities can have concrete value and outcome, such as a product, a feeling of satisfaction or enjoyment, or improving one's health (Fisher, 2003). They can also have intrinsic or symbolic value, such as contributing to self-identity or enabling a person to be identified with a subgroup or ideology (Csikszentmihalyi, 1991; Fisher, 2003). Other benefits include the way activities assist in the organisation of time, the acceptance by one's community, the enablement of self-expression or the achievement of personal goals and growth (Chapparo & Ranka, 1997; Christiansen & Matuska, 2006; Csikszentmihalyi, 1990; Durgin, 2000; McColl et al, 1998; Townsend et al, 1997, Willer & Corrigan, 1994). The meaning of an activity will vary for each person, as it is personally and culturally determined and is dependent on the purpose, environment and context in which it is performed (Chapparo & Ranka, 1997; Doig, Fleming & Tooth, 2001; Fisher, 2003; Persson et al, 2001; Yerxa et al, 1990). The value of any activity is thought to be considerably enhanced when it is relevant to a person's 'life story' rather than doing something simply to occupy time (Christiansen & Baum, 1997; Clark, 1997). People often do not explicitly acknowledge or identify the meaning and value of their participation in specific activities until participation is no longer possible (Fisher, 2003; Persson et al, 2001).

2.3.3 Range of Activities

Typically, people perform a variety of different activities, and after brain injury there is change in the nature and extent of participation in a range of meaningful activities. This can prevent people from attaining the lifestyle they expect. Loss of roles and activities can affect self identity (Gutman, 2000). One survivor summarised his experience: “I never thought this is how my life would turn out” (Gutman, 2000, p.1). The impact can be greater for those who sustain injuries as young adults, who are still developing or planning adult lifestyles and roles, as the activities that form and sustain these are often lost (Gutman, 2003). After brain injury many people feel the need to expand the range of activities they participate in to support role fulfilment and community integration (Sloan et al, 2009). Racino and Williams (1994, p.39) reported “adults with disabilities and their families want the same things other people so – a place to live, a job, an education, recreation, friendships and family life”. These problems can persist for, or arise years after the injury was sustained, even when recovery in physical and other functions are made (Dikmen, Machamer & Temkin, 1993).

The ICF Activities and Participation domain has been identified as relevant to illustrating disability experienced by people after brain injury and is employed in this review to describe changes commonly experienced in the key aspects of participation (Greenwood, 1999; Koskinen, Hokkinen, Sarajuuri & Alaranta, 2007). This emphasises the catastrophic impact of brain injury on participation, and highlights the extent to which the ICF can describe this.

2.3.3.1 Activities to Look after Oneself: Managing One’s Routine, Mobility, Communication, Self Care and Domestic Tasks

A broad range of activities are required for a person to be independent and these are found within five chapters of the ICF Activities and Participation domain: general tasks and demands, mobility, communication, self-care and domestic activities.

Communication difficulties are frequently experienced after brain injury and can include specific speech, language and reading impairments and impaired social communication (Muir & Douglas, 2007; Sloan & Mackey, 2007). Social communication problems are more complex and can exist in the absence of language impairments but result in social withdrawal, apathy, behavioural problems and decreased emotional control and empathy (Ylvisaker & Feeney, 1998). These types of problems are associated with poorer psychosocial outcome including difficulties with return to work, breakdown of relationships, social isolation and reduced quality of life (Muir & Douglas, 2007; Sloan & Mackey, 2007).

Reduced performance in self-care tasks is more common in the acute phase after injury and can include difficulty or need for assistance with eating, showering and dressing, and managing medications. By two years after brain injury the large majority of people are able to manage self-care, basic needs and domestic tasks independently (Olver, Ponsford & Curran, 1996; Sloan, Winkler & Anson, 2007). People with brain injury also have difficulty with more complex tasks to maintain their general health (AIHW, 2003a). This is evidenced by the higher incidence of morbidity for people with brain injury compared to the general population which further compounds the nature and extent of their disabilities (AIHW, 2003a; Baguley, Slewa-Younan, Lazarus & Green, 2000).

Getting around after brain injury can be problematic for a number of reasons related to both physical disabilities that impact on mobility, and the ability to return to driving or using transport, all of which are included in the mobility chapter of the ICF (WHO, 2001). In a large study in NSW, Tate and colleagues (Tate et al, 2004) reported no mobility problems were experienced by 25% of their sample and a further 35% only had mild impairments that did not interfere with daily functioning. However, the prevalence of physical impairments and mobility restrictions increases with brain injury severity

(Khan, Baguley & Cameron, 2003; Tate et al, 2004). Higher level mobility problems are more common than severe physical impairments and can include stair use, running, jumping and hopping on different surfaces and different distances, and including stopping, starting and changing direction (Williams, Robertson, & Greenwood, 2004).

Resuming driving after brain injury is difficult as complex motor, perceptual and cognitive abilities are required to drive safely (Coleman et al, 2002). While many are able to use public transport, fewer are able to return to driving (Olver, Ponsford & Curran, 1996). Estimates indicate only 40-60% of people able to return to driving after brain injury (Coleman et al, 2002). The resumption of driving is associated with better community integration outcomes and can impact on a person’s ability to participate in other activities and life roles, particularly when public transport is limited (Bryer, Hanks, & Rapport, 2006).

2.3.3.2 Activities to Enjoy Life: Leisure, Recreation, Social and Community Activities

The ICF chapter on Community, Social and Civic life includes a broad range of community, leisure and recreation activities including arts and music to participating in social organisations such as churches and social groups (WHO, 2001). Leisure activities provide the opportunity to enjoy oneself, meet people, make friends, develop skills and get involved and be supported by one’s community (Durgin, 2000; McColl et al, 1998). Reduced participation in social and shared leisure activities is a frequent and persistent problem after brain injury, even when people report improvements in other areas (Dikmen, Machamer & Temkin, 1993; Jacobsson et al, 2009; McCabe et al, 2007). Rehabilitation should support people with brain injury participate in old and new leisure activities as these can assist people to redefine their sense of meaning and self after the onset of disability (Magnus, 2001).

2.3.3.3 Productive Activities: Work, Education and Financial Independence

The key productive roles and activities for adults in western society, education, employment and financial management, are addressed in the ICF chapter, Major Life Areas (WHO, 2001). After brain injury most people do not return to work or study and those who do often return to a lower level of job or course, with reduced hours and need for some kind of support (Dikmen, Machamer & Temkin, 1993; Kersel, Marsh, Havill & Sleigh, 2001; McCabe et al, 2007). Those people who do return to work often have trouble retaining or gaining employment. Olver, Ponsford and Curran (1996) found 32% of those who were employed at two years after injury were unemployed by five years post injury and many who were studying before their injury were unemployed.

Research has demonstrated returning to work is less likely or takes longer when injuries are more severe (Heinemann & Whiteneck, 1995). The likelihood of someone returning to work is also affected by the economic climate and the person’s age at injury and pre-morbid education levels, skills and experience and pre-injury unemployment (Heinemann & Whiteneck, 1995; Kreutzer et al, 2003). ‘Returning to a previous lifestyle’, including resuming work, is a frequent rehabilitation goal and often single indicator of outcome (Hall, 1992; Heinemann & Whiteneck, 1995; O'Neil-Pirozzi, Corrigan, & Hammond, 2004; Oppermann, 2004). Employment has been associated with higher perceived quality-of-life, whereas failure to return to work has financial implications and is also strongly linked to poorer social integration, quality of life, reduced life satisfaction and physical ailments (Kreutzer et al, 2003; Kersel et al, 2001; McCabe et al, 2007; O’Neill et al, 1998). Associated with disability and failure to return to work, many people also lose their independence and ability to support themselves financially (Marsh & Kersel, 2006; Reistetter & Abreu, 2005; McColl et al, 1998; McKinlay & Watkiss, 1999).

2.3.3.4 Interpersonal Relationships and Interactions

The ICF chapter Interpersonal Interactions and Relationships includes both activities and behaviours necessary to form and maintain a variety of specified types of social relationships (WHO, 2001). Reduced participation in leisure activities with others and dissatisfaction with social networks and relationships are complex and long term problems after brain injury (Kreutzer, Marwitz, Seel & Serio, 1996; McCabe et al, 2007). Typically, people with brain injury have trouble forming and maintaining social relationships including close personal relationships and more informal relationships and contact (Kreutzer, Marwitz, Seel & Serio, 1996; McColl et al, 1998). Sloan, Winkler & Callaway (2007) report the majority of people after brain injury have no social contact except that arranged with family, spend more time alone, lack adequate social support and consequently feel isolated. Divorce and breakdown in other relationships is common after brain injury (Peters, Stambrook, Moore, & Esses, 1990; Ragnarsson, 2002). It is important people with brain injury are supported to resume past and commence new, community based activities as these can provide opportunities to develop and maintain new and existing social relationships and networks (Callaway, Sloan & Winkler, 2005).

The persistence of behavioural and psychosocial impairments, more so than physical impairments, are linked to poorer long term outcome including increased need for care and supervision, significant family distress, lack of social integration and higher unemployment (Connolly & O’Dowd, 2001; Hoofien, Gilboa, Vakil & Donovick, 2001;

Kersel et al, 2001; Kreutzer, Marwitz, Seel & Serio, 1996; Levin et al, 1987; Perlesz, Kinsella & Crowe, 1999; Winkler, Unsworth & Sloan, 2006). Socially inappropriate behaviours can include lack of initiation, depression, lowered empathy, apathy and adynamia, which are significant obstacles to effective relationships and good outcome after brain injury (Khan, Baguley & Cameron, 2003; Marin & Wilkosz, 2005). More challenging behaviours can include irritability, aggression, sexually inappropriate and perseverative behaviours and violence, however the impact of such behaviours will depend on the duration, intensity and frequency of the behaviours exhibited (Kelly et al, 2006; Kersel et al, 2001; Simpson, 2010; Ylvisaker & Feeney, 1998). Family and friends are often alienated by persistent dysfunctional behaviour exhibited after brain injury and the person with brain injury is often seen as a “difficult stranger” (Khan, Baguley & Cameron, 2003; Kreutzer, Marwitz, Seel & Serio, 1996).

2.3.4 Balance of Activities

Associated with the need to perform a wide variety of different activities is the need to have some balance in the type and amount of activities one performs. Balance in activities can be reviewed by examining the proportion of time spent in different activities and the pattern, frequency and consistency with which different activities are performed over the course of a day and week (Backman, 2005; Farnworth, 2003; Krupa, Eastabrook, & Baksh, 2003; Persson et al, 2001). This includes having sufficient time to complete a combination of obligatory activities to meet a range of requirements such as work, sleep, caring for others, and optional or desired activities (Backman, 2005; Christiansen, 1996; Matuska, 2010). Balance can also be influenced by participating in activities with varying degrees of challenge and complexity, ranging from basic activities required as a precursor to others, such as buying movie tickets, to intense activities like playing a game of netball or the total absorption that might come from making a work of art (Christiansen, 1996; Csikszentmihalyi, 1975; Farnworth, 2003; Persson et al, 2001; Zemke & Clark, 1996). Other considerations include the sequence and pattern of activities, daily routines, the number of tasks a person is doing at once and the frequency of both planned and unexpected tasks during the day and week (Erlandsson & Eklund, 2001).

The balance of a person's routines is thought to be supported when activities are completed in different environments and with different people. After brain injury, loss of control and ability to complete a range of tasks can easily disrupt the desired balance of activities. Ylvisaker and Feeney (1998, 2000) advocate that appropriately structured everyday activities and routines that include people relevant to each person's life are critical aspects of person focused rehabilitation. In this study the desired balance is in part measured by the degree to which a person's participation in the range of tasks relevant to their lifestyle has changed since their brain injury.

Factors that influence perceptions of adequate balance include the allocation of time for different activities, the perceived value attached to the activities, with whom, and where activities are completed (Christiansen, 1996; Farnworth, 2003; Matuska, 2010). People's circumstances and priorities will influence the activities they view as essential and how they allocate their time (Persson et al, 2001). A balanced range of different types of activities is essential to support good health, wellbeing and create a satisfying lifestyle but there is no consensus how balance should be determined or what level of balance is required to achieve these benefits (Matuska, 2010; Yerxa et al, 1990).

2.4 ORIGINS OF THE CONSTRUCT OF LIFESTYLE

The elements and concept of lifestyle that have been described in this thesis were drawn from the occupational therapy (OT) concept of occupational performance, the ICF concept of participation and aspects of community integration and quality of life, which are often the focus of brain injury rehabilitation practice, outcome measurement and research (American Occupational Therapy Foundation’s [AOTF] Research Advisory Council, 2000; Chapparo & Ranka, 1997; Christiansen & Matuska, 2006; Doig, Fleming, Tooth, 2001; Johansson, Högberg, & Bernspång, 2007). The concept of lifestyle in this thesis aimed to synthesise many of the key concepts of these theories in a readily understood approach to inform and improve clinical practice and client outcomes.

Successfully and independently managing one’s own life routines to include the necessary and desired balance and range of activities supports sustained health, reduced stress, positive relationships with others, a robust sense of self identity, and better quality of life (Csikszentmihalyi, 1990; Farnworth, 2003; Law, 2001; Matuska, 2010; McColl et al, 1998; Townsend et al, 1997). These are also considered powerful determinants of successful occupational performance and community integration after brain injury (McColl et al, 1997; Yerxa, 1991; Yerxa et al, 1990). The contribution of these models to the concept of lifestyle is now reported.

2.4.1 The Relationship between Lifestyle and Occupational Therapy

The concept of occupation is critical to the understanding of the construct of lifestyle defined in this study, as they both address the need for choice, meaning and performance of meaningful activities. The activities that contribute to a satisfying lifestyle could appropriately be described as occupations. Occupations are activities that are self-directed, purposeful and meaningful to each individual (Yerxa, 1991). Occupations provide people with a source of choice and control over their life. Each person interprets the meaning and value of each task according to its purpose and the context in which it is performed for that individual (Persson et al, 2001). The aim of occupational therapy practice is to facilitate occupational performance that involves the ability to choose, organise and complete a range of meaningful activities and routines to a satisfactory level as appropriate for a person’s age, environment, needs and culture (American Occupational Therapy Association, 2002; Chapparo & Ranka, 1997; Townsend et al, 1997). Successful occupational performance of a large range of activities is one of the key elements for a person to resume a satisfying lifestyle after brain injury.

2.4.2 The Relationship between Lifestyle and Participation in the ICF

The ICF conceptual model of functioning and disability provided the basis for describing and understanding the mechanisms contributing to lifestyle changes after brain injury for the purpose of this study. The classification of participation in the ICF focuses on the “lived experience” of disability and each person’s ability to complete tasks in the context of their own life (WHO, 2001, p.123). This is summarised as the person’s lifestyle in this thesis. There are also similarities between the concepts of occupation and participation as described in the ICF, which support the notion that the nature and impact of disability experienced by each person is unique. Participation does not explicitly articulate the need for the range of activities to be balanced and meaningful to people, but is inferred (WHO, 2001). The application of the ICF to support construction of an assessment to measure lifestyle changes are explored further in Sections 2.8 and 2.9.

2.4.3 The Relationship between Lifestyle and Community Integration

The concept of ‘community integration’ includes regaining or attaining a “better life”, which is commensurate with a lifestyle that enables a person to fulfil life roles and activities that are relevant to each individual’s goals and values (Brown et al, 2004). Community integration is a complex and multi-dimensional construct that includes the ability to engage in occupations, or meaningful activities, but also places considerable emphasis on the degree to which a person feels engaged and accepted by their community (McColl et al, 1998; Sloan & Mackey, 2007). In brain injury rehabilitation the primary goal is often to maximise an individual’s self-determination and support them to reintegrate back into their own community (Brown et al, 2004; McColl et al, 1998; Reistetter & Abreu, 2005; Willer & Corrigan, 1994). Important elements of successful community integration include the ability to be self-directed in participation in relationships and personally and culturally relevant productive and leisure activities (McColl et al, 1998; Reistetter & Abreu, 2005).

2.4.4 The Relationship between Lifestyle and Quality of Life

Quality of life is a complex, subjective notion, “tied to the freedom to choose our own lifestyle” (Connally, 1994, p.162). Andrews (1993) advocated that “a person’s quality of life is something only that person can decide” (p.306). McKenna (1993) supports this view and states a person’s perception of their quality of life is shaped by a comparison of their current life status to what they thought their life was or how they thought it would be. Understanding a person’s perceived quality of life can be difficult after brain injury, and describing changes to a person’s lifestyle was seen as a useful alternative approach to provide insight into how quality of life might be perceived. Johnston and Miklos (2002) describe ‘activity-related quality of life’ and report “valued activities are clearly crucial to

QOL" (p.S27). This is consistent with the view that "to improve quality of life, we need to understand which activities are most valued by the individual" (Johnston, Goverover & Dijkers, 2005, p741).

The following section reviews the assessment process in rehabilitation, the success of existing assessments and elements of effective assessments to measure lifestyle changes after brain injury.

2.5 ASSESSMENT OF PARTICIPATION AFTER BRAIN INJURY

This research was prompted by the need to identify an assessment that addressed the concept of 'my life', when the primary goal identified by people with brain injury is often 'I want my life back'. Increasingly, rehabilitation professionals are encouraged to address both a person's specific functional limitations and the overall disruption to the person's ability to engage in their chosen lifestyle in the provision of rehabilitation and measurement of outcome (Chapparo & Ranka, 1997; Cicerone, 2004; Dahl, 2002; Disability Services Act, 2006). Durgin (2000) advocated that rehabilitation after brain injury should support people to achieve a lifestyle that provides them with "a reason for living" (p.1198). To do this it is important that rehabilitation approaches acknowledge each person's experience and preferences, as there is evidence this motivates people and results in better outcomes (Clark, 1993; Doig, Fleming, Cornwell & Kuipers, 2009; Durgin, 2000; Mattingly, 1998; Turner-Stokes, 2009; Williams & Steig, 1987).

Rehabilitation assessments should be comprehensive and provide information about the client's own needs and the nature and extent of change for each person's life. This can: support clinical reasoning, client centred goal setting and treatment planning, increase the focus of therapy on the client, evaluate client and service outcomes and demonstrate that therapy is valuable to support clinical reasoning (Bond & Fox, 2007; Mackey & Nancarrow, 2006; Malec, Smigielski & DePompolo, 1991; Rauch, Cieza & Stucki, 2008; Stucki & Sangha, 1996; Tate, 2010; Unsworth, 2000; Ylvisaker & Feeney, 1998). Despite these benefits, at the time of this review, there was no gold standard or consensus regarding which were the best measures of outcome after brain injury (Badge, 2010; Haigh et al, 2001; Hall, 1992; Skinner & Turner-Stokes, 2006; Tate, 2010; Turner-Stokes & Turner-Stokes, 1997; Turner-Stokes, Williams & Abraham, 2001; Unsworth, 2000). The very small number routinely used in rehabilitation services compared to the large number of assessments available supports this view (Haigh et al, 2001; Skinner & Turner-Stokes, 2006; Turner-Stokes & Turner-Stokes, 1997).

There is an increasing number of resources to assist clinicians select appropriate assessments including lists, books and compendiums (Cook, McCluskey, & Bowman, 2006; Law, Baum, & Dunn, 2001; Trevena, Cameron & Porwal, 2004; Tate, 2010; Wade, 2003a; 2003b). These are usually not prescriptive and encourage clinicians to select assessments for use based on their own criteria to reflect service and client need (Tate, 2010). Not surprisingly, it may be difficult for clinicians to identify which assessment is the most appropriate for any given purpose. Identifying the elements of a good assessment is useful to achieve these benefits as “good assessment is fundamental to evidence based practice” (Tate, 2010, p.1).

2.6 CHARACTERISTICS OF ASSESSMENTS TO EFFECTIVELY MEASURE LIFESTYLE CHANGES

Criteria were developed for this review to evaluate the appropriateness and effectiveness of instruments. As a starting point, there is consensus among test developers that assessments need to be psychometrically robust, and clinically useful (Andresen, 2000;

Cook, McCluskey, & Bowman, 2006; Hall, 1992; Hobart, Lamping & Thompson, 1996; Law, Baum & Dunn, 2001; Polgar & Barlow, 2005; Smart, 2006; Streiner & Norman, 2003; Tate, 2010; Trevena, Cameron & Porwal, 2004; Wade, 2003a; 2003b). There is growing emphasis on the quality of assessments and many authors propose the extent to which the measure addresses the needs of the client, service or research question, should be one of the first considerations (Wade, 2003a; Ylvisaker & Feeney, 1998). These elements are supported when the purpose of the assessment is based on sound underlying theory.

2.6.1 Adequate Psychometric Properties

Modern test theories propose that measures of high quality be objective, reproducible and precise in the measurement of a wide range of the continuum of a single construct, and that this should be targeted to the people for whom the measure was designed (Andresen, 2001; Black & Jenkinson, 2009; Bond & Fox, 2007; Law, Baum & Dunn, 2001; Smart, 2006; Tennant & Conaghan, 2007; van Baalen et al, 2006; Unsworth, 2000). This information is a prerequisite for interpreting the meaning of scores in clinical practice (Black & Jenkinson, 2009; Law, King, & Russell, 2001). The primary method to evaluate measurement properties in this study is Rasch modelling as this can provide diagnostic and descriptive information of the internal consistency, reliability and validity of the scale, and individual items that can be used to improve the quality of measures (Linacre, 2010b; Tennant & Conaghan, 2007).

2.6.1.1 Reliability

Reliability refers to the precision of the instrument to measure true differences in the construct of interest as opposed to variation introduced by error, such as through rater bias, item invariance, or random change over time (Bond & Fox, 2007; Cronbach & Meehl, 1955; Streiner & Norman, 2007). Rasch analysis provides evidence of the reliability of a scale by evaluating the stability and precision of the instrument, items and people (Bond & Fox, 2007). Rasch methods can also discriminate the level of difficulty of items and ability of the people along the continuum, which supports evaluation of the appropriateness of the scale to measure the construct and targeting of items for the people on which it is used (Bond & Fox, 2007). The need for unidimensionality, which requires a single construct to be measured at one time, is an essential requirement for scientific measurement and for adequate reliability and validity of an instrument (Bond & Fox, 2007). Evidence of this can be provided by reporting the internal consistency, principal components and factor analysis of a measure. Reliability can also be described as statistical validity and is necessary for results to be valid and useful (Baghaei, 2008).

2.6.1.2 Validity

Validity is a multidimensional concept that is demonstrated by empirical methods to accumulate evidence that supports the "appropriateness, meaningfulness, and usefulness of inferences and actions that are based on test scores" (Messick, 1989, p.5) for the target population (Aiken, 2003; Popham, 1978; Streiner & Norman, 2003; Unsworth, 2000). Construct validity is an overarching type of validity that addresses the effectiveness of the instrument to represent a continuum of the construct under measurement that also informs the underlying theory (Aiken, 2003; Baghaei, 2008; Cronbach & Meehl, 1955). Content validity is an important aspect of construct validity which involves “the systematic examination of the test content to determine whether it covers a representative sample of the behaviour domain to be measured” (Anastasi & Urbina, 1997 p. 114) and can be illustrated by visual display of the item range and experts in the field or the people for whom it was designed (Streiner & Norman, 2003). Evidence of validity can also be provided by reviewing whether the hierarchy of item and people difficulty is supported by current theories and research, and whether the person measures correlate well with other test instruments evaluating the same or similar constructs (concurrent validity) (Baghaei, 2008).

2.6.2 Clinical Utility

Clinical utility is a multi-faceted concept that depends on the purpose of the assessment, and the target service and clients (Polgar & Barlow, 2005; Smart, 2006; Unsworth, 2000; Wade, 2005). A clinically useful assessment is one that is appropriate and acceptable to the clients and clinicians, provides clinically meaningful information and is realistic given the constraints on the service (Law, King & Russell, 2001; Letts et al, 1999; Liddle & McKenna, 2000; Polgar & Barlow, 2005; Unsworth, 2000; Wade, 2003b). Judgements of clinical utility also balance the value of the information obtained with the burden of completing the assessment in terms of administration and scoring time, materials, cost and training requirements and acceptability to clinicians (Gustafsson, Stibrant Sunnerhagen & Dahlin-Ivanhoff, 2004; Hall, 1992; Polgar & Barlow, 2005; Smart, 2006) as these influence whether the instrument will be used in clinical practice (Andresen, 2000; Dawson et al, 2010; McGlynn, 1998; Smart, 2006). This study was completed in the context of a small multidisciplinary team and needed to be readily available and able to be used by clinicians with different clinical backgrounds.

2.6.3 Sound Conceptual Foundation

A sound conceptual foundation is considered important as this can drive the development of objective assessments that reflect clinical priorities (Bond & Fox, 2003; Domholdt, 2005; Streiner & Norman, 2003). The construct validity of an instrument cannot be evaluated without a coherent underlying theory. This also guides development of assessments that are fit for their intended purpose and so the relevance of the instruments for a variety of applications can be judged (Cronbach & Meehl, 1955; Deyo & Carter, 1992; Powell, 1999; Streiner & Norman, 2003).

2.6.4 Fit for Purpose: Measuring the Construct of Lifestyle

In this study the construct of lifestyle is the focus of the assessment and has been clearly defined and supported by sound theoretical frameworks (See Section 2.2) (Bond & Fox, 2003; Streiner & Norman, 2003). To measure lifestyle effectively, instruments need to include a sufficiently large number of items to enable people to choose the range of activities that are meaningful in their life. Activities need to include ones related to looking after oneself, mobility, productive activities and ones to enjoy life and social relationships. It is also important to know the extent and nature of changes in the range of these activities following brain injury. Offering a range of activities that people can chose as relevant to their own lifestyles during the assessment process is thought to enable them to identify what is meaningful to them, reflecting client centred practice (Durgin, 2000; McIntyre & Tempest, 2007). Instruments can demonstrate the balance in activities by evaluating the pattern of different types of activities a person engages in over time.

A key element of a satisfying lifestyle is having the choice over what activities a person engages in. The assessment needs to be collaborative, so each person can identify what their normal lifestyle and participation involves (American Occupational Therapy Association, 2002; Dijkers, Whiteneck & El-Jaroudi, 2000; Fisher, 1992a; Liddle & McKenna, 2000; Mackey & Nancarrow, 2006; Malec, 2009; McCabe et al, 2007; Racino

& Williams, 1994; Unsworth, 2000). Brown and colleagues (2004) recommend the only way to identify the significance and value of activities for each person is to ask them (Brown, Dijkers, Gordon, Ashman, Charatz & Cheng, 2004). This provides a more accurate reflection of what ‘a better life’ consists of for individual people and their priorities, than the fixed recording nature of most existing instruments (Brown et al, 2004; Durgin, 2000; Fisher, 1992a; Fricke & Unsworth, 2001; Fuhrer, 1994; Pugh-Clark et al, 2002; Racino & Williams, 1994; Turner-Stokes, 2009; Unsworth, 2000; Wright, 2000a). This can empower people with brain injury and support better and more meaningful outcomes for the person and higher client, carer and staff satisfaction (Bajo & Fleminger, 2002; Creed, 2005; Fuhrer, 1994; Liddle & McKenna, 2000; Mackey & Nancarrow, 2006; Malec, 2009; Pugh-Clark et al, 2002; Townsend et al, 1997; Turner-Stokes, 2009; Unsworth, 2000; Wade, 2003a; Yerxa, 1991).

2.7 REVIEW OF EXISTING INSTRUMENTS

The elements of effective assessments described above (See Section 2.6) were used to evaluate the suitability of existing assessments to measure the concept of ‘my life after brain injury’. The evaluation process considered the available literature and review of the score form or questions and scoring manual where available. The assessments were rated according to the extent to which the test characteristic was supported by clear evidence, if evidence was equivocal or insufficient and further testing was required, and when no information on the test characteristic was available. In some cases, further publications since this review have addressed some areas where the instrument was considered inadequate for the purpose of this study.

The review considered the relevance to measure lifestyle changes after brain injury, judgment of clinical utility and adequate measurement properties. Decisions about the effectiveness of each tool to measure lifestyle was the main consideration and addressed whether the instrument enabled people to choose what was important to them, whether they covered a sufficiently wide variety of activities that tapped into the areas of looking after oneself, productive and leisure activities and interpersonal relationships, the balance of activities and the whether the assessment was thought to be able to reflect the concept of someone’s life. Clinical utility was judged according to user restrictions, time and cost considerations and the degree to which assessment results informed clinical practice (Law, King, & Russell, 2001; Smart, 2006). The measurement properties were evaluated on the sufficiency of information to demonstrate the precision and appropriateness of the measure for people with brain injury (Anastasi & Urbina, 1997; Bond & Fox, 2007). The reliability and validity were considered adequate if they had been demonstrated as relevant for use with people with brain injury, the measurement properties had been described and no major psychometric issues identified (Linacre, 2010b; Messick, 1989). Instruments that primarily targeted impairments at the body function level were excluded from consideration. No assessments were considered appropriate to measure lifestyle changes after brain injury. This review provided rationale of the gap in available measures to address lifestyle, and also informed selection of instruments to support validation of the Lifestyle Assessment.

Many of the tools that are now available were also in development at the time of this study so were not included in this review. These included the Participation Objective, Participation Subjective (POPS), which aims to combine the perspectives of both clinician and the person with brain injury in measuring outcome (Brown et al, 2004). This instrument considers the person’s satisfaction, but only from the predefined list of activities in the scale, so the person cannot identify the activities that contribute to their own lifestyle (Brown et al, 2004). The MayoPortland Adaptability Inventory (MPAI) was also going through a period of evaluation and refinement between 2000 – 2004 (Malec, 2004a; Malec, 2004b; Malec & Lezak, 2003; Malec, Moessner, Kragness, & Lezak, 2000). The revision process evaluated and improved the psychometric properties of the instrument, which addressed impairments, adjustment to injury and a small section on participation (Malec, 2004a; 2004b). The review focused on measures that had published information available and appeared most relevant to the construct of lifestyle.

Instruments commonly used in brain injury rehabilitation and occupational therapy that appeared relevant to the construct of lifestyle were sourced from the literature. The brain injury specific instruments assessments reviewed included: Community Integration Questionnaire (CIQ), Craig Handicap Assessment and Reporting Technique (CHART), Disability Rating Scale (DRS), Brain Injury Community Rehabilitation Outcomes scales (BICRO-39), Community Integration Measure (CIM), Reintegration to Normal Living Index (RNL) and the Impact on Participation and Autonomy questionnaire (IPA). The measures designed to evaluate occupational performance that were reviewed included the Assessment of Motor and Process Skills (AMPS), the Canadian Occupational Performance Measure (COPM) and the Occupational Therapy History Interview (OPHI).

2.7.1 Instruments Specific to Brain Injury

Assessment instruments developed specifically for use with people with brain injury were reviewed first. The Community Integration Questionnaire (CIQ), Craig Handicap Assessment and Reporting Technique (CHART), Brain Injury Community Rehabilitation Outcomes scales (BICRO-39), Community Integration Measure (CIM), Reintegration to Normal Living Index (RNL), the Impact on Participation and Autonomy questionnaire (IPA) and the Disability Rating Scale (DRS) were reviewed according to the elements described in 2.6 (See Table 2.1). None of these measures adequately assessed the construct of lifestyle and all had issues with their use in clinical practice or problems with measurement properties had been identified.

Table 2.1: Summary of Review of Existing Assessments Specific to Brain Injury

CRITERIA FOR REVIEW	CIQ	CHART	BICRO-39	RNL	IPA	CIM	DRS
Fit for purpose: Addresses Key Elements of Lifestyle							
Offers individual choice in activities	✘	✘	✘	✘	?	✘	✘
Balanced range of meaningful activities	✓	✓	✓	✓	?	✘	✘
Considered to capture a person's lifestyle	✘	✘	✘	✘	✘	✘	✘
Clinical Utility							
Could be used by range of professionals	✓	✓	✓	✓	✓	✓	✓
Commonly used	✓	✓	✘	✘	✘	✘	✓
Time	✓	✓	?	✓	✓	✓	✓
Cost	✓	✓	✓	✓	✓	✓	✓
Generates clinically useful information	?	?	✓	✓	?	?	?
Adequate Measurement Properties							
Objective: Uses interval level measure	✘	✘	✘	✘	✘	✘	✘
Single dimension or coherent separate dimensions	✘	✘	✘	✘	✘	?	?
Adequate reliability	?	?	?	?	?	?	✓
Valid and appropriate to use with people with brain injury	?	?	?	✓	?	✓	?

Legend:
✓ test characteristic reported with clear evidence
? test characteristic reported with equivocal or insufficient evidence
✘ test characteristic not reported

The Community Integration Questionnaire (CIQ) was based on the ICIDH and aimed to measure the degree of community integration after traumatic brain injury in three areas: home integration, social integration and productivity (Corrigan & Bogner, 2004; Sander et al, 1999; Willer et al, 1993). The person is not offered choice of relevant activity, and all items are expected to be endorsed. The CIQ has good test re-test reliability, inter-rater reliability between people with brain injury and their caregivers, measure change after rehabilitation, and can discriminate between people with ABI, controls and those living in settings with different levels of support (Gordon et al, 1999; Seale et al, 2002; Willer, Ottenbacher & Coad, 1994). Other reliability studies have yielded mixed results, with some providing evidence of reliability and others have identified issues with ceiling effect, subscale reliability, and possible gender bias for the Home Integration subscale, ongoing evaluation and revision is continuing (Corrigan & Deming, 1995; Dijkers, Whiteneck & El-Jaroudi, 2000; Hall et al, 2001; Hall et al, 1996; Kaplan, 2001; Sander et al, 1997). At the time this study commenced it was one of the primary and most widely used assessments for measuring community integration after brain injury (Kuipers, Kendall, Fleming, & Tate, 2004; Zhang et al, 2002).

The Craig Handicap Assessment and Reporting Technique (CHART) is based on the ICIDH (WHO, 1980) and addresses a wide range of functioning (Whiteneck et al. 1992). While some attention is paid to the balance and time spent in activities this is difficult to detect from the total score (Mellick, 2000; Mellick, Walker, Brooks & Whiteneck, 1999). The focus of the financial question was thought too simplistic and lacked clinical relevance and the total score can be misleading so lacks validity (Hall et al, 1998).

The Brain Injury Community Rehabilitation Outcomes scales (BICRO-39) gathers data from the person on both pre and post injury functioning, in a reasonable range of predetermined activities, but psychometrical issues using this approach have been identified for two of the subscales (Powell, Beckers & Greenwood, 1998). Restriction of range, issues with subscale reliability and invariance of item difficulty for the socialising subscale have been identified (Powell, 1999; Powell, Beckers & Greenwood, 1998). The Reintegration to Normal Living Index (RNL) assesses people’s perceptions of their performance and satisfaction with a good range of types of activities, relationships and roles (Pollock et al, 1990; Wood-Dauphinee et al, 1988). The limitations identified included lack of use with people with brain injury, concerns over using the instrument with people with cognitive impairment and lack of insight, and whether it could support intervention (Wood-Dauphinee et al, 1988). Both the RNL and BICRO involve collaboration with the person but fail to offer the person any control over what is measured and assumes all items are relevant for every person.

The Impact on Participation and Autonomy questionnaire (IPA) had the most comprehensive range of items but had not been evaluated for use with people with brain injury and the items for work were excluded from statistical analysis (Cardol, de Haan, de Jong, van den Bos & de Groot, 2001; Cardol, de Haan, van den Bos, de Jong & de Groot, 1999). The IPA addressed each person's perception of the adequacy or success of their autonomy in participation, but did not enable choice in what aspects were measured (Cardol, de Haan, de Jong, van den Bos & de Groot, 2001; Cardol, de Haan, van den Bos, de Jong & de Groot, 1999). Four separate subscales have been identified and use of subscale scores is recommended, but without guidance on how to do so. This was a new instrument at the time this study commenced and while it showed promise further development was needed.

The Community Integration Measure (CIM) has been validated as a measure of community integration after brain injury. It is has a sound theoretical basis and is quick to complete (McColl et al, 2001). It aims to measure the person's perception of qualitative aspects of community integration but does not include a balanced range of meaningful activities and its application to support rehabilitation interventions was not clear (Minnes et al, 2003). The instrument was in the early stages of development and while the initial investigation provided evidence to support the reliability and validity of the measure, follow up investigations into the properties of the instrument were needed

(McColl et al, 2001; Reistetter, Spencer, Trujillo, & Abreu, 2005). Subsequent examination demonstrated satisfactory psychometric properties of the tools, but no assessment of the level of measurement of the scale has been completed (Griffin, Hanks, & Meachen, 2010; Reistetter, Spencer, Trujillo, & Abreu, 2005).

The Disability Rating Scale (DRS) is a global measure that reflects the broad range of functioning experienced by people after brain injury. The DRS was designed to track individuals from very low levels of functioning, including coma, to varying levels of community re-engagement (Rappaport et al, 1982; Wright, 2000b). It measures the three categories of impairment, disability and handicap from the ICIDH (WHO, 1980). It does not consider choice in a range of meaningful activities so was not deemed to measure lifestyle. It was one of the most frequently used measures to track outcome after brain injury and describe the level of disability along the continuum of recovery. It can be used by a wide variety of professionals and is quick and easy to complete (Scheuringer et al, 2005).

There is good evidence supporting use of the DRS including high inter-rater reliability, validity, and sensitivity to clinically relevant changes in individuals in the short and long term (Fleming & Maas, 1994; Fryer & Haffey, 1987; Gouvier, Blanton, LaPorte & Nepomuceno, 1987; Hall et al, 2001; Hall, Cope, & Rappaport, 1985; Novack, Bush, Mythaler & Canupp, 2001; Rappaport et al, 1982; van Baalen et al, 2006; Wright, 2000b). It is less sensitive as a measure of change in higher functioning people as most of the items focus on the more extreme level of disability, but has been shown to be more sensitive than other similar global measures such as the Glasgow Outcome Scale (Hall, Hamilton, Gordon, & Zasler, 1993; Harradine et al, 2004; Rappaport et al, 1992). It was used as a routine assessment by the service in which this study was conducted and selected for use in this study to provide information on the levels of disability experienced by the participants.

2.7.2 Instruments Specific to Occupational Therapy

Three assessment instruments specific to occupational therapy were reviewed: The Canadian Occupational Performance Measure (COPM), the Assessment of Motor and Process Skills (AMPS), and the Occupational Therapy History Interview – version II (OPHI-II). None of these measures adequately assessed the construct of lifestyle and all had issues with their use in clinical practice or problems with measurement properties had been identified. The evaluation of these measures has been summarised in Table 2.2.

Table 2.2: Summary of Review of Existing Assessments Specific to Occupational Therapy

CRITERIA FOR REVIEW	COPM	AMPS	OPHI-II
Fit for purpose: Addresses Key Elements of Lifestyle			
Offers individual choice in activities	✓	✓	?
Balanced range of meaningful activities	?	✗	?
Considered to capture a person’s lifestyle	✗	✗	?
Clinical Utility			
Could be used by range of professionals	✗	✗	✗
Commonly used	?	?	✗
Time	✓	✓	✓
Cost	✓	✗	✗
Generates clinically useful information	✓	✓	✓
Adequate Measurement Properties			
Objective: Uses interval level measure	✗	✓	✗
Single dimension or coherent separate dimensions	✓	✓	✓
Adequate reliability	?	✓	✓
Valid and appropriate to use with people with brain injury	?	?	?

Legend:
✓ test characteristic reported with clear evidence
? test characteristic reported with equivocal or insufficient evidence
✗ test characteristic not reported

The Canadian Occupational Performance Measure (COPM) is a client centred assessment tool design to measure a person's perception of their performance and satisfaction in a range of activities of their choice in the areas of self care, play and leisure (Law et al, 1990). The COPM is limited in its ability to demonstrate the range and balance of activities across a person's lifestyle, but provides clinically useful information (Trombly, Radomski, Trexel & Burnett-Smith, 2002). Some psychometric limitations with the COPM have also been identified. The COPM demonstrated less change when used with people with cognitive problems and physical disability than physical problems Lawalone and further research was recommended to investigate whether this was due to the impact of limited self-awareness or difficulty rating self-performance by this group (Bodiam, 1999). It had not specifically been validated for use with people with brain injury at the time of this review, although this has subsequently been done with small samples to some extent (Jenkinson, Ownsworth & Shum, 2007; Trombly, Radomski, Trexel, & Burnett-Smith, 2002)

The Assessment of Motor and Process Skills (AMPS) is an observational assessment of a person's performance in activities of daily living that has been extensively evaluated in relation to its measurement properties and clinical application, although not adequately with people with brain injury (Fisher, 1997). The person chooses only two or three activities and their performance is rated according to the level of effort, efficiency, safety and independence (Fisher, 2003). The AMPS assessment enables limited client choice in what task is to be performed, but is quite specific in the elements of a task a person must perform. It does not consider the balance and range of activities that constitute a person's lifestyle, which are beyond the intended purpose of the instrument. An expensive week long training course is required to a learn how to administer it and it can only be completed by occupational therapists. Initial studies into validating it for brain injury are beginning to emerge, although one small study suggested invariance in results due to location of testing (Darragh, Sample & Fisher, 1998; Toneman, Brayshaw, Lange & Trimboli, 2010).

The Occupational Therapy History Interview – version II (OPHI-II) is a semi structured interview designed to describe the person’s level of functioning and pattern of occupational performance over time (Kielhofner, Mallinson, Forsyth & Lai, 2001). It addresses many of the issues considered relevant to the construct of lifestyle as described in this thesis, a range of activities meaningful to the person and based in the context of their own life, however it was not considered appropriate for the purpose of this study (Fossey, 1996). Evaluation of the psychometric properties of this version had only commenced at the time this review was completed. A major limitation of the OPHI-II is that it had not been validated for use with people with brain injury at the time this study commenced, although some small studies have since been completed (Trombly, Radomski, Trexel & Burnet-Smith, 2002; Jenkinson, Ownsworth & Shum, 2007). The OPHI-II can only be used by occupational therapists, which precluded its use as a service wide instrument for the purpose of this study.

2.7.3 Summary

The review indicated none of the existing assessments measured the client aim of “wanting to get my life back” after brain injury, which highlights the gap in robust assessments to describe changes to a person’s life due to brain injury (Haigh et al, 2001). Most of them were restricted by limitations of the ICIDH which described a simplistic linear model of disability, the negative experience of handicap and failed to be person centred (Dahl, 2002; Gray & Hendershot, 2000; Greenwood, 1999; WHO, 1980). Tools varied in the degree to which they addressed key elements of a satisfying lifestyle. This is consistent with previous findings that few measurement tools enabled the person being assessed to choose what was important to them (Doig, Fleming & Tooth, 2001).

Most of the existing outcome measures contain a specific number of items that reflect a predetermined definition of what is considered a normal or successful level of social and community functioning (Dijkers, Whiteneck, & El-Jaroudi, 2000). In calculating total scores from every item they are assumed to be relevant and equally important to every person after brain injury (Brown et al, 2004; Dijkers, Whiteneck, & El-Jaroudi, 2000). This fails to consider the enormous variation in how people live their lives and choices they have made regarding what activities are meaningful to them given their personal circumstances (Townsend et al, 1997; Willer & Corrigan, 1994). Consistent with previous reviews of existing measures psychometric problems were identified for many of the instruments (Hall et al, 2001; Hall et al, 1998; Dijkers, Whiteneck & El-Jaroudi, 2000; Powell, 1999; Sander et al, 1999).

The conclusions from this review were consistent with previous findings that there is a gap in current assessment and practice and occupational therapy theories that stress the client’s own roles, values and priorities should be paramount (Doig, Fleming, Cornwell & Kuipers, 2009; Farnworth, 2003; Fricke & Unsworth, 2001; Magasi & Heinemann, 2009; Fisher, 1992a, 1992b). This was not unexpected and may explain why so few measures are in routine use in brain injury rehabilitation (AOTF Research Advisory Committee, 2000). These findings justified the need for development of a new assessment and the elements of effective assessments to meet the intended purpose of this study were used to guide the methodology (Gray & Hendershot, 2000; Greenwood, 1999; Streiner, & Norman, 2003).

2.8 APPLICATION OF THE ICF TO SUPPORT INSTRUMENT CONSTRUCTION

The ICF was selected as the framework for the initial construction the Lifestyle Assessment because of its relevance to describe changes in people's lifestyles after brain injury (See Section 2.3) and because it offered a convenient and widely endorsed source of items. The ICF conceptual model provided a universal language to describe the diverse and unique nature of disability experienced by each person after brain injury (Badley, 1995; Greenwood, 1999; Tate & Perdices, 2008; WHO, 2001). This recognises the experience of disability occurs due to the complex interaction between the type and extent of their brain injury, mix of resultant impairments and the activities each person needs and wants to perform given their personal circumstances (See Figure 2.2) (Cohen & Marino, 2000; Dahl, 2002; Ragnarsson, 2002; Schneidert, Hurst, Miller & Üstün, 2003; Tate & Perdices, 2008; WHO, 2001; Willer & Corrigan, 1994). In this study, each person's lifestyle is considered unique, and the ICF offered an approach that enabled people with brain injury to be classified as individuals, functioning in the context of their life rather than being defined by their brain injury (Dahl, 2002; Greenwood, 1999; Mackey & Nancarrow, 2006).

