### VALIDITY AND CLINICAL UTILITY OF THE

## PERSONAL CARE - PARTICIPATION ASSESSMENT

### AND RESOURCE TOOL (PC-PART)

### Submitted by

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A thesis submitted in total fulfilment of the requirements of the degree of

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**Statement of Authorship and Sources** 

This thesis contains no material published elsewhere or extracted in whole or in part

from a thesis by which I have qualified for or been awarded another degree or diploma.

No parts of this thesis have been submitted towards the award of any other degree or

diploma in any other tertiary institution.

No other person's work has been used without due acknowledgment in the main text of

the thesis.

All research procedures reported in the thesis received the approval of the relevant

Ethics/Safety Committees (where required).

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### **Conflict of Interest Statement**

Susan Darzins is a Director of Darzins Consulting Pty. Ltd., which operates using the business name *The PART Group. The PART Group* distributes the PC-PART users' manual, assessment worksheets and training DVDs. Darzins Consulting Pty Ltd did not finance the research conducted within this PhD program. During the last six years (2010-2015) Susan Darzins has not received reimbursements, fees, funding or salary associated with sales of PC-PART products, from Darzins Consulting Pty. Ltd. It is possible, but unknown to what extent, Susan Darzins could benefit financially in the future from this research. Susan Darzins does not hold and is not applying for any patents relating to the contents of this thesis.

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### **Conference Presentations Arising From the Doctoral Research**

- **Darzins, S.,** Imms, C., Shields, N., Taylor, N (2015). Validity of the Personal Care Participation Assessment and Resource Tool for inpatient rehabilitation, Proceedings of the 26<sup>th</sup> Occupational Therapy National Conference and Exhibition, *Australian Occupational Therapy Journal*, 62 (Supplement 1).
- Darzins, S., Imms, C., Di Stefano, M., Radia-George, C (2015). Clinical utility of the Personal Care Participation Assessment and Resource Tool for inpatient rehabilitation, Proceedings of the 26<sup>th</sup> Occupational Therapy National Conference and Exhibition, *Australian Occupational Therapy Journal*, 62 (Supplement 1).
- **Darzins, S.**, Imms, C., Di Stefano, M., Taylor, N., Pallant, J. (2014). Evaluation of the Personal Care Participation Assessment and Resource Tool using Rasch analysis. *Proceedings of the 14<sup>th</sup> International Congress of the World Federation of Occupational Therapists, Yokohama, Japan.*
- **Darzins, S.**, Imms, C., Di Stefano, M., Taylor, N., Pallant, J. (2013). Refinement of the Personal Care Participation Assessment and Resource Tool using Rasch analysis. *Proceedings of the 21<sup>st</sup> Australasian Faculty of Rehabilitation Medicine conference*, Sydney.
- Darzins, S., Imms, C., Di Stefano, M., Taylor, N., Pallant, J. (2013). Evaluation of the Personal Care Participation Assessment and Resource Tool using Rasch analysis. Proceedings of the 25<sup>th</sup> Occupational Therapy National Conference and Exhibition, *Australian Occupational Therapy Journal*, 60, (Supplement 1, July), 97.
- **Darzins, S.,** Imms, C., Di Stefano, M. (2011). A systematic review of the measurement properties of the Personal Care Participation Assessment and Resource Tool (PC-PART), Proceedings of the 24<sup>th</sup> Occupational Therapy National Conference and Exhibition, *Australian Occupational Therapy Journal*, 58 (Supplement 1) 127.

#### **Abstract**

Background. Inpatient rehabilitation aims to facilitate people's functional recovery and return to participation in daily life roles and occupations. A critical aspect of rehabilitation is enabling people's accomplishment of activities of daily living (ADL) required for community life. Functioning in ADL is typically assessed by occupational therapists in preparation for discharge to community living using a combination of standardised and non-standardised assessment methods. Typically used standardised assessments are important but their measurement constructs are limited in scope compared to the measurement needs of the rehabilitation context. The International Classification of Functioning, Disability and Health (ICF) provides a useful internationally recognised framework to help clinicians conceptualise and operationalise measurement of the breadth of human health status and functioning. In accordance with this framework, the Personal Care-Participation Assessment and Resource Tool (PC-PART) aims to measure service-users' participation restrictions in ADL required for community life, an aspect of functioning not typically measured in rehabilitation settings. The PC-PART may fill an important measurement gap in rehabilitation and contribute to comprehensive and clinically meaningful measurement of outcomes that are relevant to service-users' life situations

*Aim.* The aim of this doctoral research was to advance knowledge about the measurement of participation restrictions in ADL required for community life, as operationalized by the PC-PART. The objectives were to evaluate the PC-PART's measurement properties and clinical utility for use in inpatient rehabilitation settings.

Measurement INstruments (COSMIN) and criteria for evaluating clinical utility of an instrument, provided frameworks to guide design and conduct of the research. The research program comprised five separate studies. Study one involved systematic review of the measurement properties and clinical utility of the PC-PART. Study two included a theoretical exploration of the PC-PART's measurement construct. Study three used a mixed-methods design to investigate occupational therapists' perceptions of the PC-PART's clinical utility for use in inpatient rehabilitation. In study four, internal construct validity of the PC-PART was evaluated using the Rasch measurement model. Study five included investigation of the PC-PART's construct validity, criterion validity and responsiveness for use in inpatient rehabilitation through hypothesis testing.

Results. The systematic review revealed existing evidence supporting the PC-PART's content validity and supported the need for further PC-PART validation research. The theoretical measurement construct of the PC-PART was identified as participation restriction in ADL required for community life. The PC-PART was perceived to enable gathering of clinically useful and comprehensive information, relevant to inpatient rehabilitation. Minor improvements to some item phrasing, operational definitions and instructions were suggested. Adequate fit of PC-PART items to the Rasch model confirmed internal validity of two unidimensional scales: the Self Care and Domestic Life scales. Both newly defined scales met 10 of 13 theoretical hypotheses related to construct validity, criterion validity and responsiveness for use in inpatient rehabilitation. Investigation of the PC-PART's reproducibility was known to

be the subject of a separate study and was therefore not undertaken during this doctoral research.

Conclusions. Evidence generated from this research program supported construct validity, criterion validity and responsiveness of the Self Care and Domestic Life scales, as measures of participation restriction in ADL required for community life, for use in inpatient rehabilitation settings. Minor revisions to the instrument are recommended to display the validated scales with their associated scoring and to address identified issues related to clinical utility. The PC-PART scales fill a measurement gap in inpatient rehabilitation. When used together with existing measures in inpatient rehabilitation settings, the PC-PART scales may enable more comprehensive and clinically meaningful measurement of outcomes relevant to service-users'. The scales may be used to evaluate effectiveness and relative costs of different interventions intending to reduce ADL participation restrictions, to investigate their value for inpatient rehabilitation. A knowledge transfer strategy is required to embed use of the instrument into clinical assessment practice.

#### **List of Abbreviations**

ADL: Activities of Daily Living

COSMIN: COnsensus-based Standards for the selection of health Measurement

**INstruments** 

CTT: Classical Test Theory

DIF: Differential Item Functioning

FIM<sup>TM</sup>: Functional Independence Measure

HR-PRO: Health Related-Patient Reported Outcome

IADL: Instrumental Activities of Daily Living

ICC: Intra-Class Correlation Coefficient

ICF: International Classification of Functioning, Disability and Health

ICIDH: International Classification of Impairments, Disabilities, and Handicaps

IRT: Item Response Theory

OMRF: Outcome Measure Rating Form

PADL: Personal Activities of Daily Living

PC-PART: Personal Care-Participation Assessment and Resource Tool

RCT: Randomised Controlled Trial

SMAF: Functional Autonomy Measurement System

WHO: World Health Organisation

### **Operational Definitions of Key Terms Used in this Thesis**

Clinical utility: The degree to which an instrument provides appropriate

and useful information for service-users' clinical management, is practical for the particular setting and is

acceptable to users and consumers.

Key informant: A person who knows about the ADL support needs of a

person receiving rehabilitation services (e.g. carer,

family member, guardian, friend).

Measurement properties: A collective term representing the concepts of validity,

reliability and responsiveness of an instrument.

Scale properties: A collective term representing an instrument's item

phrasing, response categories and scoring.

Service-user: Person receiving rehabilitation services.

### Chapter 1. Introduction, Purpose and Broad Research Objectives

#### Introduction

Enabling people's occupational performance and participation in life activities is central to the practice of occupational therapy (Townsend & Polatajko, 2013) and is the goal of rehabilitation (Heinemann, 2010; Stucki, Ewert, & Cieza, 2003). Measurement of participation-related health outcomes is critical to this practice (Desrosiers, 2005; Stucki et al., 2003). Specifically, understanding the impact of health conditions and environmental factors on inpatient rehabilitation service-users' functioning in activities of daily living is pertinent to their transition from rehabilitation to community living environments (Moreland et al., 2009). Standardised, valid measures are not typically used to measure these impacts in inpatient rehabilitation settings (Kitsos, Harris, Pollack, & Hubbard, 2011).

The body of research presented in this thesis generated evidence about the validity and clinical utility of the Personal Care Participation Assessment and Resource Tool (PC-PART), a measure of participation restrictions, that is, unmet needs, in activities of daily living (ADL) required for community life, for use with inpatient rehabilitation service-users. Evidence supporting the PC-PART's validity and clinical utility for use in this setting has potential benefits for service-users and health care providers, health care systems and governments who fund health services.

This validation and clinical utility research is situated at the intersection of three principal epistemologies: (1) occupational therapy practice in rehabilitation settings; (2) the framework and concepts of the International Classification of Functioning,

Disability and Health (ICF), published by the World Health Organisation (WHO) (World Health Organisation [WHO], 2001) and (3) measurement theory and measurement practices (see Figure 1.1). Other intersections between these epistemologies emphasise the importance of participation-focused outcomes for occupational therapy service-users in rehabilitation settings; the need for evidence-based measurement of occupational therapy outcomes; and operationalization of the measurement of ICF concepts. Measurement of the ICF concept of participation restriction is the focus of this research. A schema depicting these intersecting perspectives is provided in Figure 1.1:

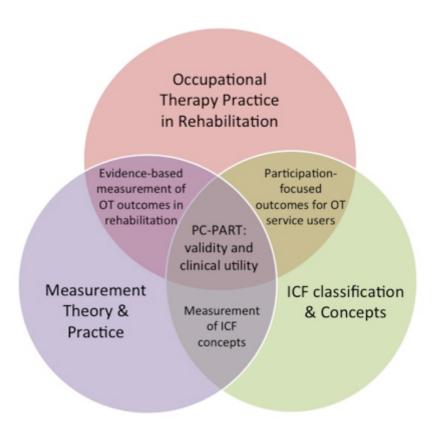


Figure 1.1. Schema of three principal overlapping epistemologies in this thesis.

This chapter includes: a description of the underlying theoretical foundations of occupational therapy practice; a description of the ICF and how it may be used to structure measurement of health status; the relevance of participation-related outcomes for occupational therapy service-users and the importance of evidence-based measurement to occupational therapy practice. The PC-PART instrument's development and use is described. In particular, the measurement of occupational therapy service-users' participation restrictions in ADL required for community life, using the PC-PART, is emphasised as an area for further validation. Clinical usefulness, or utility, of the PC-PART is also highlighted as an important aspect of its use in practice.

### Occupational Therapy, Occupation and Occupational Performance

In 2010 the World Federation of Occupational Therapists updated their definition of occupational therapy, stating:

Occupational therapy is a client-centred health profession concerned with promoting health and wellbeing through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement. (World Federation of Occupational Therapists Council, 2010, p. 1)

In occupational therapy, occupations refer to "all everyday activities people do as individuals, in families, as members of groups, and within communities to bring meaning and purpose to life and to achieve and maintain health" (World Federation of Occupational Therapists Council, 2012, p. 1). Performance of occupation meets individuals' intrinsic need for self-maintenance, expression and fulfillment in personal roles within their environments (Law et al., 1996). It is through engagement in occupation that people develop and maintain health and well-being (Wilcock, 2006). Law et al. described occupational performance as resulting from "the dynamic relationship between people, their occupations and roles, and the environments in which they live, work and play (p. 9)".

Central to occupational therapy practice is the use of a *client*-, or *person*-centred approach. Person-centred occupational therapy has been described as "an approach to service which embraces a philosophy of respect for, and partnership with, people receiving services" (Law, Baptiste, & Mills, 1995, p. 253). In this thesis, people receiving rehabilitation services are referred to as service-users. Law et al. (2005) wrote that the concepts of client-centred practice have specific implications for measurement of occupational performance. These implications are paraphrased here:

- That occupational performance problems need to be identified by serviceusers and/or their families, not by the therapist or team; if there are issues that surface, for example, regarding safety or health maintenance, the therapist will communicate these concerns directly to the service-user and family;
- 2. Evaluation of the success of occupational therapy intervention needs to focus on change in occupational performance from a measured baseline;

- 3. Measurement techniques need to enable service-users to have a say in evaluating the outcomes of their therapy intervention;
- 4. Measurement needs to reflect the individualized nature of service-users' participation in occupations;
- Measurement should focus on both subjective and observable qualities of occupational performance; and
- 6. Measurement of the environment is critical in helping therapists and service-users understand the influence of environments on occupational performance, as well as measuring the effects of changing service-users' environmental conditions through the therapy process (Law, King, & Russell, 2005, p. 8).

A person-centred measurement model allows service-users and practitioners to jointly plan and evaluate interventions. In situations where service-users do not have the cognitive capacity for independent communication or decision-making, a family-centred approach to measurement is required, where family members, or carers, provide important information about service-users' occupational performance, as well as their own roles as carers.

Commonly used ecological models in occupational therapy that guide practice are the Person-Environment-Occupation model (Law et al., 1996); the Canadian Model of Occupational Performance and Engagement (Townsend & Polatajko, 2013); the Model of Human Occupation (Kielhofner, 2008; Kielhofner & Burke, 1980); the Person-Environment-Occupation-Performance Model (Christiansen, Baum, & Bass-Haugen, 2005); and the Ecology of Human Performance model (Dunn, McClain, Brown, & Youngstrom, 2003). All of these models focus on the dynamic and unique interactions between people, their occupations and environments (C. Brown, 2014).

Occupational performance is determined by interaction of the person, environment and occupation factors, which constantly change, and as they change, so does occupational performance (C. Brown, 2014). Each model considers occupational performance as the primary outcome of interest to occupational therapists. When applied to individuals, measurement within each of these occupational therapy models focuses on individuals, their roles, their occupations, and how factors within their living, working and playing environments influence occupational performance and engagement (C. Brown, 2014). Interventions may target change at the level of the person or changes to the environment to promote occupational performance and engagement.

#### **International Classification of Functioning, Disability and Health (ICF)**

Published in 1980, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (World Health Organisation [WHO], 1980) was based on a biopsychosocial model of health and was designed to form part of a family of classifications developed by the WHO. The most established classification at the time was the ninth revision of the International Statistical Classification of Diseases, Injuries, and Causes of Death (ICD). The intention of the ICIDH was to offer a worldwide conceptual framework for information relevant to the long-term consequences of diseases, injuries and disorders. It was intended to be applicable to personal health care and to the mitigation of societal and environmental barriers. The model recognised the limited scope of the medical model of illness enshrined in the ICD, which described the etiology, pathology and manifestation of disease (WHO, 1980). The ICIDH differentiated three separate concepts related to the consequences of disease and health conditions: *impairments*, *disabilities* and *handicaps*. *Impairments* were defined as "any loss or abnormality of psychological, physiological, or anatomical structure or function"

(WHO, 1980, p. 27). *Disabilities* were defined as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO, 1980, p. 28). *Handicaps* were defined as "a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual" (WHO, 1980, p. 29). The model recognized that some individuals with disease may be only mildly disabled and yet have severe disadvantage, while others with similar disease who are more disabled, but who have greater supports within their environments, may experience less disadvantage (WHO, 1980).

Concern was expressed that the ICIDH did not clearly identify the role of social and environmental influences on the process of *handicap*. This led to changes to the ICIDH to develop a global common language for describing dimensions of disablement at three levels of functioning: (1) the body; (2) the whole person and (3) the person within their complete social and physical environmental context. Changes culminated in field testing of the International Classification of Impairments, Activities and Participation, named, the ICIDH-2 (World Health Organisation [WHO], 1998). In the ICIDH-2 functioning and disability were conceived as "a dynamic interaction between health conditions and contextual factors…contextual factors include both personal and environmental factors" (WHO, 1998, p. 12). The ICIDH-2 was drafted as the precurser to the current ICF, which was ratified by the World Health Assembly for international use in 2001 (WHO, 2001). The aim of the ICF was to:

Provide a scientific basis for understanding and studying health and health-related states, outcomes and determinants; establish a common language for describing health and health-related states in order to improve communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities; permit comparison of data across countries, health care disciplines. services and time; and provide a systematic coding scheme for health information systems. (WHO, 2001, p. 5)

The ICF framework highlighted the dynamic, non-linear and interactive relationships between its components comprising the person, their activities, and the environments that make up their life, in determining health and health outcomes. Both positive and negative states of health can be classified using the ICF. A table providing an overview of the organisation of information contained in the ICF in its two parts, *Functioning and Disability* and *Contextual Factors*, is provided in Appendix A

#### ICF Part 1. Functioning and disability.

The *functioning and disability* component contains two classifications, one for *body functions and structures* and one for *activities and participation*. Within these two classifications, three levels of human functioning are identified: functioning at the level of the body (*body functions and structures*), the whole person (*activities*), and the whole person in their complete environment (*participation*). The term *disability* "is an umbrella term for *impairments*, *activity limitation* and *participation restriction*" (WHO, 2001, p. 213). The terms *activity limitations*, and *participation restrictions* replaced the terms *disability* and *handicap* from the International Classification of Impairments,

Disabilities and Handicaps (WHO, 2001, p. 213). Definitions of key terms as given by the ICF are provided as follows, in the context of health:

*Body functions*: are the physiological functions of body systems (including psychological functions).

*Body structures*: are anatomical parts of the body such as organs, limbs and their components.

*Impairments*: are problems in body function and structure such as a significant deviation or loss.

*Activity* is the execution of a task or action by an individual.

Participation is involvement in a life situation.

Activity limitations are difficulties an individual may have in executing activities.

Participation restrictions are problems an individual may experience in

involvement in life situations. (WHO, 2001, p. 10)

The activities and participation component of the ICF covers aspects of functioning from an individual perspective and a societal perspective across nine identified life domains. Each domain contains sub-categories which can be used to denote either activities or participation constructs, or both. The identified life domains are listed in the ICF as: d1 Learning and applying knowledge; d2 General tasks and demands; d3 Communication; d4 Mobility; d5 Self Care; d6 Domestic Life; d7 Interpersonal interactions and relationships; d8 Major life areas; and d9 Community, social and civic life (WHO, 2001, p. 14).

The WHO recognised the difficulty of distinguishing between *activities* and *participation* using the domains, alone. Also, consensus on the distinction between

individual and societal perspectives based on the domains was not reached at the time of publishing the ICF (WHO, 2001). Therefore the ICF provided a single list of domains and four options that may be used to differentiate between activities and participation domains:

- a) to designate some domains as activities and others as participation, not allowing any overlap;
- b) same as (a); above, but allowing partial overlap;
- c) to designate all detailed domains as activities and the broad category headings as participation;
- d) to use all domains as both activities and participation. (WHO, 2001, p. 16)

To obtain descriptive information about functioning and disability in each domain of the ICF *activities* and *participation* component, the WHO (2001) advocated use of *capacity* and *performance* qualifiers. The *capacity* qualifier "describes an individual's abilities to execute a task or an action.... to indicate the highest probable level of functioning that a person may reach in a given domain at a given moment" (WHO, 2001, p. 15). This qualifier may be used to indicate *activity limitations*. The *performance* qualifier "describes what an individual does in his or her current environment" (WHO, 2001, p. 15). This qualifier may be used to indicate *participation restrictions*. The *gap* between *capacity* and *performance* reflects the influence of environments and personal factors on performance. Within the ICF it is suggested that because individuals' environments include a societal context, "*performance* can also be understood as *involvement in a life situation* or *the lived experience* of people in the actual context in which they live" (WHO, 2001, p. 15). This is also the WHO definition of *participation*, previously described.

The only indicator of participation within the activities and participation component of the ICF is attained through coding the performance qualifier (WHO, 2001, p. 15). Use of the performance qualifier within the ICF taps an objective *doing* aspect of participation/performance. However, the ICF also reports that *participation* should not automatically be equated with *performance* (WHO, 2001, p. 15).

Participation has an important subjective component, such as the person's sense, or feeling of involvement, inclusion or engagement in life situations, which is not captured when measuring *performance* alone (Dijkers, 2010; Granlund, Eriksson, & Ylvén, 2004; Whiteneck & Dijkers, 2009; WHO, 2001).

#### ICF Part 2. Contextual factors.

Contextual factors comprise the circumstances of people's lives and form the background to classification of their health states. Two contextual factors are identified in the ICF: *environmental* and *personal* factors (see Appendix A). *Environmental factors* "make up the physical, social and attitudinal environment in which people live and conduct their lives" (WHO, 2001, p. 10). *Personal factors* are described within the ICF as "the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health states" (WHO, 2001, p. 17). These include factors such as gender, age, habits, coping styles, social background, past and current experiences and other personal characteristics (WHO, 2001). *Personal factors* are included as a component of *contextual factors*. There is no mechanism for classifying personal factors in the ICF "because of the large social and cultural variance associated with them" (WHO, 2001, p. 8).

Both environmental factors and personal factors are described in the ICF as operating as facilitators and barriers to functioning and disability. *Facilitators* are described in the ICF as "factors in a person's environment that through their presence, improve functioning and reduces disability" (WHO, 2001, p. 214). Examples include availability of relevant assistive technology, accessible physical environments, support services, positive attitudes of people and systems and policies that enhance involvement of people with a health condition in their life situations. *Facilitators* "can prevent an impairment or activity limitation from becoming a participation restriction, since the actual performance of an action is enhanced, despite the person's problem with capacity" (WHO, 2001, p. 214). *Barriers* are "factors in a person's environment that, through their absence or presence, limit functioning and create disability" (WHO, 2001, p. 214). These include inaccessible physical environments, negative attitudes of people, unavailability of appropriate assistive technology, as well as policies, systems and services that are not available or are poorly targeted to addressing people's needs for increasing involvement in their life situations.

#### **Interactions Between Components of the ICF**

According to the ICF, an individual's functioning is a result of an interaction between an individual's health condition and contextual factors. Figure 1.2 illustrates the dynamic multiple interactions among the components, but is not a definitive representation of the relationships between the constructs (WHO, 2001).

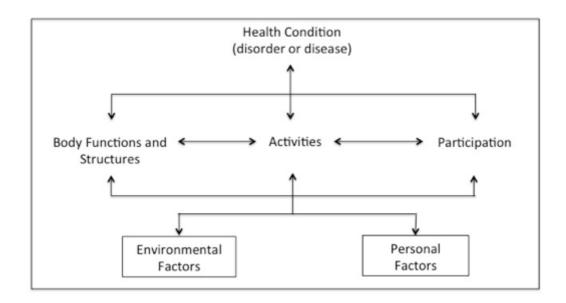


Figure 1.2. Depiction of the interactions between ICF components. Adapted from the *International Classification of Functioning, Disability and Health* by the World Health Organisation, 2001, Geneva, p.18.