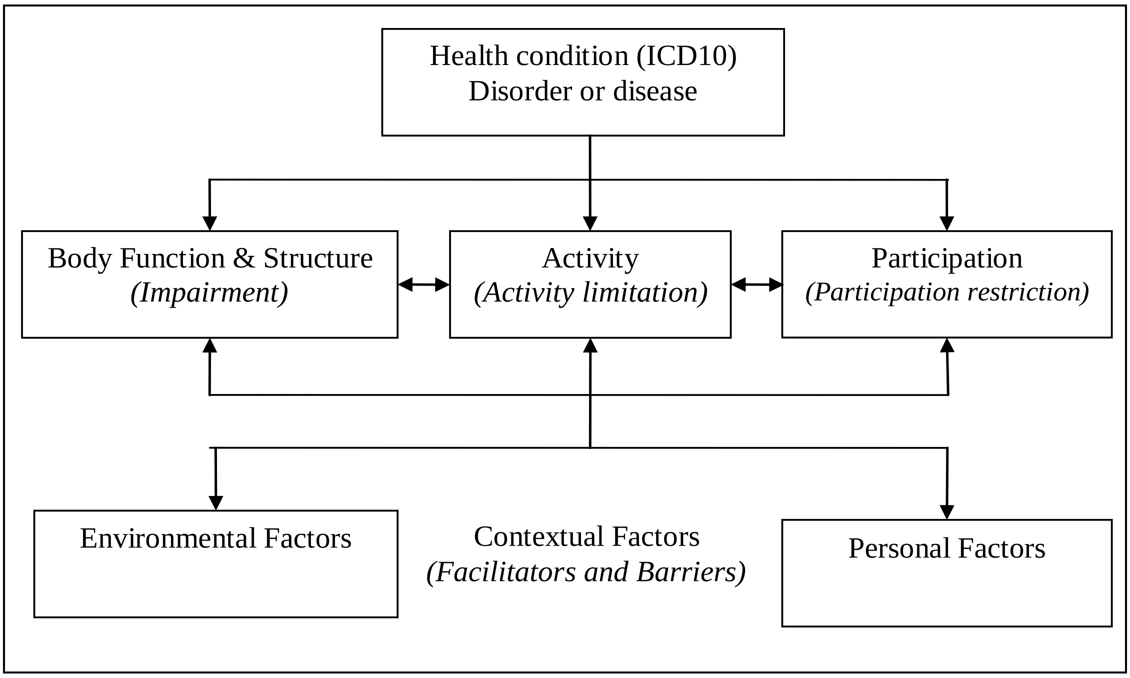


Figure 2.2: Interactions between ICF Components (WHO, 2001)

A key consideration was that the ICF provided a valid and readily accessible source of widely recognised items. The exhaustive and extensive nature of the Activities and Participation domain was thought to provide a useful basis for identifying relevant activities that contribute to a person’s lifestyle after brain injury for the purpose of this study (Bernabeu et al, 2005). There are four levels of items coded within the ICF, representing different aspects of functioning at increasing levels of detail and specificity. Level three and four items are recommended for rehabilitation and considered relevant to occupational therapy practice. The Activities and Participation domain of the ICF contained 118 items at level three and 266 items at level four codes, that provided an item pool of 384 items (Stucki, Ewert & Cieza, 2002; WHO, 2001; AOTF Research Advisory Council, 2000; Unsworth, 2000). The ICF lent itself to development of an assessment tool that required flexibility where people could choose what was relevant to their own life, as the classification is not prescriptive and recognised that the type and amount of activities people need to perform will vary (Chapparo & Ranka, 1997; Townsend et al, 1997). The large number of items available in the ICF is thought to accommodate this diversity.

The universal relevance and potential of the ICF to inform clinical practice had been highlighted (WHO, 2001). The development of the ICF included 1,800 multidisciplinary experts from 65 countries and since its publication it has been increasingly applied in clinical practice, research, education and has been accepted by 191 countries (AIHW, 2003b; Bilbao et al, 2003; Cieza & Stucki, 2005; Dahl, 2002; Koskinen Hokkinen, Sarajuuri & Alaranta, 2007; Madden, Choi, & Sykes, 2003; McIntyre & Tempest, 2007; Rentsch et al, 2003; WHO, 2001). At the time this study commenced there was increasing recognition of the need for clinically relevant and manageable applications of the ICF, including the development of client centred assessment tools to capture the “lived experience’’ (WHO, 2001, p. 123) of people with brain injury (AIHW, 2003b; AOTF Research Advisory Council, 2000; Gray & Hendershot, 2000; Greenwood, 1999; Unsworth, 2000). Aligning occupational therapy with the ICF was seen as a useful way to increase the profile of the profession although the need to explore the conceptual relationships between participation and occupation in clinical practice had been identified (American AOTF Research Advisory Council, 2000; Brayman et al, 2004). The development of the Lifestyle Assessment demonstrates one approach of how the ICF can be applied to inform an understanding of changes in each person’s participation in occupations, which in this study are described as activities that are personally meaningful and the relevant to a person’s life story (Bogner et al, 2001; Clark, 1997; Doig, Fleming & Tooth, 2001; Farnworth, 2003; Steadman-Pare et al, 2001; Ylvisaker & Feeney, 2000; Ylvisaker, McPherson, Kayes & Pellett, 2008). Although the benefits of the ICF that support instrumented construction were clear, identifying the limitations of the ICF for this purpose was also helpful in further informing the methodology for the study.

2.9 LIMITATIONS OF THE ICF FOR INSTRUMENT CONSTRUCTION

The ICF has provided a rich source of items to develop an assessment that includes a large range of meaningful activities after brain injury. However limitations in the ICF mean additional methods were required to ensure the emerging Lifestyle Assessment enabled individual choice in the range and balance of activities that were relevant to support a satisfying lifestyle for each person. A primary limitation that needed to be considered was the significant gap between the ICF conceptual model and what the actual ICF classification was able to offer. The ICF provides an extensive list of individual items but the static and categorical nature of the actual classification of these activities limited its ability to reflect the complex and dynamic nature of disability, and some key aspects of a satisfying lifestyle are not included (Magasi & Heinemann, 2009; Thomas, 2004; WHO, 2001).

The concept of participation involves participation in a life situation, but the qualifiers rate performance in individual activities, and there is no guidance about how to evaluate a person’s participation in a balanced, collective, varied and meaningful pattern of activities (Chapparo & Ranka, 1997; WHO, 2001). Wade and Halligan (2003) identified a number of important attributes of that are not included in the ICF, notably the person’s ability to choice, exercise free will and their own perceptions regarding their functioning, the concept of quality of life and social roles, which all impact both the persons’ participation and lifestyle. The balance, range and meaning of activities are not addressed by the ICF; even though there are four codes that address managing one’s routine these are quite narrowly focused on daily administration. The conceptual model of the ICF acknowledges that the meaning of activities is individually and culturally determined, but personal factors were excluded from the classification itself (WHO, 2001). Even without these, the colossal number of potential qualifiers would be impossible to use in clinical practice. Using the maximum number of codes and qualifiers available, a person's functioning could be described using up to 253,472 codes with qualifiers (including the 1424 level four codes, with an additional 178 environmental factors and up to five applications of qualifiers for each Activity and Participation items (WHO, 2001).

Another significant criticism was the ambiguous separation of Activities and Participation, as only a single list was provided to represent the two theoretical constructs (Perenboom & Chorus, 2003; Tate & Perdices, 2010). The WHO (2001) advocated that this single list could be used in any of four ways, although this flexibility may threaten the potential of the ICF for universal applications. The construct of participation was the main focus in this study as the definition is consistent with the concept of lifestyle, where all activities are performed by the person in the context of their life (WHO, 2001). In this study all items were considered as participation as this reflected the nature and purpose of the instrument most effectively. The ICF provided no guidelines for how people with disabilities could be involved in its application or how the relevance of activities to each person could be identified (Wade & Halligan, 2003; WHO, 2001). To address these issues people with brain injury would need to be involved in identifying which ICF items are relevant to their own life situation (Gething et al, 2002).

Limitations in the rating scale were also identified. The coding scale is unidirectional and measures levels of disability but not positive aspects of functioning described in the conceptual model (Gray & Hendershot, 2000; Greenwood, 1999; WHO, 2001). There is also a mismatch between the conceptual model that considered qualitative and quantitative aspects of functioning, whereas the qualifiers only quantify difficulty or the need for assistance (Greenwood, 1999; WHO, 2001). Qualitative aspects such as the person's satisfaction with functioning, feelings of social inclusion and the value, pace and balance of activities are not considered in the rating scale (Clark, 1997; Farnworth, 2003; McIntyre & Tempest, 2007; Wade & Halligan, 2003; WHO, 2001).

While some of these issues are significant, they do not preclude the application of the ICF to support tool construction. In fact they serve to identify the need for additional methodological considerations during tool development and evaluation. Despite this, the ICF has been identified as a valuable tool for brain injury rehabilitation because it provides clinicians with a framework to describe and quantify the complex nature of disability experienced by people with brain injury, which is influenced by the nature of their brain injury, the context in which they live and the activities each person wants and needs to perform (Badley,1995; Bernabeu et al, 2009; Bilbao et al, 2003; Dahl, 2002; Greenwood, 1999; Koskinen, Hokkinen, Sarajuuri & Alaranta, 2007; Schneidert, Hurst, Miller & Üstün, 2003; Tate & Perdices, 2008; WHO, 2001).

2.10 SUMMARY OF FINDINGS OUTLINED IN THIS CHAPTER

The overall purpose of the current research was to discover *how changes to an individual's lifestyle after brain injury can be assessed.* This chapter presented a review of the key constructs under study: the construct of lifestyle and how to measure changes to lifestyle commonly experienced after brain injury. The main findings from this review of the literature are summarised as follows and contribute to fulfilling the overall purpose of the research.

Finding 2.10.1

Lifestyle was described as an individual's typical pattern of varied activities to meet their needs and interests and contribute to their sense of wellbeing and self-identity. People actively choose the range and balance of activities they participate in, dependent on their personal circumstances and interests.

Finding 2.10.2

Brain injury results in a complex mix of impairments, disabilities and restrictions in participation. After brain injury, people often lead passive, uninvolved lifestyles as a consequence of reduced control, opportunity and capacity to perform activities. Common lifestyle changes after brain injury include a person's ability to engage in activities to look after themselves, manage their routine, productive and leisure activities and the nature of their relationships, especially those with friends and family. The impact of brain injury on a person's lifestyle can be extensive and is influenced by their individual preferences, interests, needs, abilities and disabilities. Consequently, rehabilitation professionals should ask people what activities are meaningful to them and help them regain a lifestyle they think is worth living.

Finding 2.10.3

The concept of lifestyle is drawn from the ICF concept of participation, the occupational performance construct from occupational therapy models, and community integration after brain injury. All these models acknowledge that to achieve a satisfying and better lifestyle people need to have opportunities to make active choices in the range of activities in which they participate to reflect their own goals, needs, roles and the social and cultural environment in which they live. Failure to achieve this can result in poorer health and reduced outcomes after brain injury.

Finding 2.10.4

To be effective at measuring lifestyle changes after brain injury assessments need to enable each person to choose what balance and range of activities are relevant to their lifestyle. The assessment should have a sound conceptual foundation and be designed to fit its intended purpose. Other essential elements of any assessment include adequate psychometric properties, appropriateness for people with brain injury and clinicians who will administer it, and the capacity to provide clinically useful information about the nature and extent of lifestyle changes experienced by each person.

Finding 2.10.5

Adequate assessment of people’s lifestyles is important to inform client centred and meaningful rehabilitation. Ten existing measures were reviewed and were found to not adequately assess the elements of lifestyle. Limitations in existing assessments included lack of choice, a prescriptive and inadequate range of meaningful activities and problems or inadequate evaluation of the psychometric properties. This highlighted the gap in robust assessments to describe changes to a person’s life due to brain injury and justified the need for a new instrument to effectively measure the client aim of “wanting to get my life back” after brain injury.

Finding 2.10.6

The application of the ICF to the construction of a tool to measure lifestyle changes after brain injury was found to be appropriate, despite limitations in the ICF. Identification of the limitations is useful as these can be addressed during instrument construction and evaluation.

CHAPTER THREE

STAGE ONE: INSTRUMENT CONSTRUCTION

This chapter describes the results from Stage One of the study, which involved the development of the nascent version of The Lifestyle Assessment that could be used to measure the status and changes in a person's lifestyle after brain injury (See Figure 3.1). Construction of this instrument addressed the first research question, which was:

How can the ICF be used to guide development of an assessment to measure changes in participation in a person's lifestyle relevant to individuals after brain injury?

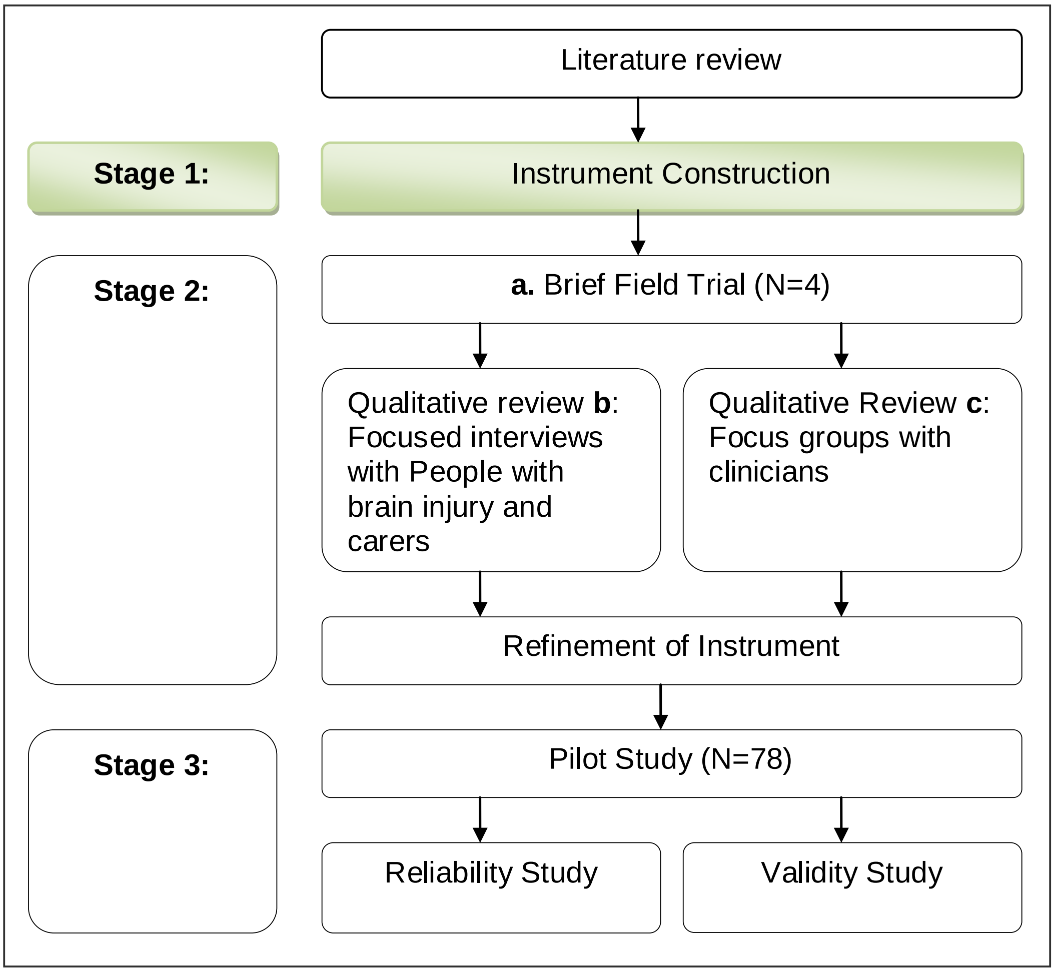


Figure 3.1: Flowchart of the Stages in This Study: Instrument Construction

This early phase of instrument construction was considered crucial because the quality of process used to develop the scale is thought to determine the success of the test in measuring the domain of concern and consequently the quality of data obtained from the resultant scale (Bond & Fox, 2001). The researcher developed the initial item pool using the methods described in this chapter. To support the initial validity of the measure, the first step in construction of the current instrument was to define the concept of lifestyle and purpose of the instrument (Aday & Cornelius, 2006; Anastasi & Urbino, 1997; Bond & Fox, 2007; Streiner & Norman, 2007). Following this, a germane source of items relevant to the construct of lifestyle was identified, and an item pool constructed based on criterion to guide selection of relevant items. This was consistent with advice from test developers who suggest that it is important that the source, content and coverage of items are relevant to the purpose of the instrument to support its validity and utility (Aday & Cornelius, 2006; Streiner & Norman, 2003). A rating scale for the new instrument was then formulated.

The format of the assessment recording form was then designed. The items and rating scale were transformed into a scale and guidelines for administration described. The language used, and the way in which the administration guidelines supported measurement of the construct of lifestyle were considered, as these features of a scale are thought to influence its utility and acceptability (Streiner & Norman, 2003). This chapter describes these initial instrument development processes and the outcome that became the nascent version of the Lifestyle Assessment.

3.1 DEFINING THE CONSTRUCT OF INTEREST

Clarifying the essential features of a satisfying lifestyle, which was outlined in Chapter Two, enabled them to be incorporated into the instrument to ensure it fulfilled its purpose

(See Section 2.2 & 2.3). The Lifestyle Assessment was developed to measure changes to a person’s lifestyle after brain injury, including the nature of participation in personally meaningful activities that people wanted and needed to perform. The aim was to replace non-standardised approaches used to measure changes to lifestyle activities, while at the same time retaining an individual, person centred approach (Dijkers, Whiteneck & El-Jaroudi, 2000).

3.2 IDENTIFYING THE SOURCE OF ITEMS

In this study, the International Classification of Functioning, Disability and Health (ICF) was selected as the primary basis for instrument construction, from which was gleaned the initial items used (World Health Organisation [WHO], 2001). The benefits outweighed the limitations of the ICF that had been identified and understanding both enabled these to be taken into consideration during instrument construction (See Sections 2.7 and 2.8). Despite the limitations and lack of clear process for using it in practice, the ICF was described as an “essential tool for identifying and measuring efficacy and effectiveness of rehabilitation services” and therefore, considered an appropriate starting point for the Lifestyle Assessment (Üstün et al, 2003, p.565).

3.3 DEVELOPMENT OF THE ITEM POOL

The ICF was reviewed and potential items were identified. Inclusion and exclusion criteria were developed to support selection of useful items that might individually be relevant to a person’s lifestyle and contribute to a sufficient range of activities. The range and content of test items are thought to provide an operational definition of the construct of lifestyle.

3.3.1 Inclusion Criteria for Items

The primary criterion for identifying items were those items considered to be meaningful to a person's lifestyle as described in the literature (See 2.2.3). To meet its purpose and ensure its validity and effectiveness, the Lifestyle Assessment required ample content and coverage of items to accommodate the significant variation in the range of meaningful activities that contribute to the lifestyles of different people (Bond & Fox, 2003; Christiansen & Matuska, 2006; Doig, Fleming & Tooth, 2001; Durgin, 2000; McCabe et al, 2007; Merriam-Webster Online Dictionary, 2010; Streiner & Norman, 2003; Wright & Stone, 1979). The frequency of participation restrictions experienced after brain injury in those activities that contribute to a satisfying lifestyle including those involved in looking after oneself, to be productive, enjoy life and positive interpersonal relationships was a further consideration (Marsh & Kersel, 2006; 1999; McColl et al, 1998; McKinlay & Watkiss, 1999; Reistetter & Abreu, 2005; Townsend et al, 1997; WHO, 2001).

Once items had been identified as relevant to the construct of lifestyle, the items were reviewed against additional criteria. In this study, the clarity of the ICF descriptions for potential items was reviewed to ensure they clearly described what each item entailed. The ICF has standardised definitions that describe aspects of functioning that are included and excluded for each domain. Wright and Stone (1979) advise that clearly defined items are a prerequisite for reliable measurement. In summary, inclusion criteria for items in the Lifestyle Assessment included a broad range of activities that were well defined, were relevant to a variety of individuals' lifestyles, and sensitive to the impact of brain injury.

3.3.2 Exclusion Criteria for Items

Three exclusion criteria for items were developed: (1) items with vague item descriptions considered difficult to reliably understand, (2) those that lacked relevance to the construct of lifestyle or, (3) items considered unlikely to differentiate lifestyle changes commonly experienced after brain injury (Streiner & Norman, 2003). The ICF Body Function and Body Structures domains were not reviewed for items, as these were thought to address impairments at the body level and were considered unlikely to address involvement in a life situation that could be relevant to the construct of lifestyle (WHO, 2001). The need for a mix of positive and negative test items was not considered necessary in the context of a criterion referenced rehabilitation assessment to describe client problems and inform client goals and clinical outcomes (Aday & Cornelius, 2006; Greenwood, 1999).

3.3.3 Initial Item Pool Formation

Items that met the inclusion criteria were drawn from the Activities and Participation domains, as this was thought to be most relevant to the construct of lifestyle. No distinction was made between the constructs of activities and participation when reviewing items, and all items were considered in terms of both individual and societal functioning (WHO, 2001; Australian Institute of Health and Welfare [AIHW], 2003b). In line with recommendations for using the ICF in clinical practice, all items were viewed as both activities and participation. This was in line with WHO (2001) recommendations and considered most useful, as in real life, people need to perform actions and tasks in the context of their own life and their broader society.

The initial item pool included 58 items including 18 ‘level three’ (Activities and Participation, ICF) items, 40 ‘level four’ (Activities and Participation, ICF) items, as these levels are considered most relevant for rehabilitation (Bernabeu et al, 2009; WHO, 2001). Items were drawn from every chapter within the Activities and Participation domain to capture range and individual variation in the activities that contribute to a satisfying lifestyle. When potential items were identified that were similar (for example, in level three and four of the same ICF category), the decision about which item to choose was made after consideration of the potential significance of the item to a person's lifestyle and the specificity of the item description. For example, items pertaining to 'moving about in different environments' were chosen rather than the more basic items such as 'walking'. Items targeting behaviour and social relationships were also included as these are typically affected by brain injury and are important aspects of satisfying lifestyles (McCabe et al, 2007; Farnworth, 2003; McColl et al, 1998; Yerxa et al, 1990; Yerxa & Locker, 1990).

The adequacy of the item description and sensitivity to brain injury were reviewed and three of the selected items were amended with the aim to improve reliability and ease of scoring in the context of clinical practice. The two ICF items for 'managing' and 'completing the daily routine' were combined into a single item in the assessment, as it was thought that differences between these two aspects were unlikely for most people with brain injury (WHO, 2001). The ICF third level item for 'informal relationships' was retained, but 'friendships' were taken out of the definition for this item (WHO, 2001). A separate item was created for friendships as these are frequently lost after brain injury but are vital for a satisfying lifestyle (Callaway, Sloan & Winkler, 2005). The nature and value of friendships was seen as different to other informal relationships with neighbours and acquaintances and so warranted a separate item (McColl et al, 1998; Tate, Strettles & Osoteo, 2003).

After these revisions the items in the Lifestyle Assessment numbered 58 which were considered consistent with descriptions of lifestyle and reflected a range of activities, relationships and behaviours that could contribute to a diverse range of individual lifestyles (See Table 3.1a and b; Two tables are provided for the single list of items as they did not fit onto one page). Items were ordered and grouped as they appear in the ICF. This functioned to keep similar activities together (for example, domestic activities, leisure and recreation), which was thought to match common areas of concern in clinical practice, and to facilitate logical flow during interviews. An extensive list of items was generated so that people could select those activities pertinent to their own lifestyle rather than be restricted by a smaller number of options.

Table 3.1a: Item Pool for First Draft of the Lifestyle Assessment (Continued in next Table)

ICF Activity / Participation Items for the Lifestyle Assessment (WHO, 2001)	
Chapter 1. Learning and Applying Knowledge	
Writing (d170)	
Chapter 2. General Tasks and Demands	
Undertaking a single simple task (d2100) Undertaking a single complex task (d2101) Undertaking multiple simple tasks (d2208)	Undertaking multiple complex tasks (d2208) Managing and completing the daily routine (d2301 ad d2302)
Chapter 3. Communication	
Conversation (d350) Using telecommunication devices (d3600)	Using computers for purposes of communication (d3601)
Chapter 4. Mobility	
Moving around within the home (d4600) Moving around within other buildings (d4601) Moving around outside (d4602) Using private motorised transport (d4701)	Using public transport (passenger) (d4702) Driving human powered transportation (d4750) Driving motorised vehicles (d4751)
Chapter 5. Self Care	
Looking after one's health (d570)	
Chapter 6. Domestic Life	
Acquiring a place to live (d610) Shopping (d6200) Preparing simple meals (d6300) Preparing complex meals (d6301) Cleaning cooking area & utensils (d6401) Cleaning living area (d6402) Using household appliances (d6403)	Washing & drying clothes & garments (d6400) Disposing of garbage (d6405) Simple home repairs (d6501) Taking care of plants and garden (d6505) Assisting others (d660)
Chapter 7. Interpersonal Interactions and Relationships	
Respect & warmth in relationships (d7100) Tolerance in relationships ((d7102) Interacting according to social rules (d7203) Maintaining social space (d7204) Regulating behaviours with interactions (d7202) Criticism in relationships (d7103) Social cues in relationships (d7104) Physical contact in relationships (d7105)	Formal relationships e.g. employers (d740) Informal social relationships(d740, d7508) Friendship relationships(d7500) Family relationships (d760) Intimate and romantic relationships (d770)

Table 3.1b: Item Pool for First Draft of the Lifestyle Assessment Continued

ICF Activity / Participation Items for the Lifestyle Assessment (WHO, 2001) cont.	
Chapter 8. Major Life Areas	
School education (d820)	Paid employment (d850)
College Education (d830)	Non-paid employment (d855)
Vocational education (d825)	Basic economic transactions (d860)
Apprenticeship (work preparation) (d840)	Complex economic transactions (d865)
Seeking employment (d8450)	
Chapter 9. Community, Social and Civic Life	
Informal associations (d9100)	Art and Crafts (d9202)
Formal associations (d9101)	Socialising (d9205)
Play (d9200)	Religious & spirituality (d930)
Sports (d9201)	

3.3.4 Items Excluded from Item Pool

Some items reviewed in the ICF were excluded from the item pool as they were considered either too vague or too broad to be objectively measured (Aday & Cornelius, 2006). For example the ICF items for ‘initiating relationships’ and ‘maintaining relationships’ included both short and long term relationships, with new acquaintances or for the purpose of developing a permanent intimate relationship. Individual performance was expected to vary for different aspects of these items making reliable scoring difficult and comparison over time or with others unhelpful. For example, a person could form short term relationships but be unable to form a long term intimate relationship. Other items were not felt to be distinguishing features of a person’s lifestyle. For example, the Activities and Participation item of ‘focusing attention’ appears to target cognitive functioning more than involvement in a meaningful life situation (WHO, 2001).

A few general items regarding communication and mobility were included as difficulties with these tasks are more common in the early phase after injury, and for people who experience ongoing severe levels of disability. However a larger range was not thought essential to measure lifestyle changes after brain injury, as these are less relevant for most people as time passes since injury, particularly once they have returned to live in the community (Olver, Ponsford & Curran, 1996; Sloan, Winkler & Anson, 2007). Furthermore other standardised, reliable and valid assessment tools already exist to measure functioning regarding body function impairments, communication, self care and mobility and duplication of existing assessments was unwarranted (Fricke & Unsworth, 1997; Linacre, 1994; Williams, Robertson, & Greenwood, 2004;).

3.4 LENGTH OF THE ASSESSMENT

The test was constructed to ‘fit’ within the context of clinical practice, so while test length was not of primary consideration, the number of items needed to be somewhat manageable in real life clinical practice, but at the same time include a sufficient number to enable the variation in individual’s lifestyles to be measured (Aday & Cornelius, 2006; Streiner & Norman 2003).

3.5 LANGUAGE

The models of community integration, participation and occupational performance formed the basis for the definition of lifestyle in this thesis. These terms are anchored in the theoretical or philosophical domain in which they are used, and while they may be commonly used are not always universally understood or defined (McColl, 1998). The term “lifestyle” sought to provide one conceptual mechanism by which aspects of community integration, participation and occupational performance could be assessed and readily understood within the context of a person’s life. Everyday language is thought to have greater ecological validity and acceptability to people than professional terms (American Educational Research Association, Psychological Association, & National Council on Measurement in Education, 1999). The benefit of familiar terms and concepts that are understood by most people during assessment and intervention is that they are thought to increase compliance and contribute to the success of the instrument (Liddle & McKenna, 2000; Magasi & Heinemann, 2009).

The use of primarily neutral terminology for ICF descriptions was considered an advantage when the ICF was selected, as the source of items allows either positive or negative functioning to be described, and because the items are not biased towards certain answers (WHO, 2001). The ICF item descriptions used in the Lifestyle Assessment were reviewed for readability and clarity because this influences the utility and acceptability of the scale to clinicians and respondents (Malec, Machulda & Moessner, 1997; Streiner & Norman, 2003). Although some of the item descriptions included some quite formal language and jargon, for example ‘human powered transport’ and ‘interacting according to social rules’, the original descriptions were retained at this stage. During the semi structured interviews carried out later in this phase of the study, clinicians were invited to balance the more formal descriptions with everyday language to enable the assessment to be easily understood by people with brain injury, particularly for those with significant cognitive and communication impairments.

3.6 DEVELOPMENT OF THE RATING SCALE

Decisions regarding the type and magnitude of the rating scale to measure item responses are important as they affect the reliability, practicality and sensitivity of the scale and items (Streiner & Norman 2003). The generic rating scale for ICF qualifiers was used as the initial rating scale for the Lifestyle Assessment as this describes different levels of functioning for all ICF domains (WHO, 2001). The Lifestyle Assessment rating scale is an ordinal five point Likert scale where a score of zero indicates no disability and scores of one to four describe increasing levels of disability (See Table 3.2) (Aday & Cornelius, 2006). Two additional ‘scores’ could be allocated if information was not specified (score of eight) or not relevant for that person (score of nine).

Table 3.2: Scoring Guidelines from ICF used in First Draft of the Lifestyle Assessment (WHO, 2001)

Rating Scale / Qualifier Descriptions	Performance	Capacity
No difficulty: (0-4%)	0	0
Mild difficulty (5-24%) low, slight	1	1
Moderate difficulty: (25-49%) medium, fair	2	2
Severe difficulty: (50-95%) extreme	3	3
Complete difficulty (96-100%) total	4	4
Not specified (missing)	8	8
Not relevant / applicable	9	9

Following the ICF guidelines (WHO, 2001) two ratings were made for each item to enable a person’s performance and capacity to be rated. Performance qualifiers in the ICF describe how a person actually performs in the context of their real life and considering all the environmental factors. They have been described as coding “the lived experience” of disability (WHO, 2001, p.229). The capacity qualifiers describe the highest level of performance in an activity a person could achieve in an ideal or standardised environment. The gap between the ratings for capacity and performance are thought to reflect the influence of the person’s usual environment on their participation (WHO, 2001).

The ICF advocates that performance should be compared according to a “generally accepted population standard” for people without health conditions (WHO, 2001, p.15). Consistent with the ICF framework, the Lifestyle Assessment is a criterion referenced instrument, using the item description and qualifiers to define the acceptable level of performance for each item (Ferrin, Bishop, & Tansey, 2010). The degree to which the rating scale succeeded in measuring changes to each person's lifestyle was evaluated in later stages of this research.

3.7 DESIGN OF THE ASSESSMENT FORM

At this stage the items and rating scale were formatted to enable administration of the instrument in clinical practice. The assessment format was guided by the need to include large amounts of information on as few pages as possible, while enabling sufficient information to be recorded. The assessment is administered via semi structured interview. Issues of readability are therefore not a major concern as the respondent does not need to read the actual form (Aday & Cornelius, 2006). The initial draft included a description of the rating scale at the top of each page, a list of activities and descriptions taken from the ICF and columns to record scores for both performance and capacity qualifiers (See Appendix 1). Only a small area is available for comments on each item. A separate score summary sheet was provided to assist in data entry that included the ICF code for every item.

3.8 ADMINISTRATION OF THE LIFESTYLE ASSESSMENT

The Lifestyle Assessment was designed to be administered through a semi structured interview with the person with brain injury. This is consistent with views of Mosey (1986) who advocates that interviews are "probably the most powerful, sensitive and versatile evaluative instrument available to occupational therapists" (p.314). Respondents are informed that the purpose of the assessment is to find out more about their lifestyle prior to their injury and how this had changed. The clinician uses open ended questions, paraphrasing the ICF item descriptors to encourage the respondents to talk about their own specific experience (Aday & Cornelius, 2006). This flexibility enables the nature of questions to be adapted to suit people with varying degrees of language and cognitive impairments that are common after brain injury (Brooks, 1972; Haslam et al, 1994; Khan, Baguley & Cameron, 2003; Masson et al, 1996; Streiner & Norman, 2003).

The interview proceeds through each item as they appear on the form. The person with brain injury or their carer/relative is asked whether the person had participated in each activity in the assessment prior to or following their brain injury. They are asked about the nature of their participation including any difficulties experienced prior to their brain injury and how their participation in particular and relevant activities has changed since their injury. A process to provide a ‘list’ of activities a person could select was considered a realistic way of developing an assessment that could be objective while still enabling individual control over what was measured. Essentially, each person acts as their own control, whereby their current performance is compared to their perception of pre-morbid lifestyle, rather than performance in an ‘ideal’ range of activities. This takes personal factors and each individual’s own circumstances and preferences into account and is considered a more effective way of measuring the impact of brain injury and success of rehabilitation than using measures where the normal or desired level of functioning is predetermined for all (Dijkers, Whiteneck, & El-Jaroudi, 2000; Streiner & Norman, 2003).

This approach has the potential to avoid the situation where people may obtain scores that reflect systematic bias from inaccurate assumptions about what constitutes normal activities for everyone (Brown et al, 2004; Fisher, 1992a; Turner Stokes, 2009). Scoring is completed by the clinician based on the perceived extent of change activities deemed relevant by the client only. Clients are asked about their estimates of the extent of change as a percentage to assist with scoring, if that method is thought appropriate for the person being interviewed. Activities that are irrelevant to the person before their brain injury are given a ‘score’ of nine.

Family members or a carer who knows the person well can participate in the interview. In some cases they can provide information to assist or on behalf of the person if they are unable to give a verbal account of the pre-morbid and current lifestyle or there is concern regarding their accuracy (Black & Jenkinson, 2009; Minnes et al, 2003). This is consistent with common practice in brain injury rehabilitation to obtain further information from other sources, including clinical notes, reports and from other people to check the accuracy of information and increase the understanding of the person’s lifestyle and brain injury (Ylvisaker & Feeney, 1998). This approach was commensurate with the routine interview style for occupational therapists in brain injury rehabilitation and thought to be acceptable to clinicians.

3.9 SUMMARY OF FINDINGS

The main research sub question addressed in this stage of the study was:

How can the ICF be used to guide development of an assessment to measure changes in participation in a person’s lifestyle relevant to individuals after brain injury?

Several findings emerged during the process of instrument construction by the researcher:

Finding 3.9.1

Defining the construct of lifestyle guided identification of an appropriate source and content of items to enable construction of a tool to meet the intended purpose of change to ‘lifestyle’ after brain injury.

Finding 3.9.2

Using specified criteria the ICF provided a broad range of items, which appeared relevant to the construct of lifestyle, were pooled to construct a new assessment tool. The categories of items in the ICF ensured a sufficient conceptual scope in item content and grouping, resulting in a logically arranged format.

Finding 3.9.3

The ICF qualifiers provided a useful basis to develop the rating scale for the new instrument that enabled the scope and nature of a person's functioning to be described in a broad range of life areas.

Finding 3.9.4

Administration guidelines, including a flexible interview format and criterion referenced approach, were developed that were flexible enough to accommodate limitations in the ICF and address important aspects of lifestyle, particularly choice in activities considered meaningful to each person's life.

Finding 3.9.5

The initial version of the Lifestyle Assessment was created, which consisted of 57 items that targeted looking after oneself, productive activities, leisure and meaningful activities and social relationships prior to and since one's brain injury, and within the context of one's particular life.

CHAPTER FOUR

STAGE TWO: FIELD TRIAL AND REFINEMENT OF INSTRUMENT

The aims of Stage Two of the study were to trial and evaluate the new instrument using qualitative approaches and to further refine the Lifestyle Assessment (Refer to Figure 4.1). In this stage of the study the length, content and face validity of the items and the instrument as a whole were examined (Aday & Cornelius, 2006; Polgar & Barlow, 2005; Streiner & Norman, 2003).

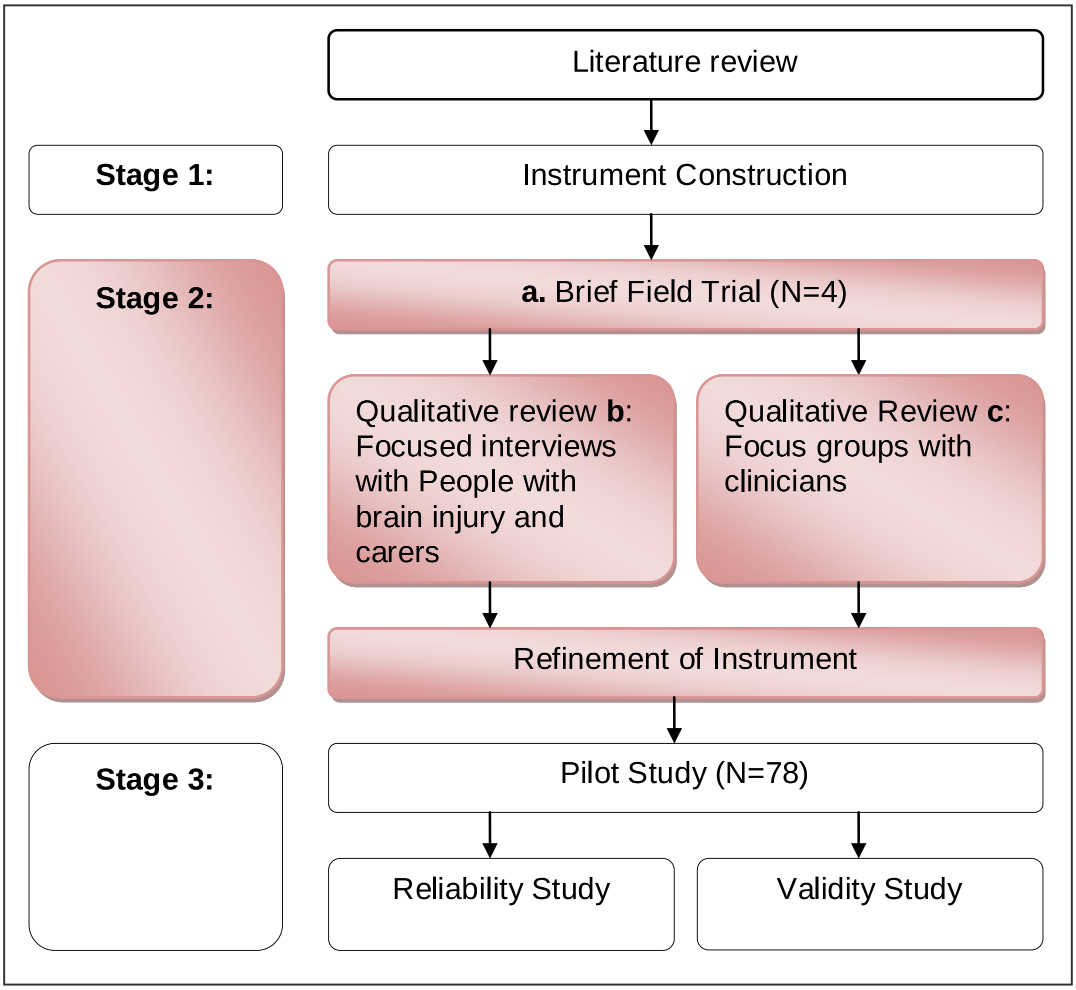


Figure 4.1: Flowchart of Stages in This Study: Qualitative Review

This stage of the study addressed the second research question, which was:

Is the Lifestyle Assessment tool acceptable to people with brain injury and their carers and clinicians who will use it?

Two sub-questions arose from the research question posed:

a. *Does the Lifestyle Assessment capture changes to a person's lifestyle considered important by people with brain injury and their carers?*

b. *Do rehabilitation clinicians think the Lifestyle Assessment is a clinically useful tool to measure changes to a person's lifestyle after brain injury?*

4.1 METHODS

Four qualitative approaches were used to examine the instrument from the perspective of those who would be using it. These approaches were considered congruent to the research question addressed at this stage of the study (Hollis, Openshaw & Goble, 2002). First, a small field trial of the Lifestyle Assessment was completed with people with brain injury and carers. Second, this was followed by brief focused interviews, generating qualitative analysis of the item range and content. Third, a focus group with clinicians from a regional brain injury rehabilitation service provided opportunities to discuss the assessment tool and gain feedback on content and administration. These two participant groups were consulted because while clinicians can provide useful observations of the performance of an assessment, the people with brain injury can provide an insider's perspective on the lifestyle changes they have actually experienced (Carpenter, 2004; Rubin & Rubin, 2005; Streiner & Norman, 2003). Finally, the tool was reviewed by the primary researcher based on the experience of administering the tool, and the feedback from the focused interviews and focus group, which informed refinement of the tool.

Ethical approval for the whole study was provided through the South Bedfordshire Community Care Trust Ethics Committee and the University of Hertfordshire, England (Appendix 2).

4.1.1 Field Trial of the Lifestyle Assessment

This section includes a description of the objectives, rationale and methods for the field trial.

4.1.1.1 Objectives of Field Trial

Although brief, the trial of the Lifestyle Assessment provided an opportunity to use the instrument with people with brain injury and addressed a number of objectives. It provided an opportunity to evaluate whether the item content, coverage, and rating scale were sufficiently comprehensive to measure a person's lifestyle changes after brain injury (Aday & Cornelius, 2006; Jackson & Furnham, 2000). The field trial afforded practical experience of the instrument to evaluate perceptions regarding clinical utility and the feasibility of using the assessment in clinical practice. This experience provided the basis for gathering information regarding the measure through the focus groups with clinicians, brie focused interviews with people with brain injury and review by the primary researcher. The final objective was to gather information to support early refinement of the Lifestyle Assessment.

4.1.1.2 Rationale for Field Trial

Field trials, including people comparable to those for whom the test is designed, are recommended as the best way of evaluating whether the items are clear, easily understood and jargon free (Streiner & Norman, 2003). Both clinicians and people with brain injury were included, as test developers advocate the people who use the test should judge these aspects of the instrument (Rubin & Rubin, 2005; Streiner & Norman, 2003). A field trial was thought to provide much more informed feedback from people with brain injury and clinicians than would have been possible from looking at the instrument and giving feedback.

4.1.1.3 Methods for Field Trial

The Lifestyle Assessment was administered, as described in Chapter Three, to four people using semi structured interview. Two researchers were present during administration and regular discussion between these two clinicians aimed to clarify considerations during scoring. Scoring was completed by the primary researcher based on information from the interview, other people, and the researcher's knowledge of that person's functional capacity. Total scores were not calculated at this stage, as verbal or numerical criteria alone do not necessarily operate on an interval basis and the statistical reliability of the scale was untested (O'Connor, 2004). At the conclusion of the assessment the participants were asked a few additional questions regarding feedback on the assessment.

4.1.2 Brief Focused Interviews with People with Brain Injury

This section includes a description of the objectives, rationale and methods for the brief focused interviews with people with brain injury.

4.1.2.1 Objective of Brief Focused Interviews with People with Brain Injury

The objective of the brief focused interviews were to gain feedback on the item content, and ensure the instrument covered activities considered relevant to individuals with brain injury.

4.1.2.2 Rationale for Brief Focused Interviews with People with Brain Injury

Inclusion of people with disabilities in the construction of the Lifestyle Assessment was considered important to ensure the content and wording were acceptable and made sense in the real life of the people with which it is to be used (American Educational Research Association, Psychological Association, & National Council on Measurement in Education, 1999; Meyers & Andresen, 2000; Wade, 2005; WHO, 2001). This methodology recognised that people with disabilities are experts in the more subjective nature of their own experience and can provide “an excellent source of items” and feedback on the relevance of items and content validity of the instrument (Hanely et al, 2004; Streiner & Norman, 2003, p.15). The interviews aimed to identify aspects of lifestyle that may have been missed when devising the item pool and ensure people with brain injury were given the ‘voice’ to identify their own priorities to fulfil the purpose of the instrument (Booth & Booth, 1994; Brown & Gordon, 2004; Merton & Kendall, 1946; Rubin & Rubin, 2005, p.12). Carpenter (2004) reports using qualitative research is compatible with a client centred approach and enables this to be incorporated into evidence base practice. Evidence based practice requires the clinician to integrate their own expertise with the best evidence available, and accommodating the clients views, values and knowledge of themselves (Carpenter, 2004).

Another advantage of the interviews is that they were a simple and practical way to obtain information to address the objectives of this stage of the study, so more in depth interviews were not considered necessary (Merton & Kendall, 1946; Rubin & Rubin, 2005). The approach was flexible and interview questions could be tailored to suit each individual dependent on the pattern of impairments following brain injury (Rubin & Rubin, 2005). It is a “responsive” approach that can accommodate different needs of people with disabilities (Rubin & Rubin, 2005, p.15). For these reasons, individual interviews are often seen as the “qualitative approach of choice” when including people with disabilities in research (Kroll, Barbour & Harris, 2007, p.697).

Semi- structured interviews in qualitative research have been criticised for problems with reliability – in that results cannot be replicated (Rubin & Rubin, 2005). However in this study, the aim was to identify the unique lifestyle of individuals, and evaluate whether these were captured by the instrument. The interviews aimed to gather the perspectives of the individual involved, so synthesis of the information across the group of participants was not required.

4.1.2.3 Methods for Brief Focused Interviews

Brief semi structured focused interviews were completed with the participants of the field trial immediately after administration of the Lifestyle Assessment. The interviews were investigative in nature, where the interview is “narrowly focused to learn what happened in a specific instance” (Rubin & Rubin, 2005, p.6). Open ended questions were used during these interviews to gain insight into participants’ experience of the assessment and whether the content reflected their perception of changes to their own life (Kvale, 1996). The questions focused mainly on whether the interviewee thought the activities in the assessment were important to them and to identify any meaningful activities that were not included. For example, “This assessment aimed to tell us more about your life before your brain injury. Was there anything you did we haven’t talked about today?” A conversational style was used to help the participants feel comfortable during the interviews (Darragh, Sample & Krieger, 2001). Brief notes were taken during these interviews that recorded identified gaps in the instrument (Rubin & Rubin, 2005). Verbatim recording of the interviews was not considered necessary to address the objectives of this stage of the study, and avoided people potentially censoring their feedback due to concern about being recorded (Rubin & Rubin, 1994).