# The ICF as a Classification System

The ICF classification system is intended for the systematic coding of human functioning and disability, which may enable data comparisons across health care disciplines, health-related services and across countries. Categories are organised in a hierarchical structure within the ICF. Components of the ICF are identified by a prefix: body functions (*b*); body structures (*s*); activities and participation (*d*) and environmental factors (*e*) (WHO, 2001, p. 219). An example of the categorisation within the activities and participation domain is provided here:

<i>d</i> 6	Domestic Life	(first level)
d620	Acquisition of goods and services	(second level item)
d6200	Shopping	(third level item)

The ICF provides coding guidelines for use of qualifiers to classify people's health-related states (WHO, 2001). The ICF categories, written without qualifiers, are neutral. Codes may be used to indicate people's impairments, activity limitations, participation restrictions or environmental barriers impacting on participation, depending on the construct being coded. This coding system is relatively complex and requires training. A description of the coding is contained in Appendix A.

### Occupational Therapy and the ICF

Occupational therapists connect easily with ICF concepts because of congruence between the concepts and language of occupational therapy models and the ICF framework (Imms, 2006; Imms & Granlund, 2014; Prodinger, Darzins, Magasi, & Baptiste, 2015; Stamm, Cieza, Machold, Smolen, & Stucki, 2006). Almost all concepts from the Model of Human Occupation, Canadian Model of Occupational Performance and Occupational Performance Model (Australia) were linked to the ICF using established linking rules (Cieza et al., 2002; Cieza et al., 2005; Stamm et al., 2006). Stamm et al. (2006) highlighted similarities in descriptions of occupational performance between various occupational therapy models, with each describing it as a dynamic relationship between people, their occupations and their environments. They also highlighted similarities between descriptions of occupational performance and the ICF concept of participation, functioning and disability, which is the result of a dynamic interaction between the person, their health condition and contextual factors (WHO, 2001). The researchers concluded that there are strong conceptual connections between the ICF and occupational therapy models, which encourages occupational therapists to use the ICF in their practice (Stamm et al., 2006).

Use of the ICF concepts and language may enhance communication about evidence supporting occupational therapy knowledge and practice across professions, organsiations and governments (Gray, 2001; Hemmingsson & Jonsson, 2005; Imms, 2006). Selection and use of outcome measures that correspond to the domains of the ICF may help to convey the role and value of occupational therapists within health and social services (Haglund, 2008; Imms, 2006).

### **Measurement of ICF Concepts**

Assessment and measurement of health status can be guided by the ICF as a framework and set of classifications (Australian Institute for Health and Welfare [AIHW], 2003; World Health Organisation [WHO], 2013). Development of instruments to measure aspects of functioning and disability where no instrument exists, may fill gaps in current measurement practices. The ICF promotes a common language that facilitates communication and dialogue between disciplines, organisations, governments and nations. This may, in turn, facilitate improvement in delivery of health services, interdisciplinary research and well-informed health policy (Imms, 2006; Jette, 2006; Ros Madden, Choi, & Sykes, 2003; Stucki, Cieza, & Melvin, 2007; Ustün, Chatterji, Bickenbach, Kostanjsek, & Schneider, 2003; WHO, 2013). Internationally, development and use of health status instruments designed to measure aspects of the ICF framework as well as theoretical descriptions about use of the ICF in clinical and rehabilitation contexts, has occurred since publication of the ICF. This provides evidence that conceptualisations within the ICF have been broadly accepted, and operationalisation of the ICF has occurred (Cerniauskaite et al., 2011; Jelsma, 2009).

Mapping of instruments to ICF categories may illuminate the specific aspects of functioning and disability they measure. Clinical assessments and outcome measures developed before publication of the ICF, which continue to be used in clinical practice or for research, can be mapped to the ICF using published linking rules developed by Cieza and colleagues (Cieza et al., 2002; Cieza et al., 2005). This process has been used to identify ICF categories covered by clinical assessments and outcome measures and has aided understanding of existing instruments' content validity in relation to the ICF framework (Cerniauskaite et al., 2011).

Although there is broad acceptance of the ICF, one of the most problematic issues is that consensus has not been reached on the conceptualisation and measurement of participation, and how it is distinct from activity, with several authors offering views on this (Badley, 2008; Dijkers, 2010; Eyssen, Steultjens, Dekker, & Terwee, 2011; Heinemann et al., 2010; Hemmingsson & Jonsson, 2005; Magasi & Post, 2010; Whiteneck & Dijkers, 2009). One approach to differentiating activity from participation has been for authors to categorise separate domains (chapters) within the activity and participation component of the ICF as belonging to either activity or participation. For example, chapters d3 to d9 have been suggested for operationalizing participation (Noonan, Kopec, Noreau, Singer, & Dvorak, 2009). Another set of authors advocated that chapters d1 to d3 be categorised as activity domains, chapters d4 and d5 contain a mixture of activity and participation, and that chapters d6 to d9 measure participation (Wilkie, Peat, Thomas, & Croft, 2004). Others have suggested that chapters 1 to 6 be designated as *activities* and the remaining chapters, 7 to 9, be designated as participation on the basis that participation refers to fulfilment of social roles and performance at the societal level, requiring a social interaction with the environment

(Whiteneck & Dijkers, 2009). These methods of differentiation are inconsistent and have relied on judgements made from researchers' perspectives. Some empirical research with stakeholders has suggested that people need to be at liberty to define domains of participation from their own perspective, rather than being categorised on the basis of pre-determined societal norms, as judged by others (Häggström & Lund, 2008; Hammel et al., 2008). An illustration of this could be that for one person, self care (d5) and domestic life (d6) ADL occupations, such as bathing or meal preparation may be no more than a means to involvement in broader social roles. However, for another person, these same self care and domestic life maintenance occupations may form a major component of their participation and involvement in their daily life situation. Thus, the methods described for differentiating activities from participation, above, have implications for consistency in measurement and do not reflect the personal and complex nature of the constructs.

The ICF describes participation as including not only a performance aspect, but also a subjective, personally experienced component. However, information for recording subjective, or person-experienced aspects of participation is not included in the ICF (WHO, 2001). Soon after publication of the ICF, Perenboom & Chorus (2003) described participation as both an objective and subjective phenomenon, defining it as:

Involvement in life situations, which includes being autonomous to some extent or being able to control your own life, even if one is not actually doing things themselves. This means that not only the actual performance should be the key indicator, but also fulfilment of personal goals and societal roles (Perenboom & Chorus, 2003, p. 578).

Since this time, several researchers have discussed and explored both subjective and objective aspects of participation (Arvidsson, Granlund, Thyberg & Thyberg, 2014); Badley, 2008; M. Brown et al., 2004; Coster & Khetani, 2008; Coster et al., 2012; Heinemann et al., 2011; Hemmingson & Jonsson, 2005; Van de Velde, Bracke, Van Hove, Josephsson & Vanderstraeten, 2010; Whiteneck & Dijkers, 2009). One recent clear explanation of the objective and subjective nature of participation is that of Chang, Coster and Helfrich (2013). Chang et al. asserted that the objective dimension of participation is operationalized as behaviours that can be observed, such as frequency, intensity, duration, and variety of activities performed. They asserted that the subjective dimension of participation addresses people's internal experience and can include a sense of belonging, perception of involvement, and satisfaction with engagement in life activities. Chang et al. highlighted both subjective and objective aspects of participation as important in understanding people's participation in life situations. They described objective, measurable aspects of participation as providing quantifiable information that can be used for detecting effectiveness of interventions and for making comparisons of outcomes across different populations and contexts. Subjective aspects of participation can provide insight and understanding into people's affective experience and meaning associated with participation (Chang et al., 2013). For example, one person may strive to be independent in self care and domestic life activities because this holds personal meaning and is an important outcome for that person, whereas, another person may not value independence in ADL and want to receive assistance in order to accomplish ADL, to allow energy for other more highly valued activities. In this example, recording of both the subjective and objective aspects of participation in self care and domestic life activities is important for an accurate measurement and explanation of the phenomenon.

Another recent empirical study analysed the participation construct and concluded that people's participation experience seems to consist of two main elements: an *attendance* element and a subsequent *involvement* element (Imms et al., 2016). The *attendance* element refers to the act of *being there* and may be measured as frequency of attending and/or the range or diversity of activities in which the person takes part (Imms et al., 2016). This concurs with the objective component of participation described by Chang et al. (2013). Imms et al. described the involvement element as the *in-the-moment* experience of participation and is the experience of participation while attending, including elements of motivation, persistence, social connection and affect. This subjective component of participation described by Imms et al. is largely consistent with the description of Chang et al. (2013). Imms et al. concluded that it is not possible to be *involved* without *being there*.

Participation is described in the ICF as a dynamic interaction between people and their contextual factors (WHO, 2001). It seems to involve a transaction that occurs at the intersection between people, their occupations and their environment. Some say that measurement of participation should capture this transaction (Hammel et al., 2015; Heinemann et al., 2011; Magasi et al., 2015; Mallinson & Hammel, 2010). The biopsychosocial model recognises the influence of the social and physical environment on people's experiences of health and participation, but there are few participation instruments developed specifically to reflect this dynamic and changing transaction between the person and their environment (Hammel et al., 2008; Heinemann et al., 2011). Madden et al. (2013) state that "in policy and clinical settings, functioning cannot be understood without understanding environment. For instance, in rehabilitation, information about the person's home and community setting and

availability of social supports are essential to planning and evaluating options for community living" (Ros Madden, Fortune, Cheeseman, Mpofu, & Bundy, 2013, p. 1095). Some authors argue that the influence of environmental factors on participation should be a particular focus of measurement to identify targets for intervention to promote participation (Magasi et al., 2015).

Hammel et al. (2015) conducted a qualitative grounded theory study using data from people with disabilities across the United States of America, in order to develop a conceptual framework to describe how environmental factors influence participation. The authors summarised everyday participation as being "influenced by environmental factors at the individual (micro), community (mesa) and societal (macro) levels" (p. 584). Examples of environmental influences on participation at the micro level were described as immediate social supports, personal finances, immediate built environment, assistive technology and personal transportation. Examples of influences at the mesa level were described as social networking and capital, community access to information technology, access to built community environment, and transportation access in the community. Examples of influences at the macro level were described as societal economic and political influence, systems and policies, civil rights legislation, societal attitudes and digital divide issues. The resulting transactional framework seems to capture several levels at which people can participate in, and be influenced by their environments in life situations ranging from their immediate living surroundings to their involvement at a societal level.

#### **Measurement in Health Care**

National and local health care systems require data about people's health-related

status to make decisions about needed interventions and resources and the costs and benefits of health care services to society (Australian Institute of Health and Welfare [AIHW], 2014). The ICF provides a useful framework for categorisation of national health data collection and is currently used across several countries for this purpose (Kostanjsek, 2011). The ICF is used as an overarching framework for categorisation of national health data collection in Australia (Australian Insitute of Health and Welfare [AIHW], 2008). However, currently, there are gaps in the type of health-related outcomes routinely measured in Australian health care systems, with currently used measures explaining a relatively small proportion of health-related outcomes (AIHW, 2014). More comprehensive assessment of health outcomes could potentially be linked to health expenditure, to assess the effectiveness and efficiency of health services (AIHW, 2014). It is important that instruments are selected carefully to ensure measurement of aspects of service-users' health status expected to change as a result of interventions, in order to produce information that is useful and relevant to their health outcomes and the health context (Ros Madden et al., 2013). Measures gathering information about people's everyday functioning both pre- and post-intervention may provide key data that leads to improved health services and policies and ultimately people's quality of life (Ros Madden et al., 2013).

To produce accurate and useful data, it is critical that measures used in health care show acceptable measurement properties, that is, validity, reliability and responsiveness for their purpose and for the context in which they will be used (Mokkink, Terwee, et al., 2010b). Valid measurement is an accurate reflection of the presence and degree of an attribute intended for measurement (Streiner, Norman, & Cairney, 2015). Reliable measurement is free from random and systematic error

(Streiner et al., 2015). Responsive measures show clinically meaningful change when such change has occurred (Streiner et al., 2015). These concepts are further discussed in Chapter 2. Valid, reliable and responsive measurement practices enable clinicians and researchers to investigate the effectiveness of health services and to conduct economic analysis of interventions designed to improve service-users' health outcomes. (Laver Fawcett, 2007; Reeve et al., 2013; Streiner et al., 2015). This type of evidence informs health care providers about effective and efficient ways to advance health care practices. In this thesis, collective reference to the concepts of validity, reliability and responsiveness will be made using the term *measurement properties*.

# **Measurement in Occupational Therapy**

For decades, occupational therapists have discussed the importance of using standardised assessments with adequate measurement properties for their purpose, as a routine part of occupational therapy practice (Law, 1987; M. Pilegaard, B. Pilegaard, Birn, & Kristensen, 2014; Unsworth, 2000). Standardised assessments have a set of unchanging procedures that must be followed and a consistent system of scoring. Standardisation helps to minimise variation in the way assessments are carried out at different times and by different users with the aim of promoting reliability of scores (Laver Fawcett, 2007). With increasing demand and pressure on health care systems, it is critical that occupational therapists measure the effectiveness and efficiency of their services. The use of reliable, valid, and responsive standardised measurement instruments in routine occupational therapy practice is advocated to generate evidence about the benefits of occupational therapy interventions (Laver Fawcett, 2007; Law, 1987; Unsworth, 2011).

Clinical utility is not a measurement property, but refers to many factors, including the degree to which an instrument provides appropriate and useful information for client clinical management, is practical for the particular setting and is acceptable to users and consumers (Laver Fawcett, 2007; Law, 1987, 2004; Law et al., 2005; Smart, 2006). Clinical utility may be influenced by characteristics of an instrument such as the clarity of instructions, format of the instrument, interpretation of scores, administration time, purchase cost, user training requirements, acceptability to service-users, and ease of use (Law, 1987). Clinical utility has been cited as an important influence on instruments' use in clinical practice (Laver Fawcett, 2007; Law et al., 2005). The term *clinical utility* has also been used, mainly in the biomedical literature, to refer to the sensitivity and specificity of diagnostic tests and screening tools for use in clinical settings. This is not how the term *clinical utility* is used, in this thesis.

#### Measurement of Functioning in ADL

One of the roles of occupational therapists is to enhance service-users' performance and engagement in their ADL. In 2012, the World Federation of Occupational Therapists produced a position statement about ADL asserting that:

Occupational therapists are experts in relation to Activities of Daily
Living and [that] they adopt a holistic approach when applying specific
skills with various people in different settings, including home, work,
and leisure contexts, with the aim of enhancing performance of, and
engagement in, their activities of daily living. (World Federation of
Occupational Therapists Council, 2012, p. 1)

Conceptually, ADL could refer to all activities that people routinely engage in, however, ADL are generally defined more narrowly in practice settings (James, 2014). In 2014, the American Occupational Therapy Association (AOTA) defined ADL as "activities that are oriented toward taking care of one's own body...also referred to as basic activities of daily living (BADL) and personal activities of daily living (PADL)" (American Occupational Therapy Association [AOTA], 2014, p. S19). The ADL activities named included: bathing/showering, toileting/toilet hygiene, dressing, swallowing/eating, feeding, functional mobility, personal device care, personal hygiene and grooming and sexual activity (p. S19). Instrumental activities of daily living (IADL) were defined by the AOTA as "activities to support daily life within the home and community that often require more complex interactions than those used in ADL" (AOTA, 2014, p. S19). The IADL named by AOTA included: care of others, care of pets, child rearing, communication management, driving and community mobility, financial management, health management and maintenance, home establishment and management, meal preparation and cleanup, religious and spiritual activities and expression, safety and emergency maintenance and shopping (AOTA, 2014, p. S19-20).

Occupational therapists and health practitioners outside of the United States of America may use different terms to refer to essentially the same ADL concepts as those used by the AOTA, or they may use the same terms, but define them differently (James, 2014). In this thesis, the terms Personal ADL (PADL) and Instrumental ADL (IADL) will be used when referring to a specific type of ADL, and the term *ADL* will be used to make reference to both PADL and IADL. It is noted that ADL are considered in the plural form.

The ICF may be useful for developing an internationally accepted and standardised taxonomy of ADL. The activities and participation component of the ICF provides three main domains of functioning encompassing primarily ADL content: d4 mobility, d5 self care and d6 domestic life. Examples of ICF level two d4 mobility categories include transferring oneself, walking and moving and moving around using transportation. Level two d5 self care categories include washing oneself, caring for body parts, toileting, dressing, eating, drinking and looking after one's health. Level two d6 domestic life categories include acquiring a place to live, acquisition of goods and services, preparing meals, doing housework, caring for household objects and assisting others.

Activities of daily living may be valued, in and of themselves, as providing meaningful participation in people's life situations. They may also be a prerequisite to enabling meaningful engagement in play, education, leisure, work and social participation. Either way, accomplishment of ADL is necessary for community living. Assessment of people's functioning in ADL occurs in health care settings and in people's homes, generally using self-report and/or observational methods (Wales et al., 2012). In rehabilitation settings, clinical assessment of ADL functioning may occur at admission to identify priorities for intervention to enhance performance of ADL. Assessment of ADL functioning may occur at subsequent times during rehabilitation to evaluate progress made towards identified ADL goals and to plan discharge to community living (Wales et al., 2012). Health professionals may use informal ADL assessment methods and/or standardised instruments (Kitsos et al., 2011; Koh, Hoffmann, Bennett, & McKenna, 2009; Wales et al., 2012). For example, available evidence suggests that most occupational therapists working in stroke rehabilitation use

a standardised assessment to evaluate service-users' functioning in PADL but do not use a standardised assessment to evaluate functioning in IADL (Kitsos et al., 2011; Koh et al., 2009). Koh et al. (2009) surveyed the assessment practices of 102 occupational therapists who work with service-users who have cognitive impairment post-stroke and found that standardised assessments of functioning in PADL most widely used in stroke rehabilitation settings in Australia were the Functional Independence Measure (FIM<sup>TM</sup>) (Uniform Data Systems for Medical Rehabilitation, 2014) and the Barthel Index (Mahoney & Barthel, 1965). Indeed, use of the FIM<sup>TM</sup> to measure service-users' activity limitations in PADL in rehabilitation settings is currently mandated (Australian Government: Australian Institute of Health and Welfare, 2015; Australian Rehabilitation Outcomes Centre, 2014). Koh et al. (2009) also found that only approximately 16% of the surveyed therapists used a standardised IADL assessment and that approximately 75% of therapists, used either no assessment of IADL or they used non-standardised, informal assessments. Interestingly, 88% of surveyed therapists reported that they used basic ADL retraining, and 84% of therapists reported using instrumental ADL retraining, as an intervention. This evidence suggests that the occupational therapists surveyed, were not able to achieve reliable measurement of the effectiveness of their instrumental ADL training interventions.

Decisions about people's need for admission to, or readiness for discharge from, health care settings are an essential part of clinical practice for the whole health care team. The aim of discharge planning is for health professionals and service-users to work collaboratively to plan for service-users' return to community living. In this thesis, different levels of community living arrangements are conceptualised as:

- independent living at home without supports;
- living at home with some supports (informal and/or formal paid supports);
- institution-based low-level supported accommodation (formal paid supports provided for some ADL);
- institution-based high-level care supported accommodation (formal paid supports provided for all ADL).

Thus, discharge planning requires assessment and identification of service-users' support needs for accomplishing ADL required for community living and organising of appropriate supports, where needed (Shepperd et al., 2010; Wales et al., 2012). Effective discharge planning may reduce length of stay and the likelihood of unplanned readmission, as well as enhance continuity of care and satisfaction of service-users, carers and families (Rudman, Tooke, Eimantas, Hall, & Maloney, 1998; Shepperd et al., 2010). Factors that can delay discharge or result in hospital re-admission can include unresolved non-medical issues, but may also include failure to provide adequate environmental supports for people, once discharged, resulting in their inability to maintain necessary ADL required for community living (New, Cameron, Olver, & Stoelwinder, 2013). Ideally, ADL assessments focus on people's abilities, their current and intended living environments and the availability of needed supports and how these impact on the person's accomplishment of their ADL (Wales et al., 2012).

Historically, Lawton & Brody (1969) suggested that IADL consists of tasks essential to community living and should be assessed to aid discharge planning. They identified eight IADL activities: managing money, using the telephone, taking medication, traveling, shopping, preparing meals, doing laundry and housekeeping. Currently, there is variation in the number and type of activities included in IADL

measures (Gitlin, 2005; James, 2014). Some examples are the Nottingham Extended ADL (NEADL) scale which includes four main areas: Mobility, kitchen (including feeding oneself), domestic and leisure activities (Nouri & Lincoln, 1987); the Kohlman Evaluation of Living Skills (KELS) which includes five main areas: Self care, safety and health, money management, transportation and telephone use, and work/leisure (Kohlman, 1992); the Functional Autonomy Measurement System (SMAF) which includes five categories: Activities of daily living (basic), mobility, communication, mental functions and IADL (Hébert, Carrier, & Bilodeau, 1988) and the Assessment of Living Skills and Resources-Revised version (ALSAR-R2) which includes 10 IADL items and one leisure item (Clemson, Bundy, Unsworth, & Singh, 2009; Williams et al., 1991). All of these assessments vary in their content and assessment structure. Historically, the absence of agreed PADL and IADL constructs and taxonomies to guide instrument development may have meant that content of early ADL assessments, such as those developed by Katz and colleagues (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963); Mahoney and Barthel (Mahoney & Barthel, 1965); and Lawton & Brody (Lawton & Brody, 1969) has influenced our understanding of the concept of ADL over time (Letts & Bosch, 2005). Establishing appropriate content for an instrument is challenging if there is not a clear and consistent internationally accepted definition of the construct (Coster et al., 2004; Letts & Bosch, 2005). Through its globally consistent language and categorisations, the ICF may be useful for identifying similarities and differences in the content of available ADL measures, and may provide an internationally recognised taxonomy of ADL.

The FIM<sup>TM</sup> is now the most commonly used standardised measure in sub-acute and non-acute health care settings in Australia as it is linked to activity-based funding

models for inpatient health care services. Sub-acute settings are those in which the primary need for care is improvement in the patients' functioning and quality of life, for example, multi-disciplinary rehabilitation units and geriatric evaluation and management units (Australian Institute of Health and Welfare, 2013). Activity-based funding models are based on the number, mix and complexity of service-users treated (Australian Institute of Health and Welfare, 2015). The FIM<sup>TM</sup> measures the person's level of dependence in 18 mobility and cognitive items covering PADL in self care, sphincter control, transfers, locomotion, communication and social cognition. Each item has seven response categories ranging from the highest score of *complete independence* (7) to the lowest score of *total assistance* (1). The FIM<sup>TM</sup> is a measure of activity limitations, according to the ICF framework (Uniform Data Systems for Medical Rehabilitation, 2014). One of the limitations of the FIM<sup>TM</sup> is its inadequacy for measuring clinically relevant changes in functioning for service-users requiring complex rehabilitation following serious injury (Richard Madden et al., 2013).

When developing and selecting a suitable ADL instrument for use, consideration needs to be given to the purpose of the measurement instrument; the population for whom it was developed; content of the instrument in relation to what needs to be assessed; evidence supporting its measurement properties for the population in which it will be used; and its clinical utility. An assessment that takes into consideration all areas of functioning necessary for living in the community is required for both discharge planning and prevention of unnecessary re-admission to hospital. To be useful and effective, this assessment must involve service-users and their family/carers in identifying critical problems and prioritisation of interventions to address these problems to enable return to community living. Recent evidence from a qualitative

study conducted in Sweden with older adults and their families directly supported this premise (Björkman Randström, Asplund, Svedlund & Paulson, 2013). Pre-discharge assessments used in Australia measuring activity limitations in PADL, such as the FIM<sup>TM</sup>, give a reliable and valid indication of people's abilities to perform PADL (Heinemann, Ehrlich-Jones, & Moore, 2013), but are not able to provide information about people's accomplishment of IADL, nor what supports are available and provided in people's living environments to address areas of dependence. Use of an instrument targeting accomplishment of both IADL and PADL would seem to be a useful addition to assessments currently used in the health care system to enable efficient and clinically meaningful measurement in all areas of functioning necessary for community living.