4.1.3 Focus Group

This section includes a description of the objectives, rationale and methods for the focus group with clinicians.

4.1.3.1 Objectives of Focus Group

The purpose of the focus group was to gather feedback from clinicians about whether the Lifestyle Assessment was considered acceptable and clinically useful, as this influences its utility and the likelihood of being used in clinical practice (Smart, 2006; Polgar & Barlow, 2005; Wade, 2003a; Andresen, 2000; Deyo & Patrick, 1989; Deyo & Carter, 1992).

4.1.3.2 Rationale for Focus Group

Focus group methodology was considered an effective and efficient approach to gather qualitative data to further contribute to instrument construction (Gray, 2009; Gustafsson, Stibrant Sunnerhagen & Dahlin-Ivanhoff, 2004; Kreuger, 1984; Stewart & Shamdasani, 1990; Stewart, Shamdasani, & Rook, 2007; Teddie & Tashakkori, 2009). Focus groups are useful as they enable complex experiential information to be collected from several people at one time (Harvey-Jordan & Long, 2002; Kroll, Barbour & Harris, 2007). Participants are chosen for their knowledge or skill and explore the topic in detail. New ideas from group members can stimulate and enhance discussion, enriching the data obtained (Harvey-Jordan & Long, 2002). The dynamic interaction between participants contributes to the richness of data obtained, but where group members express different views there is no expectation for the group to reach consensus (Harvey-Jordan & Long, 2002; Hollis, Opensahw & Goble, 2002; Kreuger, 2006). This minimises the risk of focus group participants conforming to a dominant view or being influenced by group dynamics, even though the group was quite homogenous (Morgan, 1995; Morse, 1994).

4.1.3.3 Methods for Focus Group

A focus group with clinicians from a regional brain injury rehabilitation service was held to exchange ideas and gain clarification about perceptions of the relevance of the items and utility and content validity of the Lifestyle Assessment (Aday & Cornelius, 2006; Curtin & Jaramazovic, 2001; Domholdt, 2005). A convenient group of clinicians were selected because of their experience working with people with brain injury in the community, interest in working in a client centred approach and their familiarity with the new instrument (Hollis, Opensahw & Goble, 2002; Krueger, 2006; Morgan, 1995). The room used was familiar to participants who were made comfortable (Harvey-Jordan & Long, 2002). Open ended questions were used to facilitate group discussion, but the methodology was flexible enough to allow the interviewer to probe pertinent issues that arose during the interview (Krueger, 1984). Examples of questions included the following:

- What do you think about the Lifestyle Assessment?
- How useful do you think the Lifestyle Assessment would be in how we work with clients?
- How do you think the instrument could be improved?

The facilitator made notes of the discussion.

4.1.4 Review of the Lifestyle Assessment Instrument by Primary Researcher

This section includes a description of the objectives, rationale and methods for the review of the instrument by the primary researcher.

4.1.4.1 Objectives of Review of Instrument

The researcher reviewed the instrument following the interviews with people with brain injury and focus groups with clinicians to determine its appropriateness and the extent to which it addressed the requisite elements to measure lifestyle changes after brain injury. This process was completed to support refinements to the instrument to improve its effectiveness, reliability and validity.

4.1.4.2 Rationale for Review of Instrument

The review of the instrument by the primary researcher was considered an important part of this stage of the study, as it enabled the results of the field trial, brief focused interviews and focus group to by synthesized and inform refinements to the instrument. This enabled the ‘evidence’ generated from this stage of the study to be reviewed in light of the aims of the study and literature, to inform clinical reasoning regarding further tool development (Carpenter, 2004).

4.1.4.3 Methods for Review of Instrument

The review considered the correspondence between the assessment and opportunity to allow individual choice, capture the balance and range of activities and potential issues affecting precision of measurement and clinical utility (Law, 2002). The review addressed different aspects of the instrument including item pool, item descriptions, rating scale, administration and format of the instrument. The need for refinements to each part of the Lifestyle Assessment were considered based on the results from each qualitative methodology and the primary researchers own experience from the field trial. Changes to the instrument were made when these were considered to improve the degree to which the assessment measured individual’s lifestyles, improve reliability, validity and ease of use in a clinical setting. The changes made will be described after results from the qualitative methodologies have been presented.

4.2 PARTICIPANTS

There were two groups of participants in this stage of the study. First, four people with brain injury, two supported by family member carers, participated in a field trial of the Lifestyle Assessment and brief semi structured focused interviews regarding the assessment. The second group were rehabilitation clinicians who participated in the focus group.

4.2.1 Participants in the Field Trial and Focused Interviews

Three women and one man participated in the field trial and all were known to the primary researcher. Their ages ranged from 21 – 56 years (mean = 34.5 years; median = 38.5 years). Two had traumatic brain injury (TBI) (extremely severe and moderate) and two had acquired brain injury [one person had a ruptured arterio-venous malformation (AVM) and one person had anoxic brain damage]. Time since injury varied from three months to eight years (mean = 2.8 years). Three of the participants were severely disabled and two lived in nursing homes. The other participant was living in the community with family. One mother and one adult sister participated in the assessment.

4.2.2 Clinician Focus Group Participants

The focus group comprised five clinicians: two occupational therapists, one clinical neuropsychologist and two psychology interns. All were clinicians at the Acquired Brain Injury Team in Bedfordshire. The participants varied in years of experience working in rehabilitation with an average of 12.8 years (Median = 15 years), ranging from two years to 27 years.

Three members of the group were considered experts in brain injury with a thorough knowledge of brain injury rehabilitation literature and practice. Two group members were relatively inexperienced and unfamiliar with the participants and the ICIDH-2 or ICF which formed the basis for the Lifestyle Assessment. All group members were familiar with the Lifestyle Assessment and three were aware of the development process. The experience and findings from the field trial had been shared with the focus group members. Group members were given a copy of the Lifestyle Assessment form to facilitate group discussion. One group member had been present during administration of the assessments during the field trial and three clinicians knew the field trial participants well.

4.3 RESULTS

The participants of the focused interviews provided limited feedback and mainly addressed the activities included and missing from the assessment. They made no suggestions to change the assessment format or mode of administration, but this was not surprising as their experience of the Lifestyle Assessment was via a single semi structured interview. The focus group participants provided more detailed feedback on item content and descriptions, the rating scale, administration and format of the instrument. Results from the three methods used are presented together regarding items, rating scale and format, and subsequent revisions are described.

4.3.1 Feedback Regarding Items

Feedback was provided on eight activities not included and nine existing items. People with brain injury identified six activities they thought were missing from the Lifestyle Assessment, one item that was too broad to reflect their experiences and three further items that they considered particularly important to their current lifestyles. Clinicians identified the need for two new activities they considered valuable and raised issues regarding scoring a further three items.

In total eight new activities were identified as being relevant to people’s lifestyle after brain injury. People with brain injury or carers identified ‘Participating in family events’, ‘Playing computer games or using internet’, ‘Musical activities’, ‘DIY’ (‘do it yourself’ home decoration and repair), ‘Shopping for fun’ and ‘Reading for pleasure’ (rather than reading as a skill) were important to their lifestyle. Clinicians identified the need for two additional items including ‘Using a diary’, considered an important part of managing one’s schedule, and the need to ‘Accommodate mood changes’ in the assessment. While mood changes were addressed within some existing items, clinicians reported depression and anxiety after brain injury were significant enough to warrant separate attention. Interestingly the clinicians reported the activities identified by the people with brain injury appeared too specific and relevant to only a few people and did not support the decision to add them to the instrument. However, as the aim of the assessment was to assess functioning from an individual’s perspective, those items generated by the participants with brain injury were included in the assessment.

The people with brain injury and their carers identified the item for ‘Socialising’ was too broad to be relevant to their situation, as this encompassed attending social events, receiving visitors and visiting others. They reported it was much more difficult for them to visit others than to receive visitors or attend social events within the home, particularly when mobility was restricted. When people with brain injury did go out, they most commonly visited family members, as friendships had largely fallen away, a significant change that was identified from their life prior to brain injury. Social activities with friends were either rare or they no longer occurred, and only one person had a friend who continued to visit them, only at home and only rarely.

Clinicians identified issues with the items ‘Physical contact’, ‘Looking after one’s health and ‘Apprenticeship’. The discussion indicated that the clinicians varied in what they considered when rating ‘Physical contact’, with some considering the appropriateness of all types of bodily contact, and others considering this item only in relation to inappropriate sexual behaviour. The item ‘Looking after one’s health’ was considered too broad, with clinicians reporting that people varied considerably in their participation in the range of activities included in this item. They gave the example that a person may take medication properly, but continue to misuse alcohol or fail to attend medical appointments. The item definition for ‘Apprenticeship’ was considered confusing, as this included work preparation which was considered by clinicians to include activities for people with disabilities such as supported work placements, work experience and other more general pre-work skills development. Apprenticeships were considered different from this sort of service and included activities to develop skills for trade qualifications including engaging in vocational training for jobs in open employment.

In addition to feedback on other items, the meaning and importance of four other activities was raised during discussion. For three of the people with brain injury ‘Being a passenger in a private vehicle’ was extremely important as the severity of their disabilities meant this provided the only opportunity for travel outside their home. The male participant reported ‘Completing DIY activities around the home’ was important to him as this was his primary activity now that he could no longer work. Clinicians reported ‘Diary use’ was important because this was a common rehabilitation intervention and long term strategy to enable people to manage their routine for most people.

4.3.2 Feedback Regarding the Rating Scale

Clinicians provided feedback that identified four issues with the rating scale. First, they reported that rating a person’s capacity was very subjective process and questioned the clinical usefulness of the information. The second issue they identified was that no client lives in a constant or ‘ideal’ environment, as recommended for rating capacity in the ICF, and that what constituted an ideal environment may be different for different people and activities (WHO, 2001). Clinicians also expressed concern that the range of functioning included under a score of three (50-95%) was too large and would mean the scale would be unable to detect large changes within this range. The clinicians proposed this should be represented by two separate scores so people with 50-74% and those with 75-94% functioning could be better discriminated by the rating scale.

The third issue concerned limitations in the way participation was measured by the ICF qualifiers. Group members agreed that brain injury affected a person’s participation in meaningful activities in more complex ways than their physical capabilities, difficulty or need for assistance. The group discussed whether additional aspects of functioning such as the quality or frequency of performance, attitude to any changes, a person’s effort or commitment to rehabilitation and level of insight should also be considered in the Lifestyle Assessment. One group member questioned whether scoring pre-morbid participation and current participation separately would make it easier to identify those people who had problems prior to their brain injury. This suggestion was made in relation to the clinician’s experience of people on the team’s caseload who had significant problems prior to their brain injury. The clinicians also reported they did not use the ICF codes and did not think they were necessary to include on the form. The final issue they identified was that the rating scale did not suit the items related to social relationships and behaviour, and recommended that additional descriptions would be needed to make the ratings relevant for these items.

4.3.3 Feedback Regarding Administration

Only clinicians provided feedback on administration and they varied in their perceptions about the ease of administration. The two occupational therapists reported the assessment approach was familiar and similar to their usual interview approach, but had compelled them to focus more on the quality of a person's performance in a range of different activities than they would normally target. They felt that administration of the assessment highlighted the fact that people had their own priorities and preferences for activities they valued the most. Conversely, the two most inexperienced staff (psychology interns) reported they would find it difficult to elicit sufficient information for every item and would need additional guidance on how to administer the assessment. Related to this the group discussion highlighted the need to provide enough information about test administration to ensure the Lifestyle Assessment was administered by a range of clinicians in a consistent manner.

While the focus group concentrated on the Lifestyle Assessment during discussion the team decided to align the initial interview format for the service with the items in the Lifestyle Assessment to streamline team processes and support more junior clinicians. The team thought having some information about the person's lifestyle prior to the administration of the assessment would enhance a client centred approach throughout the person's rehabilitation, reduce the administration time and make scoring easier. The more experienced team members thought this was useful but did not consider this necessary for administration of the Lifestyle Assessment. The group also thought it would be helpful if they had space to record information from the interview on the form as it was clinically useful for all team members.

The group discussed the length and potential time required to complete the Lifestyle Assessment. During the field trial it took 20-60 minutes to complete the Lifestyle Assessment. The assessment took longer when people were still able to participate in a range of activities, and people with very severe activities were quick to rate as they participated in few activities. Clinical psychology staff reported it was too long but occupational therapy staff reported it took about the same amount of time as a routine OT interview. The team discussed how the complexity and unique aspects of people's lifestyles are often not identified during standard assessment or interview approaches, and which they thought justified any additional time required. The group made no suggestions to address the time required to complete the Lifestyle Assessment.

4.3.4 Feedback Regarding the Purpose of Assessment

Positive feedback was provided about the purpose of the assessment. The mother involved in the focused interview reported that the Lifestyle Assessment was the only assessment she was aware of that demonstrated her daughter was able to participate in anything, even though the nature of her participation had changed due to her severe disabilities and relied on the family's sustained and daily support. Despite requiring high levels of care this woman regularly participated in activities she appeared to enjoy including a weekly art class and more routine activities such as supermarket shopping. The clinicians also provided support for the assessment and concept of lifestyle despite the other issues described above. Clinicians reported the information generated from the assessment contributed to formulation of rehabilitation goals and intervention planning.

Moreover, generating a total score to differentiate the degree of changes made would make a measure of outcome more objective.

The primary researcher identified one significant issue regarding the effectiveness of the Lifestyle Assessment to capture a person's lifestyle. While the field trial of the measure demonstrated the potential effectiveness of the tool in gathering information about changes to a person's participation in a range of individual activities, not all the elements of a satisfying lifestyle where clearly captured. The interview process gathered information of the range of activities, essentially in a list, but did not identify the pattern and balance of these activities. Generating a total score was thought to provide opportunity to reflect the degree of changes but this could indicate small changes in a large range of activities or very large changes in a smaller number of activities. This review identified the need for another way of demonstrating results to reflect aspects of lifestyle such as the balance and the nature and extent of changes overall.

4.4 REVISION OF THE LIFESTYLE ASSESSMENT

Information from the qualitative review process supported refinement of the nascent version of the Lifestyle Assessment. The aim of the revision process was to improve the scope, utility, reliability and validity of the new instrument prior to quantitative evaluation of its measurement properties. All revisions made and the final instrument is described below.

4.4.1 Revision of Items

All suggestions for new activities and revisions to existing items were incorporated into the assessment and the number of items in the Lifestyle Assessment increased from 58 to 73 items (See Table 4.1a and b. Note two tables have been used to list the items as they do not fit onto one page). At this stage of instrument development, the number of items was not limited. Quantitative analysis was used to identify the most effective items in a later stage of the research (See Chapter 5) (Streiner & Norman, 2003).

To develop new items the ICF was again reviewed to match the proposed activities to ICF codes. This was consistent with the approach used to generate the original item pool in Stage One of the study. All new activities identified during this stage of the study were commensurate with ICF coding, although some relied on the unspecified codes within each activity area or multiple items within a single code and one activity was drawn from Body Functions domain. The changes included the addition of nine totally new items (highlighted in **black bold** font in Table 4.1a and b), six items were revised (highlighted in *italics* in Table 4.1a & 4.1b), and a further eight new activities (**blue bold font)** were identified and one was removed (red font) (Table 4.1a and b). These changes are further described below.

Table 4.1a: Item Pool for Second Draft of the Lifestyle Assessment

ICF Activity / Participation Items for the Lifestyle Assessment (WHO, 2001)	
Chapter 1. Learning and Applying Knowledge	
Writing (d170) and *Reading (d166)** (single item)	
Chapter 2. General Tasks and Demands	
Undertaking a single simple task (d2100) Undertaking a single complex task (d2101) Undertaking multiple simple tasks (d2208)	Undertaking multiple complex tasks (d2208) Managing and completing the daily routine (d2301 ad d2302)
Chapter 3. Communication	
Conversation (d350) Using telecommunication devices (d3600)	Using computers for purposes of communication (d3601) **Using calender and diary****
Chapter 4. Mobility	
Moving around within the home (d4600) Moving around within other buildings (d4601) Moving around outside (d4602) Using private motorised transport (d4701)	Using public transport (passenger) (d4702) Driving human powered transportation (d4750) Driving motorised vehicles (d4751)
Chapter 5. Self Care	
Looking after one's health (d570)*** **Attending regular health appointments such as GP and dentist (d5702)**** **Attending rehabilitation and therapy appointments (d5702)****	**Healthy eating and drinking habits (d5701)**** **Managing medication (d5702)**** **Alcohol and drug misuse (d5702)****
Chapter 6. Domestic Life	
Acquiring a place to live (d610) Shopping (d6200) Preparing simple meals (d6300) Preparing complex meals (d6301) Cleaning cooking area & utensils (d6401) Cleaning living area (d6402) Using household appliances (d6403)	Washing & drying clothes & garments (d6400) Disposing of garbage (d6405) *Simple household maintenance (d6501)** Taking care of plants and garden (d6505) Assisting others (d660) **Home decoration and repair (d6501)****
Chapter 7. Interpersonal Interactions and Relationships	
Interacting according to social rules (d7203) Maintaining social space (d7204) Regulating behaviours with interactions (d7202) Social cues in relationships (d7104) Criticism in relationships (d7103) Friendship relationships(d7500) **Socialising with family**** Family relationships (d760)	Physical contact in relationships (d7105) Tolerance in relationships ((d7102) Respect & warmth in relationships (d7100) **Mood and emotional state**** Intimate and romantic relationships (d770) Informal social relationships(d740, d7508) Formal relationships e.g. employers (d740) **Socialising with family****

Descriptor changed* **New item *** Item replaced

Table 4.1b: Item Pool for Second Draft of the Lifestyle Assessment Continued

ICF Activity / Participation Items for the Lifestyle Assessment (WHO, 2001)	
Chapter 8. Major Life Areas	
School education (d820)	Paid employment (d850)
College Education (d830)	Non-paid employment (d855)
*Vocational education (d825)**	Basic economic transactions (d860)
*Apprenticeship (work preparation) (d840)**	Complex economic transactions (d865)
Seeking employment (d8450)	
Chapter 9. Community, Social and Civic Life	
Informal associations (d9100)	**Using computer for fun (d9208)****
Formal associations (d9101)	*Socialising (d9205)**
Play (d9200)	Religious & spirituality (d930)
Sports (d9201)	**Visiting (d9205)****
Musical activities (d9202)**	**Shopping for leisure (d9208)****
*Reading for pleasure (d9208)**	**Attending and participating in ceremonies (d9102)****
Art and Crafts (d9202)	

*Descriptor changed **New item *** Item replaced

The new items included four totally new activities that were added from the ICF chapter on Community, Social and Civic Life including ‘musical activities’ (ICF code d9202, arts and culture), ‘Shopping for leisure’ (d9208, other specified), ‘Using computer for pleasure’ (d9208) ‘Attending and participating in ceremonies’ (d9102). A new item for the scale ‘Home decoration and repair’ (d6508) was added from the ICF chapter regarding Domestic Life in addition to the existing item, ‘simple household repairs’ (d6501). The item for ‘Diary use’ was less clearly identifiable as an ICF item. This appeared to relate to both ‘Written communication’ (d345) and an activity to support how a person might ‘Manage their routine’, but not sufficiently to encompass all that this item involved (d2308, carrying out daily routine, other specified activity).

The item for ‘Depression’ was most closely aligned to the ICF Body Functions than Activities and Participation, which was in contrast to the criteria for inclusion outlined in initial item selection. However the item for ‘Emotional functions’ (b152) is similar to many of the items in the ICF chapter for Interpersonal Interactions in the Activities and

Participation domain. For example, the activity for ‘Regulating behaviours’ (d7202) includes regulating emotions and impulses with a focus on aggression. The difference between the body functions and activities items is greater focus on the control of emotions during interactions with others rather than in all situations for that person. In real life this distinction was not considered problematic for the purpose of the Lifestyle Assessment, particularly in view of the clinical importance for people after brain injury and potential to distinguish different levels of functioning.

The remaining changes were made in response to feedback regarding existing items in the Lifestyle Assessment. The item for ‘Socialising’ (ICF code d9205) was separated into two items, ‘Socialising’ and ‘Visiting’. Although separating participation in visiting from other types of socialising activity changed the nature of an ICF item, this may indicate a limitation in the ICF item, and was done to reflect the different degrees of disability and change experienced by people after brain injury. Another two items nominated ‘Socialising with friends’ and ‘Socialising with family’ were created due to the enormity of change in social relationships often experienced after brain injury and their importance to a person’s satisfaction with life. The socialising with friends and family items were inserted next to the relationship items with friends and family.

The item for ‘Writing’ was also revised and expanded to include the ability to read, and a new leisure activity, ‘Reading for pleasure’ (d9208, other specified) was created. Although reading was included in the ICF as a communication item, use of the other specified leisure activity was considered more appropriate given the purpose of reading in this item. Introduction of this greater range of leisure items was considered to improve the assessment as participating in activities that provide enjoyment are a key aspect of a satisfying lifestyle, and also provided more scope to reflect the passive activities commonly part of people’s lifestyles after brain injury.

The single item for ‘Looking after one’s health’ (d570) was replaced by five more specific items taken from ICF level four codes, to reflect individual variation in people’s participation in different aspects of looking after their own health. The new items included (1) ‘Healthy eating and drinking habits’ (d5701), (2) ‘Attending regular health appointments such as GP and dentist’ (d570/d5702), (3) ‘Attending rehabilitation and therapy appointments’ (d570/d5702), (4) ‘Managing medication’ (d5702/8) and (5) ‘Alcohol and drug misuse’ (d5702). The latter four could all be considered elements of the single item for maintaining one’s health (d5702). Again these were separated as people were thought likely to be variable in their performance in each element. The item for ‘alcohol and drug misuse’ was the only item that did not use neutral wording, but this reflected the significant negative impact this has on functioning and outcome after brain injury.

The last existing item to be amended was the item for ‘apprenticeship’, which included work preparation activities. In response to the feedback from clinicians the item descriptions differentiated these items depending upon whether the prevocational activity was available within the open employment market or a supported activity most likely to be designed for people with disabilities. This identified that vocational education may be similar to the description for apprenticeship as they both reflect open or competitive activities so these items were combined (d825 and d840). Work preparation was redefined as a separate type of activity, usually developed as part of an extended rehabilitation programme, regardless of whether paid employment was the person’s ultimate goal. Due to the changed nature of this item the unspecified code was selected as most appropriate (d859; work and employment other).

The statements describing each item were changed into questions to improve the consistency in how questions were asked during the semi structured interview. The statement or description of each item was reworded to provide examples of questions, thereby providing guidance on how to elicit information for each answer. Some changes to language were made at this time to reduce the jargon in the ICF descriptors and make the assessment more acceptable (Malec, Machulda, & Moessner, 1997; Streiner & Norman, 2003). For example “driving a human powered vehicle” was replaced with “do you ride a bike or skateboard?” which could be paraphrased as necessary, such as also asking about roller skates.

4.4.2 Revision of Rating Scale

Based on the experience of the brief trial and focus group with clinicians several changes were made to the rating scale. First, the rating scale was expanded to a six point Likert scale to reduce the range of functioning. An additional scoring category was included so that the range of ability representing 50-95% difficulty was covered by two scores, a score of three to represent significant change (50-74%) and a score of four to represent severe (75-95%) change. The score for five represented the original top range of functioning at 96-100% change.

The second major change was to remove the ratings for capacity, so only the person’s change in actual performance since the person’s brain injury was included, which was thought to be more clinically useful. This was consistent with concern about the difficulty in identifying an ideal environment that “has to be the same for all persons in all countries to allow international comparison” in the ICF (WHO, 2001, p.229).

The third, and perhaps most significant change, was that the scope of participation considered when rating the Lifestyle Assessment was changed. The aim was to improve the sensitivity of the Lifestyle Assessment to capture the important elements of lifestyle for each person and support person centred clinical reasoning. The original numerical descriptors and percentages were retained, but the description of each rating was amended to consider other issues as well as level of difficulty and need for assistance. The focus of the ratings were changed to measure the amount of change in participation, including aspects such as the quality and frequency of performance given each person’s own expectations, rather than against the standardised ‘norm’ where no need for assistance is expected. Ratings for satisfaction were also made but not scored, as it was thought a person’s satisfaction with their performance could be too different from the quality and frequency of their performance, to be included in the same rating. These separate elements were not included with separate ratings, nor was the meaning of activities explored, as this would have considerably lengthened the assessment and increased the burden to both clinicians and people with brain injury which would have reduced the clinical utility of the new instrument. These changes were thought to address the limitations identified in the rating scale during the literature review (See 2.9) and feedback from clinicians feedback provided during stage two (See 4.3.2).

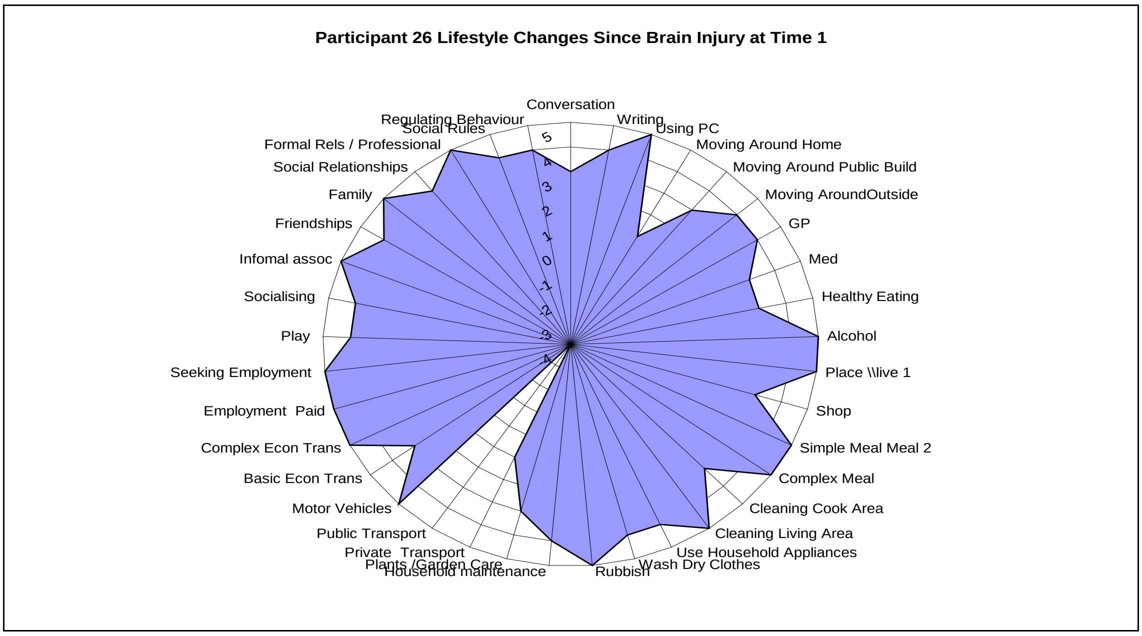
The fourth change was development of a separate rating scale for ‘Social relationships’ and ‘Interpersonal Interactions’ items to acknowledge differences in how these aspects of functioning would be addressed during an interview. The format and numerical descriptions were consistent with that for activities, but new wording was added pertaining to the nature and impact of behaviour or roles within relationships. Changes to how behavioural items were assessed were made, as behaviours cannot always be addressed during an interview. Instructions for the rater on the score form were added advising the rater to consider how the person presented during the interview and other occasions and to liaise with relatives and carers to assist in rating these items.

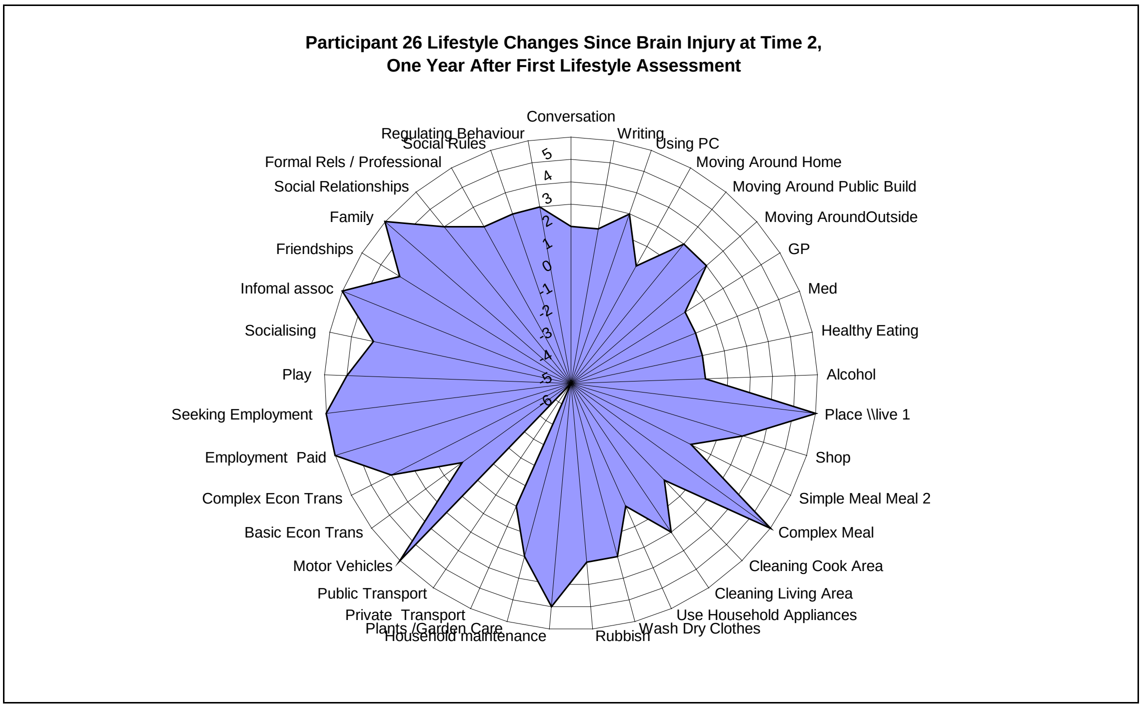
4.4.3 Scoring the Assessment

A method to calculate total scores was developed to accommodate the optional rating of items as relevant to different individuals. The total score for the Lifestyle Assessment is calculated by deriving a percentage based on the sum of raw scores and number of items endorsed. This approach enables group comparisons and individual change to be measured, even if a different number of items are endorsed. Higher total percentage scores indicate greater changes in a person’s lifestyle and functioning since their brain injury, regardless of how many items are rated. Lower total percentage scores reflect fewer or less changes the person has experienced in their lifestyle and functioning. The number of items scored was also thought to provide information about the range of activities relevant to that person’s lifestyle.

4.4.4 Revision of Format to Enhance Assessment of Lifestyle

Three amendments were made to improve the Lifestyle Assessment’s ability to reflect the balance and meaning of activities relevant to people’s lifestyles. The process developed to calculate a total score was able to accommodate variation in the number of activities identified as meaningful by each person, but could not reflect the balance of these changes. To address this, electronic charts were created using Microsoft Excel to visually display the main assessment results (Stage Two). These were called ‘personal lifestyle maps’ and charted the pattern of raw scores for 37 items considered to reflect the most common and relevant activities that are thought to contribute to satisfying lifestyles (See Figure 4.2). A selection of items was included to ensure the chart was readable and depicts the extent of change overall as well as for individual items.





Legend: Shaded area denotes extent of change in 37 selected activities addressing a range of areas from the Lifestyle Assessment at time 1 and 2

Figure 4.2: Personal Lifestyle Maps for a Client at 2 Time Points

The shaded area on the chart indicates the area between the score of zero indicating no problem and their actual score. The chart provides a basic depiction of the extent of change for a large number of key activities to give some idea of the scope of change in both the balance and range of participation in meaningful activities. The shaded area provides a subjective representation of the degree of lifestyle changes experienced by the client at the time of assessment, where the larger the shaded area the larger the lifestyle changes the person has experienced. In Figure 4.2, the personal lifestyle map for one person over two assessment points are illustrated. The top chart shows the person’s pattern and extent of lifestyle changes at time 1, indicating large changes in almost every area. The bottom chart shows the changes at time 2 for the same person. At time 2 (bottom chart), the shaded area is smaller than at times 1, which indicates the person has improved and is not experiencing lifestyle changes to the same degree. The graph provides a visual representation of scores on a single picture that is thought to be more meaningful to people after brain injury and their carers than numerical scores on a ‘test’. Using two maps was thought to support visual reflection of the nature and extent of change over time. Feedback from participants has been very positive, with one person responding: “You are the first person to really understand how much of my life I have lost”.

The next amendment was the inclusion of some qualitative questions at the end of the assessment, to provide a more informal opportunity for people to express views of their own life and their priorities for rehabilitation (See Table 4.2). These were optional and not included in the scoring. These provided an opportunity to check that the assessment captured people’s priorities, and were primarily used to support clinical practice. Space to record an action plan or recommendations was also provided at the very end of the form, which reflected the instrument was designed for clinical use.

Table 4.2: Qualitative Questions to Conclude the Lifestyle Assessment

- Is there anything you do that I haven't asked you about?
- What have been the biggest changes to your life since the injury
- What do your friends and family rate as the biggest changes?
- Which activities, and other things you do, are most important to you and how you see yourself? Which activities make you feel like yourself or help create who you are as a person?
- Which activities do you most want to change during your rehabilitation programme? What are the main things you'd like to address?

4.4.5 Revision of Administration Guidelines and Format

Extensive changes were made to the score form and the process of administration to improve consistency and quality of information collected during the assessment process. Changes included addition of standardised introduction and information, a timetable to record the pattern of activities over time, increased space to record information and changes to the order of items. At the top of the first page information for clinicians was added that prompted them to focus on the range and nature of changes people have experienced and to use multiple sources to gather information if required. Three standardised descriptions to read to respondents about what the assessment involved were also added. The first one, read at the commencement of the assessment, explained the nature and purpose of the assessment as this was thought to improve consistency and respondent co-operation (Aday & Cornelius, 2006, p.289). The second informed respondents the interview addresses the person's routine as well as individual activities and serves to sign post parts of the interview for the respondent. The sequence which the interview follows was also changed. Instead of starting directly with the items, some simple non threatening questions were asked first about the person's accommodation, living situation and ability to manage self care activities, although these items were not scored (Aday & Cornelius, 2006).

After the second introduction is read the interviewer asks the person about his/her usual routine over the course of the day and week both prior to sustaining a brain injury and at the current time. A timetable was added to the form to record this information, which provides a visual depiction of the temporal distribution of a person's activities over the course of a day and week, both before sustaining a brain injury and at the time of assessment. This quickly demonstrated the changes in the pattern and duration of activities since their brain injury. The amount of time spent in solitary or passive activities is much more clearly identified on a timetable than individual questions that focus one activity at a time and rarely address the absence of engaging in activities. This information was also thought to prompt respondents to recall general issues about changes to their activities and lifestyle and also inform subsequent questions seeking more specific information (Aday & Cornelius, 2006). Understanding the changes in participation can assist in understanding what the person wants to spend more time doing. It is not scored but has been reported as being clinically useful.

The third instruction for respondents is read prior to the social relationships and behaviour section which signals that the interview shifts to focus on the people with whom they spend time and do activities. This is read after the items regarding other activities and reflected a change in the order of items. The order of items was revised so the initial items provided better information to support scoring global and behavioural items and improve the effectiveness of the instrument and acceptability to clinicians (Aday & Cornelius, 2006). Global questions and those regarding interpersonal relationships and behaviours were moved to the end. For example, the interpersonal behaviour items were moved to the very end as it was felt these aspects of functioning cannot always be addressed through interview questions, and scoring them at the end of the interview may have allowed for behaviours to be observed during the interview to assist with scoring. Another example was 'Managing one's routine', which was moved to the end of the section on activities so it could be rated once information on specific details of a person's activities were known.

Another important change was that the interview involved asking people about his/her premorbid lifestyle and current activities, rather than just ask what had changed. Space was added to record this information separately, which enabled clinically relevant information to be recorded as well as enable client wording to be retained. Separating information about the person's lifestyle before and after sustaining a brain injury also provided better opportunity to identify any issues with performance experienced prior to the brain injury and which activities were relevant to the person's lifestyle. To accommodate the revisions made, while keeping the number of pages to a minimum, the rating scale was removed from the assessment form. The rating scale was added to a laminated sheet, with one version provided for clinicians with significant detail regarding the rating scale for activities on one side and the new rating scale for social relationships and behaviour on the other side. The second sheet was designed to be used with interviewees, when that was considered appropriate, and included the percentage scores and brief general descriptors, such as '0-4%, no change' or '50-74%, considerable change'. Separate pages to record scores were attached to the assessment after administration of the assessment as there was no longer space to record them on the form itself. The ICF codes were removed from the score sheet.

This administration format was in line with routine clinical practice of the team and enabled the assessment to remain client focused and accommodate people with varying degrees of cognitive ability and self-awareness. Domholdt (2005) cautioned administering assessments via semi structured interview may reduce reliability compared to standardised administration. The revisions made during this stage of the study were considered to improve the assessment and make it more clinically appropriate. The aim was to bridge an individual’s qualitative view of the impact of their brain injury on their functioning with a quantitative approach that enables objective measurement of this (Hartery & Jones, 1998). The degree to which this was achieved was evaluated in Stage Three of this study.

4.5 SUMMARY OF FINDINGS

This stage of the study addressed the second research question:

Is the Lifestyle Assessment tool acceptable to people with brain injury and their carers and clinicians who will use it?

The question was further divided into two parts:

Does the Lifestyle Assessment measure changes to a person’s lifestyle considered important by people with brain injury and their carers?

Do rehabilitation clinicians think the Lifestyle Assessment is a clinically useful tool to measure changes to a person’s lifestyle after brain injury?

In response to the questions, several findings emerged from this stage of the study:

Finding 4.5.1

People with brain injury were able to identify activities that were relevant to them, however clinicians did not always agree with their priorities. This highlighted the need to enable people to have choice in how the impact of their brain injury is understood, measured and addressed in rehabilitation.

Finding 4.5.2

The ICF provided a useful basis to instrument construction but required modification for application in a clinical instrument. Limitations of the ICF to describe the “lived experience” of brain injury were identified and modifications to some items and the rating scale were required.

Finding 4.5.3

The inclusion of people who would use the instrument in the early stages of instrument construction contributed to refinement of the instrument. Further, information from this preliminary evaluation process supported refinement of the nascent version of the Lifestyle Assessment.

Finding 4.5.4

Amendments were made to the rating scale, administration guidelines, items and assessment format. After revision the Lifestyle Assessment contained 73 items and the format and structure were enhanced to reflect the pattern and balance of activities over time and calculate scores that reflected people’s need to choose a different number and type of activities relevant to their own lifestyle (Appendix 3).

CHAPTER FIVE

STAGE 3: EVALUATION OF MEASUREMENT PROPERTIES OF INSTRUMENT

This chapter outlines data analysis that resulted in an evaluation of the measurement properties of the Lifestyle Assessment to address the third research question which was (See Figure 5.1):

What are the measurement properties of the Lifestyle Assessment?

Three further sub questions were addressed to provide evidence of the measurement properties of the Lifestyle Assessment. This information supports the use of this instrument to measure lifestyle changes for people with brain injury as well as diagnostic information on how the instrument can be improved:

Sub question 1: *Does the Lifestyle Assessment measure the construct of Lifestyle effectively?*

Sub question 2: *Are the Lifestyle Assessment's items stable and precise in their measurement of lifestyle changes experienced by people after brain injury*?

Sub question 3: *Does the Lifestyle Assessment represent the range of lifestyle changes experienced by people effectively?*

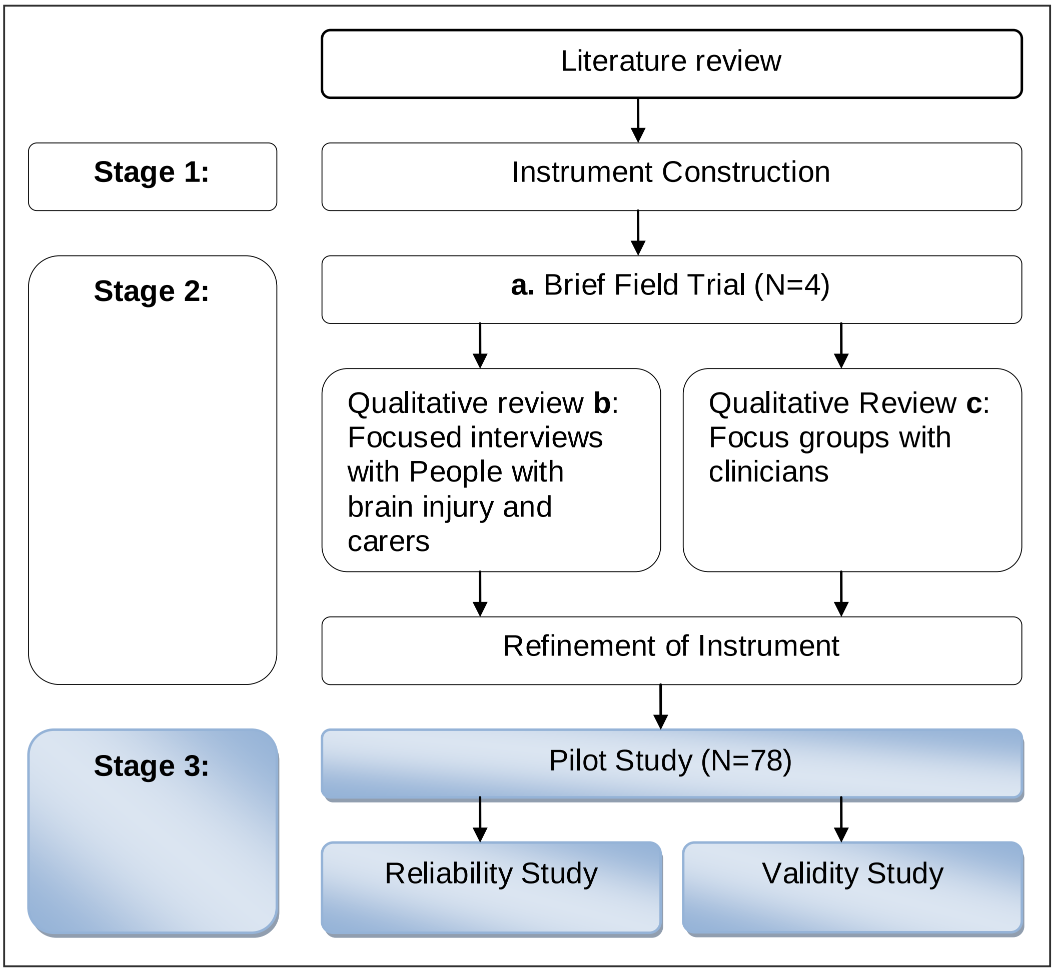


Figure 5.1: Flowchart of Stages in This Study: Quantitative Review

5.1 METHODOLOGY

5.1.1 Research Design

This was a descriptive study using quantitative analysis of group data to evaluate the measurement properties of the Lifestyle Assessment instrument.

5.1.2 Sample

A convenience sample of 71 people with brain injury was used in this study as this was considered appropriate for the research questions that focused on the properties of a measurement tool (Domholdt, 2000; Punch, 1998). Participants were included if they were over 16 years of age, and had sustained a traumatic or non-traumatic brain injury. They were excluded if they had progressive neurological conditions. Participants were recruited from the community brain injury rehabilitation service, or long term support and advocacy services such as Headway. Ethical approval for the study was given through South Bedfordshire Community Care Trust Ethics Committee and the University of Hertfordshire, England (Appendix 2). Consent to participate in the study was sought from participants and/ or their next of kin or legal guardian (Appendix 2).

Injury and demographic information about participants including gender, age, time since injury, injury type and injury severity were recorded. Participants' level of disability was described using Disability Rating Scale (DRS) categories. Information on marital and employment status and living situation were also recorded as these provided the context in which people experienced changes to their lifestyles. A sample that represented a broad range of functioning, and a broad range of lifestyle changes experienced was considered useful to comprehensively analyse the measurement properties of the items on the scale (Bond & Fox, 2003; Wright & Masters, 1982).

5.1.3 Administration Procedures

After consent was obtained assessments were usually completed during routine clinical practice and results were also used as part of rehabilitation assessment process for the service in which the study was conducted. The Lifestyle Assessment was administered as per the administration guidelines (Appendix 3). Demographic and injury information was recorded on a sheet designed for the study. The Disability Rating Scale was completed by the researcher within a week of the interview (Appendix 4). The rater for the DRS had received training from a medical specialist to ensure accuracy of ratings. The DRS was appropriate to span the range of ability in the service, and this sample. Two raters were present during the initial stages, however one rater completed the assessments to minimise the influence of rater bias (Domholdt, 2005).

5.1.4 Data Storage

De-identified data from this phase of the study were stored in individual paper files in a locked filing cabinet. Individual item scores for the Lifestyle Assessment were entered into Winsteps software (2010a, 2004). Total scores, scores from other assessments and injury and demographic information data were entered into the Statistical Package for the Social Sciences (SPSS) Version 17 (2008).

5.1.5 Measurement Model

In this exploratory stage of instrument development and review, several analyses were employed to explore the effectiveness of the Lifestyle Assessment in measuring the nature and extent of lifestyle changes experienced by people with brain injury (Messick, 1989; Polgar & Barlow, 2005; Streiner & Norman, 2003; Unsworth, 2000). Rasch analysis using Winsteps software (Linacre, 2010a, 2004) was employed to investigate the measurement properties and validity of the Lifestyle Assessment. The analysis was largely completed in 2004 and version 3.54 was the principal version used in this study (Linacre, 2004). Use of this measurement model integrated evaluation of the content, utility and meaning of test results into a unified framework (Messick, 1995). In Rasch modelling, the reliability, or precision of measurement, and the validity of measurement are closely intertwined and addressed in parallel fashion through a series of analyses to build evidence of the appropriateness and effectiveness of the instrument.