One instrument that has been used in some health care settings in Australia that is conceptually different to the FIM<sup>TM</sup> instrument, and was designed to meet this described need, is the Personal Care-Participation Assessment and Resource Tool (PC-PART) (P Darzins, 2004).

# Personal Care-Participation Assessment and Resource Tool

The purpose of the PC-PART is to identify problem areas in ADL that are necessary for community living, and which persist despite the person's own efforts, their use of adaptive equipment and/or assistance from others (P Darzins, 2004). It does this by prompting users to record the transaction between the person, their health condition and environmental factors operating in the person's living situation, resulting in measurement of both met and unmet ADL needs (P Darzins, 2004). Measurement of unmet ADL needs aids understanding of the nature and extent of problems people experience accomplishing activities of daily living required for community life. Unmet ADL needs, as measured by the PC-PART, are termed ADL participation restrictions (P

Darzins, 2004). A further intended use of the PC-PART is to measure meaningful change in people's ADL participation restrictions over a course of health care service provision. Additionally, it is intended that the PC-PART be used to discriminate between people who are able to live in the community with existing supports and those who cannot.

The intended purposes of the PC-PART may be labelled as primarily *descriptive*, *discriminative* and *evaluative*. *Descriptive* instruments use criteria or items to describe individuals within groups and ideally measure all relevant aspects of the construct to the user (Hanna et al., 2005). *Discriminative* instruments differentiate between people on the construct being measured (Hanna et al., 2005). *Evaluative* instruments are designed to measure change in the degree of an underlying construct experienced by people, over time, and may be used to determine effectiveness of an intervention (Kirshner & Guyatt, 1985; Law, 1987).

The PC-PART was designed to include 43 items across seven domains: *Clothing*; *Hygiene*; *Nutrition*; *Mobility*; *Safety*; *Residence*; and *Supports*. A copy of the PC-PART worksheet is included in Appendix B. The assessment is completed by the user, together with the person with the health concern, either in the person's home or in a health care setting. The assessment is conducted as a structured interview. Information on each item may also be gathered from a key informant, or through observation, as needed. A key informant may be an informal care-giver, such as a family member, a close friend, or a formal care-giver. Thus, the perception of the person being assessed, as well as that of the key informant, about the person's accomplishment of ADL with the usual level of support, may be obtained. Information from key informants may be gathered through direct interview or telephone. There may be discrepancies between responses of the

person and key informant. For each item, suggested questions, observations and standard tasks are provided as prompts for therapists to direct the interview and/or observations, with corresponding space on the worksheet to write notes about specific observations made. These observations and tasks may attest, or raise concerns about, the person's opinion of being able to manage with the usual supports. Usual supports are used during observations of the person performing standard tasks. Response categories for individual items capturing information about the person's accomplishment of each activity are as follows:

- OK by self (the person manages the activity alone with or without assistive devices in the living environment);
- OK with help (the person manages the activity with existing supports in the living environment);
- Not OK (the person does not manage the activity in the living environment despite their own efforts, use of assistive devices and existing support from others).

Both *OK by self* and *OK with help* are scored 0, and *Not OK* is scored 1, forming a dichotomy. Each *Not OK* represents one ADL participation restriction. The intention of the tool is to identify participation restrictions that may then be targeted for intervention. The domain, *supports*, consists of two questions addressing the adequacy and stability of available supports, with responses *OK* and *Not OK*. Conventional overall scoring of the PC-PART involves summation of *Not OK* responses to produce a total score, producing ordinal scores from 0-43.

The precursor to the PC-PART was the Handicap Assessment and Resource Tool

(HART), developed during the 1990s (P Darzins, Edwards, Lowe, McEvoy, & Vertesi, 1998; Vertesi, Darzins, Lowe, McEvoy, & Edwards, 2000). The HART was designed to correspond conceptually to the measurement of handicap (unmet needs) within the framework of the ICIDH (WHO, 1980). With publication of the ICF in 2001, the term *participation restriction* replaced the ICIDH term *handicap* (WHO, 2001). In 2004, the HART was renamed the PC-PART (P Darzins, 2004), to coincide with the newer ICF terminology. During the transition from HART to PC-PART, the instrument remained essentially unaltered, except for changes to presentation style, layout and minor adjustments to phrasing of some items (P Darzins, 2004). As the HART was developed prior to the introduction of the ICF, the extent to which content of the PC-PART coincides with ICF categories is unknown.

Three intended strengths of the PC-PART are that it:

- incorporates the assessed person's perspective as well as that of the carer or key informant, making it person-centred in its approach to assessment (Vertesi et al., 2000);
- facilitates gathering of relevant, clinically meaningful information, to aid decision-making and intervention planning (Vertesi et al., 2000); and
- includes opportunities for triangulation of information gathering because it is administered as a structured interview with the opportunity for structured observations of task performance if required (Vertesi et al., 2000).

Triangulation in information gathering can help to form a more enriched and complete picture of the whole phenomenon being examined (Curtin & Fossey, 2007).

The PC-PART seems to have the potential to enhance occupational therapy practice by enabling:

- Routine and meaningful standardised descriptive measurement of ADL participation restrictions in acute, subacute and community settings;
- Evaluative measurement of the effects of interventions targeting unmet ADL needs, such as negotiating adequate formal and informal supports relevant to community living;
- 3. Differentiation between people who are able to live in the community with existing supports and those who cannot, at the time of assessment;
- 4. Descriptive measurement of the intensity and type of supports most needed in specific populations to inform service providers in the allocation of staff and resources.

#### Research Need

For clinicians and health care providers to be confident that the PC-PART is a robust measure, it is necessary for the assessment to demonstrate sound validity, reliability and responsiveness in the settings where it will be used. It also needs to provide clinically meaningful information and have acceptable clinical utility for clinicians and service-users. Prior to this doctoral research, it was known that there was a small body of research reporting evidence about the PC-PART's reliability, validity, responsiveness and clinical utility for use in various health care settings. However, there was an awareness that further investigation of the PC-PART's measurement properties and clinical utility using robist methods was required to provide high-quality evidence to fill gaps in knowledge about the instrument.

### **Research Purpose**

The broad purpose of this doctoral research was to develop a body of evidence about the measurement properties and clinical utility of the PC-PART for use with subacute inpatient rehabilitation service-users. Sub-acute inpatient rehabilitation was chosen as the setting for the research as it was one of the identified contexts for further investigation of the PC-PART's measurement properties and clinical utility and was accessible to the researcher. It was also known that the PC-PART was being used in this setting as an outcome measure during a large randomised controlled trial (RCT) involving 996 participants (Taylor et al., 2010), and that access to this PC-PART data for secondary analysis was possible.

#### **Research Significance**

This research has significance for service-users, clinicians, health care services, governments and researchers. If the PC-PART instrument is shown to have adequate measurement properties and clinical utility for use in inpatient rehabilitation, it will enable:

- More comprehensive and clinically meaningful assessment for rehabilitation service-users, than is currently practised;
- Occupational therapy clinicians to measure the effectiveness of occupational therapy service provision;
- 3. Health care services and governments to investigate the effectiveness and efficiency of interventions and resources utilised to reduce ADL participation restrictions, to inform allocation of health care funds;

4. Researchers undertaking clinical trials to measure the effectiveness of interventions expected to effect change in participants' ADL participation restrictions.

#### **Broad Research Objectives**

The broad research objectives were to:

- Conduct a systematic review of the measurement properties and clinical utility of the PC-PART to summarise existing evidence and to identify gaps in knowledge requiring further research;
- 2. Design and conduct a series of studies to investigate the measurement properties and clinical utility of the PC-PART for use with inpatient rehabilitation service-users, to fill gaps in knowledge about the instrument.

### **Thesis Structure**

This program of study involved completion of a systematic review, three instrument validation studies and one study investigating clinical utility of the PC-PART. One manuscript, intended as a peer-reviewed journal publication, was produced from each study. At the time of thesis submission three manuscripts were published and two manuscripts were undergoing peer review by international journals. Manuscripts under review have been presented in the thesis using the reference style required by each respective journal. Besides these two manuscripts, the referencing style used in this thesis conforms to the sixth edition of the American Psychological Association publication manual (American Psychological Association, 2009).

Each thesis chapter is devoted to a single study and its associated published or submitted paper (i.e. manuscript). An introduction precedes the published or submitted paper and a conclusion follows the paper. All references used in all chapters, published papers and submitted papers are listed immediately following Chapter eight. All appendices are located immediately following the references.

#### **Thesis Outline**

# Chapter 1: Introduction, purpose and broad research objectives.

The introductory chapter has contextualised the doctoral research and provided justification for its purpose. Broad research objectives have been stated. The thesis structure and an outline of thesis chapters were given.

# Chapter 2: Thesis research design framework and methods.

Background to the theoretical frameworks used to inform the study designs and methods used in this body of research are described in chapter two. Test validation theories and a framework for evaluating the quality of test validation research are introduced. A framework guiding research examining clinical utility of an instrument is presented.

#### **Chapter 3: Systematic literature review.**

Study one, a systematic review, summarised existing evidence and identified gaps in knowledge about the measurement properties and clinical utility of the PC-

PART. A brief introduction is followed by insertion of the published journal article, Paper 1:

Darzins, S., Imms, C., Di Stefano, M. (2013). Measurement properties of the Personal Care Participation Assessment and Resource Tool: A systematic review, *Disability and Rehabilitation*, 35: 265-281. SciMago Journal Rank: Q1 (Medicine); SJR: 0.88; Journal Impact Factor 2013: 1.837; 5-Year Impact Factor: 1.973.

The publication is followed by an update of the systematic review, a summary of evidence gathered from the systematic review and a statement of the specific research objectives developed for the subsequent four studies comprising this doctoral research. Of note, knowledge of an ongoing study of reliability of the PC-PART, independent to this doctoral research, meant that no further investigation of reliability was planned for this doctoral research. Conclusions provided a link to the next chapter and study.

#### **Chapter 4: Measurement construct of the PC-PART.**

The purpose of study two, a theoretical validation study, was to explore the theoretical measurement construct of the PC-PART. This information was used to generate hypotheses and aid interpretation of results of the subsequent empirical validation studies. An introduction to the study is followed by insertion of Paper 2, which has been submitted for publication and is undergoing peer review. Following the publication is a conclusion for this chapter, highlighting the contribution of this study to the body of research. Paper 2 is:

Darzins, S., Imms, C., Di Stefano, M., (under review). Measurement of activity limitations and participation restrictions: An examination of ICF-linked content and scale properties of the PC-PART and FIM<sup>TM</sup> instruments, *Disability and Rehabilitation*, SciMago Journal Rank: Q1 (Medicine): SJR: 0.88; Journal Impact Factor 2013: 1.837; 5-Year Impact Factor: 1.973.

#### Chapter 5: Clinical utility of the PC-PART for inpatient rehabilitation.

The purpose of study three was to gather perceptions of occupational therapists who had experience using the PC-PART, about its acceptability to them, and to service-users, as a measure of participation restrictions in ADL required for community life, across a range of clinical utility criteria. Within the thesis, this study precedes the test validation studies because it focused on therapists' perspectives about the original instrument, as used by them, prior to the validation studies. It was reasoned that insights gained from this clinical utility study could potentially support interpretation of results obtained during evaluation and refinement of the PC-PART instrument's measurement properties. The introduction to this chapter includes details about the study methods and is followed by Paper 3, which has been submitted for publication and is undergoing peer review. Following the manuscript is the conclusion for this chapter. Paper 3 is:

Darzins, S., Imms, C., Di Stefano, M., Radia-George, C. (under review). Personal Care-Participation Assessment and Resource Tool: Clinical utility for inpatient rehabilitation, *Canadian Journal of Occupational Therapy*, SciMago Journal Ranking: Q1 (Health Professionals); SJR: 0.67; Journal Impact Factor 2013: 0.742.