5.2 DATA ANALYSIS METHODS

In this study traditional statistical analyses using SPSS Version 17 (2008) were used to describe the sample characteristics. Rasch analysis using Winsteps software was the primary analysis methodology employed (Linacre, 2010a, 2004). The relationship between Rasch and traditional statistical analysis is summarised in Figure 5.2. The blue shaded areas indicate evidence of validity, the pink shaded areas provide evidence of reliability, and the areas with both colours represent evidence from analyses that offer information about both reliability and validity.

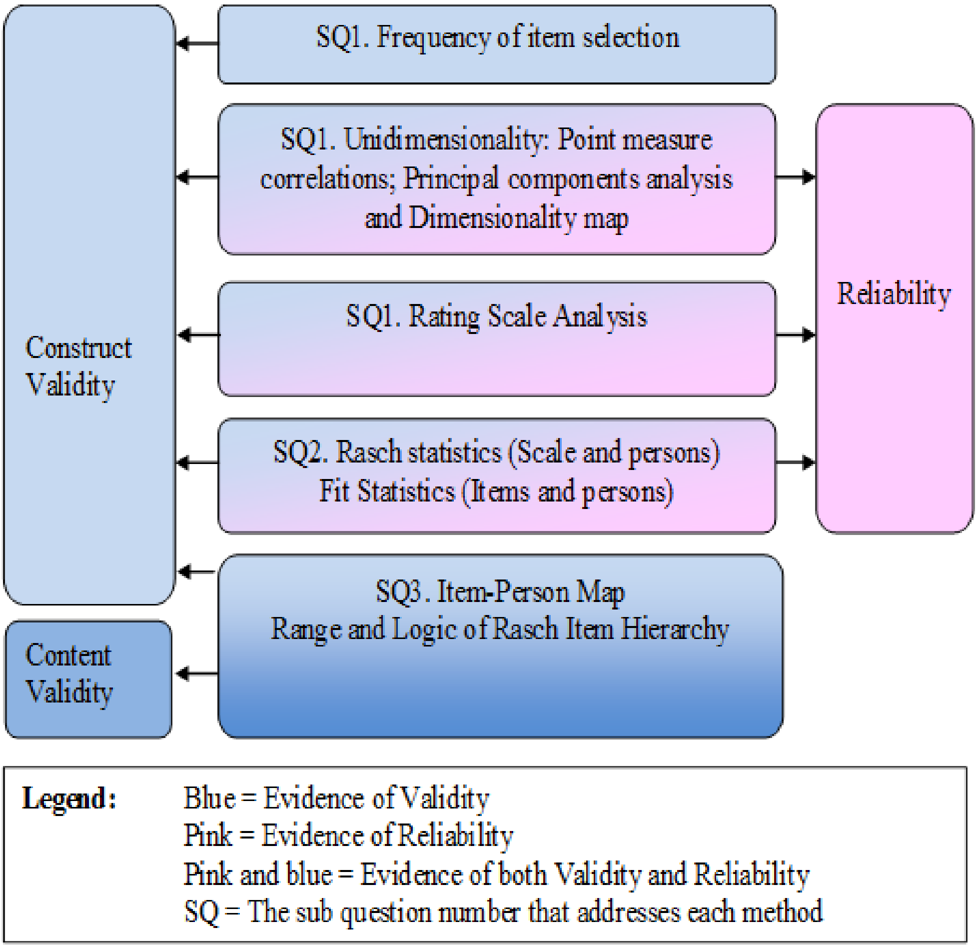


Figure 5.2: Summary of Statistical Analyses and Relationship to Traditional Statistical Approaches

Sub questions 1 and 2 provided initial information about the precision and reliability of the new instrument. Specifically, the results of these initial analyses were used to determine whether the measurement properties of the Lifestyle Assessment were sufficiently robust to warrant ongoing analyses. In response to problems found with some aspects of the measure, strategies to amend the Lifestyle Assessment to accommodate these initial findings were made. Statistical analyses were then repeated to further address all three sub-questions to evaluate the extent to which the changes improved the measurement properties of the instrument and inform further application of the instrument, as described below.

5.2.1 Rasch Methods: Rating Scale Analysis

Rasch analysis was completed to evaluate the extent to which the psychometric properties of the Lifestyle Assessment met the criterion of rigorous scientific measurement principles (Bond & Fox, 2001). Rasch analysis is thought to support initial test development by investigating:

- Whether the data support the theoretical basis for the scale in question
- The measurement properties of each item on the scale and the test as a whole
- The degree to which individual items contribute meaningfully to measurement of the line of inquiry, in this case, the degree to which people with brain injury “get their life back”.
- The reliability of the data for each person in the sample and each item of a test
- The relationship between people and items (Bond & Fox, 2071; Linacre, 2010b; Wright & Masters, 1982; Wright & Stone, 1979).

To meet the requirements for measurement, Rasch modelling converts ordinal level scaling into interval level measures and evaluates the degree to which these contribute to a single unidimensional construct. In Rasch analysis, information about the level of difficulty of the item and level of functioning of the people, referred to as person ability, are estimated on the same interval level logit (log odds unit) scale (Bond & Fox, 2007; Wright & Masters, 1979). Logit values are estimated for people and items based on an estimate of “the distance between a person’s ability and the item difficulty, [which] is expressed as the logarithm of the odds of success of the person on the item” (Wu & Adams, 2007, p. 29). “A person’s ability [expressed] in logits is their natural log odds for succeeding on items of the kind chosen to define the ‘zero’ on the scale. And an item’s difficulty [expressed] in logits is its natural log odds for eliciting failure from persons with ‘zero’ ability” (Wright & Masters, 1979, p.17). The measure, the interval level equivalent to a raw test score, is the estimate of the person ability based on the pattern of raw scores and item difficulty (Linacre, 2010b). The Rasch model is probabilistic, where more able people are more likely to have more ability in the construct under review. In this study, reflecting fewer or less changes to their lifestyle reflected by resumption of more pre injury activities and relationships. Rasch provides information about the performance of people on the range of items that reflects varying degrees of the underlying construct

Rasch analysis generates some of the same information about a test that is calculated using traditional statistics, but addresses many of the measurement issues that beset traditional statistics where participant numbers are low (Wright & Stone 1979). A primary advantage of Rasch is that assumptions about the level of measurement are empirically tested rather than assumed to be adequate for statistical analyses (Fisher, 1992b). Commencing evaluation of the measurement properties of an instrument with

Rasch analysis is considered useful as this can provide evidence of whether the instrument is likely to meet the assumptions for traditional statistical analyses. Traditional approaches are based on different statistical assumptions and usually evaluate reliability and validity separately.

5.2.2 Analyses Used to Address Sub Question 1: Does the Lifestyle Assessment Represent the Construct of Lifestyle Effectively?

Three analyses were completed to address this sub-question to provide initial evidence of the effectiveness of the Lifestyle Assessment to represent and measure the construct of lifestyle changes for people after brain injury. First, the frequency with which each item was selected, and the range in the total number of items people selected. This provided information on how selective people were in identifying only items relevant to their life, and those activities that were considered relevant by most people as opposed those activities identified as relevant by a smaller number of people. Following this, the unidimensionality of the instrument was examined for evidence of conformity with the Rasch measurement model and construct validity. Third, the effectiveness of the rating scale was evaluated. These analyses were repeated, first using the initial instrument, and again following a revision process that is described.

5.2.2.1 Frequency Distributions of Items

Frequency distributions of the number of times each item was selected and the number of items selected by each person were calculated. During administration of the Lifestyle Assessment people could choose to rate only items they considered as relevant to their own life, as the freedom to choose personally meaningful activities is a key element of a satisfying lifestyle (Aiken, 2003). The degree to which people availed themselves of this flexibility was thought to provide information to support the relevance of items to the population, the success and validity of the instrument to facilitate personal choice. Understanding how many times items were selected by people and the range in the number of items people considered representative of their lifestyle was also important as sufficient data is required to calculate reliable estimates of item difficulty and person ability.

5.2.2.2 Internal Consistency and Uni-dimensionality

In this study several empirical methods were applied to evaluate the degree to which the Lifestyle Assessment is a unidimensional scale. First, the point measure correlations were calculated, which reflected the direction and size of correlation of items to the overall measure (Linacre, 2010b). These correlated the observations and Rasch generated measures and were computed as Pearson product-moment correlation coefficients. They provide the first evidence that the response level scoring was effective and logical (Linacre, 2010b). A homogenous group of items are moderately correlated with each other and the total score and this information provides support for the internal consistency of the measure (Streiner & Norman 2003). For maximum utility, an item should have reasonably high correlation to the total scale but lower correlation to the other items, so that they measure different aspects of the same construct (Aiken, 2003).

The second method to evaluate the reliability of the Lifestyle Assessment was a principal component analysis of residuals, illustrated with a dimensionality map using Winsteps software (Linacre, 2004). These provide quantitative and qualitative information regarding both the uni-dimensionality and construct validity at the scale and item level (Arrindell & van der Ende, 1985; Bond & Fox, 2007; Fisher, 1993; Linacre, 2010b). The

Rasch principal component analysis of residuals identifies whether any other common variance in the 'residual' data exists after an interval measure has been generated from the ordinal level data by Rasch analysis (Bond & Fox, 2007). It involves an estimation of the fit statistics of items, followed by a "factor analysis of the (ordinal level) residuals that remain after the linear Rasch measure has been extracted from the data set" (Linacre, 1998, 2010b). This approach is considered superior to traditional factor analysis because it relies on interval level data to generate correlations whereas traditional factor analysis generates correlations based on "sample-dependent ordinal level data" and is not tolerant of missing data (Bond & Fox, 2007, p.252). Unexplained variance by the first factor should ideally be less than two Eigen value units (Linacre, 2010b).

Standardised residual principal component values for individual items are reported in the Principal Component Analysis Table and represented visually on a dimensionality map. The dimensionality map is a factor plot of the item measure (using Rasch generated estimate in logits rather than raw scores) against the size of the factor loading for each item identified during the principal components analysis (Bond & Fox, 2007). Linacre (2010b) reported items with loading values of greater than ±.4 may reflect high loading on a separate factor within the scale. A random pattern is expected with few high loadings. Those with higher factor loadings could be suggestive of a separate construct and are reported at the top and bottom of the dimensionality map. Researchers are advised to consider the magnitude of variance as well as whether any additional variance identified is meaningful when making decisions regarding how to deal with any variance (Linacre, 1998).

Fit statistics generated by Rasch analysis also provide evidence of the unidimensionality of the measure as they represent the degree to which items meet the Rasch model expectations (Linacre, 1998). These were described in the sub question 2 as they were most relevant to describing the effectiveness of the items to measure the construct of interest. Demonstration of the uni-dimensionality of the scale is important to confirm that the items are additive and thereby validates summing of total scores, and to support the reliability and construct validity of the scale (Aday & Cornelius, 2006; Bond & Fox, 2007; Fischer, 1994; Wright & Stone, 1999). Linacre (2010b) advises that many factors threaten uni-dimensionality and most data will not perfectly fit model requirements of uni-dimensionality (Bond & Fox, 2007). Statistical analyses determine whether the extent of problems with uni-dimensionality detected are “sufficiently large to threaten the validity” of results (Linacre, 2010b, p.433).

5.2.2.3 Analysis of Effectiveness of Rating Scale

The effectiveness of the rating scale for the Lifestyle Assessment was analysed to determine the success at measuring increasing levels of change in participation on items as scores increase from zero through to the top score of five. This is critical to the effectiveness of the instrument. A summary table of the category structure for the scale as a whole was reported as the distribution of the mean of measures in each category, which should reflect the sequential nature of the rating scale that aims to measure increasing lifestyle changes as scores increase from zero through to five. The category structure was also visually depicted using category probability curves which show the probability of each response (rating or score) and should reflect the relative difficulty of each rating across the measurement continuum, given the difference on estimates between person abilities and item difficulties (Bond & Fox, 2007; Linacre, 2010b; Wright & Masters, 1982). The intersection of category probability curves provides a visual indication of the threshold where different ratings become more probable for the scale as a whole (Wright & Masters, 1982).

Following this, the category structure of individual items examined whether the order of ratings was sequential for each individual item. This provided information on the effectiveness of the rating scale at an item level, and enabled the utility of a single rating scale for every item to be reviewed (Tennant, 2004). The effectiveness of the rating scale is fundamental to the assumptions of Rasch, where increasing scores should reflect systematic increase in the construct under investigation. The first iteration identified problems with the rating scale. The analyses to address question 2 were completed to inform revisions to address these problems. The revisions made at this point are described and the success of these to improve the measurement properties of the revised instrument were evaluated by addressing the three sub-questions in sequence.

5.2.3 Analyses Used to Address Sub Question 2: Are the Lifestyle Assessment's items stable and precise in their measurement of lifestyle changes experienced by people after brain injury?

This question addressed both the reliability and validity of the lifestyle assessment through the provision of evidence of the precision and effectiveness of the individual items and the success of the instrument to measure different levels of person performance. The results from the performance of both items on the test and people provided information about the underlying theory, in this case, how well the Lifestyle Assessment was able to represent the degree and nature of changes to their lifestyle a person experienced after brain injury (Bond & Fox, 2001). Winsteps yields several fit statistics to describe how effectively the instrument was working as a whole for the collection of items and persons in the sample, and for individual items and persons.

5.2.3.1 Rasch Statistics

Winsteps provided total scale statistics for people and items including reliability and separation statistics, which provided initial information on the success of the tool for the sample and items. The total scale reliability values generated by Rasch were considered appropriate for this study, as unlike Cronbach’s alpha they are not influenced by a larger number of items and missing data (Linacre, 2010b). Missing data were expected from the Lifestyle Assessment as it allows people to rate only relevant items. In Rasch reliability refers to the replicability of item difficulty and person ability estimated on the logit scale (Bond & Fox, 2007).

The item and person separation index values are additional estimates of reliability. Item separation refers to the ability of the test to define statistically different groups or levels of performance the test (Bond & Fox, 2007; Wright, 1996; Wright & Masters, 1982). Separation is the number of statistically different performance strata that the test can identify in the sample. Adequate separation values for both items and people rely on sufficient replicability, or reliability, as they are affected by the size of the error of measurement. Separation indexes as a ratio estimated from the variance among person estimates explained by the Rasch model in the sample divided by the average measurement error for the sample (variance unexplained by the Rasch model) (Andrich, 1982). The separation index provided information on the number of strata, or levels that can be reliably distinguished. A separation of at least two is desirable to reflect that at least two levels can be detected from the measure for items or people (Bond & Fox, 2007).

5.2.3.2 Fit Statistics

Fit statistics are provided to summarise the degree to which the scale and group of persons meet the Rasch model expectations. They are provided separately for persons and items but are calculated and interpreted in similar ways. They can indicate the reliability of each and the degree to which the range of item difficulty is targeted for the ability of the persons (Bond & Fox, 2007).

All fit statistics are provided as two types of values. The Infit statistic is an information weighted mean square statistic, which is dependent on the variance of each item and more sensitive to unexpected responses to items near the person’s level of ability (Bond & Fox, 2003; Linacre, 2010b). The Outfit statistic is based on the conventional sum of squared standardised residuals and is more sensitive to outliers, or unexpected responses on items far from the person’s level of ability (Bond & Fox, 2003; Linacre, 2010b). Rasch model expectations are that infit statistics should ideally range between 0.6-1.4 for rating scales. Items scoring 1.5 to 2 will not distort measurement but may need review, whereas items with MNSQ values exceeding two are considered to have a deleterious impact on the quality of measurement (Bond & Fox, 2007; Linacre, 2010b; Wright & Masters, 1982). Standardised values are expected within the range of -2 to 2 (Bond & Fox, 2007). Items are considered to misfit when the infit mean square values are outside .4 – 1.6, with scores exceeding two (Bond & Fox, 2007).

Opinion is divided about which fit statistic is considered most important, however as different fit statistics are available to detect different aspects of deviation from Rasch model expectations, no single statistic should be considered most critical (Wu & Adams, 2007). Wu and Adams (2007, p.85) advise that “fit statistics should serve as an indication for detecting problematic items rather than for setting concrete rules for accepting or rejecting items”. Misfitting items reduce the reliability of estimates so need to be reviewed to determine whether they should be modified or discarded, or indicate a need to review the construct being measured (Baghaei, 2008). Factors that can contribute to misfitting items include: low sample size, high levels of missing data, poor operational definition of items, items that do not fit with the construct, data entry errors, and multidimensionality within the construct as operationalised in the test items (Baghaei, 2008; Linacre, 2010b). For the purpose of this study, fit statistics were primarily used to identify problematic items and inform strategies to address these to improve the measurement properties of the instrument.

5.2.3.2.1 *Individual Item Fit Statistics*

Item fit statistics summarise “the extent to which the sample’s pattern of response to that item is consistent with the way these people have responded to the other items” (Wright & Stone, 1999, p.170). The items that fit are likely to be measuring the single dimension intended by the construct theory, so can provide further evidence of the unidimensionality of the instrument. Items that misfit the Rasch model expectations can provide information that can be used to guide action to improve the measurement properties of the whole scale. Item level analyses provide robust data to support refinement of items and instruments to produce significant improvements in test effectiveness (Aiken, 2003).

5.2.3.2.2 *Individual Person Fit Statistics*

Fit statistics were also calculated for individual people in the sample. This provided more detailed information about how appropriate the people in the sample were to be assessed by this measure. These are determined by the degree to which the person's scores meet expectations of the Rasch model (Bond & Fox, 2007).

5.2.4 Revisions to the Instrument

After the first iteration of the Lifestyle Assessment, problems were identified with the measurement properties of the instrument. The data were reviewed to guide amendments to the rating scale and some items. Following these changes, analyses to address the first two questions were repeated. The results supported further analysis and the third question was then addressed.

5.2.5 Analyses Used to Address Sub Question 3: Does the Lifestyle Assessment Measure the Range of Lifestyle Changes Experienced by People Effectively?

This question addressed the effectiveness of the Lifestyle Assessment by considering the people in the sample and items together, with particular attention placed on the range and distribution of item difficulty, and the extent to which this is appropriately targeted for person ability. This provided information about the construct and content validity of the Lifestyle Assessment, which aimed to measure the change that has occurred since injury at the time of assessment. Winsteps produced an 'Item-Person Map', which provided a visual display of the range of functioning measured by a test via the distribution of item difficulty and person ability along the logit scale used for both (Bond & Fox, 2007; Fisher, 1993; Granger, Deutsch & Linn, 1998; Linacre, 2010b).

The Item-Person maps demonstrate some fundamental Rasch concepts. Importantly, the performance of persons and items are measured on the same scale. The degree to which item difficulty and spread is appropriately targeted for the spread and ability of persons (Bond & Fox, 2007; Granger, Deutsch & Linn, 1998). Rich information is presented about whether the range and coverage of items reflect the continuum of lifestyle changes experienced by people after brain injury. The logic of the hierarchies for both people and items illustrated on this map will be reviewed in relation to expectations about the nature of lifestyle changes experienced after brain injury in general, and by the people in this sample. Another key feature is that Item-Person maps provide information to evaluate whether more able people are expected to perform better on easier items, and less able people are expected not be able to succeed at hard items. In Rasch modelling, the construct validity of an instrument is supported by the extent to which the range and hierarchy of the items matches the expectations of the theoretical construct underpinning the assessment (Bond & Fox, 2007; Wright & Masters, 1982). This supported the methods applied earlier in the study to identify those aspects relevant to lifestyle and considered meaningful to people with brain injury and clinicians.

5.2.5.1 Description of the Item-Person Map

The Item-Person map generated by Winsteps (Linacre, 2010a, 2010b) reported the hierarchy of the level of difficulty of the items along the logit scale on one side, and the level of ability of the persons on the other. Increasing scores on the Lifestyle Assessment indicate the person experienced larger changes to their lifestyle. This is reflected in the direction of the hierarchy depicted on the Item-Person map. People with the highest measures, which indicate they have experienced the largest changes to their lifestyle, are located towards the top of the Item-Person map. These people will be expected to have the most significant levels of disability. Items at the top of the hierarchy are endorsed less often than others, as only the most affected people should find these items difficult. People with fewer lifestyle changes (more ability) are not expected to endorse ‘easier’ items. Towards the bottom of the hierarchy items will be more difficult, and are expected to be endorsed by most people. People towards the bottom of the Item-Person map hierarchy are considered to experience the least changes to their lifestyle, and are expected to have the lowest levels of disability.

5.2.5.2 Logic of Person and Item Hierarchies

In this study several features of the map were reviewed using a qualitative approach. The distribution of the items and persons along the continuum were reviewed to assess the sufficiency of the item spread and coverage. The Item-Person map can demonstrate the degree to which an assessment is appropriate for the people it has been used with, as well as the relationship between people and items. Adequate content validity of the instrument is partially illustrated on the Item-Person map by an adequate range of items, indicating that there is an adequate sampling of the entire construct under measure (Cronbach & Meehl, 1955; Domholdt, 2005;). Although the Item-Person Map contains information on both items and persons, the map is used in the results in this part of the research in two ways, one to demonstrate details regarding the items, and one to illustrate information about the persons denoted by their level of disability. Essentially, this step involved reviewing whether the items and people were behaving as expected, given clinical expertise and the literature regarding how participation in activities and lifestyles change after brain injury.

5.3 RESULTS

In this section the characteristics of the sample are described and then the results of data analyses outlined above are presented in relation to the first two sub questions. The subsequent amendments to the instrument that occurred as a result of these analyses are then outlined. Following this, the results related to the first two sub-questions are presented, followed by the results that were pertinent to the third sub-question posed.

5.3.1 Sample Characteristics

Sample characteristics are summarised in Table 5.1. The sample was considered to be representative of people participating in brain injury rehabilitation, in terms of their diversity in the mechanism of injury and level of disability, which is important in the evaluation of construct validity (Domholdt, 2005) (See Appendix 5). The sample did range considerably in time since injury. At the time of assessment the range of time since injury was 0.4 – 21.71 years, but within this large range 75% of people had sustained their injury within 3 years (39% of the sample had sustained their injury within one year, 55% had sustained their injury within 2 years). The large majority of clients with traumatic brain injury sustained severe, very or extremely severe brain injuries. Data regarding injury severity was not recorded for nine participants, as access to medical information was not available for those people recruited from long term support services including Headway, and this group tended to have had longer time since injury so could not recall this information.

Table 5.1: Sample Characteristics (N=71)

Characteristic	Numbers	Percentages
Age (years)		
Mean (Median)	34 (28)	-
Range	16-69	-
Gender		
Male	58	82%
Female	13	18%
Marital Status		
Married	26	36%
Unmarried	40	56%
Divorced / separated	5	7%
Work/ Study at Time of Injury		
Employed, including:	55	74%
Unskilled / semiskilled jobs	(34)	(58%)
Skilled	(5)	(7%)
Professional / managerial	(16)	(23%)
Unemployed	9	13%
Students	5	7%
Homemakers	2	3%
Living Situation		
Lives in community in private accommodation	69	99%
Lives in residential care	2	1%
Type And Cause of Brain Injury		
Traumatic Brain Injury, including:	63	89%
Motor vehicle Accidents	(54)	(76%)
Assault	(6)	(9%)
Fall	(3)	(4%)
Non Traumatic Brain Injury, including:	8	11%
Anoxic brain damage	(5)	(7%)
Arterio-venous malformation (AVM)	(2)	(3%)
Cerebro-vascular accident (CVA)	(1)	(1%)
Injury Severity		
Moderate	3	4%
Severe	23	33%
Very Severe	12	17%
Extremely severe	23	32%
Chronic Amnesic State (>6 months PTA)	1	1%
Missing	9	13%
Time Since Brain Injury(years)		
Mean (Median)	2.97 (1.67)	-
Range (months)	.04 - 21.71	-

The level of disability experienced by each of the participants was reported using categories from the Disability Rating Scale (DRS). The majority of the sample (N=60, 85%) experienced partial to moderately severe disability as measured using the DRS categories based on total scores (Table 5.2). Eight people represented the extremes of high and low disability. Three people did not have DRS scores as these were not recorded at the time of data collection. People in this sample did not experience all levels of disability reflected by DRS scores.

Table 5.2: Frequency of Levels of Disability of Participants (Disability Rating Scale categories)

DRS Total Score	Disability Category Description	Frequency	
		Number	Percentage
1	Mild disability	4	5.6%
2-3	Partial disability	21	29.6%
4-6	Moderate	22	31%
7-11	Moderately severe	17	23.9%
12-16	Severe	3	4.2%
22-24	Vegetative state	1	1.4%
	Missing	3	4.2%
	TOTALS	71	100%

5.3.2 Results Relating to Sub Question 1 (1st iteration): Does the Lifestyle Assessment Measure the Single Construct of Lifestyle Effectively?

5.3.2.1 Frequency of Endorsement for Lifestyle Assessment Items

The Lifestyle Assessment enabled people to choose which items were relevant to their lifestyle. The frequency with which individual items were endorsed is reported in Table 5.3. People varied in the number of items they endorsed from 36 – 65 (Mean = 55.5; Median = 57). No person endorsed every item, and the number of times items were selected by a single person ranged from 3-71 [Mean = 55 (77%), SD = 20; Median = 66 (93%)] (See Table 5.3; Appendix 6). The range of items that were endorsed suggests that people utilised the assessment as planned, and only identified items that were relevant to their own situation.

Table 5.3: Frequency of Item Selection

ITEMS	Frequency Item Endorsed		ITEMS	Frequency Item Endorsed	
	N=	%		N=	%
Moving around home	71	100	Relationships with friends	66	93
Moving around other buildings	71	100	Informal relationships	66	93
Moving outside	71	100	Disposing Rubbish	65	92
Private motor transport	71	100	Socialising with family	65	92
Appointments	71	100	Visiting	64	90
Healthy diet	71	100	Socialising with friends	64	90
Basic money skills	70	99	Public Transport	63	89
Conversation skills	70	99	Sports	63	89
Telecom devices	70	99	Socialising	63	89
Simple meal	69	97	Seeking work	62	87
Use appliances	69	97	Diary, calender use	62	87
Use appliances	69	97	Washing / drying clothes	61	67
Regulating behaviours	69	97	Medication	57	80
Driving	68	96	Reading pleasure	56	79
Complex finances	68	96	Close / romantic relationships	55	77
Paid work	68	96	Household maintenance	53	75
Reading & writing skills	68	96	Plant & Garden Care	50	70
Maintaining appropriate social space	68	96	Playing games	47	66
			Computer skills	47	66
Social Cues	68	96	Formal relationships	47	66
Dealing with criticism	68	96	Human powered transport	39	55
Physical contact in relationships	68	96	Music	39	55
Tolerance of others	68	96	Computer pleasure	39	55
Respect, warmth and appreciation in relationships	68	96	Ceremonies	30	42
			Complex Meal	28	39
Mood & emotional state	68	96	Voluntary work	27	38
Acquiring Place to live	67	94	Assisting others	22	31
Shopping	67	94	Work preparation	20	28
Cleaning cooking area	67	94	Arts & Crafts	18	25
Clean living area	67	94	House decoration	16	23
Relationships with family	67	94	Religious activities	15	21
Alcohol & Drug Use	66	93	Voc education	14	20
Managing daily routine	66	93	College	10	14
Managing one simple task	66	93	Professional organisations	9	13
Managing multiple simple tasks	66	93	Shopping leisure	9	13
Managing one complex task	66	93	School	3	4
Managing multiple complex tasks	66	93			

5.3.2.2 Internal Consistency and Uni-dimensionality

5.3.2.2.1 *Point Measure Correlations*

The point measure correlations for all items were positive (range 0.25-0.98; See Appendix 6). This provided initial evidence that all items on the test contributed to measurement of a single dimension, lifestyle (Linacre, 2010b, 1998). The item correlations for five items were outside the desirable range of 0.4 – 0.8. Two items had low correlations, voluntary work 0.25 and driving 0.3. Three items had high correlations (>0.90; school, professional organisations and shopping for leisure). While they may not contribute much to the total estimate of a person's ability, their inclusion was thought to not detract from the measurement.

5.3.2.2.2 *Principal Component Analysis of Residuals and Dimensionality*

The Principal Component Analysis suggests the measure explains 84.7% of variance (Linacre, 2010b) (Table 5.4). Unexplained variance by the first factor is 9.6 Eigen value units. Although this may indicate a second dimension, at less than (2.1%), it may not be sufficient to prevent the scale being considered sufficiently unidimensional for practical purposes (Linacre, 2010b). Variance by the second factor is around 4.4 Eigen value units (<1%) which is higher than what might be expected by chance but unlikely to represent a meaningful separate construct (Linacre, 2010b).

Table 5.4: Principal Components Analysis: Variance Explained by the Lifestyle Assessment

Explained and Unexplained Variance by Measure	**Empirical**		**Modeled**
	Eigen values	**%**	**%**
Total variance in observations	469.9	100%	100%
Variance explained by measures	397.9	84.7%	85.7%
Unexplained variance (total)	72.0	15.3%	14.3%
Unexplained variance explained by 1st factor	9.6	2.1%	-
Unexplained variance explained by 2nd factor	4.4	0.9%	-

The items contributing to unexplained variance in the first factor were reviewed to identify the meaningfulness of the factor. The principal components (standardized residual) table and factor plot show 11 items that have significant positive factor loadings greater than +0.4 (shaded pale aqua) and 14 items had high negative factor loadings (> -0.4; shaded pale pink) (See Table 5.5 & Appendix 6 for Factor Plot) (Bond & Fox, 2007). The first factor included items with positive loading that mainly addressed social skills and relationships and items with negative loading that included a range of non-specific and instrumental daily living tasks. As a whole, the items within the factor do not appear to suggest a homogenous, and therefore meaningful, separate construct. The items identified within this factor are reviewed closely in subsequent analyses to investigate any pattern or relationship between these items. This finding supported the decision to proceed with further analysis of the Lifestyle Assessment using all items as a single scale (Bond & Fox, 2007; Wright & Masters, 1982). This is consistent with proponents of the Rasch measurement model who advocate that the decision to retain items that may be part of a separate dimension needs to balance the size and meaningfulness of the separate factor against the contribution of the items to the construct of interest (Bond & Fox, 2007; Linacre, 1998).

Table 5.5: Standardized Residual Variance identifying First Factor (including items with positive and negative loadings)

Positive Loading Items	**Code**	**Loading**	**Measure**	**Infit MNSQ**	**Outfit MNSQ**
Tolerance of others	A	0.76	54.44	1.32	1.96
Respect, warmth and appreciation in relationships	B	0.74	54.88	0.88	0.89
Regulating behaviours	C	0.69	53.24	1.06	1.47
Socializing with family	D	0.62	51.45	0.99	1.12
Relationships with family	E	0.61	49.59	0.93	1.05
Interacting according to social rules	F	0.6	54.14	0.92	1.1
Relationships with friends	G	0.58	45.8	0.79	0.79
Dealing with criticism	H	0.58	55.76	1.29	2.19
Mood & emotional state	I	0.54	51.49	0.96	1.42
Socialising with friends	J	0.46	45.18	0.94	2.15
Social Cues	K	0.41	55.49	0.53	0.5

Negative Loading Items	**Code**	**Loading**	**Measure**	**Infit MNSQ**	**Outfit MNSQ**
Basic money skills	A	-0.63	56.68	1.01	0.96
Managing one complex task	B	-0.59	51.68	0.46	0.45
Managing multiple complex tasks	C	-0.52	47.01	0.41	0.42
Moving around other buildings	D	-0.52	58.67	1.26	1.12
Managing one simple task	E	-0.51	61.21	0.6	0.51
Simple meal	F	-0.48	53.8	0.95	0.89
Shopping	G	-0.48	47.56	0.96	0.89
Moving around home	H	-0.47	61.16	1.13	1.1
Use appliances	I	-0.46	56.5	1.2	1.09
Washing / drying clothes	J	-0.45	51.08	0.85	0.77
Managing multiple simple tasks	K	-0.44	54.75	0.42	0.39
Moving outside	L	-0.43	51.31	1.2	1.19
Public Transport	M	-0.41	50.98	1.11	1.04
Diary, calender use	N	-0.4	50.31	0.64	0.59

5.3.2.2.3 *Analysis of Rating Scale: Category Structure*

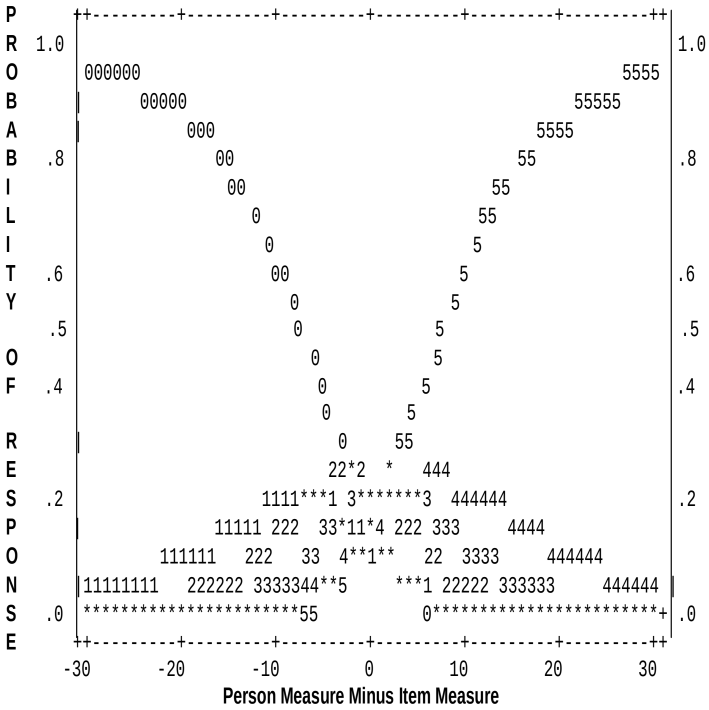
The category structure of the rating scale for the Lifestyle Assessment was examined by reviewing the observed frequency of ratings, the average measures for each rating and the category function probability curves. The mean category measure for each rating were all in ascending order, which demonstrated that the rating scale was working as expected and the sequence of each rating represented sequential and distinct levels of lifestyle change (Table 5.6). The overall separation or range of the rating scale is over 33 logits, which indicates that the Lifestyle Assessment measures a very broad range of changes to a person's lifestyle after brain injury.

Table 5.6: Summary of Category Structure

Rating 'Score'	Category Measure	Observed Count (Frequency) (N=)	%	Fit Statistics (MNSQ) Infit	Outfit
0 None	-16.53	985	25%	1.09	1.30
1 Mild	-7.12	391	10%	.95	1.13
2 Moderate	-2.12	525	13%	0.96	1.19
3 Significant	1.88	512	13%	.87	.87
4 Severe	7.02	476	12%	1.07	0.96
5 Total	17.02	1044	27%	.97	1.05
Missing		1164	23%		

The category use frequencies indicate the distribution of responses is not equal, with scores of zero and five being endorsed much more often than other ratings. The smaller number of observed ratings for scores of one to four may reduce the reliability of these estimates and suggested there may be problems in how scores were being used, or that people cannot reliably distinguish between all the available ratings.

Problems with the rating scale were also reflected by the category probability curves, which demonstrated that the thresholds at which scores one, two, three and four became more probable were unclear (See Figure 5.3). When rating scales function effectively, the curve for each rating should have a distinct peak, which indicates it is the most probable rating (‘x’ axis) at one point on the measurement continuum (‘y’ axis) (Bond & Fox, 2007). These are expected to be equal, which would be seen by the intersection of curves equidistant from the next. Analysis of the Lifestyle Assessment indicated probability curves for scores of 1 - 4 were quite flat and not clearly differentiated. This reflects the probability of allocating a score of 1-4 is much less than allocating a rating for zero or five (Andrich, 1996). The flat curves and lower frequency of these ratings may suggest people do not discriminate that many levels of lifestyle change (Bond & Fox, 2007).



```
P      ++---------+---------+---------+---------+---------+---------++
R  1.0 |                                                              | 1.0
O      |000000                                                   5555 |
B      |      00000                                         55555     |
A      |           000                                  5555          |
B   .8 |              00                              55              | .8
I      |               00                          55                 |
L      |                  0                       55                  |
I      |                   0                     5                    |
T   .6 |                    00                  5                     | .6
Y      |                      0                5                      |
    .5 |                      0              5                        | .5
O      |                        0            5                        |
F   .4 |                         0          5                         | .4
       |                         0        5                           |
R      |                           0     55                           |
E      |                          22*2  *   444                       |
S   .2 |                   1111***1 3*******3  444444                 | .2
P      |              11111 222  33*11*4 222 333     4444             |
O      |        111111   222   33  4**1**   22  3333     444444       |
N      |11111111   222222 3333344**5     ***1 22222 333333     444444 |
S   .0 |***********************55           0************************+| .0
E      ++---------+---------+---------+---------+---------+---------++
      -30       -20       -10         0        10        20        30
                      Person Measure Minus Item Measure
```

Figure 5.3: Category Function Probability Curves

The same information is also available for individual items that reflect the average ‘ability’ of the people who endorsed that score on that item. At this finer level of detail, the rating scale is disordered for 25 items and the sequential increase in scores from 0-5 is not seen (Appendix 6). These items were reviewed in relation to issues that can reduce the effectiveness of the rating scale (Appendix 6). Several factors can contribute to the effectiveness of the rating scale including how the assessment is administered, the number of possible ratings and those items where a review of the item itself or item description may be contributing to unreliable scores.

All the items with disordered ratings had low frequencies of ratings (<10), which suggests there may have been insufficient data in this sample to gain accurate estimates of the rating scale at the item level (Appendix VI, Table A7). Six items were rarely selected (See also 5.3.2.1). The items for ‘Music’, ‘Arts and crafts’, ‘Healthy diet’ and ‘Alcohol and drug use’ did not appear to meet Rasch expectations that more able people will score better than low functioning people. The descriptions for ‘Music’ and ‘Arts and crafts’ were selected to represent change in activities with a wide variation in the level of challenge and nature of participation involved, but were important for the people who selected these items. On closer examination the items for ‘Healthy diet’ and ‘Alcohol and drug use’, appeared to be different to other items included in this instrument. They did not seem to conceptually fit with the other items, even though they are described in participation under the ICF (codes d5701, d5702), as they could be described as related to consumables, and have an impact of a person’s participation, rather than be activities in this context (WHO, 2001).

Although a lack of data may have contributed to these findings, the problems with the category structure effects the effectiveness of the instrument. Addressing disordering of a rating scale was considered critical to support development of a reliable and valid instrument. The fit statistics for items were reviewed to inform remediation of the instrument.

5.3.3 Results Relating to Sub Question 2 (1^{st} iteration): Are the Lifestyle Assessment's items stable and precise in their measurement of lifestyle changes experienced by people after brain injury?

Rasch produced reliability statistics for the scale and sample as a whole and for each person and item.

5.3.3.1 Rasch Reliability Statistics

Person and item reliability (equivalent to Cronbach's alpha) both exceed 0.9, which suggest good overall reliability and that this order of item estimates will remain stable when the assessment is administered to other samples (See Table 5.7) (Bond & Fox, 2007). The person separation of 5.28 exceeds the desirable person separation of at least three, which indicates that six levels of participation can be distinguished in this sample (Linacre, 2010b). The item separation of 4.19 indicates five levels of difficulty can be reliably determined among the items (Linacre, 2010b). The person and item separation scores suggest the Lifestyle Assessment captures the range of changes in people's lifestyles after brain injury.

Table 5.7: Rasch Statistics for Items and People

RASCH STATISTICS	Reliability	Separation
Persons	.97	5.28
Items	.95	4.19

5.3.3.2 Individual Item Fit Statistics

Winsteps produced fit statistics for each item on the Lifestyle Assessment, enabling a detailed analysis of how well each item on the scale contributes to the scale (See Appendix 7). Results for the items that misfit are reported in Table 5.8 (p.133). Only misfitting items are reported here, as the purpose of this analysis was to identify how the rating scale and instrument could be improved.

Table 5.8: Item Fit Statistics in Misfit Order

ITEMS	**Total Count**	**Model Standard Error**	**Infit**		**Outfit**	
			MNSQ	**ZSTD**	**MNSQ**	**ZSTD**
Driving	68	1.32	**2.22**	**3.9**	**2.74**	**3.8**
Physical contact in relationships	66	1.32	**2.25**	**3.9**	**1.75**	1.9
Maintaining appropriate social space	67	2.09	**1.88**	2.0	1.32	.70
Alcohol & Drug Use	66	1.32	**1.82**	**2.8**	**1.71**	1.9
Arts & Crafts	18	1.87	**1.81**	**2.2**	1.44	1.1
Human powered transport	39	1.72	**1.79**	**2.2**	**2.14**	**2.2**
School	3	4.08	**1.67**	1.0	**1.53**	0.90
Close / romantic relationships	55	1.10	**1.61**	2.7	**1.43**	**1.6**
Paid work	68	1.39	**1.47**	1.7	1.50	1.4
Acquiring a place to live	67	1.25	**1.43**	1.7	1.20	.70
Socialising with friends	64	1.07	0.96	-0.2	**2.25**	**3.9**
Dealing with criticism	67	0.95	1.32	1.8	**2.24**	**4.2**
Tolerance of others	67	0.93	1.37	**2.1**	**2.08**	**4.0**
Mood & emotional state	66	0.92	0.99	0.0	1.53	**2.4**

Fourteen items appeared to misfit the Rasch model expectations (See Table 5.8). The two most misfitting items were ‘Driving’ and ‘Human powered transport’ which had all four fit statistics identifying misfit. Eight of the items with disordered rating scales (see p131) were also misfitting: maintaining appropriate space, alcohol and drug use, physical contact in relationships, arts and crafts, socialising with friends, driving, paid work and human powered transport.

Aside from those items with disordered ratings, other reasons for misfitting need exploration as this can inform what steps needed to be taken to improve the measurement properties of the instrument. In this instance, the factors that may be contributing to the misfit of items include missing and insufficient data, extreme category overuse and the nature of the item for ‘Alcohol and drug use’ and ‘Healthy diet’ (Aday & Cornelius, 2006; Linacre, 2010b). There are also some issues about unexpected responses by participants that may have contributed to misfit being identified. For example, several people had resumed driving despite considerable disability. Issues related to unexpected responses by persons are explored in more detail as part of examination of person fit statistics.

Six misfitting items were measuring ability at the extremes, for people with the lowest and greatest level of lifestyle change since their brain injury. Three of the hardest items including ‘Paid work’, ‘Driving’ and ‘Human powered transport’ and only five people were matched to this level of ability. At the other end, ‘Maintaining appropriate space’, ‘Physical contact in relationships’, ‘Alcohol and drug use’ were the three easiest activities. The lack of people at these levels provided little information to calculate reliable estimates for these items. Unexpected response are more likely for extreme items in that a greater number of the possible responses will be more unexpected, but for most people there should be a clear divide when the difference between item difficulty and person ability is largest.

In addition to issues with unexpected responses for some items, all misfitting items had low endorsement frequency on the Likert scale (<10), indicating that insufficient data are available to generate reliable difficulty estimates for these items (Linacre, 2010b, 2000, 1999). Overuse of some ratings for many of these items suggests the rating scale may not be effective for these items. For example, some items had a large proportion of people endorse a score of zero, indicating they had no problem: ‘Physical contact’ (80%), ‘Maintaining appropriate social space’ (90%), ‘Alcohol and drug use’ (65%). In other items a large proportion of the sample endorsed the maximum score, indicating total change in activities: ‘Driving’ (76%), ‘Human powered transport’ (77%), ‘Close romantic relationships’ (53%), with other ratings being infrequently endorsed. Two items, ‘School’ and ‘Arts and crafts’, were scored by only a small number of people, which suggested they were not relevant activities for most people in the sample.

5.3.3.3 Individual Person Fit Statistics (1st Iteration)

Persons were identified by a numerical code and level of disability from DRS categories. Thirteen participants (23%) appeared to misfit the Rasch model expectations and issues that may have contributed to this were reviewed. They were not a homogenous group and varied in their level of disability and degree of lifestyle change. Three participants appeared to be particularly unusual. Three people were engaged in productive activities despite little participation in other areas, one was working part time, albeit in a semiskilled job, driving and played semi-professional sport, one was able to work and drive but did little else and another lived independently in appropriate accommodation with supports and studied a basic vocational course part time. One participant had such severe challenging behaviour that he was living in a secure rehabilitation environment, even though the problems existed to some degree prior to his injury. Two people had very severe disabilities but they had excellent family supports that facilitated their maximal participation. Participant 53 sustained his brain injury at birth and the fact he misfitted from Rasch expectations may be that he should be considered from a different population (Linacre, 2010b). Two other participants were participating in study or semi-professional sports, despite having quite significant disabilities restricting their lifestyle in many other areas. Four of the misfitting persons had co-morbidities including depression, and post-traumatic stress disorder and one participant was being investigated for the onset of post traumatic dementia shortly after the assessment, although results were not known at the time of this study. Sixty-eight participants were within usual expectations of people attending a clinical brain injury rehabilitation service.

Table 5.9: Persons who Misfit Rasch Model Expectations

Person		Model	Infit		Outfit	
	Measure	S.E.	MNSQ	ZSTD	MNSQ	ZSTD
42:Partial	71.56	2.23	2.22	2.5	3.03	3.0
3: Partial;	53.02	1.01	1.72	3.4	2.72	5.4
50 Partial	54.90	1.02	1.55	2.7	2.45	4.8
8: Moderately severe	60.33	1.18	2.38	4.8	1.68	2.2
70: Moderately severe	54.96	1.10	0.88	-0.6	2.18	3.8
4:Partial	50.72	1.03	1.78	3.6	2.14	4.1
27:Severe	74.10	2.69	2.13	2.0	1.05	0.3
62:Moderately severe	35.35	1.65	1.39	1.3	1.94	1.9
17:Partial	47.12	1.07	1.83	3.6	1.85	3.0
22: Severe	63.88	1.41	1.78	2.6	1.55	1.6
18:Moderately severe	57.02	1.10	1.74	3.2	1.49	1.8
21:Partial	37.3	1.49	1.66	2.1	1.56	1.4
13:Moderate	34.9	1.75	1.64	1.8	1.02	0.2

5.3.4 Improving the Measurement Properties of the Lifestyle Assessment

The data from the category structure for the scale and items, combined with the individual item and person fit statistics, suggested the need for change to improve some of the measurement properties of the Lifestyle Assessment. A summary of the main problems identified above included:

- The ratings from 1-4 were not used as frequently as the ratings for one and five
- Twenty five items had disordered ratings, with eight of these misfitting
- A further six items were misfitting, although no disordering of the rating scale for these items was identified.

- Thirteen people (23%) were misfitting, three of whom appeared to demonstrate some different or very rare characteristics than are experienced after brain injury.

5.3.4.1 Strategies to Address Measurement Problems of the Lifestyle Assessment

Several options for collapsing rating were explored, including (1) only for items with disordered ratings, (2) collapsing ratings for groups of items in different ways to accommodate item difficulty, frequency of endorsement of ratings and average measures for ratings for each item, or (3) collapsing the rating scale for the whole measure in different combinations (Linacre, 2010b). Several items were considered for removal, including those most misfitting, the three that did not meet Rasch expectations, and those rarely selected. Some of these problematic items were retained due to their clinical significance, and because the revision process may improve their measurement properties (Bond & Fox, 2007; Linacre, 2010b). For example, driving and attending school are highly important activities to many people, even though in this sample only a few people participated in them.

Decisions about inclusion or exclusion of participant data were more complex. The people who were very low functioning were not so well targeted by this instrument, but are a common group of people seen in most brain injury rehabilitation services. The need to remove some people in order to gain a robust understanding of the instrument was made based on those people who were considered least representative, and considered to have the most unexpected combination of scores that skewed analysis of the instrument.

5.3.4.2 Changes Made to Address Measurement Properties of the Lifestyle Assessment

Based on the results of analyses outlined above, the following changes were made to the Lifestyle Assessment data before proceeding with further analysis of this sample:

- Collapse the rating scale to a four point rating scale. Although data were collected on a six point rating scale this involved reanalysing data as though it was a four point scale. The most effective solution was found to convert scores of 1-2 to analyse as a score of two, and scores of 3-4 to be analysed as a score of four.
- Remove items for ‘Healthy diet’, and ‘Alcohol and drug use’ as these seemed conceptually different from the other items.
- People with highly unusual presentations were removed. This included participants 3, 17 and 27. These three people were not considered representative of people with brain injury. One person lived in secure accommodation due to dangerous challenging behaviour, one person appeared to experience changes related to mental health issues more so than the impact of brain injury and one person’s ability to perform in work, driving and other skills was so unexpected in light of his significant cognitive impairments that he was considered to have extreme scores.

The success of this strategy to improve the measurement properties of the Lifestyle Assessment is investigated below (Bond & Fox, 2007). It was anticipated that these changes would even the distribution of each rating on the scale as a whole, correct the disordered ratings and reduce the number of items and people that misfit.

After an initial trial on the best approach, changes were made to the rating scale for the items for ‘Driving’ and ‘Human powered transport’, ‘Physical contact in relationships’ and ‘House decoration’. The rating scales for these four items were dichotomised [collapsed from 4 to 2 categories – analysed as zero (original scores of 1-4) or five], as they continued to demonstrate disordered ratings. Insufficient data contributed to these persisting problems, although the extent to which other factors may contribute was examined after this problem was addressed. Most people in the sample had no problem with ‘Physical contact in relationships’ (51, 75%), and only 12 people endorsed the scores of two, four or five. ‘House decoration’, while identified as meaningful to some people during Stage 2 of this study, was only selected by 15 people, ten of whom were unable to participate or had experienced total change.

The analysis was completed as per the methodology described in Section 5.2. The first two sub-questions were again addressed based on the modified data file. The third research sub-question was addressed for the first time.

5.3.5 Sub Question 1 (2^{nd} iteration): Does the Amended Lifestyle Assessment Measure the Single Construct of Lifestyle Effectively?

5.3.5.1 Frequency of Endorsement for Lifestyle Assessment Items

Two items and data from two persons were removed for this analysis, however the frequency of item selection was not recalculated as the original analysis (5.3.2.1) represented the actual choices made by participants, and the original interpretation remained pertinent.

5.3.5.2 Internal Consistency and Uni-dimensionality

5.3.5.2.1 *Point Measure Correlations*

Point measure correlations were all positive and ranged from 0.21 - .96. The item correlations for three items were outside the desirable range of 0.4 – 0.8 (See Appendix 10 with Item Fit Statistics). Seven items had low correlations. This included four of the same items: ‘Voluntary work’ (.21), ‘Driving’ (.26), ‘Dealing with criticism’ (.39) and three items that did not demonstrate low correlations in the initial analysis, ‘Tolerance of others’ (.38), ‘Physical contact in relationships’ (.21), ‘Household maintenance’ (.34) and ‘Human powered transport’ (.38). The item for ‘Conversation skills’ (.37) no longer demonstrated low correlation. Two items had high correlations, ‘Professional organisations’ (.96) and ‘Managing multiple simple tasks’ (.83), but ‘Shopping for leisure’ was now within the desired limits. These results were very similar to the first iteration, and provided initial support for the internal consistency of the instrument following the revisions.

5.3.5.2.2 *Principal Component Analysis of Residuals and Dimensionality*

The dimensionality table provides information regarding principal component contrasts for the instrument as a whole (Table 5.10). The Principal Component Analysis reported very similar results to the initial analysis. This demonstrated the measure explains 84.25% of the variance with only 2% and 0.9% of unexplained variance explained by the first and second factors. Both factors represent more variance than what might be expected by chance, but are considered unlikely to represent meaningful separate constructs (Linacre, 2010b).

Table 5.10: Variance Explained by the Amended Lifestyle Assessment: Standardized Residual Variance (2nd iteration)

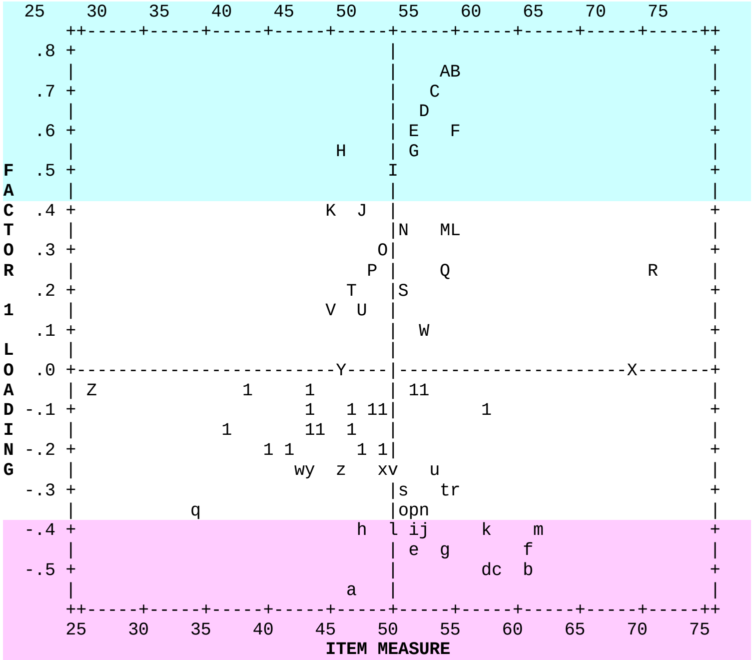
Explained and Unexplained Variance by Measure	Empirical Eigen values	%	Modeled %
Total variance in observations	436.0	100%	100%
Variance explained by measures	367.0	84.2%	85.4%
Unexplained variance (total)	69.0	15.8%	14.6%
Unexplained variance explained by 1st factor	8.8	2.0%	
Unexplained variance explained by 2nd factor	4.4	.9%	

The principal components (standardized residual) table and factor plot showed the number of items with significant loading (>.4) decreased from 11 to 9 with positive loading (shaded pale aqua) and 14 to 9 items with negative loading (> -0.4; shaded pale pink) (See Table 5.11) (Bond & Fox, 2007). As per the previous analysis the positive loading items continued to include social skills and relationships and the negative loading items within this factor mainly included a range of non-specific and instrumental daily living tasks. This factor does not appear to contribute to a logical second dimension. The Principal Components of Residuals Factor Plot was almost identical to the first and no clear distinction was apparent for the items within the factor from the remainder of the items (Figure 5.4). As with the previous these findings do not appear significant enough to prevent further analyses of the Lifestyle Assessment as a single scale (Bond & Fox, 2004; Wright & Masters, 1982).

Table 5.11: Standardized Residual Variance identifying First Factor (positive and negative loadings), Amended Lifestyle Assessment (2nd Iteration)

Positive Loading Items	Code	Loading	Measure	Infit MNSQ	Outfit MNSQ
Tolerance of others	A	0.76	54.16	1.43	2.51
Respect, warmth and appreciation in relationships	B	0.75	54.83	1.00	1.27
Interacting according to social rules	C	0.70	53.71	0.93	1.27
Regulating behaviours	D	0.65	52.57	0.85	1.18
Socialising with family	E	0.62	51.57	1.07	1.12
Dealing with criticism	F	0.61	54.99	1.39	2.49
Mood & emotional state	G	0.56	51.67	1.06	1.79
Relationships with friends	H	0.53	45.64	0.76	0.76
Relationships with family	I	0.51	49.80	1.04	1.06

Negative Loading Items	Code	Loading	Measure	Infit MNSQ	Outfit MNSQ
Managing multiple complex tasks	A	-0.54	46.67	0.36	0.37
Managing one simple task	B	-0.52	60.67	0.69	0.62
Moving around other buildings	C	-0.50	58.68	1.48	1.39
Basic money skills	D	-0.49	57.46	0.92	0.96
Disposing Rubbish	E	-0.47	52.04	0.75	0.69
Moving around home	F	-0.44	60.47	1.28	1.28
Simple meal	G	-0.44	54.34	0.97	0.93
Shopping	H	-0.42	47.82	1.05	1.03
Moving outside	I	-0.42	51.60	1.12	1.31



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  25    30    35    40    45    50    55    60    65    70    75
      ++-----+-----+-----+-----+-----+-----+-----+-----+-----+-----++
   .8 +                              |                              +
      |                              |    AB                        |
   .7 +                              |   C                          +
      |                              |  D                           |
   .6 +                              | E   F                        +
      |                         H    | G                            |
F  .5 +                              I                              +
A     |                              |                              |
C  .4 +                        K  J  |                              +
T     |                              |N   ML                        |
O  .3 +                             O|                              +
R     |                            P |    Q                   R     |
   .2 +                          T   |S                             +
1     |                        V  U  |                              |
   .1 +                              |  W                           +
L     |                              |                              |
O  .0 +-------------------------Y----|----------------------X-------+
A     | Z              1     1       | 11                           |
D -.1 +                      1   1 11|        1                     +
I     |              1       11  1   |                              |
N -.2 +                  1 1      1 1|                              +
G     |                     wy  z   xv   u                          |
  -.3 +                              |s   tr                        +
      |           q                  |opn                           |
  -.4 +                           h  l ij     k    m                +
      |                              | e  g       f                 |
  -.5 +                              |        dc  b                 +
      |                          a   |                              |
      ++-----+-----+-----+-----+-----+-----+-----+-----+-----+-----++
      25    30    35    40    45    50    55    60    65    70    75
                               ITEM MEASURE
```

Figure 5.4: Principal Components Map, Amended Lifestyle Assessment (2nd Iteration)

5.3.6 Analysis of Rating Scale with Collapsed Categories

Data were analysed as a four point scale (Table 5.12). The ‘new’ codes were assigned descriptors: ‘Minor’ for ratings of two, ‘Moderate’ for ratings of four, to aid interpretation for the purpose of the analyses. Unlike the first iteration, the distribution of ratings was now even and average measures continued to increase as expected.

Table 5.12: Summary of Category Structure for Collapsed Rating Scale (2nd Iteration)

Current Revised (Collapsed) Rating ‘Score	Original Rating Scale	Category Measure	Observed Count (Frequency) (N=)	%	Fit Statistics (MNSQ) Infit	Outfit
0 None	0	-15.01	887	19%	1.20	1.53
2 Minor	1,2	-2.91	860	19%	0.90	0.94
4 Moderate	3,4	6.19	938	20%	1.05	0.93
5 Total	5	19.25	896	19%	0.85	1.00
Missing	-	-	1042	23%	-	-

The Category Function Probability Curves are peaked and more uniform and the thresholds that indicate the point at which each score becomes more probable are distinct as per Rasch model expectations (Figure 5.5) (Andrich, 1996; Bond & Fox, 2007). These results indicate the rating scale was improved by these changes.

```
      CATEGORY PROBABILITIES: MODES - Structure measures at intersections
P      ++---------+---------+---------+---------+---------+---------++
R  1.0 +0000000                                                      +
O      |       000000                                                |
B      |             000                                         5555|
A      |                00                                    555    |
B   .8 +                  0                                555       +
I      |                   0                            555          |
L      |                    0                         55             |
I      |                     0                      55               |
T   .6 +                      0                   55                 +
Y      |                       0                 5                   |
    .5 +                        0              55                    +
O      |                         0222      444*                      |
F   .4 +                        2*   22 444 55 444                   +
       |                      22  0    *   5      444                |
R      |                     2     0  4 225          44              |
E      |                    2       *4   52            444           |
S   .2 +                  22       4 0 55  2              444        +
P      |                22        4   *     22               4444    |
O      |             222        44  55 00     22                 4444|
N      |       222222       4444 555     000    22222                |
S   .0 +*************************************************************+
E      ++---------+---------+---------+---------+---------+---------++
      -30       -20       -10         0        10        20        30
                       PERSON Minus ITEM MEASURE
```

Figure 5.5: Category Probability Curves for Collapsed (Amended) Rating Scale (2nd Iteration)

5.3.6.1 Analysis of Rating Scale for Each Item

Following the revisions, all items had ordered rating scales, including the four items that had been dichotomised for this analysis (See Table A10, Appendix VIII). Low frequency for some ratings was still apparent for some items (See Table 5.15 below). While some compromise was involved at the item level in collapsing items, it was essential that the rating scale worked effectively for every item. This was a major achievement as the effectiveness of the rating scale is imperative for robust measurement for the scale as a whole which supports ongoing analysis of the Lifestyle Assessment using the amended data (Wright & Linacre, 1989).

5.3.7 Sub Question 2 (2nd Iteration): Are the Lifestyle Assessment's items stable and precise in their measurement of lifestyle changes experienced by people after brain injury?

5.3.7.1 Rasch Reliability Statistics

Person and item reliability (equivalent to Cronbach's alpha) both remained high which support reliability of the instrument (See Table 5.13) (Bond & Fox, 2007).

Table 5.13: Rasch Statistics for Items and People

RASCH STATISTICS	Reliability	Separation
Persons	.96	4.78
Items	.94	3.80

The person separation decreased slightly but was still able to detect five levels of functioning, which remains a positive initial indicator of the sensitivity of the instrument to measure change. The item separation was also slightly lower, most likely related to the reduced number of ratings per item, but remains acceptable (Linacre, 2010b). These results support the use of the data as per the amendments.

5.3.7.2 Individual Item Fit Statistics

Fit statistics were calculated for individual items as per the revisions described (See Appendix 9). The purpose of this analysis was to review how well each item, with the revised rating scale, contributed to the measures. The number of items that demonstrated misfit increased from 14 to 15 items, but the number that demonstrated misfit for both infit and outfit statistics dropped from eight to five items (Table 5.14). Three items were no longer misfitting in this analysis including ‘School’, ‘Close / romantic relationships’ and ‘Paid work’. Five items demonstrated misfit for the first time including ‘Voluntary work’, ‘Moving around other buildings’, ‘Household maintenance’, ‘Socialising’ and ‘House decoration’ (the latter of which had been dichotomised for this analysis). Two of the other dichotomised items, ‘Driving’ and ‘Human powered transport’, continued to misfit Rasch expectations. Reasons contributing to the performance of these items were reviewed.

Table 5.14: Misfitting Item Fit Statistics in Misfit Order for Amended Lifestyle Assessment (2nd Iteration)

			Infit		**Outfit**	
Item	**Measure**	**SE**	**MNSQ**	**STDZ**	**MNSQ**	**STDZ**
Driving	43.16	1.2	**3.24**	**6.5**	**3.93**	**6.2**
Human powered transport	43.58	1.46	**2.99**	**5.0**	**3.66**	**4.8**
Tolerance of others	54.16	0.91	*1.43*	**2.4**	**2.51**	**5.4**
Dealing with criticism	54.99	0.91	1.39	**2.2**	**2.49**	**5.2**
House decoration	49.07	1.99	**2.3**	**2.7**	1.98	1.9
Physical contact in relationships	69.14	1.81	**2.23**	**2.7**	1.16	0.5
Socialising with friends	45.11	1.16	0.79	-0.9	**2.06**	**3.1**
Maintaining appropriate social space	70.64	2.01	*1.84*	1.8	1.21	0.5
Voluntary work	38.53	2.76	*1.83*	1.4	1.3	0.7
Mood & emotional state	51.67	0.93	1.06	0.4	*1.79*	**3.3**
Arts & Crafts	52.15	1.82	*1.64*	1.8	1.29	0.8
Acquiring a place to live	41.37	1.33	*1.54*	2	1.37	1.2
Moving around other buildings	58.68	0.94	*1.48*	**2.6**	1.39	1.5
Household maintenance	44.37	1.30	*1.46*	1.7	1.1	0.4
Socialising	47.76	1.05	*1.45*	**2.1**	1.4	1.6

Legend: **Bold=** Misfit distorting measurement
Italics = Misfit indicated, but not degrading to measurement

Items with high infit mean square values are the biggest threat to validity, particularly those with mean square values exceeding two (Linacre, 2010b). Items with mean square values between 1.5 and 2 are unconstructive but do degrade measurement, so are not of such primary concern. These results suggest the most problematic items include ‘Driving’ and ‘Human powered transport’, which have all fit statistics suggesting misfit. Two items, ‘House decoration’ and ‘Physical contact in relationships’, have problematic infit mean square values, which suggest unexpected scores are obtained for people at the level targeted by the items. The first three of those items are somewhat harder and the last item is one of the easiest items; the lack of people at these levels will reduce the ability to obtain accurate estimates of these items (See average measures for these items, reflected in ‘Measures’ column, Table 5.14). The items for ‘Tolerance of others’, ‘Dealing with criticism’ and ‘Socialising with friends’ have problematic outfit mean square values that suggest these items are more inconsistently scored for people further away from the level of difficulty of these items, and can usually be corrected (outliers). Three other items, ‘Mood and emotional state’, ‘Moving around other buildings’ and ‘Socialising’ have problematic standard scores, but Linacre (2010b) advised these are of less concern. For the purposes of this study all issues that may have contributed to these problems are reviewed.

In line with issues identified during the first iteration several issues appear to be contributing to the identification of misfit for these items (See Table 5.15). This includes a lack of sufficient data, either through low selection, low frequency of ratings or category over use. The fit of some items may be influenced where a person’s performance was significantly dependent on both their capacity as well as environmental factors. In some cases the items may benefit from further review, and it is possible the items cover too broad an area of functioning to be considered a single item. In this case person responses are more likely to be unexpected, where there is inconsistency between the level of difficulty of the item and the ability of the person endorsing a particular rating. Although indications of misfit can affect the quality of measurement the importance of each tem to the construct of lifestyle is considered in whether to remediate or remove items. For example, although driving is one of the most problematic items it is of significant importance after brain injury, as it often used as an indicator of outcome. The reasons for and implications of the misfitting items are reviewed in the discussion.

Table 5.15: Summary of Factors That May Contribute to Misfitting Items (2nd Iteration, Amended Lifestyle Assessment)

MISFITTING ITEMS	ITEM	ISSUE WITH RATINGS			PEOPLE	
	Description	Rare Items (Item N=70)	Low Frequency Ratings	Category Over use	Not Targeted	Unexpected Responses
Driving			✓	✓	✓	✓
Human powered transport	✓	✓ (39)	✓	✓	✓	✓
Physical contact in relationships	✓		✓	✓	✓	✓
House decoration		✓ (15)	✓	✓	✓	✓
Maintaining appropriate social space	✓		✓		✓	
Tolerance of others	✓		✓			✓
Dealing with criticism	✓		✓			✓
Socialising with friends	✓		✓			✓
Voluntary work		✓(25)	✓		✓	✓
Acquiring Place to live			✓	✓	✓	
Mood & emotional state	✓		✓			✓
Moving around other buildings	✓		✓			
Socialising				✓		✓
Arts & Crafts		✓ (17)	✓			✓
Household maintenance		✓		✓		

Legend: Bold = Participation in item can include different levels of challenge or involvement

Italics = Item also identified in First Factor (Principal Components Analysis of Residuals)

5.3.7.3 Individual Person Fit Statistics

Persons were reported using numerical code and level of disability from DRS categories. Thirteen participants (23%) appeared to misfit the Rasch model expectations and reasons for this were reviewed (Table 5.16) (Appendix 9).

Table 5.16: Misfitting Persons (2nd Iteration, Amended Lifestyle Assessment)

		Model	**Infit**		**Outfit**	
Person	**Measure**	**S.E.**	**MNSQ**	**ZSTD**	**MNSQ**	**ZSTD**
46 Severe	74.46	2.78	**2.43**	**2.6**	**3.15**	**3.8**
4 Partial	51.37	1.01	**2.21**	**5.3**	**3.12**	**6.3**
8 Mod Severe	59.98	1.28	**2.57**	**4.5**	1.98	**2.8**
56 Partial	55.87	1.10	*1.75*	**3.1**	**2.48**	**4.3**
53 Mod Severe	59.11	1.25	*1.47*	1.8	**2.17**	**3.2**
22 Severe	65.25	1.74	**2.07**	**2.7**	**2.06**	**2.5**
68 Partial	38.76	1.36	*1.49*	1.7	*1.89*	1.6
18 Mod Severe	56.85	1.17	*1.81*	**3.1**	*1.53*	1.8
2 Moderate	53.33	1.00	*1.62*	**3.0**	*1.78*	**2.8**
50 Partial	55.39	1.11	1.34	1.6	*1.69*	**2.3**
13 Moderate	37.21	1.48	*1.61*	1.9	1.01	0.2
15 Moderate	52.87	0.98	1.27	1.5	1.60	**2.4**
26 Mod Severe	56.75	1.20	*1.56*	2.2	1.35	1.2

Legend: **Bold=** Misfit distorting measurement
Italics = Misfit indicated, but not degrading to measurement

As with items, high infit mean square values are the biggest threat to validity, particularly those with mean square values exceeding two (Linacre, 2010b). Four people (Participants 4, 46, 8 & 22) had misfitting infit statistics of this magnitude in the analysis of modified data. Participant 4 had unexpected scores regarding work and driving and no longer lived independently. As identified in the first iteration (See 5.3.3.3) a group of people with misfitting scores were able to engage in a mix of activities and continued to live with their families despite their level of disability and associated care needs care needs (Participants

46, 8, 22 & 18). These people lived in environments and received social support that facilitated their participation in a larger range of activities than might be possible for other people with this level of disability. The idiosyncrasies with other misfitting persons were discussed in 5.3.3.3.

The ability to review the extent to which people are suitable for measurement using an instrument is unique to Rasch measurement. In this study factors of both environment and skill appeared to influence the degree to which a person could resume or maintain their lifestyle. Implications for the Lifestyle Assessment are explored in the discussion.

5.3.8 Results Relating to Sub question 3: Does the Amended Lifestyle Assessment measure the range of lifestyle changes experienced by people effectively?

The amendments to the Lifestyle Assessment improved the psychometric properties of the instrument. Further analyses to address the remaining research questions relied on the modified data set as used for the second iterations in section 5.3.5, 5.36 and 5.3.7.

5.3.8.1 Item-Person Map

The logic of the hierarchies of both item difficulty and person ability from the Item-Person Maps (version 1 and 2) were evaluated regarding the extent to which they matched theory underlying lifestyle and participation changes after brain injury. Two versions of this map were generated with the same information presented, one which focuses on the *items,* and one which focuses on the *persons* (Figure 5.6 and 5.7; Appendix 11 for magnified portion Figure 5.6).

```
PERSONS LOGITS    ITEMS:
Largest           Easiest to Endorse
Changes X 90
         |
         |
         |
         |
         |
         |
        80
         |
         |
         |
      X  |
         |
         |
        70   Maintaining appropriate social space
         |   Physical contact in relationships
         |
      X T|
         |T
      X  |
         |   Private motor transport
      X 60   Moving around home   Managing one simple task
 XXXXXXX S|  Telecommunication devices, Moving around other buildings
   XXXXX  |S Basic money skills,  Use appliances
   XXXXX  |  Managing multiple simple tasks
   XXXXX  |  Conversation skills, Simple meal, Cleaning cooking area, Interacting according to
             social rules, Social Cues, Dealing with criticism, Tolerance of others, Respect,
             warmth and appreciation in relationships, Informal relationships
XXXXXXXXXX|  Regulating behaviours, Medication, Arts & Crafts, Religious activities
  XXXXXX M|  Reading & writing skills, Washing / drying clothes, Disposing Rubbish
             Mood & emotional state, Appointments, Moving outside, Managing one complex
             Task, Reading pleasure, Socialising with family, Public Transport
     XXX 50 M Diary, calender use, Computer skills, Computer pleasure, Relationships
             with family, Formal relationships
    XXXX  |  Plants & Garden care, House decoration, Clean living area, Playing games, Music,
             Community organisations
  XXXXXX  |  Vocational education, Shopping, Managing daily routine, Managing multiple
             complex tasks, Socialising, Ceremonies, Shopping for leisure
             Close / romantic relationships
     XXX S|  Complex finances, Sports, Socialising with friends, Relationships with friends
       X  |  Household maintenance  Assisting others, Complex Meal, Visiting,
             Human powered transport
      XX  |S Professional organisations, Driving
       X  |  Acquiring Place to live
     XXX 40  Work preparation
       X T|  Voluntary work
       X  |  Paid work
          |T
          |  Seeking work
          |
          |
         30
          |
          |
          |  College
          |
          |
          |
         20
          |
          |
          |
          |
          |
          |
Harder   10  School
Items     | People with fewer lifestyle changes, More able people
```

LEGEND: **X** =Two Persons, **M** = Mean, **S** = 1st Standard deviation (SD), **T** = 2nd SD
Items of different difficulty level alternatively *italicised* for clarity while reading – no other meaning
🟨 = **Items** within 2SD above mean for **items**
🟥 = **Items** within 2SD below mean for **items**
Logit scale used to measure person ability & item difficulty

Figure 5.6: Item Person Map (Amended Lifestyle Assessment): Items

5.3.8.1.1 *Comparative Distribution of Items and People*

People and items at the same level of difficulty are needed to obtain reliable estimates for both. In this study the range for both people and items was very close, indicating the Lifestyle Assessment is relevant for people after brain injury. In the middle section of the Item-Person Map there are many items measuring the same level of lifestyle change (Bond & Fox, 2007). Aiken (2003) advocates that items that are useful should be able to differentiate people in relation to the construct of interest. Moreover, the presence of several items is probably needed in an assessment where people select only those activities that are meaningful for their own lifestyle.

The Item-Person map was reviewed in relation to the frequency with which items were endorsed. Items above the mean (50 logits), tended to be scored by most people, and could be viewed as more universal activities (Items within 2SD above the mean for items are shaded yellow). Items below the mean (logit score >50) were more likely to be elected by a smaller number of people as relevant to their lifestyle (Items within 2SD below mean are shaded pale pink). The primary exceptions were ‘Arts and crafts’, Religious activities’, ‘Computer for pleasure’ and ‘Computer skills’. Some harder activities were considered by the large majority including: ‘Diary, calender use’, ‘Relationships with family’, ‘Clean living area’, ‘Shopping’, Managing multiple tasks’, ‘Sports’, the two items for socialising and relationships with friends, ‘Visiting’, ‘Sports’, Driving’ and ‘Paid work’.

The easier items that were selected by most people may warrant further review. Linacre (2000) advises items that are independently measuring the same level of difficulty can increase the precision or accuracy of the ability of people at this level and only interdependent items should be considered psychometrically redundant. The items identified as ‘overfitting’ may be interdependent. However they were thought to add to the length of the test rather than distorting the measurement. In this case removing some of these items in favour of more difficult and easier items would minimise the length of the test and address the construct underrepresentation for people with very high and low degrees of lifestyle change (Bond & Fox, 2007). However in this instrument the presence of several items at the same level of difficulty may be advantageous as people select only those activities that are meaningful for their own lifestyle.

The spread of items was not consistent and there was some evidence of gaps at the extremes for people with very small and large changes after lifestyle. At the top of the map there were three people with no items of corresponding difficulty including one person achieving the maximum score. The items that were closest to them, ‘Maintaining appropriate social space’ and ‘Physical contact in relationships’ are misfitting items which suggest no items adequately measured lifestyle for the most severely disabled group of people in this sample. This may indicate loss of sensitivity for this instrument to measure people with the greatest degree of lifestyle change, typically the people with the highest levels of disability.

At the bottom of the map three items, ‘Seeking work’, ‘College’, and ‘School’ were more difficult than the level of ability for all people. The location of these items in the hierarchy appears to be impacted by the fact only a very small number of people selected them, and no person returned to school. This may also indicate a loss of instrument sensitivity for the most able people, as the ability estimates are not as accurate for these higher functioning people with lower levels of change to their lifestyle.

Both areas of gaps in the item distribution could indicate the construct of lifestyle is underrepresented in these areas and this is known as ‘construct deficiency’, or ‘construct under-representation’ (Baghaei, 2008; Hudgens et al, 2004). Addressing the issues of construct under-representation is usually achieved by adding new items targeting this level of ability (Hudgens et al, 2004). This is recommended because “if the measure does not adequately reflect the outcome of interest, the most important outcomes may be left unevaluated” (Backman, 2005, p.259). Alternatively, the instrument could be considered to lack sensitivity or relevance for people at this level and alternatives should be explored. There were very few people at these levels so this may not be an urgent priority unless the instrument is to be used with people at these levels.

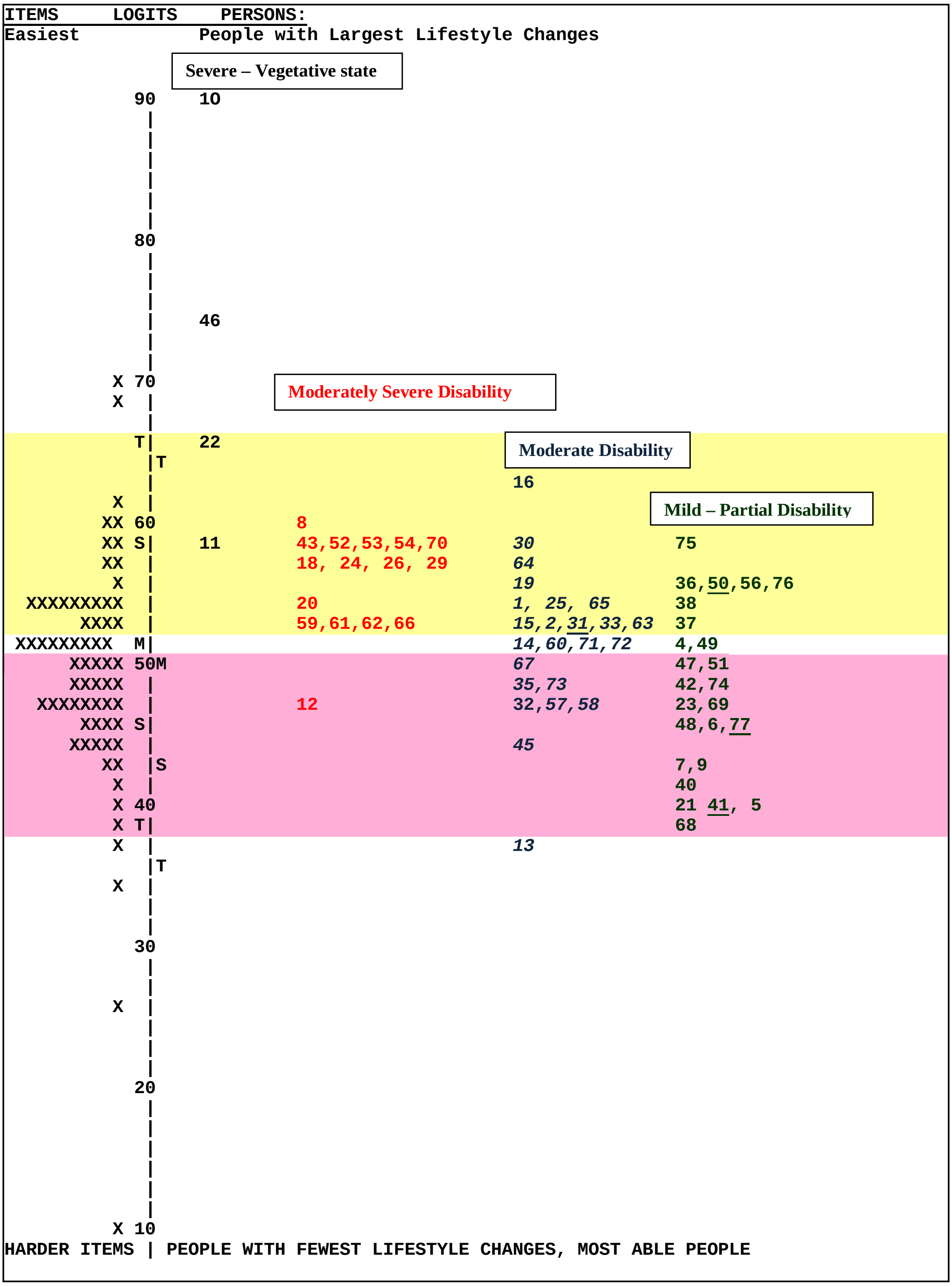
5.3.8.1.2 *Logic of Item Hierarchy*

The hierarchy of Lifestyle Assessment items found in this phase of the study was consistent with the literature on brain injury sequelae, providing some evidence for the construct validity of the measure (Wright & Masters, 1982). Items at the bottom of the Item-Person Map were the most difficult ones to return to after brain injury (Figure 5.7). Most people are expected to have difficulty resuming these activities with all but the highest functioning person with minimal lifestyle changes being able to successfully return to work, driving and find their own place to live. The location of school, college and seeking work are thought to be excessively high and their position is thought to be influenced by the very small numbers who participated in these activities. The hierarchy also reflected maintaining social relationships and activities and more complex tasks such as managing finances are more difficult for people with brain injury than typical people, suggesting the majority of people with brain injury have trouble with these activities. The literature supports the majority of people are unable to resume these activities after brain injury (Coleman et al, 2002; Kersel et al, 2001; McCabe et al, 2007).

The easiest activities are those at the top of the Item-Person Map (Figure 5.7). These activities were not a significant problem for most people, and only people who are very low functioning would be expected to have difficulty with these items. The easier activities are consistent with clinical experience and brain injury literature and include being a passenger in a car, moving around the home and the appropriateness of physical contact with others (Sloan, Winkler & Anson, 2007). The range of item difficulty and the item hierarchy for the Lifestyle Assessment supports the clinical utility of the instrument as information on how change occurs for an individual can be derived from test scores, except perhaps for those with the most severe level of disabilities.

5.3.8.1.3 *Logic of Person Hierarchy*

The Item-Person Map version 2 (Figure 5.7) contains the same type of information as in Figure 5.6 above but on this version ‘X’ is used to identify items rather than persons who are labelled to enable the logic of the person hierarchy to be reviewed. The logic of the hierarchy of people was demonstrated using the level of disability as rated by the Disability Rating Scale to distinguish those that are higher functioning from those that are lower functioning in this sample.