# **Chapter 6: Internal construct validity of the PC-PART.**

The purpose of study four was to explore internal construct validity of the PC-PART using Rasch methods to determine if the items in the instrument form a unidimensional scale and provide interval-level measurement. The chapter commences with a detailed discussion of classical test theory and item response theory, including Rasch methods. This is followed by insertion of Paper 4, the published journal article. Following the publication is the conclusion for this chapter, highlighting the contribution of this study to the overall body of research. Paper 4 is:

Darzins, S., Imms, C., Di Stefano, M., Taylor, N.F., Pallant, J. (2014). Evaluation of the internal construct validity of the Personal Care-Participation Assessment and Resource Tool (PC-PART) using Rasch analysis, BMC *Health Services Research*, 14:543. SciMago Journal Ranking: Q1 (Medicine); SJR: 0.864; Journal Impact Factor 2014: 1.71.

Chapter 7: Construct validity, criterion validity and responsiveness of the PC-PART.

The purpose of study five was to investigate construct validity, criterion validity and responsiveness of the PC-PART for inpatient rehabilitation. This study used the Rasch-derived scale scores developed in the previous study to test hypotheses about the PC-PART's scores when compared to the scores on other measures. The introduction to the chapter provides background to the methods used and is followed by the insertion of paper 5, the published journal article. Following the publication is the conclusion for this chapter. Paper 5 is:

Darzins, S., Imms, C., Shields, N., Taylor, N.F. (2015). Responsiveness, construct and criterion validity of the Personal Care-Participation Assessment and Resource Tool (PC-PART), *BMC Health and Quality of Life Outcomes*, 13:125. DOI: 10.1186/s12955-015-0322-5. SciMago Journal Ranking: Q1 (Medicine); SJR: 0.98; Journal Impact Factor 2014: 2.11.

# **Chapter 8: Overall discussion and conclusions.**

Chapter eight presents an integrated discussion of the findings from the preceding five chapters in the context of the entire research program. It draws together the discussion points raised at the end of each chapter. The chapter includes discussion of the findings in light of identified limitations in the research. Significance of the doctoral research to service-users, occupational therapists, health care organisations, governments and researchers is discussed, and future research directions are identified.

# Chapter 2. Thesis Research Design Framework and Methods

### Introduction

In this chapter, the principal research frameworks guiding design of this doctoral research are presented. Two theoretical approaches to test validation are introduced: Classical Test Theory and Item Response Theory, and the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) framework, which is used to guide methods for this validation research, is described. A framework guiding research examining clinical utility of an instrument is also presented. These frameworks together informed the methods used for each phase of this research.

#### **Test Validation Research**

It is necessary that health status measurement instruments have demonstrated adequate measurement properties before they are used in clinical practice and research to provide assurance that the measurements taken are a valid reflection of the construct intended for measurement. Validation research is undertaken to collect evidence to support the types of inferences that are able to be drawn from the results of measurement instruments and involves investigating instruments' measurement properties for their particular purposes (Laver Fawcett, 2007). Reference is often given to the purpose of instruments as being predominantly descriptive or discriminative (used to describe groups and distinguish between individuals or groups), evaluative (used to measure change over time); or predictive (used to classify people into predefined groups according to an existing *gold standard*) (Portney & Watkins, 2009). These distinctions have been used to argue that the purpose of an instrument determines

how items are scaled, how procedures are used to select the items, how reliability and validity are assessed and how responsiveness is measured (Streiner et al., 2015). However, instruments are used in many ways and whether or not they can be used for a particular purpose depends on whether the instrument has been validated for that purpose (Streiner et al., 2015). Thus, it is the use for which an instrument is put, that is the focus of instrument validation, not the instrument itself. The three main types of measurement properties of concern in validation research are reliability, validity and responsiveness.

# Reliability.

Reliability of an instrument refers to the amount of random and systematic error inherent in any measurement (Streiner et al., 2015). The degree of reliability of an instrument informs the rater how accurately its' scores reflect the true performance of the person taking the test. Reliability data are used to provide an index of the degree of test-related measurement error (Laver Fawcett, 2007). The reliability coefficient expresses the ratio of variability between people, to the total variability (the sum of people's variability and measurement error), so that 0.0 indicates no reliability and 1.0 indicates perfect reliability, in other words, no measurement error. This ratio reveals the proportion of the total variance in the measurements attributable to *true* between-people differences (Streiner et al., 2015). Sources of measurement error may come from: The rater (e.g. during administration, scoring and interpretation); the instrument (e.g. calibration of the instrument); error from the person taking the test (e.g fluctuating or temporary behaviour change as a result of say, motivation, interests, mood, effects of medication, understanding of instructions and test anxiety); and random error. The goal for instrument developers and researchers is to identify and reduce sources of

controllable measurement error to establish confidence that the observed score approximates the true score (Laver Fawcett, 2007). Different types of reliability indicate the extent to which instrument scores for people who have remained stable are the same when measurements are repeated under different conditions, for example:

- when repeated over time (test-retest);
- when used by different persons on the same occasion (inter-rater);
- when used by the same persons on different occasions (intra-rater);
- when using different sets of items from the same instrument (internal consistency) (Mokkink et al., 2015).

Evidence that an instrument has a high degree of reliability is a positive attribute. However, it is possible to have perfect reliability in measurement, but fail to measure the construct of interest. Thus, validity of an instrument for use in a particular context is critical.

# Validity.

Validity is the degree to which we can draw conclusions about the presence and degree of an attribute for an individual from scores on a measurement instrument when used with a particular group of people, for a particular purpose (Streiner et al., 2015). An instrument is considered to have validity when research demonstrates that it succeeds in measuring what it purports to measure. Therapists need to know whether items contained in a measure adequately represent the domains and/or constructs they are designed to measure (Laver Fawcett, 2007). Specific types of validity have been described as:

- content validity the degree to which the content of an instrument is judged to sample all the relevant or important content or domains of the construct to be measured (Streiner et al., 2015);
- face validity the degree to which the items of an instrument appear to be assessing the intended construct to be measured (Streiner et al., 2015);
- construct validity the degree to which scores of an instrument are consistent
  with hypotheses based on the assumption that the instrument is a valid measure
  of the construct intended for measurement (Mokkink et al., 2015);
- criterion validity the degree to which the scores of an instrument are an adequate reflection of a *gold standard* (Mokkink et al., 2015).

Conclusions about validity of an instrument are ongoing, existing on a continuum, rather than being a dichotomy (valid versus invalid) (Streiner et al., 2015). That is, it is not possible to definitively declare an instrument *valid*, or *invalid*. Evaluation about validity of a measure involves synthesis of evidence from many sources. This can lead to different conclusions being reached between people evaluating the evidence, and is dependent on their views about the construct being measured and intended use of the instrument (Cizek, 2012). Cizek asserts that "validation efforts are integrative, subjective and can be based on different sources of evidence such as theory, logical argument, and empirical evidence" (p. 36). Thus, validation research has become a process of hypothesis testing in recent decades. The focus in this form of research is on whether a-priori hypotheses contained in test validation studies make sense in relation to what the scale is designed to measure and whether the results support the hypothesised inferences about the people under study (Streiner et al., 2015). The types of validity tested in this doctoral research are described in detail in chapter 4 (content

and construct validity), chapter 6 (internal construct validity) and chapter 7 (construct and criterion validity).

# Responsiveness.

Responsiveness, which is an aspect of validity, is the ability of an instrument to measure a meaningful or clinically important change when change has occurred (Streiner et al., 2015). Responsiveness of an instrument is critical if, for example, the instrument is intended to measure type and amount of change over time in people's behaviour or functioning, as a result of an intervention designed to improve the same behaviours or functioning (Laver Fawcett, 2007). It is important that measures can identify clinically meaningful changes, even if these are relatively small, to inform decisions about the effectiveness of health care interventions on service-users' health and well-being. A description of how responsiveness of the PC-PART was tested in this research is provided in chapter 7.

# **Test Theory**

Instrument validation research methods investigating reliability, validity and responsiveness of an instrument may be informed by two theoretical test theories:

Classical Test Theory (CTT) and Item Response Theory (IRT).

# **Classical Test Theory (CTT).**

Classical Test Theory (CTT) has provided the basis for developing health measurement instruments over the last century and for evaluating instruments' measurement properties (DeVellis, 2006; Velozo, Wang, Lehman, & Wang, 2008).

CTT consists of a set of principles that can be used to determine how well proxy indicators (such as questionnaire items or clinical assessment items) can estimate characteristics that are not directly observable (latent constructs) within a population sample (DeVellis, 2006). Making inferences about latent constructs is an inherently imperfect process and therefore, the proxy measurements used are prone to error (DeVellis, 2006). CTT holds an assumption that an observed test score for each item in such conditions is made up of two components: A true component and an error component (Spearman, 1904). The error component for individual item scores is assumed to be random and independent from one another. Accurate items yield scores that closely reflect true scores. In these items, when error sources are combined, they have minimal or no effect on item means. In contrast, presence of error from less accurate items increases item mean score variability (DeVellis, 2006). These assumptions led to the formulation of the reliability coefficient as the ratio of true variance to true plus error variance of an item (Spearman, 1904; Streiner et al., 2015). Commonly used forms of reliability aligned to CTT approaches include inter-item reliability (internal consistency), test-retest reliability, intra- and inter-rater reliability.

CTT relies on inter-item correlations to establish item reliability. It assumes that more strongly correlated items are also strongly correlated with the latent construct's *true* scores. These items are considered *better* items and have greater discrimination than less accurate items. (DeVellis, 2006; Novick, 1966). A scale's reliability is typically expressed as an item-total correlation using Cronbach's coefficient alpha, referred to as a measure of internal consistency. Internal consistency reliability is the proportion of variance in a set of scores that can be attributed to a common influence on the scores of the individual items (Cronbach, 1951). Although CTT is concerned with properties of individual items, its primary emphasis is on items as a group (Cano &

Hobart, 2011). CTT proposes that measures achieve strength through the number of items they comprise, so that more items yield higher scale reliability (DeVellis, 2006).

The goals of scale validation using CTT are to provide convincing evidence that the scope of the scale's items correspond to the scope of the latent construct of interest and to demonstrate that the scores yielded by the scale represent values that are consistent with our understanding of how the construct of interest varies in the real world (DeVellis, 2006). Procedures for evaluating validity of scales based on CTT include factor analysis and factor rotation. The goal of factor analysis and rotation is to identify variables or dimensions along which items differ substantially, and describe the relationships among a set of items to find a perspective that emphasises each item's single strongest characteristic (DeVellis, 2006). One assumption of factor analysis is that the data are continuous. If data produced from health measurement scales can be assumed to be interval-level data, then factor analysis may be used. This can be a problem as health assessment instruments frequently produce ordinal-level data, where individual items cannot be assumed to contribute equally as indicators of a common underlying variable.

# Item Response Theory (IRT).

During the 1960s, two main groups of researchers were working to modify CTT in an attempt to overcome its disadvantages. In North America, Birnbaum outlined a new approach to test development (Birnbaum, 1968), and in Denmark, Rasch developed a new mathematical method of separately estimating parameters about test items and the people taking the test (Rasch, 1960). These two areas of development have come together in what is now called Item Response Theory (IRT). IRT refers to a framework,

not to a specific technique, and encompasses a group of measurement models. Where CTT is concerned with scale-level information, IRT is concerned with item-level information (Streiner et al., 2015). There are two main categories of IRT models: Unidimensional and multidimensional. In this thesis, only the unidimensional model is discussed.

Unidimensional models assume: (1) that a given scale is unidimensional, that is, items tap only one construct, or ability, and (2) the probability of a person answering any one item in the positive direction (reflecting more of the construct) is unrelated to the probability of answering any other item positively, for people with the same amount of the construct. This is known as local independence, or invariance (Streiner et al., 2015). If these two assumptions are met then two hypotheses follow: (1) people's performance on the test may be predicted by a set of abilities or latent constructs; and (2) a relationship between people's performance on any item and the underlying construct can be described by an *S* shaped item characteristic curve, or item response function (Streiner et al., 2015).

Where CTT methods do not provide information about, or allow evaluation of both items and people separately, IRT focuses on individual items within an assessment, and the relationship of peoples' item responses to a single underlying construct. IRT methods reveal the hierarchical order of item *difficulty* and the level of construct *ability* of the person. Velozo et al. (2012) described that a central principle of IRT is that the probability of correct responses to an item is a function of the level of the construct within the person and the parameters of the item (e.g. item *difficulty*), and the item's ability to discriminate people's levels of the construct. More *difficult* items are expected

to have a greater probability of being endorsed by people with higher levels of the latent construct than people with lower levels of the construct (Velozo et al., 2012).

The simplest IRT model is the Rasch model, also known as the *one-parameter model* (Tennant, McKenna, & Hagell, 2004). According to this model, the only factor differentiating the item characteristic curve of the various items is item *difficulty*. It assumes that all of the items have equal discriminating ability, reflecting that the slopes of the item characteristic curves are parallel, but placed at points along the construct continuum.

The Rasch model was developed for items with dichotomous response categories (Streiner et al., 2015) but was extended for use with instruments containing polytomous items, that is, items with more than two response categories (Andrich, 1978). Instruments that contain items allowing for a range of responses, such as Likert scales rarely show interval-level properties as it cannot be assumed that the distance between responses from one level of the continuum to another is constant (Streiner et al., 2015). However, it has been common practice to assume that the ordinal data are close to interval-level data so that this distinction can be overlooked, or to decide that by summing over a number of items, the total score will be near to normally distributed and may therefore be treated as interval-level data (Streiner et al., 2015). Using IRT, this questionable practice is not required. Methods for evaluating scales with multiple item response categories allow for the evaluation of the probability of responding to each of the response categories within an item, rather than to a dichotomous item, as for the Rasch model (Streiner et al., 2015). Other IRT models, such as the partial credit model and the graded response model are used when it is evident that each item has its own rating scale structure. They can be used to accommodate different numbers of

response categories between the items (Streiner et al., 2015). In summary, IRT is typically used to test the structural validity of a scale and to enable scales generating ordinal-level data to be expressed as a unidimensional scale with interval level measurement properties.

# **Evaluating Quality of Test Validation Research: COSMIN**

Only validation research of high methodological quality can ensure appropriate conclusions are formed about an instrument's measurement properties for its purpose (Mokkink et al., 2010b). If methodological quality of validation research is inadequate, the results "cannot be trusted and the quality of the instrument under study remains unclear" (Terwee et al., 2012, p. 652). To evaluate the quality of instrument validation research, standards are needed that specify study design criteria and favoured statistical methods used to investigate measurement properties of health status instruments. The impetus for development of the COSMIN checklist (Mokkink et al., 2010b) was a lack of consensus in peer reviewed literature about the measurement properties that are relevant to health status instruments, what concepts they represent and what study design and statistical methods should be used to investigate these measurement properties (Mokkink et al., 2010b, 2010c).

The COSMIN checklist is a consensus-based modular checklist, developed in an international Delphi study by a group of researchers in the Netherlands, for "evaluating the methodological quality of studies on measurement properties of [health-related patient reported outcomes] (HR-PROs)" (Mokkink et al., 2010a, p. 5). The authors stipulated that the checklist is also relevant for use to evaluate validation research for other health-related measurement instruments, for example, performance-based

instruments and clinical rating scales. The underlying premise of the COSMIN checklist is that "studies evaluating measurement properties [of an instrument] should be of high methodological quality to guarantee appropriate conclusions about the measurement properties of an instrument" (Mokkink et al., 2010b, p. 540). The aim of the COSMIN checklist is to provide a useful tool for enabling evidence-based health-related instrument selection (Mokkink et al., 2010a).

The COSMIN group performed a Delphi study in which international consensus was reached on domains, terminology and definitions of measurement properties (Mokkink et al., 2010b, 2010c). A taxonomy showing the relationships of measurement properties was formed. The Taxonomy is shown, below, in Figure 2.1.



Figure 2.1. The COSMIN taxonomy of relationships of measurement properties. *Abbreviations*: COSMIN, COnsensus-based Standards for the selection of health Measurement INstruments; HR-PRO, Health Related-Patient Reported Outcome. This figure was published in the *Journal of Clinical Epidemiology, Volume 63*, L.B

Mokkink, C.B Terwee, D.L. Patrick et al., "The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes", p. 741, Copyright Elsevier 2010, Reprinted with permission (see Appendix C).

The COSMIN taxonomy includes three quality domains: (1) *reliability*, which includes internal consistency, repeatability and measurement error; (2) *validity*, which includes content/face, criterion and construct validity, which in turn, includes hypothesis testing, structural validity, cross-cultural validity, and (3) *responsiveness*. Interpretability is included in the taxonomy as a key characteristic of a measurement instrument, despite not being considered a measurement property in itself (Mokkink, Terwee, Knol, et al., 2010; Mokkink et al., 2010a; Mokkink et al., 2010b). The definition for each term in the taxonomy is shown in Figure 2.2.

	Term		Definition
Domain	Measurement property	Aspect of a measurement property	
Reliability			The degree to which the measurement is free from measurement error
Reliability (extended definition)			The extent to which scores for patients who have not changed are the same for repeated measurement under several conditions: e.g. using different sets of items from the same health related-patient reported outcomes (HR-PRO) (internal consistency); over time (test-retest); by different persons on the same occasion (inter-rater); or by the same persons (i.e. raters or responders) on different occasions (intra-rater)
	Internal consistency		The degree of the interrelatedness among the items
	Reliability		The proportion of the total variance in the measurements which is due to 'true' <sup>†</sup> differences between patients
	Measurement error		The systematic and random error of a patient's score that is not attributed to true changes in the construct to be measured
Validity			The degree to which an HR-PRO instrument measures the construct(s) it purports to measure
	Content validity		The degree to which the content of an HR-PRO instrument is an adequate reflection of the construct to be measured
		Face validity	The degree to which (the items of) an HR-PRO instrument indeed looks as though they are an adequate reflection of the construct to be measured
	Construct validity		The degree to which the scores of an HR-PRO instrument are consistent with hypotheses (for instance with regard to internal relationships, relationships to scores of other instruments, or differences between relevant groups) based on the assumption that the HR-PRO instrument validly measures the construct to be measured
		Structural validity	The degree to which the scores of an HR-PRO instrument are an adequate reflection of the dimensionality of the construct to be measured
		Hypotheses testing	Idem construct validity
		Cross-cultural validity	The degree to which the performance of the items on a translated or culturally adapted HR-PRO instrument are an adequate reflection of the performance of the items of the original version of the HR-PRO instrument
	Criterion validity		The degree to which the scores of an HR-PRO instrument are an adequate reflection of a 'gold standard'
Responsiveness			The ability of an HR-PRO instrument to detect change over time in the construct to be measured
Interpretability*	Responsiveness		Idem responsiveness  Interpretability is the degree to which one can assign qualitative meaning - that is, clinical or commonly understood connotations – to an instrument's quantitative scores or change in scores.

<sup>&</sup>lt;sup>†</sup> The word 'true' must be seen in the context of the CTT, which states that any observation is composed of two components – a true score and error associated with the observation. 'True' is the average score that would be obtained if the scale were given an infinite number of times. It refers only to the consistency of the score, and not to its accuracy (ref. Strainer & Norman).

Figure 2.2. Definitions of domains, measurement properties, and aspects of measurement properties in the COSMIN taxonomy. *Abbreviations*: HR-PRO=Health Related-Patient Reported Outcome; CTT,=Classical Test Theory. This figure from the COSMIN checklist was published as a table in the *Journal of Clinical Epidemiology*, *Volume 63*, L.B Mokkink, C.B Terwee, D.L. Patrick et al., "The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes", p. 743, Copyright Elsevier 2010, Reprinted with permission (see Appendix C).

number of times. It refers only to the consistency of the score, and not to its accuracy (ref Streiner & Norman)

\* Interpretability is not considered a measurement property, but an important characteristic of a measurement instrument

There are 12 methodological quality boxes contained in the COSMIN checklist (Mokkink et al., 2010a; Mokkink et al., 2010b), as follows:

- Box A Internal Consistency;
- Box B Reliability;
- Box C Measurement error;
- Box D Content validity;
- Box E Structural validity;
- Box F Hypothesis testing;
- Box G Cross-cultural validity;
- Box H Criterion validity;
- Box I Responsiveness;
- Box J Interpretability;
- Box IRT;
- Box Generalisability (applied for each measurement property).

Nine separate boxes define appropriate study design criteria required to produce evidence of different measurement properties (Box A to Box I) (see Appendix C). One box enables evaluation of the quality of a study related to *Interpretability* of the tool. One box provides general requirements for studies that applied IRT models. An additional *Generalisability* box is applied for each measurement property. Several of the named boxes provide method requirements if specifically using CTT or IRT methods (i.e. Boxes A, C, E and G).

Each COSMIN box contains between 5 and 18 items describing the methodological criteria that should be met in validation research for the given

measurement property. These criteria enable assessment of the methodological quality of each validation study for a specific instrument, on a specific measurement property (Mokkink et al., 2010c; Terwee et al., 2012). A separate COSMIN box needs to be completed for evaluation of each measurement property. The COSMIN checklist manual provides instructions for its use (Mokkink et al., 2010a).

One of the main applications of the COSMIN checklist is when conducting systematic reviews of measurement properties of health-related measurement instruments (Mokkink et al., 2015). The COSMIN checklist criteria may also be used to aid design of a new study investigating measurement properties of an instrument (Mokkink et al., 2010b). Both applications of the COSMIN checklist were used for the research contained in this thesis.

In 2012, a COSMIN checklist scoring system was developed to enable calculation of quality scores for each measurement property of a health measurement instrument. The intent was for the scoring system to be used to calculate *quality scores* for each measurement property when undertaking systematic reviews of measurement properties of instruments (Terwee et al., 2012, p. 651). To date, the reliability and validity of the scoring system has not been published on the COSMIN website, nor in peer-reviewed literature (Mokkink et al., 2015; Terwee et al., 2012). As this scoring system was published following completion of the systematic review of the PC-PART's measurement properties contained in this thesis, it was not used in the present study.

The COSMIN checklist enables evaluation of the quality of *methods* used in instrument validation studies; it does not evaluate the quality of the health-related measurement *instrument*. To assess the quality of the *instrument*, quality criteria were

published in 2007 to provide a structure indicating the adequacy of a health-related measurement instrument (Terwee et al., 2007). The quality criteria enable evaluation of the adequacy of existing collective evidence from validation research investigating an instrument's measurement properties. These are not consensus-based criteria, and are open to further discussion and refinement (Terwee et al., 2007). These criteria were used to evaluate the quality of the PC-PART's measurement properties during the systematic review, to illuminate areas for further validation research.

# **Clinical Utility of an Instrument**

One aspect related to use of measurement instruments in clinical practice and research that is not covered by the COSMIN checklist is the concept of an instrument's clinical utility for the settings in which it is used. Law (1987) discussed criteria for evaluating clinical utility of an instrument as including format, cost, training requirements, acceptability to clinicians and service-users and *utility*. Utility referred to whether the results of the assessment provided information that could be used in the clinical management of the service-user (Law, 1987). In 2004, the Outcome Measures Rating Form (OMRF) was developed (Law, 2004) (see Appendix D), which included clinical utility. The form identified clinical utility criteria as: Clarity of instructions; format; administration time; examiner qualifications; and cost. Laver Fawcett (2007) also drew on Law's clinical utility criteria, listing aspects of clinical utility as cost; time; energy and effort; portability; and acceptability of an instrument to both therapist and service-users. The following criteria were identified for examination of clinical utility for the PC-PART using a combination of Law and Laver Fawcett's suggested criteria (Laver Fawcett, 2007; Law, 2004): Clarity of instructions; format of administration; completion time; cost; examiner qualifications and training; effort required;

acceptability to clinician and service-user; and clinical usefulness of information gathered.