```
ITEMS     LOGITS    PERSONS:
Easiest           People with Largest Lifestyle Changes
            90    10
             |
             |
             |
             |
             |
             |
            80
             |
             |
             |
             |    46
             |
             |
          X 70
          X  |
             |
            T|    22
             |T
             |                                 16
          X  |
         XX 60             8
         XX S|    11       43,52,53,54,70      30             75
         XX  |             18,  24,  26,  29   64
          X  |                                 19             36,50,56,76
  XXXXXXXXX  |             20                  1,  25,  65    38
       XXXX  |             59,61,62,66         15,2,31,33,63  37
 XXXXXXXXX  M|                                 14,60,71,72    4,49
      XXXXX 50M                                67             47,51
      XXXXX  |                                 35,73          42,74
   XXXXXXXX  |             12                  32,57,58       23,69
       XXXX S|                                                48,6,77
      XXXXX  |                                 45
         XX  |S                                               7,9
          X  |                                                40
          X 40                                                21 41, 5
          X T|                                                68
          X  |                                 13
             |T
          X  |
             |
             |
            30
             |
             |
          X  |
             |
             |
             |
            20
             |
             |
             |
             |
             |
             |
          X 10
HARDER ITEMS | PEOPLE WITH FEWEST LIFESTYLE CHANGES, MOST ABLE PEOPLE
```

LEGEND: **X** =Item, **Number** = Person code, **M** = Mean, **S** = 1st SD, **T** = 2nd SD

🟨 = **Persons** within 2SD above mean for **persons**

🟥 = **Persons** within 2SD below mean

Level of Disability = Based on DRS categories. Underlined person codes = no DRS level available.

Logit scale measures person ability & item difficulty

Figure 5.7: Item Person Map (2nd Iteration, Amended Lifestyle Assessment): Persons.

The people with most significant changes to their lifestyle are located in the area at the top of the map. Five of the six people identified as experiencing the highest degree of lifestyle change had severe level of disability, two scored higher than 2SD from the mean (Participants 10, 46, 22, 8 and 11). Their location on the Item-Person map correctly identified this group all had severe restrictions on their ability to participate in activities and their lifestyle had changed enormously since they sustained their brain injuries. These people all needed 24 hour nursing care, two reside in nursing homes and the others went for regular residential respite.

Participant 16 was rated as having moderate disability on the DRS, but was considered to be correctly placed towards the top of the Item-Person map as he did not engage in almost any activity relevant to his premorbid lifestyle. In addition to brain injury this person had significant mental health problems. The Lifestyle Assessment focuses on the extent of lifestyle change measured by changes to activities, whereas at the level of activities the DRS focuses on the person’s cognitive ability to perform tasks rather than other reasons for reduced participation.

The people with lower levels of lifestyle change are located in lower half of the map. Only one person scored greater than 2SD of the person mean. The people who experienced the least changes to their lifestyle were expected to have mild or partial disabilities as reflected by DRS categories. The nine people with the lowest scores had returned to work or full time study (Participants 5, 7, 9, 13, 21, 40, 48, & 68), which may be expected of people whose lifestyles have been less disrupted by brain injury at the time of the assessment. This also matches Rasch expectations that more able people are more likely to succeed at more difficult items. Participant 13 scored as the person who had experienced the least amount of change to their lifestyle, despite having moderate disability. This person was successful at returning to full time study and was able to develop and maintain friendships. This person was able to maintain participation in two of the hardest activities, despite considerable disabilities, and the low level of lifestyle changes indicated for this person were considered an appropriate reflection of the success they achieved in rebuilding a meaningful and satisfying lifestyle.

Most people with higher levels of disability, as measured by the DRS, endorsed much higher levels of lifestyle change and vice versa. For a small group of people (10 people) this was not true. Considering each of these people in turn, the Lifestyle Assessment appeared to accurately reflect the lifestyle changes where the DRS lacked the sensitivity and specificity to reflect the person's level of disability, mainly for people with co-morbidities to traumatic brain injury such as mental health problems. Seven people (Participants 36, 37, 38, 50, 56, 75 & 76) with partial to mild disability scored above mean (50 logits), representing higher than average degree of lifestyle change. All of these had significant mental health problems that were not detectable on the DRS, and their placement at this level on the map is considered appropriate.

One person with moderately severe disability (Participant 12) scored well below the mean and two people with moderate disability (Participant 45 & 13) scored lower than might be expected. The lifestyle of participant 13 has already been reviewed. Participant 12 and 45 had very supportive social environments; they had maintained long term relationships, parenting roles and one worked on a regular but casual basis from home. Although the impact of the brain injury had been significant for both people, they were able to preserve important aspects of their lifestyle with support.

The Lifestyle Assessment was able to reflect lack of engagement in a range of other activities and relationships better than the DRS. This finding appears to reflect the reduced sensitivity of the DRS identified for people with milder disability (Harradine et al, 2004; Rappaport et al, 1992). The Lifestyle Assessment is more comprehensive at the level of activities, however for most people provided a reasonable indicator of level of disability and was considered reasonable for the purpose to which it was applied. When the DRS and individual circumstances were reviewed the hierarchy of person ability met clinical expectations that contributed to evidence for the validity of the Lifestyle Assessment to describe the varying degrees of lifestyle changes experienced by this group of people.

5.4 SUMMARY OF FINDINGS FROM CHAPTER FIVE

This stage of the study addressed the third research question, which was:

What are the measurement properties of the Lifestyle Assessment?

The following findings were identified:

Finding 5.4.1:

People are able to choose activities that are relevant to their own lifestyle from those appearing on the Lifestyle Assessment. The range of activities on the Lifestyle Assessment appeared to provide people who had a range of abilities with a sufficient range of options for identifying how their life had changed after brain injury. Some activities were selected by the majority of people and could be considered more universal. Activities that were selected by fewer people tended to be items with a greater degree of difficulty. In some cases these rarely selected activities appeared to be extremely valuable for the person concerned, for example competition level sport and their omission would have been a serious loss to understanding changes to these people’s lifestyle.

Finding 5.4.2:

The original rating scale used for the Lifestyle Assessment was not able to effectively represent increasing performance as scores increased for all items. Collapsing the rating scale so that data were analysed as a four point scale yielded a more effective scale and improved the measurement properties of the Lifestyle Assessment. Following the revision the rating scale, the Lifestyle Assessment performed as expected, where higher scores were indicative of sequentially increasing levels of lifestyle changes experienced by people with brain injury.

Finding 5.4.3:

Rasch analysis identified and informed remediation of measurement problems, and resulted in a Lifestyle Assessment scale with improved measurement properties. Information generated by these quantitative analyses supported the findings generated by qualitative methodology employed in Stage 1 and 2 of the study that sought feedback about the Lifestyle Assessment from people with brain injury and clinicians.

Finding 5.4.4:

Most items within the Lifestyle Assessment effectively measured variation in the level and nature of changes people experienced to their lifestyle after brain injury. Thirteen items continued to misfit Rasch expectations even after the rating scale was collapsed and two problematic items removed.

Finding 5.4 5:

Activities that are dependent on other people or specific environmental conditions were often identified as misfitting Rasch model expectations. Similarly, some people with severe disabilities who unexpectedly participated in a range of activities were often identified as misfitting Rasch model expectations. This may be due to the facilitative effect of good social support and adequate services.

Finding 5.4.6:

It is difficult to collect sufficient data for analysis when endorsing items is optional. Combining the flexibility of a person centred assessment with the rigorous requirements of objective measures was challenging. However, the results of this phase of the research provide initial support that it is possible.

Finding 5.4.7

Following the revisions to the items and rating scale the study provided initial information about the reliability and validity of the Lifestyle Assessment. Evidence of the reliability of the measure included the point measure correlations, proportion of variance explained by the measure and category function probabilities. These analyses demonstrated evidence that the instrument measures a single construct, termed ‘lifestyle’, which supporting both reliability and validity of the instrument. There was evidence that higher scores in the instrument indicated more lifestyle changes for the scale as a whole and all individual items. The instrument was able to identify three statistically separate levels of performance amongst people, which provided initial support for the sensitivity of the instrument. The results suggest that the Lifestyle Assessment is sensitive to changes in activities purported to measure lifestyle in people with brain injury.

CHAPTER SIX

DISCUSSION AND CONCLUSION

The purpose of this chapter is to review the research as a whole and the significance of the main findings in relation to the overall purpose of the study, which was to explore how the changes to a person's lifestyle after brain injury can be assessed. A brief overview summarising the purpose, methods and outcomes of each stage of the study is provided first. Then the major findings of the research as a whole are discussed in relation to current literature and clinical practice. Next, the limitations of the research are reviewed and the clinical, theoretical, empirical and methodological contributions of the study are identified. Finally, recommendations for future research are outlined.

6.1 OVERVIEW OF STUDY

This research was prompted by the need to address the desire, often stated by people with brain injury of 'wanting to get my life back'. For the purpose of the study, 'life' in this statement, has been interpreted as the person's 'lifestyle'. The purpose of this research was to develop an assessment with the capacity to effectively measure changes to each person life. The overall aim of the study was to address:

How can changes to an individual's lifestyle after brain injury be assessed?

The literature review confirmed that the consequences of brain injury are usually complex and unique for each person. The impact on each person's lifestyle and participation are influenced by the nature and severity of the initial brain injury and impairments, premorbid activities and interest and the circumstances in which they live (Khan, Baguley, & Cameron, 2003; Ragnarsson, 2002; Tate et al, 1989; Willer & Corrigan, 1994). To inform the study the construct of lifestyle was defined as follows to provide a conceptual foundation for the new instrument. A person’s lifestyle is a complex phenomenon that addresses a person’s participation in a meaningful range of activities that fulfil a variety of needs and purposes dependent on the interests, roles and circumstances of the person. This construct was developed from occupational therapy models, information about community integration after brain injury, and items from the ICF domain of participation. Ten existing measures relating to lifestyle were reviewed, however none were able to effectively address all key elements of an individual’s lifestyle.

The Lifestyle Assessment was constructed from the ICF and refined following feedback from a small number of people with brain injury, their carers, and a small group of clinicians. The Lifestyle Assessment was then evaluated using Rasch analysis, and revisions were made to improve the measurement properties of the new instrument.

The outcome of this study was the development of the Lifestyle Assessment, a semi-standardised criterion referenced instrument that enables individual choice in what is considered important. Law (2002) suggests the appropriateness of an outcome measure or indicator is largely determined “by the correspondence between the definition of the construct and the operationalisation of the measures’ (p.56). The findings largely address 1) the success of the measure to effectively measure lifestyle, 2) the extent to which the instrument is relevant and appropriate for people with brain injury, and 3) the adequacy of the range of items that form the Lifestyle Assessment to represent a person’s lifestyle.

6.2 DISCUSSION OF FINDINGS

This section draws together the findings from the three stages of the study to represent the overall findings from the research in its entirety. This discussion addresses each of the following main findings of the study:

Finding 1. People with brain injury were able to choose which activities were relevant to their life, although clinicians identified some different priorities.

Finding 2. The Lifestyle Assessment contains a range of activities that target the nature and degree of changes to people's lifestyle experienced after brain injury.

Finding 3. The Lifestyle Assessment is appropriate to use to measure the lifestyle changes experienced by most people after brain injury.

Finding 4. There is sufficient beginning evidence of the reliability and validity of the Lifestyle Assessment to support ongoing research into its use as an instrument to measure changes to people's lifestyles based on the perceptions of their own life.

6.2.1 People were able to choose what activities were relevant to their life although clinicians identified some different priorities

Findings from Stage Two and Three of the study indicated that people with brain injury, including those with severe disabilities, were able to choose which activities were relevant and important to their own life. In Stage Two, people were able to identify aspects of their life that were *not* on the Lifestyle Assessment. In Stage Three, people were selective in choosing activities on the Lifestyle Assessment that *were* relevant to their life. As reported by Johnston, Goverover and Dijkers (2005), people "have diverse appraisals of various community activities" and what is important to them (p.743). The Lifestyle Assessment fulfils the need for assessments that can be customised to each person and enables them to identify activities that are important to them (Heinemann et al, 2011; Heinemann et al, 2010). As with other assessments in the field of brain injury, while the aim was to measure each person's lifestyle, the assessment guidelines for this assessment required therapist or family assistance to complete the assessment where needed, particularly for those people with difficulty with self-awareness, problems and disabilities (Doig, Fleming, Kuipers, & Cornwell, 2010).

From the 72 original items available on the Lifestyle Assessment, only six items were relevant to all people; otherwise people chose a wide range of items. These findings are consistent with other research that has found most people with brain injury were able to report both the nature and extent of changes in their activities and disabilities (Doig, Fleming, Kuipers, Cornwell, 2010; Powell, Machamer, Temkin, Dikmen, 2001). Those selected by most people ranged in level of difficulty (See 5.3.8.1.1). The range of difficulty of tasks was comparable to research of similar items, and found work, relationships, managing finances to be more difficult, and shopping, moving around, managing IADL tasks to be easier for most people (Kielhofner, Forsyth, Kramer & Iynger, 2009; Malec, 2005; Mellick, 2000; Pollock et al, 1990).

Twenty four (34%) of the 72 items were endorsed by more than 95% of people, which reflects the majority of people have identified that the majority of items are relevant to their lifestyle. Eight items were rated by less than 25% of the sample, and most of these were more difficult items. These included a range of leisure and activities completed with other people such as ‘Games’, ‘Close relationships’, ‘Community organisations’ and those requiring complex skills including ‘Managing one's routine’, ‘Complex finances’, ‘Home maintenance’ and ‘Home management’. The items for ‘School’ and ‘College’ were selected by only a few people in this sample. No-one returned to school, and this appeared to have contributed to these activities being identified as the hardest in the item pool (Magasi & Heinemann, 2009). The exceptions were ‘Arts and craft’, ‘Religious Activities’, ‘Computer for pleasure’ and ‘Computer skills’, which offer legitimate and appropriate activities for people with lower levels of participation.

Data to empirically investigate the reasons for item selection were not gathered as part of this study. It is unclear why activities were chosen as relevant and others ‘dropped’. Several explanations might be proposed. First, the choice of activity might be related to years since injury as observed by other researchers (Dijkers, Whiteneck & El-Jaroudi, 2000; Tate, Pfaff, Veerabangsa, Hodgkinson, 2004). Second, Kielhofner and colleagues (2009) identified a hierarchy of activity importance that was related to capacity. People with less capacity identified basic activities as most important, and as capacity increased, activities that enabled them to manage their life became greater priorities. Only when these basic activities were no longer difficult, did client concern move to activities that contributed to quality of life, broadly reflecting Maslow’s hierarchy of needs. Third, within the context of rehabilitation, it is possible that people with more severe disabilities fail to be offered opportunities to participate in a wider range of activities that represent previous notions of ‘my life’, so they lose relevance to their current circumstances and may not be rated, even though participation may be desired.

Interestingly, clinicians identified different activities as important to people with brain injuries. Although examination of the difference was not a major focus of this research this finding is consistent with other research which has demonstrated that, while the priorities identified by people with brain injury, their families and service funders overlapped, each group assigned priorities differently, reflecting their different perspectives (Condeluci, Ferris & Bogdan, 1992). They reported while independence in activities was an agreed priority, people with brain injury then prioritised autonomous living situation, good health and adequate finances, families and payers thought communication, mobility and behaviour management were greater priorities. Richard and Knis-Matthews (2010) identified that clinicians often identified goals within constraints of the service in which they worked and made judgements on what was realistic for clients, whereas clients set goals based on the broader picture of what they wanted to achieve in life. Darragh, Sample and Krieger (2000) had mixed feedback on the degree to which clinicians acted upon the priorities of people with brain injury although the clear message was that services needed to be individualised for each person. Ensuring the insider voice in measurement is vital to empowering individuals in the rehabilitation process and enabling them to live to their full potential despite disability (Gordon, Brown, Bergman, & Shields, 2006).

These findings highlight the proposition that clinicians are unable to assume that their clinical priorities match those of the client. Although the need to tailor rehabilitation to suit the needs of each person is not new (Willer & Corrigan, 1994), it is clear that mechanisms to support this in practice are needed (Magasi & Heinemann, 2009). While the Lifestyle Assessment offers an instrument that enables client choice, Brown and Gordon (2004) report this to be only the first step to ensure client centred practice is delivered. They advise that clients need not only a choice, which they have labelled as ‘voice’, but also the ‘muscle’, as evidenced by service delivery that enables their priorities to then be acted upon in intervention and measurement.

In summary, this study provides evidence suggesting that assessment that enables *choice* in how brain injury impacts on activities that *best represent* people’s lifestyle offers a useful and valid approach to assessment of life participation (Brown et al, 2004; Deb et al, 2007; Dijkers, Whiteneck, & El-Jaroudi, 2000). The Lifestyle Assessment views clients as experts in their own experience, identifying a person's goals as the criterion standard (Brown & Gordon, 2004). The need to review the delivery of assessment and rehabilitation is important as this is considered ethical practice and improves client compliance (Doig, Fleming, Cornwell & Kuipers, 2009; Durgin, 2000; Johnston, Goverover & Dijkers, 2005; Magasi & Heinemann, 2009; Malec, 2009; Sumison, 2005). This identifies future research directions that the Lifestyle Assessment could take, involving not only whether the instrument truly represents clients' views of their own life, but how this can be incorporated into rehabilitation processes to ensure the 'insider's voice' is supported in practice.

6.2.2 The Lifestyle Assessment contains a range of activities that are targeted to reflect the nature and degree of changes to people's lifestyle experienced after brain injury.

The amended Lifestyle Assessment contains 70 items that are considered to 1) represent *a range of activities* that are relevant to people with different levels of lifestyle changes, 2) *different levels of disability* after brain injury and, 3) a *sufficient number* of activities to reflect the variation in people's lifestyles. Results presented in Chapter Five indicated that the Lifestyle Assessment contains items that cover a broad range of lifestyle change, which means it is appropriate to people with different levels of participation. Participants in this study could choose activities in the instrument that were relevant, enabling participants with different types of lifestyle to be measured using the same instrument. Within the scope of the instrument, bias derived from rating non-relevant items is largely removed.

In relation to the *scope* of the instrument, most of the items are well targeted to describe the level of lifestyle changes experienced by the people with brain injury in this research. In some cases the ‘easier’ activities could be considered direct precursors to more difficult activities. For example, preparing simple meal, and cleaning the cooking area were identified by participants as easier activities, in comparison to complex meals and cleaning living areas. Although the relationship between sets of other activities in the instrument is less obvious, the result of Rasch analysis does reflect that activities vary in level of difficulty based on the perception of the people doing them.

This study generated an *item difficulty hierarchy* that reflects the items that change the most to the least after brain injury, offering beneficial information for clinical practice. For example, if people identify rehabilitation goals that target activities that are too difficult for their current level of ability, activities on the hierarchy positioned closer to their level of ability may provide an appropriate starting point for intervention (Kielhofner & Forsyth, 2001; Nott, 2008). The item hierarchy provided information about the sequential level of difficulty which people either resumed or experienced change in their lifestyle after brain injury and could be used to guide identification of treatment priorities (Fisher, 1992b, 2003; Griffin, 2007).

The scope of the instrument was found to be limited at either end of this hierarchy, but particularly for the most disabled people. The four participants who experienced the highest degrees of lifestyle change effectively had no items of equivalent difficulty on which estimates of their ability could be based. The two items that do represent this level both misfitted the Rasch model expectations. Additional items are needed at this level to represent the level of lifestyle change experienced by people with severe disabilities. It is clear that future development of this instrument involve people with this level of disability in identifying what activities are relevant to them. It is possible that more basic self-care activities including eating, ‘being part of things’, being cared for, may be appropriate items for people with the most disabilities (Chapparo & Ranka, 1997, p.5). Other leisure options might be appropriate to add such as watching a movie or sitting at the family dinner table. While some leisure activities, such as art, music and computer use were relevant to some of the participants in this study, the level of challenge and nature of participation may be different for people with severe disability, and warrants separate items from those included in the current version. This is consistent with views of other researchers who have identified these types of activities to have greater meaning for people whose capacity for occupational performance is largely restricted by severe disability (Chapparo & Ranka, 1997).

While overall the items within the instrument function effectively and target different levels of ability, some items continued to misfit Rasch model expectations. Until these items have been addressed the stability of the item hierarchy will need further review. Items with poor fit statistics can still be summed to calculate measures but they can distort the results (Linacre, 2010b). Several factors were thought to contribute to these results. Inadequate data on some items prevented robust analysis of their measurement properties. Analysis with a larger data set is recommended however while this will improve the precision of estimates it would not remediate items that are not effective. The results also suggest many of these items would benefit from review to ensure the item descriptions are relevant to the range of person ability, and revised, or additional items created where the variation is too large to be considered within a single item.

The item ‘Driving’ was misfitting in this study despite the very strong evidence that driving is difficult after brain injury (Olver, Ponsford & Curran, 1996). The item description seemed appropriate but only a small number of participants scored other than a score of five. In this study a much higher proportion of this sample were unable to drive compared to published figures (Coleman et al, 2002). The lack of data for a score other than five, considered together with the few people with moderate disability who were still driving suggests no further amendment to this item at this time. Further evaluation of these items when the instrument is administered to a larger sample is warranted.

Similar issues were found for the item ‘Human powered transport’. However in this case non-participation was strongly influenced by choice as well as capacity. Motivation to resume bike riding was affected for some people, even though they had the physical capacity, and for others this was so important to them they resumed it despite moderate disabilities. Comparing them to people who were unable to resume is misleading, even though in this study both may have scored five. The instructions could be expanded to identify how to score items where non-participation is largely through choice.

The data generated by this study also suggests the need to amend several items. The ICF items descriptions that formed the basis for the study are quite broad, and this may have contributed to the misfit of some items. Within some items, there appeared to be different levels of challenge to participation. Clarifying how these should be scored or creating new items may be warranted. For example, for items like ‘Art & crafts’, ‘Music’ and ‘Sport’, unusual ‘talent’ in an activity enables participation in activities of greater complexity and can be seen as idiosyncratic to that person. Other people who have a more passive style of participation, or those involved at a very basic level with supported community services may require similar item accommodation. Similarly, voluntary work depends on the organisation and what roles are available and considered appropriate by the person. In this study the people who engaged in voluntary work did so in quite different capacities dependent on their abilities and what roles organisations had available. For one person voluntary work provided a source of structure and supervision, while another person provided high level contributions to support the organisation. Both levels of participation were meaningful for the people who engaged in them. Separate items would enable the difference in the level of performance to be more accurately reflected.

Similarly, for the interpersonal interaction items, the presence of problems with behaviour did not appear to be solely related to level of disability. For some, this appears to reflect how ratings were made for people with problematic behaviours who were high and low functioning. Additionally people who did not respond in social situations may have needed different items to address this than these items that focused on inappropriate or difficulty behaviour during social interactions, although both types of behaviour are considered challenging (Marin & Wilkosz, 2005). Clearer guidelines on how to score people with different levels or types of behaviour may facilitate a consistent approach to scoring and address the invariance identified in these items.

The *items about relationships and interpersonal interactions* were of particular interest in the results of this study. The number of items that were identified as part of a separate dimension dropped from three to one after the revisions to the rating scale. This suggested item error was involved in this separate factor, which remained too small to be considered meaningful for removal from the instrument at this stage. In the literature there seem to be some inconsistencies in how social relationships are viewed (Chapparo & Ranka, 1997; Jette, Tao & Haley, 2007; McColl et al, 1998; WHO, 2001). In occupational therapy literature, the social relationships one has form part of the context of a person’s social environment, and interpersonal interactions are considered performance components within the context of all activities, rather than a specific set of ‘social activities’ per se (See for example, Chapparo & Ranka, 1997). In the ICF social relationships are included under participation and also mentioned as being part of one’s environment (WHO, 2001). In other studies factor analyses have demonstrated several factors, including a distinct one for social relationships, exist within items from the ICF Activities and Participation domain (Jette, Tao & Haley, 2007). It is possible different studies yield different results because different ‘domains’ may be ascribed dependent on the context and nature of any interaction.

Relationships, because of their complexity are possibly harder to describe than other items on the instrument. Social behaviour depends on the quality of interaction with other people, and thus the success of a person’s behaviour can be largely affected by the way the other person behaves (Ylvisaker & Feeney, 1998). After brain injury, family are often providers of care and support, and the nature of relationships may be affected by the burden of care plus dealing with changing roles and behaviour of the person with brain injury.

Literature demonstrates, for example, how friendships can change in terms of frequency of contact, the quality of the relationships or can be lost altogether (Callaway, Sloan & Winkler, 2005; Eames, et al, 1996; Olver, Ponsford & Curran, 1996). The people involved in friendship relationships may be old or new, and can include friendships with other people with disabilities or their carers (McCluskey, 2000). While meaningful, this represents a distinct change from the type and meaning of pre-injury relationships (Johnston, Gorerover & Dijkers, 2005; McColl et al, 1998).

The relationships one has provide a context in which other activities need or want to be performed, and conversely, activities are only considered meaningful when they are performed in the context of one's relationships and within their community (Callaway, Sloan & Winkler, 2005; Hammel et al, 2008; Salzberg &Langford, 1981). Activities have their own value, and sometimes this can include providing opportunities for social contact. In the second phase of the research clinicians identified the need to develop a different set of relationship descriptors from the other activities. Exploring the nature and experience of changes in relationships is recommended and may warrant the development of different items in the future, to capture these complexities.

The item for 'Mood and emotional state' was added from Body Functions at the request of clinicians, but is also listed as a health condition for 'Mood disorder in the ICD-10 (WHO, 2007). Mood impairments can be independent from the ability to participate in tasks as this can affect people across the continuum of ability. This is different to the other interpersonal interaction items in the instrument that relate to engagement with others. This conceptual difference may contribute to the misfit of the item 'Mood' and may indicate it should not be included in the instrument.

This study has identified groups of items that are relevant to lifestyle but also appear to be strongly influenced by factors not included in the Lifestyle Assessment. The item where people obtained unexpected scores contributes to the misfit identified for both these items and persons, yet the hierarchy of person ability was logical and expected. In this sense these items contribute to the understanding of lifestyle changes but are not as constructive for measurement (Bond & Fox, 2007; Linacre, 2010b). Aspects of each person's environment and the degree to which these support participation are currently not included in the assessment. Exploring those factors that impacted their resumption and participation in activities discussed in the lifestyle assessment would be a useful step forwards to improve how the relationship between these are understood and addressed in rehabilitation (Mallinson & Hammel, 2010).

Strategies to improve misfitting items have been proposed. Item revisions would only be considered successful when evidence of improved measurement properties of the instrument and items are obtained (Linacre, 2010b).

Ultimately decisions regarding whether to retain these items will depend on whether the clinical utility of the item outweighs the measurement noise contributed by problematic items. This judgement is frequently made during test development as invariance is the exception rather than the rule (Bond & Fox, 2007; Kean, Malec, Altman & Swick, 2011; Tate, 2011). In the meantime clinical interpretation of scores on these items must be informed by knowledge of these results, particularly in regards to those items where it is difficult to predict scoring based on person ability alone.

6.2.3 The Lifestyle Assessment is appropriate to use to measure the lifestyle changes experienced by most people after brain injury

The Lifestyle Assessment could distinguish between groups of people with different levels of lifestyle change (See 5.3.7.1). The analysis of the Lifestyle Assessment generated a logical hierarchy of individual people that distinguished people with different levels of lifestyle change reflecting their level of disability and person circumstances (See 5.3.8.1). In this way the Lifestyle Assessment might be considered to validly reflect one aspect of the ‘lived experience’ of disability after brain injury for each individual (WHO, 2001, p. 229; Wright & Masters, 1982). People with increasing levels of disability were generally identified by the instrument as experiencing greater levels of change to their lifestyle. While the Disability Rating Scale, a measure designed to monitor global progress after outcomes, was not always sensitive to the complex myriad of people's disabilities, the Lifestyle Assessment could detect the variation in people's experience even when their level of disability was compounded by co-morbidities such as mental health problems or reduced due to the positive affect of supportive environments. However, there was a reduction in the precision and sensitivity of the instrument for people with the highest levels of lifestyle change in particular, and to a lesser extent for people with the lowest levels of disability (See Section 5.3.8).

Results reported in Section 5.3.7.2 indicated there were some anomalies in the way a small number of people with severe disabilities who lived in the community performed on the Lifestyle Assessment. Initially this suggested the nature of participation for people with severe disabilities was different but a review of these people indicated that they had very good social support and continued to live in the community despite severe disability. These people had limited capacity but their environments, both through living in the family home and having families who made choices in their best interests, provided opportunities to maximise their active participation as much as possible, which is consistent with other findings (Dijkers, Whiteneck & El-Jaroudi, 2000; Durgin, 2000; Sloan, Balicki & Winkler, 1996; Tham & Kielhofner, 2003). It appears that this facilitative affect was relevant to only a specified number of activities and could not mediate the impact in other areas, which would explain why these people were identified as misfitting, as their pattern of performance in tasks of similar level of difficulty was variable.

In brain injury rehabilitation there is increasing attention being paid to the environment in which people live as both contextual factors that support or hinder participation, and as the focus of intervention (Badley, 2006; Feeney, 2010; Fleming et al, 2009; Glover, 2003; Whiteneck, Gerhart & Cusick, 2004; Winkler, Sloan, & Callaway, 2007; Swan, & Alderman, 2004; Tham, & Kielhofner, 2003; Young People in Nursing Homes Alliance, 2010;). Dijkers, Whiteneck and Al-Jaroudi (2000) point out “one’s residence dictates to a large degree the number, variety and nature of roles and relationships’ (p.S64). In line with findings of this study, Vangel, Rapport and Hanks (2011) demonstrated the variable impact of the social environment in which people live. Their study demonstrated positive carer behaviour and those with good support were able to moderate the effect of level of disability, cognitive impairment and distress; and that the reverse was true for people with poor support.

The performance of this group was in contrast to the two other most severely disabled people, who lived in nursing homes, did not have the same opportunities or support and consequently participated in almost no activities. These two people did not misfit the Rasch model. The difference in performance for these two groups of severely disabled people suggests it is unlikely that reliance on proxy raters contributed to the misfit. This is consistent with other studies which have reported the reliability of proxy rating (Cusick, Gerhart, & Mellick, 2000).

Results of the study demonstrated that people with co-morbidities were more likely to misfit the Rasch model. It is probable that problems with social and behavioural items generate changes in participation in a different way to people with brain injury without co-morbid conditions. There are several alternative explanations for this result. First, the items for social relationships and interaction have been identified as requiring review.

Second, participation is dependent upon people who may be involved in the rating process, and who may act to either facilitate or hinder performance. Whilst only a small proportion of unexpected variance was explained by these items it does highlight the need for further investigation in this area of the instrument.

At the other end of the continuum, people who demonstrated ‘talent’, or ‘special skills’, and were identified as high performers, were able to preserve important aspects of their lifestyle even in the presence of other disabilities and impairments (Badley, 2006). There were few items targeted for people at this level, which will have impacted on the precision of estimates, with related reduction of sensitivity of the scale for this group. Addition of items to represent people with this level of disability that considered special talent, or high levels of competence is recommended.

Finally, the review of misfitting people also identified some people who were able to participate in harder tasks despite problems in other areas. The findings of this group are consistent with results by Doig, Fleming, and Tooth (2001) which identified a distinct pattern of participation and identified a group who resumed productive work but at the expense of participation in household, community and social activities. For this group, the ‘cost’ of performing a much harder than average activity, appears to have come at the expense of other easier activities. This could be explained by the findings of Dumont and colleagues (2004) who identified positive person factors, such as perceived self-efficacy and determination can contribute to greater resilience and social participation after brain injury. The motivation or will to perform some activities over others may be driven by a person’s self identity: *“that’s something that a me sort of person does”* (Ylvisaker, McPherson, Kayes, & Pellett, 2008, p.715).

While the instrument shows promise, caution would be advised when using the Lifestyle Assessment for clinical purposes with people with severe disability living in nursing homes and higher functioning people where talent or unusual skills enables them to maintain their participation in certain activities. Clinical interpretation of test results for these groups needs to accommodate the variable performance on these items may indicate stronger impact of factors other than participation. Further research to investigate the effect of environment, motivation and talent on participation in activities completed in the context on a person’s life is recommended as this could inform clinical practice (Dumont, Gervais, Fougeyrollas & Bertrand, 2004; Mallinson & Hammel, 2010; Kielhofner & Forsyth, 2001).

6.2.4 There is sufficient evidence of the reliability and validity of the lifestyle assessment as an emerging instrument to measure changes to people’s lifestyles based on their own life.

This study developed a criterion-referenced assessment that showed the potential to distinguish different levels of ability of performance against the criterion (Glaser, 1983, 1961; Griffin, 1963). The concept of criterion-referenced assessments have undergone considerable revision since inception and are now closely aligned to the Rasch requirement whether thresholds identify separate different levels on a single performance continuum (Bond & Fox, 2007; Glaser, 1963, 1983; Griffin, 2005). Rasch analysis was ideally suited to evaluate the properties of the Lifestyle Assessment, which was conceptualised as a criterion-referenced assessment that considered a person’s ability relative to the level of difficulty of the task and the context of performance (Bond & Fox, 2007; Griffin, 1995, 2007).

Crucial evidence of the measurement properties of the scale included the reliability by which items differentiate people of different ability, the validity of the items to the underlying scale and the effectiveness of the rating scale to measure these. After revision, the rating scale functioned as expected, with increasing scores demonstrating increasing degrees of lifestyle change for all items. There is evidence the instrument works well for the majority of people after brain injury, but may lack sensitivity for people who are both very high functioning, particularly where unusual ‘talent’ or skill’ contributes to preserving their lifestyle, and for those most severely disabled. Problems with some items were identified even after the revision process. No further action to remove or amend the instrument further is recommended until there is a larger data set upon which to base decision. In line with findings about the affect of the environment on people, the items that did not meet expectations were those where the presence of other people or other particular environmental requirements were a prerequisite for participation. The problems and strategies to address these are consistent with development experience of similar tools (Kielhofner & Forsyth, 2001; Kielhofner, Forsyth, Kramer & Iyenger, 2009). This study has demonstrated relevance and appropriateness for people with brain injury, consulted clinicians regarding clinical utility and demonstrated promising results in relation to the measurement properties of this instrument.

This study has described the development and initial validation of the Lifestyle Assessment that is consistent with recommendations that assessment needs to accommodate the unique lifestyle and needs of each person. Participants at the International Symposium on Measurement in Participation Research highlighted the need, and questioned whether it could be achieved, to develop measurement systems that was able to account for differences in the meaningfulness and relevance of activities for different people, given “the texture of people’s lives is quite varied” (Heinemann et al, 2010, p.S73). The analysis completed has provided initial evidence that the Lifestyle Assessment measures a sufficiently uni-dimensional construct to justify using summed scores for all items, while enabling people to choose which items were relevant to their lives (See 5.3.5). The benefits of the mixed methods approach used in this study, which included qualitative and Rasch data analysis, is consistent with other reports that this “can lead to the development of instruments that are conceptually and psychometrically robust as well as sensitive to and representative of the values of multiple stakeholder groups” (Magasi & Heinemann, 2009, p.938).

Although this assessment is criterion-referenced, at a certain point this becomes closely aligned with what is ‘normal’. Dijkers, Whiteneck and El-Jaroudi (2000) report “deviation is central to the concept of disability” (p.S67). The issue arises when addressing the priorities of individual is that what is ‘normal’ for them may be a different experience from that of most people. They propose that enabling the person with brain injury to identify when thresholds of performance have been reached is one solution that remains challenging in its attempt to straddle subjective and objective phenomenon.

The instrument is less successful for people at either end of the scale as has been discussed. Further revision to expand the range of the items is recommended to enable it to be used across the continuum. Given the impact environmental supports can have on functioning it is recommended these be assessed together to explore the interaction between the person, their activities and environment and increase the sophistication of the instrument to detect the complexity of the ‘lived experience’ after brain injury (Mallinson & Hammel, 2010; WHO, 2001, p.229). The analysis provided initial evidence the Lifestyle Assessment is able to detect levels of lifestyle change experienced by people but sensitivity to detect statistically significant change over time requires objective analysis.

6.3 LIMITATIONS OF STUDY

Limitations of the research have been examined prior to the evaluation of the significance and contributions of the study. Where possible, attempts were made to minimise the impact of the limitations during the study design. The findings of the research or recommendations for further research are not considered to be seriously affected by the limitations that have been identified.

6.3.1 Stage One: Limitations of Initial Instrument Construction

The primary limitation at this stage of the study was that the ICF was essentially used verbatim as the basis for instrument construction, despite some awareness of the limitations. This was an appropriate procedure for the initial stages of instrument construction as at the time, there was little evidence of the significance of its shortcomings to clinical practice. The ICF was advocated as a as solution of many clinical needs in health and other arenas and applying the model in its published form afforded an opportunity to test the potential benefits in practice.

6.3.2 Stage One: Limitations of Interviews with People with Brain Injury and their carers

There were several limitations of the qualitative approaches used in this stage of the study. First, only a small number of participants from a single service were involved and had only a small role. Limitations in sampling may have affected the information provided. Three of the four people involved had severe disabilities which may have provided a skewed picture of lifestyle related activities that may not be representative of the wider brain injury community’s preferences (Streiner & Norman, 2003).

Second, time constraints limited the number and duration of interviews that could be completed within the scope of this project. Interviews were not continued until the interviewees identified no further changes, known as sampling to redundancy (Streiner & Norman, 2003). The time allocated was intentionally restricted, as the interviews were completed in the context of clinical practice and clinical needs were considered paramount. However the interviews yielded activities that were included in the assessment, and highlighted that people with brain injury and clinicians can have different views on what should be the priorities.

The third limitation was that the topic addressed during the interviews and focus groups was not the construct of lifestyle per se, but the instrument designed to measure this. Greater focus on what lifestyle meant to participants may have provided other suggestions for item inclusion in the instrument. Fourth, the revisions made as result of this process were not reviewed again by people with brain injury prior to the pilot study. Although this second review may have assisted in gaining further insight into the relevance, clarity, and language used for the assessment, it was outside the constraints imposed by this project. This will be incorporated into recommendations for future research.

6.3.3 Stage Two: Limitations of Focus Group Methodology Used in the Study

There are several limitations of the data collected from the focus group in this study. The individuals who comprised the group and nature of interaction between them influence the information obtained through focus groups (Kreuger, 1984). The smaller numbers within a single group may have limited the total range of experience possible (Kreuger, 1994). While five members made recruitment and management of the interviews easier, this fell short of the recommended number of 6-12 members (Kreuger, 1994). Inclusion of staff from additional disciplines to make a larger clinical reference group may have yielded different feedback than obtained from the members in this study. The chosen focus group were staff members of a single brain injury service in the UK, within which the tool was developed and piloted. To this extent focus group members were homogenous as allocation was not representative of wider opinion. The issues discussed during the focus group were not transcribed verbatim. Written notes of the main points discussed were made to support revision of the tool. Transcribing the complete discussion from the group may have yielded more details.

6.3.4 Stage Three: Limitation with Quantitative Study

The sample size in this study is lower than the recommended sample size of 100-250 to calculate fit statistics and principal components analysis (Arrindell & van der Ende, 1985; Linacre, 2003). There was insufficient data to obtain reliable estimates on some difficult items, but despite this the study has produced evidence to support the reliability and validity of the early form of the Lifestyle Assessment. In Rasch analysis, the size of the sample required to produce reliable estimates is determined by several factors: the number and quality of items, the degree to which the sample are matched or targeted to the level of difficulty of the items (Linacre, 1994). The present study has provided information about what levels of difficulty need the most attention. Revisions made in response to data analysis have also improved the measurement properties of the instrument. The recommendations to increase the number of items, or at least amend them would suggest that a much larger sample is needed for subsequent analysis. While a convenience sample was appropriate for this stage of the study more selective criteria may be needed for the next stage. A sample with an even spread of levels of disability, including those with lower and higher levels would provide improved information about the usefulness of the instrument.

This study has provided initial information about the properties of the Lifestyle Assessment, but some questions remain unanswered. The responsiveness of the instrument to measure change over time to support its use as an outcome measure is considered a priority. Rater reliability has not been investigated. Understanding and addressing error associated with items was considered the priority of this research before further aspects of reliability can be addressed.

The Lifestyle Assessment aimed to measure changes in the nature of participation in a balanced range of activities considered meaningful to each person's life. Although the pattern of activities can be determined from the 'lifestyle maps' and timetables developed in Stage 2**,** the degree to which the range of activities was perceived to be balanced was not objectively determined in this study (See 3.9.1.4). Informal feedback suggests that the Lifestyle maps demonstrate the overall pattern of change, and the timetables provide temporal information about when activities are performed, and often the very large tracts of time spent doing nothing or passive and often solitary activities. Given the benefits of Rasch analysis that have been identified using an objective approach to provide visual display of a person's pattern of responses across activities of different type and difficulty is recommended. Assessing the environmental factors that affect performance received cursory examination and considered an important area for further study.

6.4 CONTRIBUTIONS OF STUDY

The methodology and results of this study have made contributions to clinical practice in brain injury rehabilitation, to empirical and theoretical knowledge and to the methodology for instrument construction.

6.4.1 Clinical Contribution

The development and refinement of the Lifestyle Assessment has made a potentially significant contribution to brain injury rehabilitation by providing an assessment tool that enables individual choice while providing an objective measure of a person's participatory function. The assessment provides clinically useful information that accommodates the nature and extent of changes in activities they consider relevant to them and could be considered to reflect their 'lived' experience of disability after brain injury. The Lifestyle Assessment offers an assessment approach that acknowledges the elements involved for someone to 'get my life back', the aim of this study, by giving people choice and control through enabling people to identify how brain injury had changed their lives (Brown & Gordon, 2004; Darragh, Sample & Krieger, 2001). Another second important contribution was the demonstration that activities, people and the environment intersect to facilitate participation. This highlights the need to more formally consider environmental factors in assessment and intervention.

This study demonstrated the gap that continues to exist between the theory and practice of client centred therapy (Bright et al, 2012). Evidence that clinician priorities did not agree with client's priorities is concerning, given the many benefits of a client centred approach. This highlights the urgent need for clinicians to review not only their assessment approach but the processes needed across the board to provide client centred services.

6.4.2 Empirical Significance

Data were generated in the course of this research that supports process of application and limitation of ICF in clinical practice, and to understand lifestyle changes after brain injury. To date there is little data published about the range of activities considered relevant by people with brain injury, and service and theoretical models drive this information. The data support the use of the Lifestyle Assessment in clinical practice, including those for whom it is appropriate in its current form, and those for whom it is not, providing the basis upon which further research can be completed.

6.4.3 Theoretical Significance

This study links the theories of occupational therapy, participation and community integration. Highlighted in particular, is the need to enable client choice, which is common to all three epistemologies. Information about the relative difficulty of common activities relevant to lifestyle has also been provided that can be used to support clinical reasoning.

6.4.4 Methodological Significance

Use of mixed methods to develop client-centred assessment instruments is deemed essential (Magasi & Heinemann, 2009). This research supports the proposition that people with brain injury and clinicians can collaborate on instrument construction and both add value to this process. This study described the process to develop an objective assessment that accommodates the needs of individual. The study demonstrated how Rasch analysis can be used to evaluate and improve the degree to which the criterion-referenced items contributed to an objective measure of different levels of lifestyle change experienced by people after brain injury (Glaser, 1981; Griffin, 2007; Wright & Masters, 1982). The practical aspects of applying the ICF in clinical practice were identified. Finally, this study involved the development and application of desired criterion to inform construction of an instrument for a given purpose (Fisher, 1992a).

6.5 RECOMMENDATIONS FOR FURTHER RESEARCH

In line with recommendations by Hanley et al (2004), the inclusion of people with brain injury in planning further research as well as a role as participants will be explored. This is supported by current health system initiatives where inclusion of health service consumers is now recognised in legislation (Tebbutt, 2009). The findings from this study have identified several areas for future research.

6.5.1 Further qualitative research is recommended which may aim to:

- Explore the perceived impact of environment in facilitating a person's participation in activities relevant to their lifestyle, particularly when the level of disability is severe.
- Explore the value of being asked to identify what activities are relevant to people and being involved in developing rehabilitation programmes that genuinely reflect people's own priorities. In response to this, people with brain injury can act as further referents to judge whether the activities addressed in the Lifestyle Assessment meet aim of describing 'their life' and whether these 'provide a reason for living' (Durgin, 2000).
- Explore protective benefits of 'talent' in maintaining a satisfying lifestyle.
- Explore people's views on the changes to their lifestyle and factors that they feel contribute to resuming previous activities and develop new ways of participating

where the level of participation has changed or resumption of previous activities is no longer possible.

6.5.2 Further Quantitative Research is Recommended:

- After further qualitative review and confirmation of the appropriateness of the revised instrument, further quantitative analysis of the Lifestyle Assessment items with a larger data set is recommended to provide further evidence of the measurement properties and appropriateness of the Lifestyle Assessment. Investigation of the instrument's sensitivity to reflect change over time is recommended at this stage, now that the basic measurement properties of the instrument have been confirmed.
- Given the impact participation on people's lifestyle future research should aim to incorporate both participation in relevant activities and aspects of the environmental and personal factors that support or hider performance that may contribute to a more sophisticated multidimensional model to support clinical practice (Bond & Fox, 2007).
- Development of a keyform chart to provide a visual display of results from the Lifestyle Assessment. This is gaining momentum as an approach to improve the clinical relevance of test results in rehabilitation assessments and could be generated from data produced in this study (Badge, Bentnall & Gillis, 2008; Kielhofner, Dobria, Forsyth & Basu, 2005). Keyform charts enable clinicians to identify an estimate of the Rasch generated interval level person ability estimate from the ordinal raw scores from the instrument and demonstrate the pattern of a person's performance over easier and harder items. The keyform charts would

provide a more objective alterative to the Lifestyle Maps described in this study while offering similar information.

- Other measurement properties also need exploration, including test-retest reliability, proxy versus clinician ratings and rater reliability, which ideally would be considered as a separate factor using facets multidimensional analysis.

6.6 CONCLUSION

This research focused on measurement of how a person's lifestyle changes after brain injury. A new instrument was developed based on items from the ICF and qualitative information from people with brain injury, their carers and clinicians to offer people choice to describe what their lifestyle involved and how this was disrupted by brain injury. The Lifestyle Assessment offers a clinically appropriate tool to measure lifestyle changes experienced after brain injury effectively. While the study provided initial evidence of the reliability and validity of this instrument several issues require further exploration. This is the beginning of a line of research to develop and refine the instrument.

The Lifestyle Assessment presents an objective assessment approach that is a shift towards person-centred assessment, recognising individuals are unique and make their own choices about which activities are important to them. This research demonstrated that people are able to identify what activities are important to them and that this may be different from the priorities identified by clinicians. This research recommends clinicians need to empower people with brain injury and ensure they are able to identify their own priorities. In doing so, occupational therapy and rehabilitation services might be enhanced and partnerships between the person with brain injury, their family and rehabilitation professionals might be strengthened.

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APPENDIX I

The Lifestyle Assessment (Version 1, Study 1) (5 pages)

The Lifestyle Assessment, Version 1

Page 1 of 5

NAME:	**DATE:**	**ASSESSOR:**

Scoring Instructions for qualifiers of ACTIVITIES AND PARTICIPATION

Score	**% assistance**	**Definitions of level of difficulty and amount of assistance required for participation**	
0	0 – 4%	No difficulty	Requires no or negligible assistance
1	5 – 24%	Mild difficulty	Requires slight or low level of assistance
2	25 – 49%	Moderate difficulty	Requires medium or fair amount of assistance
3	50 – 95%	Severe difficulty	Requires high or extreme level of assistance
4	96 – 100%	Complete difficulty	Requires total assistance
8		Not specified	
9		Not applicable	Person did not engage in activity / participation prior to onset of health condition; lack of participation not due to a health condition

Participation restriction in life situations for the purposes of this tool needs to be as a consequence of a health condition eg, brain injury, disease. For accurate scoring you need to be aware how a person performed prior to the brain injury. You need to ask how did the person participate in each dimension / task before onset, has participation changed since the brain injury and by how much? How much assistance do they need to perform the task now?

Activities / Participation	**Performance Score**	**Capacity Score**	**Comment**
GENERAL TASKS AND DEMANDS			
Undertaking a single simple task: Carrying out simple co-ordinated actions related to the mental and physical components of a single task; such as initiating a task, organising time, space and materials, pacing task performance, carrying out, sustaining and completing a simple task without the assistance of others. A simple task has a single major component, such as reading a book, writing a letter or making a bed. Task performance does not include acquiring skills, solving problems or making decisions.			
Undertaking a single complex task: requirements as for simple task but a complex task which has more than one single component, which may be carried out in sequence or simultaneously, such as arranging the furniture in one's home or completing an assignment for school, without the assistance of others.			
Undertaking multiple simple tasks independently: preparing, initiating and arranging the time and space for multiple simple tasks, and managing and executing co-ordinated actions as components of several integrated tasks together or sequentially, on one's own without the assistance of others; such as watching the TV and reading the newspaper and wiping the kitchen bench.			
Undertaking multiple complex tasks: As for multiple single tasks but related to completion of tasks which have several major components; such as putting on a load of washing and cleaning the bathroom and paying the household bills.			
Managing & completing the daily routine: carrying out simple or complex and co-ordinated actions in order to plan, manage and complete the requirements of day-to-day procedures or duties, including arranging the energy and time demands required; such as making plans and scheduling several activities through the day and managing one's own activity levels. This is separate to undertaking multiple tasks.			
COMMUNICATION			
Conversation: starting, sustaining and ending an interchange of thoughts and ideas carried out by spoken, written or other form of communication with one or more person in any setting; including introducing oneself, taking turns in speaking, introducing new ideas and bringing closure to the topic.			
Using telecommunication devices: such as telephones, faxes, mobile phones for purposes of communication.			
Using computers or other writing machines for purposes of communication.			
Writing: using or producing symbols or language to convey information, such as producing a written or printed record of events or ideas or drafting a letter.			
MOBILITY			
Moving around within the home: walking or moving around by any means eg. Wheelchair, around one's own home, including within a room, between rooms, from floor to floor and around the whole residence or living area.			
Moving around within buildings other than the home: Moving around other people's homes, community and private buildings and enclosed areas.			
Moving around outside the home and other buildings: Walking or moving around using a wheelchair close to or far away from one's home and other buildings without the use of private or public transportation such as moving / walking for short or long distances around the neighbourhood, town or village.			

The Lifestyle Assessment, Version 1

Page 2 of 5

NAME:	**DATE:**	**ASSESSOR:**

Scoring Instructions for qualifiers of ACTIVITIES AND PARTICIPATION

Score	**% assistance**	**Definitions of level of difficulty and amount of assistance required for participation**	
0	0 – 4%	No difficulty	Requires no or negligible assistance
1	5 – 24%	Mild difficulty	Requires slight or low level of assistance
2	25 – 49%	Moderate difficulty	Requires medium or fair amount of assistance
3	50 – 95%	Severe difficulty	Requires high or extreme level of assistance
4	96 – 100%	Complete difficulty	Requires total assistance
8		Not specified	
9		Not applicable	Person did not engage in activity / participation prior to onset of health condition; lack of participation not due to a health condition

Participation restriction in life situations for the purposes of this tool needs to be as a consequence of a health condition eg, brain injury, disease. For accurate scoring you need to be aware how a person performed prior to the brain injury. You need to ask how did the person participate in each dimension / task before onset, has participation changed since the brain injury and by how much? How much assistance do they need to perform the task?

Activities / Participation	**Performance Score**	**Capacity Score**	**Comment**
TRANSPORT			
Using private motorised transportation: being transported as a passenger by private motorised vehicle over land, sea or air, such as a taxi or privately-owned aircraft or boat			
Using public transportation: being transported as a passenger by a motorised vehicle over land, sea or air designed for public transportation, such as being a passenger on a bus, train, subway or aircraft. Ask the person do you now need to use public transport because you are no longer able to drive due to the brain injury? If yes, do score current performance.			
Driving human-powered transportation: driving a human-powered vehicle, such as a bicycle, tricycle, or rowboat.			
Driving motorised vehicles: driving a vehicle with a motor, such as an automobile, motorcycle, motorboat or aircraft.			
LOOKING AFTER ONE'S HEALTH			
Looking after one's health: ensuring physical comfort, health and mental wellbeing such as by maintaining a balanced diet, appropriate level of physical exercise, keeping warm or cool, avoiding risks to health and to prevent ill health such as physical injury, communicable diseases, drug taking and sexually communicated disease's by getting physical check ups, getting immunisations, taking precautions, seeking professional assistance.			
DOMESTIC LIFE			
Acquiring a place to live: buying, renting, furnishing and arranging a house, apartment or other dwelling *Inclusions: buying or renting a place to live and furnishing a place to live*			
Shopping: Obtaining, in exchange for money, goods & services required for daily living, including shopping in a shop or market, using the internet or instructing an intermediary to do shopping. Shopping includes selecting food, drink, cleaning materials, household items or clothing, comparing quality & price of items required, negotiating and paying for selected goods and transporting the goods.			
Preparing simple meals: organising, cooking and serving meals with a small number of ingredients that require easy methods of preparation and serving, such as making a snack or small meal, and transforming food ingredients by cutting and stirring, boiling and heating food such as rice or potatoes. Includes selecting edible food and drink, getting together ingredients, cooking with heat and preparing cold foods and drinks and serving the food.			
Preparing complex meals: planning, organising, cooking and serving meals with a large number of ingredients that requires complex methods of preparation and serving, such as planning a meal with several dishes, and transforming food ingredients by combined actions of peeling, slicing, mixing, kneading, stirring, presenting and serving food in a manner appropriate to the occasion and culture. Also includes selecting ingredients, using heat to cook.			
Cleaning cooking area & utensils: cleaning up after cooking, such as by washing dishes, pans, pots & utensils; cleaning tables and floors around cooking and eating area.			
Cleaning living area: cleaning the living areas of the household, such as by tidying and dusting, sweeping, swabbing, mopping floors, cleaning windows and walls, cleaning bathrooms and toilets, cleaning household furnishings			

The Lifestyle Assessment, Version 1

Page 3 of 5

NAME:	**DATE:**	**ASSESSOR:**

Scoring Instructions for qualifiers of ACTIVITIES AND PARTICIPATION

Score	**% Assistance**	**Definitions of level of difficulty and amount of assistance required for participation**	
0	0 – 4%	No difficulty	Requires no or negligible assistance
1	5 – 24%	Mild difficulty	Requires slight or low level of assistance
2	25 – 49%	Moderate difficulty	Requires medium or fair amount of assistance
3	50 – 95%	Severe difficulty	Requires high or extreme level of assistance
4	96 – 100%	Complete difficulty	Requires total assistance
8		Not specified	
9		Not applicable	Person did not engage in activity / participation prior to onset of health condition; lack of participation not due to a health condition

Participation restriction in life situations for the purposes of this tool needs to be as a consequence of a health condition eg, brain injury, disease. For accurate scoring you need to be aware how a person performed prior to the brain injury. You need to ask how did the person participate in each dimension / task before onset, has participation changed since the brain injury and by how much? How much assistance do they need to perform the task?

Activities / Participation	Performance Score	Capacity Score	Comment
DOMESTIC LIFE cont.			
Using household appliances: using all kinds of household appliances, such as washing machines, dryers, irons, vacuum cleaners and dishwashers			
Washing & drying clothes & garments: washing clothes & garments by machine or hand and drying them by machine or hanging them out to dry.			
Disposing of garbage: disposing of household garbage such as by collecting trash and garbage around the house, preparing garbage for disposal, using garbage disposal appliances, eg. Taking bin out for rubbish collection			
Simple household maintenance: Maintaining and repairing household and other personal objects including replacing light bulbs or washers in taps , repairing simple fixtures or furniture			
Taking care of plants and garden: such as by watering plants, weeding, trimming and caring for plants, mowing lawn			
Assisting others: Person has primary role in assisting or caring for others with their self care, movement within the house or outside, communication interpersonal skills, nutrition and health maintenance.			
MANAGING FINANCES / MONEY			
Basic economic transactions: engaging in any form of simple economic transaction, such as using money to purchase food or bartering, exchanging goods or services; or saving money			
Complex economic transactions: engaging in any form of complex economic activity that includes maintaining a bank account, paying the household bills, buying major household appliances, arranging pensions or loans.			
EDUCATION AND EMPLOYMENT			
School education: Engaging in all activities required for participation in school and curriculum activities, including learning course material, taking directions from teachers, organising, studying and completing tasks and projects. Co-operating with other students, engaging in school responsibilities			
College or higher education: Engaging in all activities required for advanced educational programmes in colleges, universities and professional schools and learning all aspects of the curriculum for certificates, diplomas, degrees and other accreditations.			
Vocational education: engaging in all activities and curriculum for vocational education programme. Excludes on the job vocational skill training.			
Apprenticeship (work preparation): engaging in training related to preparation for employment, such as performing the tasks required of an apprenticeship, internship, articling and in-service training; generally work place based.			
Seeking employment: locating and choosing a job, in a trade, profession or other form of employment, and performing the required tasks to get hired, such as preparing a CV, preparing for and participating in a job interview			

The Lifestyle Assessment, Version 1

Page 4 of 5

NAME:	**DATE:**	**ASSESSOR:**

Scoring Instructions for qualifiers of ACTIVITIES AND PARTICIPATION

Score	% assistance	Definitions of level of difficulty and amount of assistance required for participation	
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4	96 – 100%	Complete difficulty	Requires total assistance
8		Not specified	
9		Not applicable	Person did not engage in activity / participation prior to onset of health condition; lack of participation not due to a health condition

Participation restriction in life situations for the purposes of this tool needs to be as a consequence of a health condition eg, brain injury, disease. For accurate scoring you need to be aware how a person performed prior to the brain injury. Also ask whether the person now does extra tasks because they are no longer working as a result of the brain injury. You need to ask how did the person participate in each dimension / task before onset, has participation changed since the brain injury and by how much? How much assistance do they need to perform the task?

Activities / Participation	Performance Score	Capacity Score	Comment
EDUCATION AND EMPLOYMENT cont.			
Paid employment: engaging in all aspects of work, as an occupation, trade, profession or other form of employment, for payment, as an employee, full or part time, or self-employed, doing the required tasks of the job, attending work on time as required, supervising other workers or being supervised, and performing required tasks alone or in groups			
Non-paid employment: engaging in all aspects of work in which pay is not provided, full-time or part-time, including organised work activities, doing the required tasks of the job, attending work on time as required, supervising other workers or being supervised, and performing required tasks alone or in groups, such as volunteer work, charity work, working for a community or religious group without remuneration. Include working around the home only when this is the primary productive role for that person.			
COMMUNITY LIFE, RECREATION AND LEISURE			
Informal associations: engaging in social or community associations, organised by people with common interests, such as local social clubs or ethnic groups eg. Rotary Club, Bridge Club, gym or leisure centre			
Formal associations: engaging in professional or other exclusive social groups, such as associations of lawyers, physicians or academics eg. Women Engineers Group,			
Play: engaging in games with rules or unstructured or unorganised games and spontaneous recreation, such as playing chess or cards, board games or children's play.			
Sports: engaging in competitive and informal or formally organised games or athletic events, performed alone or in a group, such as bowling, gymnastics or soccer			
Arts and Crafts: engaging in activities such as painting, drawing and handicrafts, such as pottery or knitting			
Reading: performing activities involved in the comprehension & interpretation of written language for the purposes of obtaining general knowledge or specific information eg. Books, instructions, newspapers in text or Braille or computer.			
Computer: Using a computer for recreation and enjoyment; does not include use for purposes of communication.			
Socialising: engaging in informal or casual gatherings with others for purpose of socialising, without leaving present accommodation or environment.			
Visiting: visiting friends or relatives or meeting in public places for purpose of socialising.			
Religion and spirituality: engaging in religious or spiritual activities, organizations and practices for self-fulfilment, finding meaning, religious or spiritual value and establishing connection with a divine power, such as is involved in attending a church, temple, mosque or synagogue, praying or chanting, meeting religious persons or leaders, actively using time for a religious or spiritual purpose.			

The Lifestyle Assessment, Version 1

Page 5 of 5

NAME:	**DATE:**	**ASSESSOR:**

Scoring Instructions for qualifiers of ACTIVITIES AND PARTICIPATION

Score	**% assistance**	**Definitions of level of difficulty and amount of assistance required for participation**	
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8		Not specified	
9		Not applicable	Person did not engage in activity / participation prior to onset of health condition; lack of participation not due to a health condition

Participation restriction in life situations for the purposes of this tool needs to be as a consequence of a health condition eg, brain injury, disease. For accurate scoring you need to be aware how a person performed prior to the brain injury. You need to ask how did the person participate in each dimension / task before onset, has participation changed since the brain injury and by how much? How much assistance do they need to perform the task now?

Activities / Participation	Performance Score	Capacity Score	Comment
INTERPERSONAL RELATIONSHIPS			
Friendship relationships: Creating and maintaining friendship relationships that are characterised by mutual esteem and common interests			
Family relationships: Creating and maintaining relationships with one's parents, children, siblings and extended family eg. Cousins, aunts etc.			
Intimate and romantic relationships: Creating and maintaining close or romantic emotional and physical relationships between individuals, by beginning and maintaining interactions with others in a contextually and socially appropriate manner. Includes relationships that could lead to long term intimate relationship such as lovers or sexual partners and established relationships such as husband and wife, long term partners.			
Informal social relationships: entering into relationships with others, including introducing oneself, and beginning and maintaining interactions with others in a contextually and socially appropriate manner, such as casual relationships with people living in the same community or residence, or with co-workers, students, playmates or people with similar backgrounds or professions *Inclusions: informal relationships with friends, neighbours, acquaintances, co-inhabitants and peers*			
Formal relationships: creating and maintaining specific relationships in formal settings, such as with employers, professionals or service providers *Inclusions: relating with persons in authority, with subordinates and with equals*			
INTERPERSONAL INTERACTIONS			
Interacting according to social rules: acting independently in social interactions and complying with social conventions governing one's role, position or other social status in interactions with others			
Maintaining social space: Ability to maintain a distance between one self and others that is contextually, socially and culturally appropriate			
Regulating behaviours within interactions: regulating emotions and impulses in interactions with others, in a contextually and socially appropriate manner; includes controlling verbal and physical aggression, tears, euphoria, depression			
Social cues in relationships: giving and reacting appropriately to signs and hints that occur in social interactions; includes responding to the feelings of others.			
Criticism in relationships: providing and responding to implicit and explicit differences of opinion or disagreement, in a contextually and socially appropriate manner			
Physical contact in relationships: making and responding to bodily contact with others, in a contextually and socially appropriate manner			
Tolerance in relationships: showing and responding to understanding and acceptance of behaviour, in a contextually and socially appropriate manner			
Respect, warmth and appreciation in relationships: showing and responding to consideration and esteem, satisfaction and gratitude, in a contextually and socially appropriate manner			

APPENDIX II

Participant Information Sheet

Participant Information Letter

Participant Consent Form

Relative Consent Form

Ethics Application

Participant Information Leaflet for Study:

DEVELOPING AN ASSESSMENT TO MEASURE THE IMAPCT AND OTUCOME AFTER ACQUIRED BRAIN INJURY

Participant Information Sheet

ABOUT THE STUDY

The primary aim of the research is to support the development and measure the effectiveness of a new assessment. The Lifestyle Assessment is a semi-structured interview which aims to measure the impact the brain injury has had on your ability to participate in important activities and social roles. I hope this new tool helps us to understand how the brain injury has affected your everyday life. Many people after brain injury state ‘they want to get their life back’, and this assessment should assist rehabilitation professionals to understand what was important in your life. I hope that better understanding of the impact of the brain injury on your life will enable your family, friends and services to offer better support to you.

The Lifestyle Assessment has been based on the new International Classification of Functioning, Disability and Health, published by the World Health Organisation in 2001. It has been developed over the past few years in both England and Australia as part of clinical service development and as part of a Doctorate of Philosophy Degree. Your participation will help me to ensure the Lifestyle Interview will be more sensitive to changes that can occur for several years and more accurately measure the real life impact brain injury has on an individual and their family.

WHAT WILL PARTICIPATING IN THE STUDY ACTUALLY INVOLVE?

I will explain what participating in the study actually involves and will be happy to discuss this with you in further detail. The process would start with an interview with you and a family member or other person, to find out more about you and things you did prior to the brain injury and what you spend your time doing now. I will want to discuss what has changed in your daily routine and relationships and how much your life has changed. The nature of this change and how you feel about this will be useful information. I will ask for information about your schooling, work history, interests and responsibilities. This interview usually takes up to 1,1/2 hours to complete. I will also use information about your brain injury and details such as your age and living and work situation.

The second part of the assessment involves completing a formal assessment of your ability to complete practical daily tasks. You will be asked to choose 2 or 3 activities you usually or used to do from a list provided such as making coffee and toast, vacuuming or making a bed. This will provide information about how you are currently managing and how the brain injury has impacted on your ability to complete activities. Following the two parts of the assessment, you will be offered feedback via a brief summary report with some basic recommendations. I can also speak to you or your family member about ideas to help you.

WHAT WILL HAPPEN AFTER THE ASSESSMENTS HAVE BEEN COMPLETED?

Following assessment you and a relative/carer will be offered a feedback session to discuss the results of the assessments. If you are interested we can also send you a summary of the research once it has been completed. We will be able to offer support to the local services to use the test results in deciding how best to work with you to minimise problems and maximise your recovery.

You are under no obligation to take part in the study. Whether you do or not will not influence the service you receive from your local service or any other Acquired Brain Injury Service. I am happy to discuss the study further if you have any questions. If you would like to participate in the study please contact Helen Badge on 01582 709 020 to arrange an appointment.

Participant Information Letter

Acquired Brain Injury Service
Disability Resource Centre
Poynters House, Poynters Road
Dunstable, Bedfordshire
LU5 4TP

Tel: 01582 709037 (internal 2037)
Fax: 01582 709057 (internal 2057)

Date
Address
Dear Mr/Ms

Re - (Participant Name)

I am currently carrying out a study to develop an assessment aimed at measuring the impact brain injury can have on an individual’s life, routines, activities and relationships. We all know brain injury can have devastating consequences for both the individual and their family. I’m hoping that developing an assessment sensitive to people’s own lifestyles will enable rehabilitation professionals to tailor therapy to assist people to ‘get their lives back’.

I enclose an information sheet that will just give you an outline of the study and consent form for completion. I would grateful if you could complete the consent form if you wish for (participant name) to participate in the study and return it in the envelope provided. If you have any questions please contact me. I can call you back should ringing a mobile phone be a problem for you or leave a message including your details and I will return your call as soon as I am able.

Thank you for your assistance.
Yours sincerely

Helen Badge
Occupational Therapist

Participant Consent Form

PARTICIPANT CONSENT FORM

Developing an Assessment to Measure the Impact and Outcome after Acquired Brain Injury

Participant Name ……………………………………..……………………….

- I give my consent to participate in the study.
- I understand the information given in the handout explaining the purpose of the research.
- I understand that the results of the assessments will be kept anonymously as part of the study information.
- I understand that the results of the study may be shared with other clinical staff and may be published but that I will not be identifiable in any way.
- I understand that I can withdraw from the study at any time should I wish to, without giving an explanation.
- This form will not influence the service I receive from any service I am currently involved with as a result of my brain injury.

Signature…………………………………………………... Date ……………………..…

Witnessed by (signature)…………………………………………………………..…

Relationship to participant…………………………..……..Date………………………

Relative Consent Form

RELATIVE CONSENT FORM

Developing an Assessment to Measure the Impact and Outcome after Acquired Brain Injury

As the participant named may have difficulty giving informed consent to participate in this study I have been nominated to give consent on his/her behalf.

Participant Name ……………………………………..……………………….

- I give consent for the participant to participate in the study.
- I understand on behalf of the participant the information given in the handout explaining the purpose of the research.
- I understand on behalf of the participant that the results of the assessments will be kept anonymously as part of the study information.
- I understand on behalf of the participant that the results of the study may be shared with other clinical staff and may be published but that the participant will not be identifiable in any way.
- I understand on behalf of the participant that he/she can withdraw from the study at any time should he/she wish to, without giving an explanation.
- This form will not influence the service the patient receives any services.

Signature:…………………………………….…………………….Date:……..……

Name: …………………..……….……Relationship to participant:…………………

Witnessed by
(signature):……..………………………………………………Date:……………………

Ethics Application

Ethical approval for this study was sought in two stages. The initial project commenced as part of a larger study investigating potential to predict outcome, which is not addressed in this thesis. Approval for this study was obtained through South Bedfordshire Community Care Trust Ethics Committee, UK in 1999 - 2000. When the present study was identified as a separate study to be completed as part of a higher degree separate approval was sought through the University of Hertfordshire, England, once the researcher was enrolled as a post graduate student.

FORM PEC1

UNIVERSITY OF HERTFORDSHIRE
PSYCHOLOGY DEPARTMENT ETHICS COMMITTEE

Session 2002 - 2003

Application for approval of a study involving human subjects carried out by a PhD student/Staff member or an undergraduate student with a problematic ethics approval request.

Investigators are advised to consult their supervisor and read the Ethical Guidelines of the Psychology Department at this University. Please ensure that you supply adequate information to enable the Ethics Committee to judge whether your study complies with the spirit of the guidelines (http://psynes.herts.ac.uk/guidelines.html).

All applications must be word processed and signed by the supervisor. Try to answer each point within 100 words but attach additional information if appropriate.

1. **Study Title:**

Measuring the impact of disability on lifestyle.

2. **Name:**

Helen Badge
- Undergraduate year 1
- Scheme of study: MPhil Psychology
- Supervisor: Professor Ben Fletcher
- Director of Studies:

3. **Chair of School/Departmental Ethics Committee or Chair of School/Departmental Research Committee**
Name:

4. **Background and research aims of the programme** (state aims or hypotheses as precise as possible):

Aims:
1. Development of assessment tool to adequately measure the impact of brain injury on a person's lifestyle and functioning.
2. Validation of this same assessment tool.
3. Measurement of outcome, including level of ability and participation, for a population of adults at various stages following brain injury using existing standardized measures.

Hypotheses:
1. The more severe the initial brain injury will result in greater changes in a person's lifestyle and daily functioning.
2. The extent and amount of support offered by social networks will effect the impact of brain injury. That is, a person with severe brain injury may engage in a range of premorbid activities as a result of the level of support offered by others.
3. The ICF Lifestyle Assessment will demonstrate more accurately the full extent of the impact of brain injury on a person's lifestyle and functioning.

Background:
Measuring outcome after brain injury is a difficult process due to the complex nature of problems after brain injury. Many of the existing outcome measures for brain injury were based on the International Classification of Disability and Handicap (ICIDH), published by the World Health Organisation in 1980. However there is currently no tool currently available that measures outcome that reflects normal activities and wellness, rather than just the negative consequences of disease in terms disabilities (Greenwood, 1999). The ICIDH has been revised and the International Classification of Functioning, Disability and Health (ICF) was published in 2001. The current research involves the development and analysis of a new assessment tool, based around the new ICF designed to measure the impact of brain injury and other health conditions on a person's everyday functioning.

The ICF recognises that the experience of disability and handicap occur due to the complex interaction between the disease, impairments and the physical, social and cultural environment in which an individual lives (Greenwood, 1999; Badley,1995). This is commensurate with the practice of occupational therapy. Several authors (Johnston et al,1991; Wood and Badley, Greenwood, 1999) and others have identified the need for research and for the development of appropriate tools for assessment and outcome using the ICF.

At it's heart the ICF has been adapted in order to evaluate a clients current level of functioning and activities, measure the change that has occurred from pre-morbid functioning, describe client centred needs, support the development of specific rehab treatment goals and measure the effectiveness of community based rehabilitation programmes after brain injury and other health conditions (Greenwood,1999; Unsworth, 2000; Gray at al, 2000; Johnston et al, 1991). The ICF Lifestyle Assessment is a comprehensive semi-structured interview and scoring system designed to reflect the person's pre-morbid and current lifestyle and quantify the level of change. In so doing so it is hoped to measure the impact of the injury / health condition on a person's ability to return as far as possible to previous activities and life situations, the primary long term goal of most rehabilitation programmes.

The Lifestyle Assessment has been developed over the past year through clinical pilots, focus groups with clinicians and discussing issues regarding outcome with client's and their families. A semi-structured interview is completed with the client and their primary caregivers. Information from this interview, combined with knowledge of the person's capabilities is later used to score the level of change. Information regarding their routine specific activities the person participates in the context of their own life is gathered. The preliminary questionnaire are 45 items that cover issues such as mobility, transport, household tasks, managing finances/money, education & employment, leisure and recreation, communication and managing one's own routine.

Preliminary scoring guidelines have been modified from the ICF to make them more appropriate for clinical use and to enhance reliability. Details for scoring include information regarding the need for varying levels of assistance, supervision or difficulty, frequency of participation, happiness with level of performance and level of change with each activity. Scores are awarded for pre-morbid and current performance and an assessment regarding their likely capabilities without their current supports. Finally the assessment considers the change in social relationships and social activities, interpersonal behaviours and the level of support offered by various people around the client, eg. family, friends, health professionals. Separate scoring guidelines are available for these areas.

The initial study will discuss the development and application of the ICF Lifestyle Assessment with people with acquired brain injury. Following this the psychometric properties of the assessment will be measured. Validity will be gauged by comparing the Lifestyle Assessment with a range of existing standardised measures. These include Assessment of Motor and Process Skills (an occupational therapy behavioural assessment designed to measure the level of disability; Fischer A., 1984), Barthel Scale and Community Integration Questionnaire (Willer, 1994). The relationship between the Lifestyle Assessment and measures of injury severity including lowest Glasgow Coma Score (Teasdale & Jennett, 1984) and length of Post Traumatic Amnesia (PTA) and specific cognitive impairment including the ability to learn will also be measured.

The assessment will be refined following this analysis and the final study will then further evaluate the psychometric properties of the tool. Additionally the sensitivity of the Lifestyle Assessment to measure change in a person's functioning will be evaluated. Assessments will be repeated with as many people as possible approximately 6 months after their initial ICF Assessment. Assessments will be completed with people with multiple sclerosis or brain injury so performance of the assessment with people with different conditions can be evaluated.

5. **Number of subjects:** 150 - 200

6. **Nature of subjects:** Adults with acquired brain injury

7. **Confirmation of subject availability**
   Bedfordshire Heartlands Primary Care Trust have confirmed subjects can be obtained through existing services.

8. **Probable duration of programme:** from July 2002 – July 2005

   Ethical approval obtained from Local Research Ethics Committee, Luton & Dunstable Hospital in 2001,

9. **Where will the study take place?**
   i. The study will be mainly completed in Bedfordshire, within the Brain Injury Service. Additional data will be periodically obtained from subjects in Sydney, Australia.
   ii. Current Contact details: Ph: 00 61 2 94111 291
   Fax: 00 61 2 94111 291
   Email: helenbadge@hotmail.com
   iii. Study Contact details: PH: 01582 709 037
   Fax: 01582 709 057
   Email: helenbadge@hotmail.com

10. **Description of procedures to be used.** Give sufficient detail to the Committee to be clear what is involved in the programme. (Continue on separate sheet if necessary.)

Clients will be requested to participate in one or two interviews. Lasting approximately 1-1.5 hours each. During the interviews they will be asked questions regarding their premorbid and current functioning in regards daily routine, activities, social relationship and behaviour. They will also be asked brief questions form standardized assessments. Some questions can be scored by the examiner without participant responses.

The participant will also be asked to complete a standardized functional assessment. This will involve the completion of two household / community tasks such as preparing bacon and eggs, vacuuming, shopping. The time required depends on the tasks chosen and the capability of the participant. Most assessments take 0.5 – 1 hour to complete.

The whole assessment process will be repeated 6 months after the initial assessment to measure change.

A sample of approximately 20 participants will have repeat testing completed within 2 weeks of assessment via a brief interview re any changes that have occurred in their routine.

The assessments that will be used include the following:

I. The ICF Lifestyle Interview is a semi structured interview aimed at measuring the degree to which participation in activities, social relationships and behaviour has changed as a result of brain injury and other health conditions.

II. The assessment of motor and process skills is a standardized objective functional assessment

III. Glasgow Coma Scale is a brief standardised assessment tool to describe the depth of altered consciousness after cerebral trauma, from mild confusion to deep coma. It can be used to distinguish the severity of the brain injury.

IV. The Disability Rating Scale is a standardised assessment designed to charter patients progress from coma and back to the community, taking into account impairment, disability and handicap due to brain injury.

V. The Barthel Scale is a brief standardized objective assessment of the level of assistance needed for basic self care activities and can be used to document the level of disability.

11. Will the study involve the use of invasive procedures NO

12. Will the study involve the administration of any substance(s)? NO

13. Are there any other potential hazards to subject(s) and/or investigator(s) from the proposed investigation?

No adverse effects are anticipated from participation in the study. As this research forms part of the normal service provided by the Acquired Brain Injury Service, the same standard of professionalism and ethical considerations will be accorded to those participating in the study, as all patients who are referred to the service.

14. Might the study cause discomfort or distress of a mental or emotional character?

YES

If YES, please indicate its nature and the precautions to be taken:

In essence the assessments completed for the purpose of the study mirror the normal routine for patients seen by the Acquired Brain Injury Service. If any participants report or exhibits feelings of distress following assessment they will be offered expedient access to support provided by a Clinical Psychologist. Following assessment a brief summary and general recommendations will be given to each participant or their carer. Should any participant experience changed levels of distress they will be offered a session with the researcher or Clinical neuro-psychologist to discuss any issues. As with all patients for the service further follow up services can be arranged as necessary through local services as appropriate, eg. Mental health, Headway.

15. State previous experience of the supervisor, or academic staff applying for a standard protocol, of investigations causing hazards, risks, discomfort or distress as specified.

The principal researcher has worked as an occupational therapist for 12 years, primarily with brain injury and neurological services. She has currently been employed as a rehabilitation case manager for people after severe brain injury for 5 years. This role involves providing support, comfort and advice to each client and their family as necessary. The associate supervisor for the research is a Senior Consultant Clinical Neuro-psychologist with *** experience who has worked in a variety of brain injury, mental health services.

16. Is it likely that medical or other aftercare may be needed by subjects?

YES

17. If YES, who will provide the aftercare?

Aftercare will be provided by Dr Gary Kupshik, Consultant Clinical Psychologist and Helen Badge, Occupational Therapist as part of the Acquired Brain Injury Service.

18 (a) Have those who will be asked to provide aftercare been informed of the nature of the study?

YES

(b) Have they confirmed that the aftercare can be provided free of charge to the subjects?

YES

Most participants will be existing clients of the Acquired Brain Injury Service. This is an NHS Service provided free of charge.

19. Information to Participants

Please refer to attached information and consent forms that will be provided to every participant and/or their guardian / primary care giver. It clearly states on the information sheet and the consent form that participants are free to withdraw at any time without giving a reason.

The initial phase of the research aims to evaluate current clinical practice of the Acquired Brain Injury Team. During the initial contacts a leaflet outlining the role of the Acquired Brain Injury Team is given to the patient and/or their family and this is fully explained. As the three month point approaches patients will be invited to participate in the research element of the study. Given the nature of acquired brain injury informed consent will be difficult to obtain from many patients eligible for participation in the study. Consent will be requested, where necessary from the patient's family. Advice from the Ethics Committee will be appreciated in how to address this if this arrangement is insufficient.

An information sheet describing the proposed study will be provided to the patient and their family along with a consent form which they can complete and return if they want to be included in the study. These forms are included in Appendix 3. As well as explaining the background of the research, the following will be made clear to all participants and their families:

- Information derived from the assessments will be confidential.
- Informed consent is indicated by signature on the consent form.
- Participation in the study is voluntary, and non participation will not affect their status for further assessment and intervention with the Acquired Brain Injury Service.
- All data kept by the Team with regard to the study will be identified using a numbered code only.

(a) Will it be necessary to obtain explicit consent from (or on behalf of) the subjects participating in the proposed study?

YES

Please refer to the copy of the consent form for further details.

(b) How long before they take part in the study will subjects' consent be sought?

1 week

(c) What will subjects be told as to the nature of the investigation?

PLEASE REFER TO ATTACHED COPY OF THE INFORMATION TO BE SUPPLIED.

(d) Will subjects be given an opportunity to put questions to the investigator, arising from what they have been told?

YES. The assessment is a semi structured interview and many answers may be more fully discussed. At the end of the interview the participant will be asked if there is anything further they wish to discuss or comment on regarding the impact of their brain injury.

(e) Will subjects consent be requested:

- after briefing orally and in writing?		YES
- after they have been briefed in writing?		NO ?
- after oral briefing?		NO ?
- some other way?	GIVE DETAILS	NO ?

(f) How will consent be recorded (e.g. signed, completed questionnaire as consent etc.):

Please refer to copy of consent form with copy of information provided to each participant.

20. **If the subject is a minor, or is otherwise unable for any reason to give full consent on their own, state whose consent will be obtained (subject and/or**

parent and/or guardian and/or head teacher and/or other (to be specified)), and how will it be obtained.

Consent from guardian's / primary caregivers will also be obtained due to the possibility that problems related to the brain injury will limit ability to give fully informed consent. Please refer to attached form for consent requested from participants guardian's and / or primary caregivers / next of kin.

21. **Financial Rewards**
(a) Is the investigator receiving any financial or other reward connected with this project?

NO

(b) Is any one else receiving financial or other reward connected with this project?

NO

22. **Are personal data of any sort (including name, age, sex, or occupation, etc.) to be obtained from or in respect of the subjects?**

YES

(a) If YES, give details.
Demographic information including age, sex, occupation, socioecomonic status (through occupation), medical history . living situation will be obtained. Whilst names will be known for existing clients to the service, all information held for purposes of research will be stored through coded system to preserve anonymity / confidentiality.

(b) Indicate what steps will be taken to prevent the disclosure of personal data beyond the immediate investigative team.
Computers for the service have restricted password access to prevent any person outside the immediate investigative team. Data is stored in line with NHS standards and guidelines re privacy and confidentiality.

(c) Indicate what assurances about the security and the non-disclosure of personal data will be given to subjects.
Information regarding this will be included in the information sheet given to all participants. As the data will be used for clinical purposes as well as for research the assessment will be held on patient files where applicable. The Trust can provide leaflets re storage of confidential information.

23. Any other relevant matters:
Due to personal circumstances the participant will be returning to Australia for brief periods throughout the proposed study period. It is possible that data may be obtained during this time from participants in Australia. The same protocol will be adhered to, except participants will be recruited as volunteers through Headway, a charitable organization who provides long term support services to people after brain injury and their families.

Cont.

24. DECLARATION BY APPLICANT

(I) I confirm that, in formulating the above proposal, I have complied with the following ethical code(s)

(SPECIFY CODE(S) HERE):

(ii) I undertake to abide by accepted ethical principles to the best of my ability in carrying out or supervising this programme.

(iii) Data relating to identifiable subjects will be treated as confidential and not passed to others without the written consent of the subject.
Where the subject is minor, or is otherwise unable for any reason to give full consent on their own, or to receive full explanation of the nature of the investigation and its risks, 'subject' in this context is to be understood as referring to the person or persons having responsibility for the subject of the investigation (see sections 19 and 20 above).

(iv) The nature of the investigation and all possible risks will be fully explained to potential subjects. Where the subject is a minor, or is otherwise unable for any reason to give full consent of their own, or to receive full explanation of the nature of the investigation and its risks, 'subject' in this context is to be understood as referring to the person or persons having responsibility for the subject of the investigation (see sections 20 and 21 above).

(v) All subjects will be informed that they

(a) are not obliged to take part

and

(b) may withdraw from the programme at any time without disadvantage, or having to give a reason.

(vi) I will inform the Ethics Chair immediately and before continuing the research if there is any change in the protocol or duration of the programme and seek approval.

Name of applicant

Signature of applicant

Date

Cont.

25. DECLARATION BY SUPERVISOR

I confirm that the proposed study has been appropriately vetted within the School in respect of its aims and methods as a piece of research; that I have discussed this application for Ethics Committee approval with the applicant and approve its submission; that I accept responsibility for guiding the applicant so as to ensure compliance with the terms of the protocol and with any applicable Code(s) of Practice.

Name of Supervisor

Signature of Supervisor

Date

26. DECLARATION BY DIRECTOR OF STUDIES

I confirm that the proposed study has been appropriately vetted within the School in respect of its aims and methods as a piece of research; that I have discussed this application for Ethics Committee approval with the applicant and approve its submission; that I accept responsibility for guiding the applicant so as to ensure compliance with the terms of the protocol and with any applicable Code(s) of Practice.

Name of Director of Studies

Signature of Director of Studies

Date

27. Signature of Chair of School/Departmental Research/Ethics Committee

I confirm that I am aware of and agree the above proposal.

Name

Position

Signature

Date

APPENDIX III

The Lifestyle Assessment (Version 2, Study 2) (9 pages)

Administration Guidelines, The Lifestyle Assessment Version 2

The Lifestyle Assessment

Patient Name: **Date of Assessment :**
Others present & relationship to patient:

The Lifestyle Assessment is a semi structured interview designed to identify what people do and how the injury has changed their usual routine. The interview should be completed with the client when possible, and often it is helpful for someone who knows them well to also be present. The assessment aims to measure the impact of brain injury on a person's lifestyle with a particular focus on the tasks they perform and social activities that they participate in. You will need to gather information regarding what activities they performed prior to the injury and what activities they currently perform. Try to capture changes in the activities that people do. What has changed: amount of time, frequency, quality of performance, satisfaction with performance?? Scoring should be done based on information from the client, their family/ primary carers as well as your own judgement as a clinician. What information do the notes have regarding this E.g. From AMPS assessment? Discussing scoring as multidisciplinary team may be beneficial.

Introducing the Assessment

The activities we do can shape the way we feel about ourselves and the way other people see us. I want to talk to you about the sorts of activities you did before the brain injury, the things you do now and how these have changed. I'm interested in the general everyday things that you do as well as how often you do these things, how satisfied you are with your performance, how important the activities were/are to you and how you see yourself. First I'll ask you about where you are living and how you are managing basic self care activities (do not score this section).

Accommodation	**PRE MORBID ACCOMODATION**	**CURRENT ACCOMODATION**
Type:	Bungalow/terrace/semi-detached/flat	Bungalow/terrace/semi-detached/flat
Ownership:	Owner occupied/private landlord/Council/Housing Association	Owner occupied/private landlord/Council/Housing Association
Access and Layout: Bathroom/ Bedrooms/ steps/ external:		
Did you arrange to move in and furnish your home?	Who made arrangements, how long ago?	Who made arrangements? Did you need to find somewhere else to live after your ABI?
Self Care Activities	**PRE MORBID FUNCTIONING**	**CURRENT FUNCTIONING**
Able to wash and dress, groom? Need for assistance / equipment? Does it take longer than previously? Current Barthel Score		
Able to manage toileting, cContinence, menstruation? Need for assistance / equipment? Frequency of accidents?		
Eating / drinking:		

I'd like move on by asking you about your usual routine in the weeks preceding the injury/illness. After that, we'll consider your normal weekly routine now. Then I may need to ask extra questions about some of the activities you do, or changes you describe to understand the impact that this injury/illness has had on your life. Do you have any questions?

DAILY ROUTINE

Describe a typical week prior to your accident. Can you tell me how you spend your time and what things you usually do on each day of the week now? Do you need help to manage and complete your daily routine? Do you find you have enough to do; do you do have the opportunity to do things you feel are important? And enjoyable?

USUAL DAILY ROUTINE: Pre morbid		**After Injury**
7 – 9AM		
9 – 11 AM		
11AM – 1PM		
1 – 3PM		
3 – 5PM		
5 – 7PM		
7PM ONWARDS		
SLEEP ROUTINE		
SPECIFIC SCHEDULED ACTIVITIES THROUGH THE WEEK		
MONDAY		
TUESDAY		
WEDNESDAY		
THURSDAY		
FRIDAY		
SATURDAY		
SUNDAY		

ACTIVITIES & PARTICIPATION	**DESCRIPTION OF FUNCTIONING**	
	PRE MORBID	**CURRENT**
HOUSEHOLD TASKS		
Are you able to obtain, in exchange for money, goods & services required for daily living, including shopping in a shop or market, using the internet or instructing an intermediary to do shopping. Shopping includes selecting food, drink, cleaning materials, household items or clothing, comparing quality & price of items required, negotiating and paying for selected goods and transporting the goods.	Where did you shop? HOW OFTEN? How long does it take? Did they buy their own clothes?	Do you need someone with you? How do you get there. Score need for assistance with transport under shopping AND Transport. Satisfaction?
Are you able to prepare and cook simple meals? Includes selecting edible food and drink, gathering ingredients, organising, preparing cold or cooking with heat, and serving meals. Meals made with a small number of ingredients that require easy methods of preparation and serving, such as making a snack or small meal, and transforming food ingredients by cutting and stirring, boiling and heating food such as rice or potatoes.	How often did you cook complex meals. IS it routine or only on special occasions.	What sort of meals do you cook now? Give examples on what you have cooked in the past week/ few days. (Most AMPS cooking tasks will be simple). HOW LONG DOES IT TAKE? Satisfaction?
Are you able to plan, organise, cook and serve complex meals with a large number of ingredients that requires complex methods of preparation and serving. Including planning a meal with several dishes: peeling, slicing, mixing, kneading, stirring, presenting and serving food in a manner appropriate to the occasion and culture. E.g. roast dinner with gravy, vegetables, meat, dessert.	How often did you cook complex meals? Is it routine or only on special occasions?	Do you cook like this less since the brain injury? AMPS tasks include pasts, meat and sauce. Satisfaction?
Are you able to clean cooking area & utensils? Cleaning up after cooking, such as by washing dishes, pans, pots & utensils; cleaning tables and floors around cooking and eating area.	How often did they do their washing up. E.g. After every meal, at end of day?	Did they do it after AMPS cooking? Is their kitchen clean of dishes? Satisfaction?
Do you help with cleaning the living areas of the household, such as by tidying and dusting, sweeping, swabbing, mopping floors, cleaning windows / bathrooms and toilets, cleaning household furnishings	How often did you clean the home? What's the usual routine for cleaning?	Is this different from previously? ? AMPS appropriate. HOW LONG DOES IT TAKE? Satisfaction?

ACTIVITIES & PARTICIPATION	DESCRIPTION OF FUNCTIONING	
	PRE MORBID	CURRENT
Are you able to wash, dry and iron your clothes? Include washing by machine or hand, drying in machine or hanging out to dry?	Did you do hand & machine washing? Iron clothes?	How frequently do you do a load of washing for clothes, linen and towels? Satisfaction?
Are you able to use household appliances, like the Vacuum cleaner, iron, dryer and washing machine?		Have you observed them use them. If you haven't ask them about one item, E.g. How much powder goes in machine, what setting / attachments do they use? Satisfaction?
Are you able to dispose of garbage by collecting trash around house, preparing for disposal, using appliances, E.g. Take garbage bin out for collection?	Who took it out most weeks now and before your injury?	What day is your garbage collected? Satisfaction?
Do you complete simple household repairs and maintenance such as replacing washers in taps, light bulbs, repairing simple fixtures?		What was the last job you did? How does these jobs for you? Satisfaction?
Are you able to maintain the plants and gardens? Includes watering, weeding, trimming and caring for plants, mowing the lawn.		Satisfaction?
Do you have a need as a primary carer to help other people in the house, E.g. assisting children with self care, mobility, communication, health maintenance, interpersonal skills, nutrition?		What arrangements have you made to get assistance since the injury? Satisfaction?
Do you participate in house decorating and maintenance tasks such as painting and wallpapering, making home decorations.		Satisfaction?

MANAGING FINANCES / MONEY

Can you shop for snacks / toiletries / basic items eg milk?	What did you buy?	By what percentage has this changed since the injury? Satisfaction?
Can you manage your own finances, including paying the bills, arranging loans, buying household appliances etc?	Where did you bank? How much rent / income do you have?	Are you in receipt of benefits? Who pays bills, rent / loans? Need assistance? Satisfaction?

ACTIVITIES & PARTICIPATION	DESCRIPTION OF FUNCTIONING	
	PRE MORBID	CURRENT
EDUCATION / EMPLOYMENT		
Were you a school student at the time of your injury? Includes all activities required for school and curriculum: including learning course material, taking directions from teachers, organising, studying and completing tasks / projects.	Length of time / Course / Institution attended? What level did / have you reached? Describe past schooling achievements.	If you were premorbidly, are you still at school? Satisfaction?
Were you a university / college / technical college student at the time of the injury? Includes engaging in all activities required for advanced educational programmes in colleges, universities and professional schools learning curriculum for certificates, diplomas, degrees etc. Length of time / course / institution attended?	What level did you reach? Describe any previous achievements	. Satisfaction?
Vocational education: Learning work skills, may be supported course		Are you trying to get back to work at the moment? Satisfaction?
Work preparation: Supported work experience, job skills training?		Satisfaction?
Apprenticeship: Formal work qualification programme.		Satisfaction?
Were you working at the time of the injury? Includes engaging in all aspects of work, as an occupation, trade, profession or other form of employment, for payment, as an employee, full or part time, or self-employed, doing the required tasks of the job, attending work on time, supervising other workers or being supervised, and performing required tasks alone or in groups	How long in current job, brief description of work history?	If working, have you gone back to the same job? Do you need any changes to your work to manage? Do you have systems in place to support you to do your job? Satisfaction?
Were / are you engaged in voluntary/ unpaid work on either a full-time or part-time basis at the time of the injury? Performance as for paid work but related to E.g. charity work, working for a community or religious group without remuneration. Homemaker (if primary productive role for that person).	How long in last / current job? brief description of work history?	If working, have you gone back to the same job? Do you need any changes to your work to manage? Do you have systems in place to support you to do your job? Satisfaction?
Seeking Employment: Did you / have you looked for work before / since ABI? Locating and choosing a job, in a trade, profession or other form of employment, and performing the required tasks to get hired, such as preparing a CV, preparing for and participating in a job interview.		How far did you get the last time you applied for a job? Satisfaction?

ACTIVITIES & PARTICIPATION	DESCRIPTION OF FUNCTIONING	
	PRE MORBID	CURRENT
LEISURE AND RECREATION		
Were / are you involved in playing games with rules E.g. Board / card games?	Which games did/do you play?	Satisfaction?
Were / are you engaging in competitive or informal sports or athletic events such as swimming, football, bowling, going to beach?	What sports? How often?	Do you play to the same standard? Satisfaction?
Were / are you involved in activities such as painting, pottery, needlepoint, handicrafts?	Which ones, where did you do them?	Did they start participating after injury? Satisfaction?
Dancing, singing, playing an instrument, listening to music, going to concerts?	Attend classes / perform, at home?	Satisfaction?
Did /do you read for the purpose of obtaining knowledge or for pleasure E.g. Books, magazines, newspaper?	What did you read?	Do you read the same things as before? Same type of information / length of tim Satisfaction?
Did you play computerised games such as play-station, computer games etc?	How often did they play?	Has your usual score changed by much injury? Satisfaction?
Were / are you involved with social or community (informal) associations, such as services / ethnic club, groups with common interests E.g. Bridge clubs?	What club? How often did you go?	Has this changed? Satisfaction?
Were / are you involved with formal associations related to professional groups, exclusive social groups?	Which?	Satisfaction?
Were / are you involved in actively using your time for religious or spiritual activities: going to church / mosque/ temple, praying?	How frequently?	Has this changed since the injury? Satisfaction?
Socializing: How often do you meet up with friends and family? What do you do? Has this changed since the injury?	What else have you done?	Satisfaction?
Visiting: Do you go out to visit other people at their home / other place? How often do you go out before the injury / now?		Satisfaction?
Ceremonies: Attendance / participation at weddings, christenings, funerals, other significant social ceremonies?		What have you attended or missed? Satisfaction?
Shopping as leisure activity: Wandering around shops, go for coffee, visit shopping centre / mall		Satisfaction?

ACTIVITIES & PARTICIPATION	DESCRIPTION OF FUNCTIONING	
	PRE MORBID	CURRENT
COMMUNICATION Are they able to maintain conversation? Take turns. Can they recall topic of conversation? Participate without prompting? Do others feel they talk re. same topics at same level?		How significant is the change in %? Satisfaction?
Able to use phone, mobile phone, fax?		Can you use the menu functions to find friends ph. numbers? Satisfaction?
Use diary / calender / filofax / palm pilot system? What for? E.g. to organise day, recall appointments		Did you need to use them in this way previously? Satisfaction?
Computers (not games)	What programmes used?	Satisfaction?
Reading / writing: Able to read and write in order to manage daily demands?	What is primary language?	Satisfaction?

GENERAL **Score the following based on your information from the rest of the interview.**

	PREMORBID	CURRENT FUNCTIONING
Are you spending much time doing nothing much at all?		How much of your time? Is this OK?
Do they need assistance with managing & completing the daily routine? Including carrying out simple or complex and co-ordinated actions in order to plan, manage and complete the requirements of day-to-day procedures or duties, including arranging the energy and time demands required; such as making plans and scheduling several activities through the day and managing one's own activity levels. This is separate to undertaking multiple tasks		Describe how they do this? What assistance do they need / get to arrange their time? Issue for rehabilitation? **Satisfaction?**
Undertaking a single simple task: Carrying out simple co-ordinated actions related to the mental and physical components of a single task; such as initiating a task, organising time, space and materials, pacing task performance, carrying out, sustaining and completing a simple task without the assistance of others. A simple task has a single major component, such as reading a book, writing a letter or making a bed. Task performance does not include acquiring skills, solving problems or making decision.		List examples from interview information.
Undertaking multiple simple tasks independently: As above, plus managing and executing co-ordinated actions as components of several integrated tasks together or sequentially, Eg. watching the TV and reading the newspaper and wiping the kitchen bench.		List examples from interview information.
Undertaking a single complex task: requirements as for simple task but a complex task which has more than one component, which may be carried out in sequence or simultaneously, such as arranging the furniture in one's home or completing a school assignment.		List example from interview where possible.
Undertaking multiple complex tasks: As for multiple single tasks but related to completion of tasks which have several major components; such as putting on a load of washing and cleaning the bathroom and paying the household bills.		List example from interview where possible.

SOCIAL RELATIONSHIPS AND BEHAVIOUR

This section is related to whom you choose to spend your time with and those people that are important to you. (Clinicians: The nature of relationships can change significantly after brain injury and it will be important to speak with both the patient and their family / friends / carers).

SOCIAL RELATIONSHIPS	**DESCRIPTION OF FUNCTIONING**	
	PRE MORBID	**CURRENT**
GETTING ON WITH OTHERS		
Do you still socialise with family? Creating and maintaining relationships with one's parents, children, siblings and extended family E.g. Cousins, aunts etc.	What did you usually do when you meet up? Where did you go?	Do you do the same sort of activities & as often as you did previously with your family? Satisfaction?
Have your relationships with members of your family changed?		Change in relationships can sometimes be a positive or negative thing. What is different? Is it how you feel about them or vice versa? Satisfaction?
Are you able to maintain a close or romantic relationship with your partner? Including close or romantic emotional and physical relationships between individuals, by beginning and maintaining interactions with others in a contextually and socially appropriate manner. Includes relationships that could lead to long term intimate relationship / sexual partners and established long term relationships such as marriage.	Were you in a romantic / long term relationship?	Do you or your partner feel your ability to maintain your relationship has changed? Satisfaction?
Do you still socialise with friends? Creating and maintaining friendship relationships that are characterised by mutual esteem and common interests		What do you usually do when you meet up? Where do you go? Do you do the same sort of activities you did previously with your family? Satisfaction?
Have your relationships with your friends changed?		Satisfaction?
Has your ability to deal with others in casual relationship? E.g. Neighbours, shop keepers, co-workers changed? Including introducing oneself, beginning and maintaining interactions in an appropriate manner?		Satisfaction?

INTERPERSONAL BEHAVIOUR and PSYCHOLOGICAL STATE

This section can be completed by the assessor following the interview. How have you observed them behaving? During the interview note how appropriate they are, do they maintain appropriate space, take turns when speaking, understand how their behaviour can affect other? Liaise with relatives/ carers regarding changes in this area. Note changes from premorbid behaviour.

BEHAVIOUR	**DESCRIPTION OF FUNCTIONING**	
	PRE MORBID	**CURRENT**
Interacting according to social rules: Acting independently, complying with social conventions, governing their role/social status during interactions.		
Maintaining appropriate social space		
Regulating behaviours within interactions: Including controlling verbal & physical aggression, tears, euphoria, and depression.		
Social cues: Reaction to and giving signs appropriately, including responding to the feelings of others.		
Dealing with criticism: Providing and responding appropriately to implicit/explicit differences of opinion/disagreement.		
Physical contact in relationships: Making and responding appropriately to bodily contact.		
Tolerance for others: Responding to and showing appropriate understanding/ acceptance of behaviour.		
Respect, warmth & appreciation in relationships: Responding to and showing appropriate consideration and esteem, satisfaction and gratitude.		
Mood / Emotional state		

DESCRIBE ANY EXAMPLES OF BEHAVIOUR:

The Lifestyle Assessment Administration Guidelines

The Lifestyle Assessment is administered via semi-structured interview with the person with brain injury and/or their primary carer. Primary carers may be interviewed if the person is unable to verbally discuss their lifestyle or needs support. As far as possible the person with brain injury should lead or be involved in the assessment. A standardised introduction is used to inform the person of what is involved in the assessment and the nature and purpose of collecting information.

The first information collected is basic information about their residence including access and layout of their accommodation, and how they are managing looking after themselves. This provides basic information necessary for the clinician as part of the rehabilitation assessment process, but is not scored for the purpose of the Lifestyle Assessment.

The next stage of the assessment is introduced using the standardised information. The person is then asked to describe a typical week and day, including how they spend their time and their ability to manage their routine. This information is recorded on the timetable format, with the usual routine recorded on a 7 day week, and specific activities at different times entered on a section from 7am – evening, with sleep routine also recorded. The daily routine may be different on different days but a usual day is described, and variations are recorded in the weekly timetable. This can be used flexibly dependent on the person’s routine.

Information from the timetable can be used to support scoring items for managing their daily routine and managing multiple tasks. It also provides a snap shot view of changes to their routine and the pattern and balance of activities across the week. The timetable also introduces the range of activities a person does as part of their lifestyle which can assist in the flow and structure of the interview from then on. Participants are asked if they have any questions about the assessment at this point.

The interview proceeds by focusing on specific activities, followed by relationships and lastly interpersonal interactions or behavioural items. Dependent on the level of functioning, the interviewer asks questions in the order in which items appear on the form. Alternatively, the administrator can ask questions about activities reported in the timetable, and then proceed through the form.

Suggested questions are provided for each item to improve consistency of information collected while retaining the flexibility of the interview approach. Clinicians could adapt these questions according to the level of functioning of the person. If the person did not do an activity prior to their brain injury, and had not started participating in the activity following their brain injury this activity was considered irrelevant to that person’s lifestyle.

For relevant activities the person was asked about their participation prior to their brain injury and the nature and extent of any changes in their participation. A laminated card with basic descriptors on the level of change in participation (rating scale) was available for the person to have during the interview if this was considered appropriate for their level of functioning.

The section on social relationships and behaviours is introduced using the standardised introduction. The nine questions about social relationships follow, including the two on socialising with friends and family. This is followed by the behaviour questions. These items are not always rated via interview, but may be rated according to the person's behaviour during the interview and feedback from others. Some questions, such as ability to deal with criticism, tolerate others and mood can usually be asked of the person directly. There is space on the form to record any examples of problematic behaviour which may need to be addressed as part of the person's rehabilitation programme, to support the clinical utility of the instrument. The assessment concludes with several optional questions which enable the administrator to gather final information about the person's own view of changes to their life since the brain injury. These are not scored.

The assessor scores each person based on information from the interview, other people, and the assessor's knowledge of that person's functional capacity. The provision of separate scoring guidelines for activities, social relationships, and interpersonal interactions acknowledges the different nature of these issues. Once the assessment has been rated the personal lifestyle maps can be generated by entering the raw scores into an excel spreadsheet developed for this purpose. These were developed to provide a quick depiction of the nature and amount of lifestyle changes experienced by a person, to be used with either the person with brain injury, their family and / or rehabilitation and care staff.

APPENDIX IV

The Disability Rating Scale score form

DISABILITY RATING SCALE **Patient Name:**			
Categories and Scoring Guidelines		**Date:** **25.3.03**	**Date:**
Cognitive ability to undertake following activities Needs to show awareness of where and how to perform activity, physical ability is not required/tested. **0** **= COMPLETE**: Patient shows continuous awareness that he knows how to feed, toilet or groom him or herself and can convey unambiguous information that he or she knows when this activity should occur. **1** **= PARTIAL:** Patient intermittently shows awareness and intermittently conveys reasonable clear information that he or she knows when the activity should occur. **2** **= MINIMAL:** Patient shows questionable or infrequent awareness that he or she knows in a primitive way how to do the activity and shows infrequently by certain signs, sounds or activities that he or she is vaguely aware when the activity should occur. **3** **= NO COGNITIVE ABILITY TO ACHIEVE.**		**Feeding:** ________ **Toileting:** ________ **Grooming:** ________	**Feeding:** ________ **Toileting:** ________ **Grooming:** ________
Level of functioning: **Dependence upon others** (Note : this does take account of need for physical help) **0** **= Completely independently** - Patient is able to live as he or she wishes with no restrictions. **1** **= INDEPENDENT IN SPECIAL ENVIRONMENT** - Patient can function independently when needed requirements (mechanical aids) are met. **2** **= MILDLY DEPENDENT** - Needs limited assistance; non-resident helper. **3** **= MODERATELY DEPENDENT** - Needs moderate assistance; person in home. **4** **= Markedly dependent** - Needs assistance with all major activities at all times. ***5*** **= Totally dependent** - Requires 24 hour nursing care.		________	________
Employability: Psycho-social **Adaptability** This considers overall cognitive and physical ability to be an employee, homemaker or student. The determination considers the patient's ability: • to understand, remember and follow instructions • to plan and carry out simple tasks and assignments • to remain oriented, relevant and appropriate in work situations • to get to and from work and shopping effectively • to deal with number concepts • to handle simple money exchange problems • to meet schedules and keep appointments **0 = NOT RESTRICTED** **1 = SELECTED JOBS, COMPETITIVE** - Can compete in a limited job market for a relatively narrow range of jobs: can assume many but not all responsibilities associated with home-making; or can carry out many but not all school assignments. **2 = SHELTERED WORKSHOP, NON-COMPETITIVE** - Cannot complete successfully in any job market because of moderate or severe cognitive and/or physical limitations and cannot do home-making or school work without major assistance. **3 = NOT EMPLOYABLE**		________	________
Eye opening: As per GSC Instructions. 0 = Spontaneous, 1 = To speech, 2 = To pain, 3 = None			
Best verbal response: Assess as per GCS. 0 = Oriented, 1 = Confused, 2 = Inappropriate, 3 = Incomprehensible, 4 = None			
Best motor response: Assess as per GCS. 0 = Obeying commands, 1 = Localises pain, 2 = Flexes to pain, 3 = Extends to pain, 4 = None			
Disability category. Delete as appropriate: 0 = none, 1 = mild, 2-3 = partial, 4-6 = moderate, 7-11 moderately severe, 12-16 = severe, 17-21 = extremely severe, 22-24 = vegetative state, 25-29 extreme vegetative state, 30 = death	**Total =**	**/ 30**	**/ 30**
	Initials:		

APPENDIX V

This Appendix contains information related to Participants in Study 3:

Participant Age at Injury and Time since Injury (Descriptive data)

- Participant Time since Injury (Graph)
- Participant Age at Injury (Graph)

Description of Employment categories

Participant Injury Severity:

- Length of Post Traumatic Amnesia and Injury Severity Categories
- Frequency of Injury Severity Categories (Pie chart)

Demographics Information

Table A 1: Descriptive Information: Participant Age and Time since Injury

	N	Minimum	Maximum	Mean	Std. Deviation
Age At Injury	71	16	92	34.94	16.630
Time Since Injury	71	.43	1269.23	53.5432	154.50703
Valid N (listwise)	56				

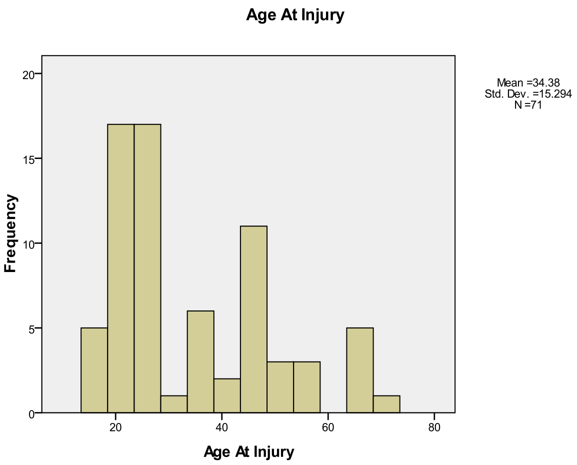


Figure A 1: Frequency: Age of Participants

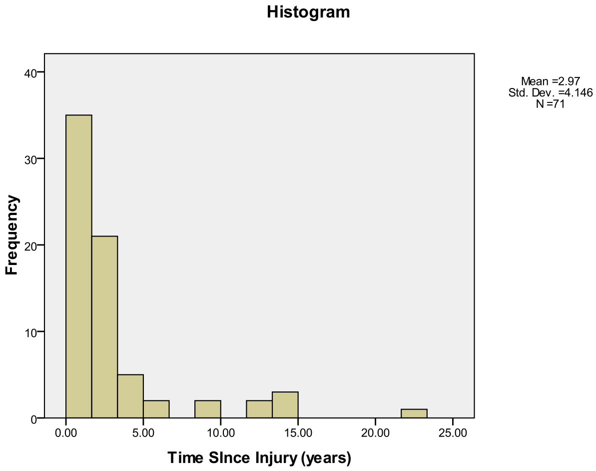


Figure A 2: Frequency: Time since Injury

Table A 2: Job Categories Used to Describe Sample Characteristics

JOB CATEGORY	DESCRIPTION
PROFESSIONAL	**Professional** work is done by professional workers such as doctors and lawyers, who possess unique or higher order skills and specialist knowledge. Professionals require formal training and qualifications, such as a university course in law, together with work experience in a community legal centre.
SKILLED	**Skilled** work requires formal training and qualifications and leads to such jobs as trades (like carpentry or auto electrical work).
SEMI-SKILLED	**Semi-skilled** work is normally the work completed in trades or office-based jobs, which may lead to skilled work (like a builder's apprenticeship).
UNSKILLED	Unskilled jobs require low levels of training, like in factory work. You could aim to do these types of jobs casually whilst studying. Unskilled jobs like building site labouring or delivering pizzas tend to pay the lowest levels of income and don't allow you to develop a wide range of skills. Importantly, employers usually require professionals, semi-skilled or skilled workers to fill jobs.

Taken from http://www.skwirk.com.au/p-c_s-18_u-130_t-359_c-1257/education-training-and-employment/nsw/education-training-and-employment/employment-issues/work-environment on 20/2/11.

Table A 3: Levels of Injury Severity based on Length of PTA

Length of Post Traumatic Amnesia (PTA)	Level of Injury Severity
1-4 hours	Mild brain injury
<= 1 day	Moderate brain injury
2-7 days	Severe brain injury
1-4 weeks	Very severe brain injury
1-6 months	Extremely Severe Brain Injury
> 6 months	Chronic amnesia state

Available http://www.itim.nsw.gov.au/go/knowledge-base/clinical-resources/head-and-facial-injuries/other-information-on-head-injuries/post-traumatic-amnesia-pta [Accessed on 21_2_2011].

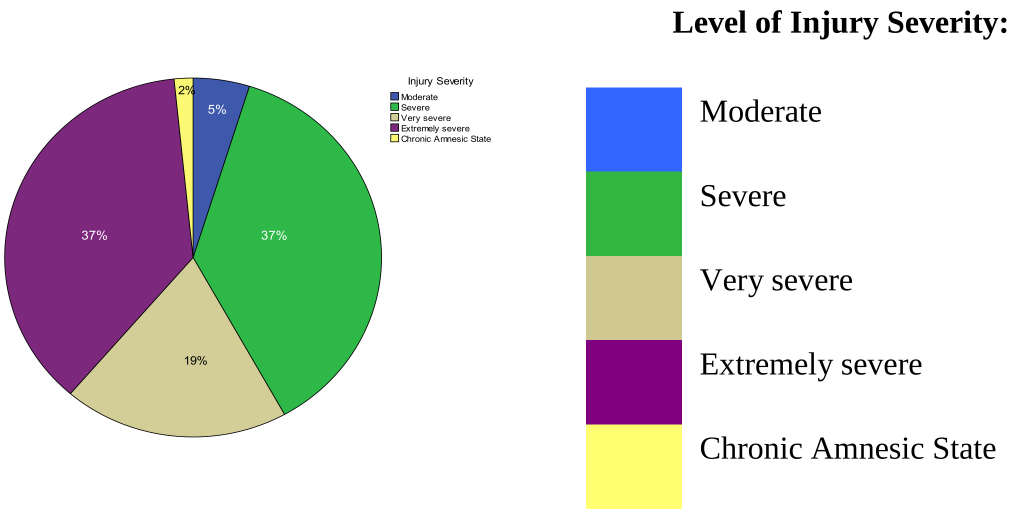


Figure A 3: Frequency of Injury Severity Categories

APPENDIX VI

This Appendix contains information related to Study 3, Question 1a. *Does the Lifestyle Assessment Measure the Single Construct of Lifestyle Effectively?*

Descriptive Data:

Frequency Each Item was Selected (Descriptive Data)

Number of Items People Selected as Relevant to Their Lifestyle

Point Measure Correlations for Items (1st Iteration, Lifestyle Assessment Version 2)

Principal Components Analysis of Residuals Factor Plot

Rating Scale analysis: Items with Disordered rating scale and Potential Contributing Factors

Table A 4: Descriptive data for Frequency in which Items were Selected

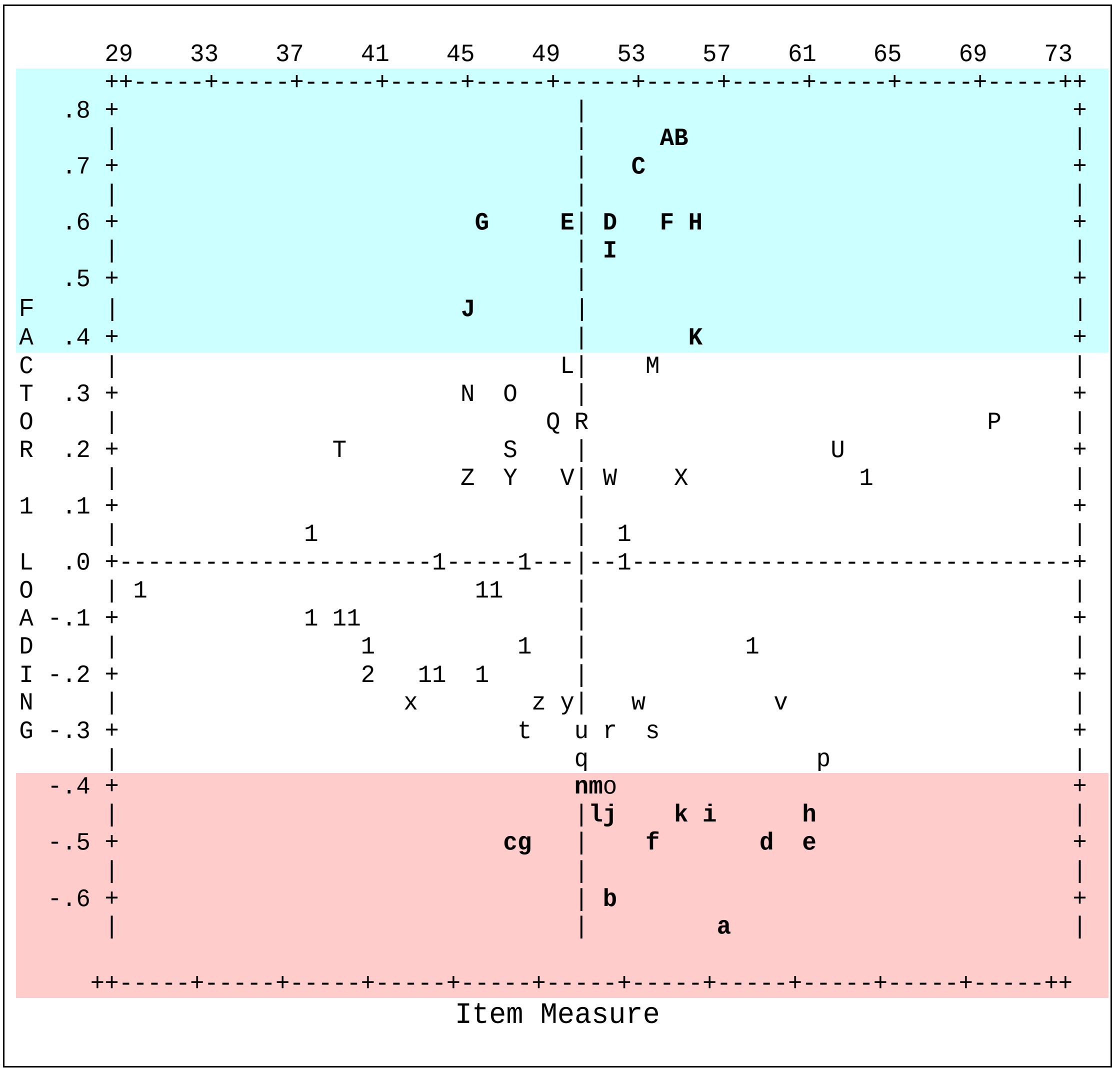
	Frequency Items Endorsed (N=73)	
Statistic	Number	Percentage
Mean	54.97	77.43
Median	66.00	92.96
Std. Deviation	19.856	27.97
Range	68.00	95.77
Minimum	3.00	4.23
Maximum	71.00	100.00

Table A 5: Range of number of items endorsed per person (N=71)

Statistic	Number
Mean	55.52
Median	57.00
Mode	58.00
Std. Deviation	6.01
Range	29.00
Minimum	36.00
Maximum	65.00

Table A 6: Point Measure Correlations, Lifestyle Assessment Items (Q.1a)

ITEMS	Point Measure Correlation	ITEMS	Point Measure Correlation
Driving	0.30		
		Respect, warmth and appreciation in relationships	0.61
Physical contact in relationships	0.54	Sports	0.57
Socialising with friends	0.49	Computer pleasure	0.67
Dealing with criticism	0.46	Conversation skills	0.59
Human powered transport	0.48	Disposing Rubbish	0.64
Tolerance of others	0.45	Washing / drying clothes	0.63
		Computer skills	0.68
Maintaining appropriate social space	0.63	Plant & Garden care	0.52
Alcohol & Drug Use	0.49	Relationships with friends	0.56
Arts & Crafts	0.53	Reading & writing skills	0.63
School	0.98	Clean living area	0.62
Close / romantic relationships	0.45	Formal relationships	0.64
College	0.41	Complex Meal	0.53
Mood & emotional state	0.52	Professional organisations	0.97
Paid work	0.49	Telecom devices	0.70
Acquiring Place to live	0.46	Diary, calender use	0.67
Music	0.50	Managing one simple task	0.73
Voluntary work	0.25	Work preparation	0.72
Household maintenance	0.61	Vocational education	0.77
Playing games	0.52	Assisting others	0.80
Healthy diet	0.56	Social Cues	0.72
Socialising	0.42	Managing one complex task	0.70
Community organisations	0.54		
Moving around other buildings	0.57	Managing multiple simple tasks	0.73
Complex finances	0.51		
Moving outside	0.54	Managing multiple complex tasks	0.68
Reading pleasure	0.55	Shopping leisure	0.90
Use appliances	0.60	Managing daily routine	0.71
Private motor transport	0.68		



```
      29    33    37    41    45    49    53    57    61    65    69    73
      ++-----+-----+-----+-----+-----+-----+-----+-----+-----+-----+-----++
   .8 +                                |                                  +
      |                                |     AB                           |
   .7 +                                |   C                              +
      |                                |                                  |
   .6 +                         G     E| D   F H                          +
      |                                | I                                |
   .5 +                                |                                  +
F     |                        J       |                                  |
A  .4 +                                |       K                          +
C     |                               L|    M                             |
T  .3 +                        N  O    |                                  +
O     |                              Q R                            P     |
R  .2 +               T           S    |                 U                +
      |                        Z  Y   V| W    X            1              |
1  .1 +                                |                                  +
      |             1                  |  1                               |
L  .0 +----------------------1-----1---|--1-------------------------------+
O     | 1                       11     |                                  |
A -.1 +             1 11               |                                  +
D     |                 1          1   |           1                      |
I -.2 +                 2   11  1      |                                  +
N     |                    x        z y|   w         v                    |
G -.3 +                            t   u r  s                             +
      |                                q                p                 |
  -.4 +                                nmo                                +
      |                                |lj    k i      h                  |
  -.5 +                           cg   |    f       d  e                  +
      |                                |                                  |
  -.6 +                                | b                                +
      |                                |         a                        |

     ++-----+-----+-----+-----+-----+-----+-----+-----+-----+-----+-----++
                              Item Measure
```

Legend: First Factor:

Aqua = Positive factor loading

Pale pink = Negative factor loading

Figure A 4: Principal Components Analysis of Residuals (standardized residual) Factor Plot (1st Iteration) (See Table 5.6)

Table A 7: Items with Disordered Ratings: 1st Iteration (Question 1a)

ITEMS	**< 10 ratings**	**Rare item**	**Item / Description needs review**	**Misfit Identified**	
				Infit	**Outfit**
Maintaining appropriate social space	✖			✖	✖
Alcohol & Drug Use	✖		✖	✖	
Physical contact in relationships	✖			✖	✖
Healthy diet	✖		✖		
Simple meal	✖				
Regulating behaviours	✖				
Arts & Crafts	✖	✖			✖
Mood & emotional state	✖				
Religious activities	✖				
Moving outside	✖				
Computer skills	✖				
Computer pleasure	✖	✖			
Playing games	✖				
Music	✖		✖		
Community organizations	✖	✖			✖
Plants & Garden care	✖				
Socializing	✖				
Complex finances	✖				
Socializing with friends	✖				
Complex Meal	✖	✖			
Household maintenance	✖				
Work preparation	✖	✖			
Driving	✖			✖	✖
Paid work	✖				
Human powered transport	✖	✖			

APPENDIX VII

This Appendix contains information related to Study 3, Question 2.a. *Are the Lifestyle Assessment's Items Stable and Precise in Their Measurement of Person Ability?*

Individual Item Fit Statistics

Individual Person Fit Statistics

Table A 8a: Item Fit Statistics, Misfit order (1^{st} Iteration) (Part 1 of 2)

ITEMS	Measure	Model S.E.	INFIT		OUTFIT		Measure Correlation
			MNSQ	ZSTD	MNSQ	ZSTD	
Driving	38.56	1.32	2.22	3.9	2.74	3.8	0.30
Physical contact in relationships	63.29	1.32	2.25	3.9	1.75	1.9	0.54
Socialising with friends	45.08	1.07	0.96	-0.2	2.25	3.9	0.49
Dealing with criticism	55.71	0.95	1.32	1.8	2.24	4.2	0.46
Human powered transport	37.47	1.72	1.79	2.2	2.14	2.2	0.48
Tolerance of others	54.55	0.93	1.37	2.1	2.08	4.0	0.45
Maintaining appropriate social space	71.35	2.09	1.88	2.0	1.32	0.7	0.63
Alcohol & Drug Use	63.68	1.32	1.82	2.8	1.71	1.9	0.49
Arts & Crafts	52.29	1.87	1.81	2.2	1.44	1.1	0.53
School	46.89	4.08	1.67	1.0	1.53	0.9	0.98
Close / romantic relationships	45.22	1.1	1.61	2.7	1.43	1.6	0.45
College	29.24	4.31	1.12	0.4	1.53	0.8	0.41
Mood & emotional state	51.53	0.92	0.99	0.0	1.53	2.4	0.52
Paid work	37.88	1.39	1.47	1.7	1.50	1.4	0.49
Acquiring Place to live	40.24	1.25	1.43	1.7	1.20	0.7	0.46
Music	48.85	1.22	1.17	0.8	1.37	1.3	0.50
Voluntary work	39.49	2.14	1.36	1.0	1.09	0.4	0.25
Household maintenance	43.33	1.23	1.35	1.5	1.17	0.7	0.61
Playing games	48.95	1.16	1.27	1.3	1.33	1.2	0.52
Healthy diet	59.74	1.06	1.18	1.0	1.33	1.2	0.56
Socialising	47.2	1.01	1.28	1.5	1.31	1.3	0.42
Community organisations	47.84	1.29	1.29	1.2	1.04	0.3	0.54
Moving around other buildings	58.88	1.02	1.28	1.5	1.14	0.6	0.57
Complex finances	45.44	1.01	1.26	1.4	1.19	0.9	0.51
Moving outside	51.33	0.89	1.23	1.4	1.22	1.1	0.54
Reading pleasure	50.54	1.03	1.20	1.1	1.22	1.0	0.55
BETTER FITING ITEMS OMITTED							
Respect, warmth and appreciation in relationships	54.99	0.94	0.92	-0.4	0.94	-0.2	0.61
Sports	45.45	1.06	0.86	-0.7	0.94	-0.2	0.57
Computer pleasure	49.90	1.22	0.91	-0.4	0.88	-0.4	0.67
Conversation skills	55.43	0.92	0.69	-2.1	0.90	-0.4	0.59
Disposing Rubbish	51.89	0.93	0.89	-0.7	0.79	-1	0.64
Washing / drying clothes	51.09	0.95	0.87	-0.8	0.79	-1.1	0.63
Computer skills	50.1	1.07	0.87	-0.7	0.84	-0.7	0.68

Table A8b: Item Fit Statistics Continued, Misfit order (1st Iteration) (part 2 of 2)

		Model	INFIT		OUTFIT		Point Measure Correlation
ITEMS	**Measure**	**S.E.**	**MNSQ**	**ZSTD**	**MNSQ**	**ZSTD**	
Plants & Garden care	47.75	1.09	0.83	-0.9	0.75	-1.1	0.52
Relationships with friends	45.70	1.02	0.81	-1.0	0.82	-0.8	0.56
Reading & writing skills	52.44	0.91	0.74	-1.8	0.81	-1.0	0.63
Clean living area	47.93	0.95	0.77	-1.4	0.73	-1.4	0.62
Formal relationships	49.66	1.13	0.76	-1.3	0.77	-0.9	0.64
Complex Meal	43.89	1.64	0.76	-0.8	0.68	-0.9	0.53
Professional organisations	40.38	3.17	0.68	-0.4	0.52	-0.7	0.97
Telecom devices	58.25	1.00	0.67	-2.1	0.62	-1.8	0.70
Diary, calender use	50.31	0.96	0.65	-2.3	0.59	-2.2	0.67
Managing one simple task	61.48	1.17	0.60	-2.1	0.51	-1.9	0.73
Work preparation	40.14	2.37	0.44	-1.5	0.59	-0.7	0.72
Vocational education	46.17	2.14	0.57	-1.2	0.54	-1.1	0.77
Assisting others	42.78	2.09	0.56	-1.2	0.47	-1.2	0.80
Social Cues	55.62	0.95	0.55	-3.2	0.52	-2.6	0.72
Managing one complex task	51.72	0.92	0.46	-4.2	0.45	-3.5	0.70
Managing multiple simple tasks	54.86	0.93	0.42	-4.6	0.40	-3.7	0.73
Managing multiple complex tasks	46.94	1.00	0.42	-4.2	0.42	-3.3	0.68
Shopping leisure	51.63	2.64	0.39	-1.6	0.40	-1.1	0.90
Managing daily routine	48.29	0.96	0.31	-5.6	0.32	-4.4	0.71
Mean	50.00	1.34	1.05	0.0	1.07	0.1	-
SD	7.16	0.68	0.40	1.8	0.47	1.6	-

Table A 9a: Person Fit Statistics, Misfit Order (1st Iteration) (Part 1 of 2)

			Model	INFIT		OUTFIT	
PERSON		Measure	S.E.	MNSQ	ZSTD	MNSQ	ZSTD
46	Severe	71.56	2.23	2.22	2.5	3.03	3.0
3	Partial	53.02	1.01	1.72	3.4	2.72	5.4
56	Partial	54.90	1.02	1.55	2.7	2.45	4.8
8	Mod Severe	60.33	1.18	2.38	4.8	1.68	2.2
76	Partial	54.96	1.10	0.88	-0.6	2.18	3.8
4	Partial	50.72	1.03	1.78	3.6	2.14	4.1
27	Severe	74.10	2.69	2.13	2.0	1.05	0.3
68	Partial	35.35	1.65	1.39	1.3	1.94	1.9
17	Partial	47.12	1.07	1.83	3.6	1.85	3.0
22	Severe	63.88	1.41	1.78	2.6	1.55	1.6
18	Mod Severe	57.02	1.10	1.74	3.2	1.49	1.8
21	Partial	37.30	1.49	1.66	2.1	1.56	1.4
13	Moderate	34.90	1.75	1.64	1.8	1.02	0.2
15	Moderate	51.57	0.97	1.26	1.5	1.57	2.4
52	Mod Severe	58.81	1.12	1.03	0.2	1.56	1.9
2	Moderate	52.79	0.99	1.55	2.8	1.48	2.0
5	Mild	38.07	1.77	1.31	1.0	1.43	1.0
47	Partial	48.63	0.95	1.34	1.9	1.41	1.9
26	Mod Severe	56.46	1.12	1.33	1.6	1.21	0.9
58	Moderate	46.65	1.07	1.29	1.5	1.13	0.6
72	Moderate	51.48	0.94	1.07	0.5	1.26	1.3
32	Moderate	45.79	1.03	1.24	1.3	1.05	0.3
30	Moderate	57.15	1.15	1.04	0.3	1.23	0.9
9	Mild	41.29	1.23	1.21	0.9	0.87	-0.3
11	Mod Severe	58.53	1.13	1.19	0.9	1.08	0.4
57	Moderate	45.72	1.06	1.07	0.4	1.17	0.7
		BETTER FITING ITEMS OMITTED					
45	Moderate	42.99	1.19	0.89	-0.5	0.73	-0.9
12	Mod Severe	47.59	1.03	0.86	-0.7	0.78	-1.0
43	Mod Severe	58.67	1.13	0.85	-0.7	0.72	-1.1
40	Partial	39.03	1.59	0.84	-0.5	0.70	-0.7
24	Mod Severe	56.31	1.03	0.83	-0.9	0.74	-1.2
48	Partial	43.36	1.17	0.82	-0.9	0.83	-0.5
53	Mod Severe	58.25	1.16	0.83	-0.8	0.73	-1.0
49	Partial	50.40	0.92	0.80	-1.3	0.81	-1.0
1	Moderate	53.99	1.08	0.80	-1.1	0.76	-1.0
69	Partial	46.00	1.10	0.79	-1.1	0.76	-0.9
23	Partial	46.12	1.10	0.78	-1.1	0.66	-1.5
51	Partial	49.57	1.10	0.66	-2.0	0.77	-1.0

Table A9b: Person Fit Statistics Continued, Misfit order (1st Iteration)(Part 2 of 2)

PERSON			Model	INFIT		OUTFIT	
Code	Disability Level	Measure	S.E.	MNSQ	ZSTD	MNSQ	ZSTD
41		35.77	1.67	0.61	-1.4	0.72	-0.6
65	Moderate	53.26	0.99	0.72	-1.8	0.69	-1.6
42	Partial	47.87	1.09	0.70	-1.7	0.70	-1.3
29	Mod Severe	55.58	1.02	0.69	-1.9	0.63	-1.7
62	Mod Severe	52.36	0.96	0.69	-2.0	0.67	-1.8
19	Moderate	54.27	1.02	0.68	-2.0	0.66	-1.8
74	Partial	48.15	1.09	0.68	-1.9	0.67	-1.5
66	Mod Severe	51.18	0.95	0.67	-2.2	0.61	-2.2
60	Mod Severe	50.22	0.96	0.62	-2.6	0.55	-2.6
61	Mod Severe	51.46	0.96	0.61	-2.7	0.56	-2.6
59	Mod Severe	51.06	0.96	0.55	-3.2	0.50	-3.0
20	Mod Severe	53.85	0.98	0.42	-4.4	0.41	-3.6
38	Partial	53.15	0.98	0.34	-5.3	0.41	-3.7
67	Moderate	48.21	0.95	0.39	-4.8	0.38	-4.0
	Mean	51.95	1.4	1.06	-0.1	1.09	0.1
	SD	9.83	2.02	0.43	2	0.52	1.9

APPENDIX XIII

This Appendix contains information related to Study 3, Question 1b. *Does the Lifestyle Assessment Measure the Single Construct of Lifestyle Effectively?*

Data was modified for this analysis: items were removed and the data were analysed using a collapsed rating scale.

Rating scale analysis: Changes to Rating Scale Analysis for items analysed as dichotomous items after initial rating scale collapse to 4 point scale.

Two sets of data for the 4 items analysed as dichotomous items on the second iteration are provided. The first identified the rating scale is disordered (values in **bold*)** even when analysed as a 4 point scale (0,2,4,5). The second set indicates the rating scale for each items is ordered when the item is analysed as a dichotomous item (0,0,0,5), and the average measures increase sequentially as expected. This provides justification for analysing these items as dichotomous items in second analysis. Note low frequency for some ratings.

Table A 10: Rating scale analysis: Rating Scale performance for items analysed as dichotomous items. (2nd Iteration)

ITEM	1st Amendment (not reported in thesis)			2nd Iteration (reported)		
	Score	N(%)	Average Measures	Score	N(%)	Average Measure
Physical Contact in Relationships						
	0	51 (75%)	50.75	0	51 (75%)	50.62
	2	3 (4%)	55.92	0	4 (6%)	54.49
	4	4 (6%)	**55.20***	0	3 (4%)	55.57
	5	5 (7%)	72.54	5	5 (7%)	72.53
	Missing	5 (7%)	52.63	Missing	5 (7%)	52.46
House Decoration						
	0	1 (1%)	39.66	0	1 (1%)	39.79
	2	1 (1%)	53.61	0	3 (4%)	48.91
	4	3 (4%)	**49.56***	0	1 (1%)	53.33
	5	10 (15%)	54.89	5	10 (15%)	54.78
	Missing	53 (78%)	53.06	Missing	53 (78%)	52.90
Driving						
	0	4 (6%)	42.57	0	4 (6%)	42.92
	2	4 (6%)	50.85	0	5 (7%)	48.93
	4	5 (7%)	**49.84***	0	4 (6%)	50.27
	5	51 (75%)	54.54	5	51 (75%)	54.16
	Missing		53.45	Missing	4 (6%)	52.89
Human powered transport						
	0	3 (4%)	39.10	0	3 (4%)	39.45
	2	2 (3%)	52.05	0	4 (6%)	49.35
	4	4 (6%)	**50.09***	0	2 (3%)	51.42
	5	30 (44%)	53.25	5	30 (44%)	52.95
	Missing	29 (43%)	55.13	Missing	29 (43%)	54.63

***Disordered rating**

APPENDIX IX

This Appendix contains information related to Study 3, Question 2.b. Are the Lifestyle Assessment’s Items Stable and Precise in Their Measurement of Person Ability?

Data was modified for this analysis: Items were removed and the data were analysed using a collapsed rating scale.

Individual Item Fit Statistics

Individual Person Fit Statistics

Table A 11a: Item Fit Statistics, Misfit order (2^{nd} Iteration) (Part 1 of 2)

ITEMS	Measure	Model S.E.	INFIT MNSQ	INFIT ZSTD	OUTFIT MNSQ	OUTFIT ZSTD	Measure Correlation
Driving	43.16	1.2	3.24	6.5	3.93	6.2	0.26
Human powered transport	43.58	1.46	2.99	5.0	3.66	4.8	0.38
Tolerance of others	54.16	0.91	1.43	2.4	2.51	5.4	0.38
Dealing with criticism	54.99	0.91	1.39	2.2	2.49	5.2	0.39
House decoration	49.07	1.99	2.30	2.7	1.98	1.9	0.55
Physical contact in relationships	69.14	1.81	2.23	2.7	1.16	0.5	0.57
Socialising with friends	45.11	1.16	0.79	-0.9	2.06	3.1	0.44
Maintaining appropriate social space	70.64	2.01	1.84	1.8	1.21	0.5	0.60
Voluntary work	38.53	2.76	1.83	1.4	1.30	0.7	0.21
Mood & emotional state	51.67	0.93	1.06	0.4	1.79	3.3	0.44
Arts & Crafts	52.15	1.82	1.64	1.8	1.29	0.8	0.50
Acquiring Place to live	41.37	1.33	1.54	2.0	1.37	1.2	0.41
Moving around other buildings	58.68	0.94	1.48	2.6	1.39	1.5	0.48
Household maintenance	44.37	1.3	1.46	1.7	1.10	0.4	0.62
Socialising	47.76	1.05	1.45	2.1	1.40	1.6	0.34
Playing games	48.69	1.25	1.04	0.3	1.42	1.4	0.46
Paid work	36.78	1.71	1.38	1.2	1.11	0.4	0.52
Moving outside	51.60	0.90	1.12	0.8	1.31	1.5	0.50
Moving around home	60.47	1.01	1.28	1.4	1.28	1.0	0.52
Reading pleasure	50.98	1.03	1.27	1.4	1.28	1.2	0.48
Respect, warmth and appreciation in relationships	54.83	0.91	1.00	0.1	1.27	1.3	0.52
Public Transport	50.81	0.95	1.25	1.4	1.26	1.2	0.46
Close / romantic relationships	46.91	1.12	1.25	1.2	1.15	0.7	0.42
Complex finances	45.48	1.09	1.2	1.0	1.21	0.9	0.46
Music	48.79	1.29	1.04	0.2	1.19	0.7	0.53
Community organisations	48.94	1.29	1.19	0.8	0.95	-0.1	0.50
BETTER FITING ITEMS OMITTED							
Formal relationships	50.50	1.13	0.80	-1.0	0.86	-0.5	0.57
Medication	53.00	1.00	0.86	-0.8	0.79	-0.9	0.60
Professional organisations	42.83	3.09	0.85	-0.1	0.65	-0.3	0.96
Cleaning cooking area	54.42	0.90	0.82	-1.1	0.74	-1.4	0.61

Table A11b: Item Fit Statistics Continued, Misfit order (2^{nd} Iteration) (Part 2 of 2)

ITEMS	Measure	Model S.E.	INFIT MNSQ	INFIT ZSTD	OUTFIT MNSQ	OUTFIT ZSTD	Point Measure Correlation
Seeking work	34.45	2.12	0.81	-0.4	0.53	-1.5	0.61
Computer skills	50.55	1.07	0.80	-1.1	0.79	-0.9	0.72
Sports	45.90	1.12	0.79	-1.0	0.75	-1.0	0.54
Work preparation	39.76	2.67	0.68	-0.6	0.77	-0.2	0.57
Washing / drying clothes	51.92	0.95	0.76	-1.5	0.71	-1.5	0.59
Relationships with friends	45.64	1.09	0.76	-1.2	0.76	-1.0	0.50
Complex Meal	43.64	1.80	0.73	-0.7	0.75	-0.5	0.46
Disposing Rubbish	52.04	0.94	0.75	-1.6	0.69	-1.7	0.60
Clean living area	48.79	0.98	0.74	-1.5	0.67	-1.6	0.57
Assisting others	43.75	2.22	0.73	-0.6	0.59	-0.8	0.75
Telecommunication devices	57.88	0.92	0.65	-2.4	0.72	-1.3	0.64
Managing one simple task	60.67	1.03	0.69	-1.8	0.62	-1.3	0.65
Diary, calender use	49.98	0.99	0.69	-1.9	0.63	-1.9	0.60
Computer pleasure	49.81	1.25	0.66	-1.6	0.67	-1.3	0.72
College	25.73	7.09	0.65	0.1	0.65	0.0	0.44
Voc education	46.98	2.20	0.63	-0.9	0.55	-0.9	0.75
Managing one complex task	51.49	0.94	0.57	-3.0	0.57	-2.5	0.61
Social Cues	54.49	0.91	0.54	-3.4	0.55	-2.6	0.65
Managing multiple simple tasks	55.05	0.91	0.52	-3.6	0.5	-2.9	0.65
Shopping for leisure	46.64	3.11	0.51	-0.8	0.44	-0.8	0.83
Managing multiple complex tasks	46.67	1.09	0.36	-4.2	0.37	-3.3	0.63
Managing daily routine	47.80	1.04	0.31	-4.9	0.29	-4.2	0.63
Mean	49.68	1.63	1.07	0	1.09	0.1	
SD	7.46	2.30	0.52	1.9	0.64	1.9	

Table A 12a: Person Fit Statistics, Misfit order (2^{nd} Iteration) (Part 1 of 2)

PERSON		Measure	Model S.E.	INFIT MNSQ	INFIT ZSTD	OUTFIT MNSQ	OUTFIT ZSTD
46	Severe	74.46	2.78	2.43	2.6	3.15	3.8
4	Partial	51.37	1.01	2.21	5.3	3.12	6.3
8	Mod Severe	59.98	1.28	2.57	4.5	1.98	2.8
56	Partial	55.87	1.10	1.75	3.1	2.48	4.3
52	Mod Severe	59.11	1.25	1.47	1.8	2.17	3.2
22	Severe	65.25	1.74	2.07	2.7	2.06	2.5
68	Partial	38.76	1.36	1.49	1.7	1.89	1.6
18	Mod Severe	56.85	1.17	1.81	3.1	1.53	1.8
2	Moderate	53.33	1.00	1.62	3.0	1.78	2.8
50	Partial	55.39	1.11	1.34	1.6	1.69	2.3
13	Moderate	37.21	1.48	1.61	1.9	1.01	0.2
15	Moderate	52.87	0.98	1.27	1.5	1.60	2.4
26	Mod Severe	56.75	1.20	1.56	2.2	1.35	1.2
21	Partial	39.81	1.28	1.46	1.7	1.34	0.8
76	Partial	56.22	1.18	0.94	-0.2	1.45	1.5
58	Moderate	47.32	1.01	1.28	1.5	1.38	1.4
41		39.79	1.32	1.02	0.2	1.38	0.9
47	Partial	49.98	0.92	1.31	1.8	1.34	1.5
14	Moderate	51.77	0.99	1.20	1.1	1.29	1.3
5	Mild	40.25	1.54	1.26	0.9	1.05	0.3
32	Moderate	46.83	0.96	1.20	1.2	1.08	0.4
40	Partial	42.10	1.34	0.89	-0.4	1.15	0.5
64	Moderate	57.64	1.18	1.14	0.7	0.98	0.0
72	Moderate	51.21	0.92	1.05	0.4	1.14	0.7
30	Moderate	58.05	1.28	1.13	0.6	1.1	0.4
57	Moderate	46.63	0.99	1.13	0.8	1.07	0.4
		BETTER FITING ITEMS OMITTED					
38	Partial	54.31	1.03	0.61	-2.4	0.98	0.0
49	Partial	50.91	0.91	0.95	-0.3	0.97	-0.1
77		46.02	1.20	0.78	-1.0	0.93	-0.2
45	Moderate	43.96	1.10	0.91	-0.4	0.75	-0.7
71	Moderate	51.55	0.93	0.78	-1.4	0.90	-0.4
1	Moderate	54.30	1.10	0.89	-0.5	0.86	-0.5
7	Mild	42.31	1.18	0.86	-0.6	0.69	-0.8
53	Mod Severe	57.88	1.22	0.82	-0.7	0.78	-0.7
24	Mod Severe	57.03	1.13	0.80	-0.9	0.68	-1.3
65	Moderate	54.69	1.05	0.80	-1.1	0.76	-1.0
43	Mod Severe	58.67	1.23	0.79	-0.9	0.71	-1.0
51	Partial	50.66	1.06	0.73	-1.6	0.79	-0.8

Table A12b: Person Fit Statistics Continued, Misfit order (2^{nd} Iteration)(Part 2 of 2)

PERSON		Measure	Model S.E.	INFIT MNSQ	INFIT ZSTD	OUTFIT MNSQ	OUTFIT ZSTD
6	Mild	45.46	1.03	0.76	-1.4	0.72	-1.0
23	Partial	46.94	1.03	0.75	-1.5	0.76	-0.9
69	Partial	46.73	1.03	0.73	-1.6	0.74	-1.0
75	Partial	58.19	1.22	0.67	-1.5	0.71	-1.0
19	Moderate	56.08	1.11	0.67	-1.7	0.69	-1.3
42	Partial	48.67	1.03	0.65	-2.1	0.67	-1.4
62	Mod Severe	53.28	0.98	0.60	-2.6	0.67	-1.6
66	Mod Severe	52.79	0.97	0.65	-2.2	0.61	-2.0
29	Mod Severe	56.77	1.12	0.63	-1.9	0.57	-1.9
60	Mod Severe	51.89	0.96	0.63	-2.5	0.58	-2.2
74	Partial	48.76	1.04	0.61	-2.4	0.60	-1.7
20	Mod Severe	54.83	1.03	0.58	-2.6	0.56	-2.1
61	Mod Severe	52.36	0.96	0.57	-2.9	0.54	-2.5
59	Mod Severe	52.73	0.98	0.48	-3.7	0.48	-2.9
67	Moderate	49.61	0.91	0.44	-4.4	0.44	-3.3
	Mean	52.81	1.4	1.07	0	1.11	0.2
	SD	9.87	2.09	0.44	1.9	0.55	1.7

APPENDIX X

This Appendix contains information related to Study 3, Sub Question 3: *Does the Lifestyle Assessment Measure the range of Lifestyle Changes Experienced by people Effectively?*

Item-Person Map (portion of map with items enlarged – otherwise same as Figure 5.6, p.151.

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         70   Maintaining appropriate social space
          |   Physical contact in relationships
          |
       X T|
          |T
       X  |
          |   Private motor transport
       X 60   Moving around home   Managing one simple task
 XXXXXXX S|   Telecommunication devices, Moving around other buildings
   XXXXX  |S  Basic money skills,  Use appliances
   XXXXX  |   Managing multiple simple tasks
   XXXXX  |   Conversation skills, Simple meal, Cleaning cooking area,
              Interacting according to social rules, Social Cues, Dealing with
              criticism, Tolerance of others, Respect, warmth and appreciation
              in relationships, Informal relationships
XXXXXXXXXX|   Regulating behaviours, Medication, Arts & Crafts, Religious
              activities
  XXXXXX M|   Reading & writing skills, Washing / drying clothes, Disposing
              Rubbish
              Mood & emotional state, Appointments, Moving outside, Managing
              one complex task, Reading pleasure, Socialising with family,
              Public Transport
     XXX 50 M Diary, calender use, Computer skills, Computer pleasure,
              Relationships with family, Formal relationships
    XXXX  |   Plants & Garden care, House decoration, Clean living area,
              Playing games, Music,
              Community organisations
  XXXXXX  |   Vocational education, Shopping, Managing daily routine, Managing
              multiple complex tasks, Socialising, Ceremonies, Shopping for
              leisure, Close / romantic relationships
     XXX S|   Complex finances, Sports, Socialising with friends, Relationships
              with friends
       X  |   Household maintenance  Assisting others, Complex Meal, Visiting,
              Human powered transport
      XX  |S  Professional organisations, Driving
       X  |   Acquiring Place to live
     XXX 40   Work preparation
       X T|   Voluntary work
       X  |   Paid work
          |T
          |   Seeking work
          |
          |
         30
          |
          |
          |   College
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Figure A 5: Magnified Portion of Item-Person Map (Items) (Research Question 3)