There are no known consensus-based taxonomies, similar to the COSMIN checklist, for evaluating the methodological quality of research investigating clinical utility of an instrument. Investigation of an instrument's clinical utility requires information from the users of the instrument about their perceptions of the instrument when used for a particular purpose in a specific setting. This type of information may be gathered through surveys or from interviews or focus groups, producing primarily qualitative data as well as descriptive quantitative data. Thus, clinical utility of an instrument may be investigated using primarily qualitative research methods but also using quantitative survey methods. In order to evaluate studies of clinical utility of an instrument, a structure for evaluating the methodological quality of both qualitative and quantitative research methods was deemed necessary. The McMaster Guidelines for Critical Review Form: Qualitative Studies (Version 2.0) (Letts et al., 2007); guidelines for appraising trustworthiness of qualitative studies (Curtin & Fossey, 2007); and McMaster Guidelines for Critical Review Form: Quantitative Studies (Law et al., 1998) were chosen as the structures for appraising these studies. These guidelines and forms have been widely used and cited in occupational therapy literature.

# **Chapter 2 - Conclusions**

The principal research frameworks guiding design of this doctoral research were presented in this chapter. The COSMIN checklist and the established clinical utility criteria just described, were chosen to structure the systematic review of existing literature evaluating the methodological quality of studies investigating the

measurement properties and clinical utility of the PC-PART. These frameworks were also used to prioritise and establish specific aims and objectives for the test validation studies undertaken in this doctoral program. Detailed explanations of specific research designs, methods, sampling procedures and data analysis used in each separate study are presented in chapters three to seven.

# **Chapter 3. Systematic Literature Review**

### Introduction

This chapter presents the systematic critical appraisal of existing literature examining the measurement properties and clinical utility of the PC-PART. The aim of this literature review was to identify aspects of reliability, validity, responsiveness and clinical utility of the PC-PART that required further investigation in specific clinical contexts. The literature review took the form of a systematic review. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were used to guide the systematic review process and reporting structure (Liberati et al., 2009). PRISMA is an evidence-based, minimum set of items for reporting in systematic reviews and meta-analyses, designed to assist authors to improve reporting of systematic reviews (PRISMA, 2015). The systematic review research design frameworks described in Chapter 2 (COSMIN checklist and clinical utility criteria) were used to inform and guide the content of the review. Published guidelines for critical review of qualitative research (Letts et al., 2007) were also used to guide the review, when needed.

Around the same period that this systematic review was undertaken, it was known that a separate study was investigating the inter-rater reliability of the PC-PART. The published systematic review, inserted in the following pages, is followed by an updated review conducted in 2015 which incorporates new evidence available since publication of the original systematic review published in 2013. Following the summery

of the updated systematic review, details of the *specific* research objectives for the body of this doctoral research are presented. This is followed by a conclusion for Chapter 3.

# Paper 1. Measurement properties of the PC-PART: A systematic review.

Darzins, S., Imms, C., Di Stefano, M. (2013). Measurement properties of the Personal Care Participation Assessment and Resource Tool (PC-PART): A systematic review, *Disability & Rehabilitation*, 35(4):265-281. SciMago Journal Rank: Q1 (Medicine); SJR: 0.88; Journal Impact Factor 2013: 1.837; 5-Year Impact Factor: 1.973

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#### **REVIEW**

# Measurement properties of the Personal Care Participation Assessment and Resource Tool: a systematic review

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Purpose: To systematically review research investigating measurement properties of the Personal Care Participation Assessment and Resource Tool (PC-PART), formerly the Handicap Assessment and Resource Tool (HART). Data sources: Seven databases were searched using (i) HART or PC-PART terms and (ii) known authors. Reference list searches, citation searches and author contact were secondary search methods. Study selection: Searches retrieved 492 articles. Those investigating at least one HART or PC-PART measurement property were selected. Three articles met review criteria. Secondary searching produced four additional studies. *Data extraction*: Two reviewers independently critiqued each article, using published quality criteria for (i) study methods and (ii) each measurement property. Results: There was positive evidence supporting content validity of the PC-PART in adult in-patient and community based, sub/acute health settings. Clinical utility was largely supported. There was inconclusive evidence for inter-rater reliability, construct validity and responsiveness. Conclusions: The PC-PART shows promise as a clinically relevant and useful assessment to aid decision making about admission or discharge from health care settings. Further research is needed to establish the PC-PART's place in clinical practice across a range of patient groups and settings using sound methods to investigate structural validity, reliability, criterion validity, construct validity, clinical utility and responsiveness.

**Keywords:** Activities of Daily Living, discharge planning, ICF, Personal Care Participation Assessment and Resource Tool

#### Introduction

Decisions about admission to, or discharge from health care settings are an essential part of clinical practice for the whole health care team. The aim of discharge planning is to

#### Implications for Rehabilitation

- The PC-PART was designed to assess patients' participation restrictions in necessary Personal and Instrumental Activities of Daily Living (PADL and IADL) for community living.
- The assessment may aid rehabilitation team decision making about priorities for intervention and readiness for discharge.
- Although there is strong evidence to support content validity, further testing of the PC-PART's measurement properties is warranted to strengthen evidence to support its use.

ensure that patients are safely returned to the community with (i) minimal likelihood of an unplanned readmission, (ii) continuity of care, and (iii) high service satisfaction of patients and carers/others [1]. Factors that can delay discharge, or result in hospital admission can include unresolved nonmedical issues, including inadequate environmental supports for the patient once discharged, resulting in their inability to maintain necessary "Personal" and "Instrumental," "Activities of Daily Living" (PADL and IADL, respectively) required for living in the community [2,3]. PADL are the most basic and routine activities for looking after oneself, such as washing and drying oneself, dressing, toileting, eating, drinking, grooming, managing medications and moving around indoors and outdoors [4]. IADL are the more complex, but necessary activities essential to daily living in the community such as meal preparation, managing household tasks, shopping for necessities, money management, laundering of clothes, using communication devices, driving and managing

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home security [5]. The abbreviations PADL and IADL are commonly used in clinical settings. They denote areas of ADL that appear to broadly match the "self-care" and "domestic life" domains of the activity and participation component of the International Classification of Functioning, Disability and Health (ICF) [6]. The degree to which the content of PADL and IADL measures match these corresponding ICF domains is not yet established, and is the subject of separate investigation. For the purposes of this review, the original PADL and IADL abbreviations are used.

The discharge planning process or the prevention of unnecessary admission to hospital requires an assessment that takes into consideration all areas of functioning necessary for living in the community. To be effective, this assessment must identify critical problems and aid in prioritization of interventions to eliminate or minimize them to enable the patient's return to the community. Predischarge assessments used in Australia, such as the Functional Independence Measure (FIM) [7] and the Barthel Index (BI) [8], give a reliable indication of the patient's PADL abilities. That is, they measure PADL capabilities at the level of the individual. In these assessments, lower scores are obtained if the patient uses adaptive devices or assistance from others to complete any PADLs.

Conceptually different to the FIM and the BI, the Personal Care Participation Assessment and Resource Tool (PC-PART) [9] was designed to identify problem areas in both PADL and IADL that are necessary for living in the community, and which persist despite the person's own efforts, their use of adaptive equipment and/or assistance from others [9]. These problem areas are termed PADL and IADL "participation restrictions", using the disability terminology provided by the ICF [6]. The PC-PART contains 43 items covering seven domains: clothing, hygiene, nutrition, mobility, safety, residence and supports (see Appendix I). Each item is scored as a dichotomy: "OK by self" (0), "OK with Help" (0), or "Not OK"(1). The total score is the frequency of "Not OK's". Each "Not OK" provides a target for intervention aimed towards enabling discharge or preventing admission to in-patient care. Administration of the PC-PART is not currently discipline specific. The PC-PART was designed for use in any adult population where issues related to a person's ability to live in the community need to be addressed. The PC-PART was not developed to measure involvement in social aspects of participation such as leisure or productive work roles as these areas are not relevant to the purpose of the tool [10].

The PC-PART was originally named the Handicap Assessment and Resource Tool (HART) [10]. The original purpose of the instrument was to measure personal care "handicap" according to the concept of "handicap" contained in the International Classification of Impairments, Disabilities and Handicaps (ICIDH) [11]. With the development of the ICF, the concept of "participation restriction" replaced the term "handicap" [6]. The name change from HART to PC-PART was made in 2004 to align the instrument with ICF terminology [12].

Purported strengths of the PC-PART are that it (i) incorporates the patient perspective as well as that of the carer or key informant; (ii) is administered as a structured interview

with the opportunity for structured observation, as required and (iii) is efficient for the clinician gathering relevant information for decision-making and intervention planning. For clinicians and health care providers to be confident that the PC-PART is a valid and useful measure of PADL and IADL participation related to living in the community, it is necessary for the assessment to demonstrate sound reliability, validity, responsiveness and utility in the settings where it will be used.

The purpose of this systematic review was to (i) identify all studies investigating measurement properties of the HART or PC-PART; (ii) use a structured and systematic review process for each study to establish research quality and known measurement properties of the instrument and (iii) identify measurement properties that require further investigation. This will provide clinicians and researchers with a summary of evidence about the properties of the PC-PART that can be incorporated into practice and inform future research investigating the measurement properties of the PC-PART.

#### Methods

Procedures in the Cochrane Handbook for Systematic Reviews of Interventions Version 5.0.2 were used as a guide for structuring the search and selection of relevant articles [13]. The PRISMA (Preferred Reporting Items for Systematic reviews and Met-Analyses) statement was used as a guide for reporting the systematic review [14].

#### **Data sources**

Comprehensive searches were conducted in the following electronic databases: Medline, CINAHL, AMED, Ageline, Embase, PubMed, PsychINFO and the full Cochrane Library. "HART" or "PC-PART" were searched in journal text. "HART" or "PC-PART" were searched in journal title or abstract. Known authors, individual authors of the HART, and reference lists from retrieved articles were searched to identify other potentially relevant studies. Google Scholar was used to perform a citation search of retrieved articles. On request, the developer of the HART and PC-PART, Peteris Darzins, provided methods, data and results for two unpublished, yet peer-reviewed studies presented at conferences. Searches were completed in August 2010. Articles were limited to those written in English and studies involving adult participants.

#### Study selection

After removing duplicates, articles were independently assessed for inclusion by two reviewers (SD and MDS). Studies were included if they: (i) investigated at least one measurement property of the HART or the PC-PART and (ii) included adults 18 years or over. Unpublished studies were only selected if they could be reasonably sought and if there were sufficient details available of the methods and results to enable an assessment of the quality of the study. An *a-priori* decision was made not to exclude studies during the selection process on the basis of actual methodological quality, as quality assessment was part of the review process itself.

#### **Quality assessment process**

Each included study was evaluated to determine (i) the quality of the study methods for investigating specific measurement properties, and (ii) the quality of the measurement property of the instrument based on the findings. Critical review of each included study, was completed independently by two reviewers (SD and CI). Disagreements in quality ratings were discussed until consensus was reached.

#### Evaluation of reliability, validity and responsiveness

We used the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) checklist [15-17]. The COSMIN checklist criteria may be used to evaluate the methodological quality of studies investigating aspects of (i) reliability (internal consistency, repeatability and measurement error), (ii) validity (content/face, criterion and construct [hypothesis testing, structural validity, cross-cultural validity]), (iii) responsiveness and (iv) interpretability of health measurement instruments [18,19]. The generalizability of each study is also rated using the eight COSMIN criteria.

#### Evaluation of clinical utility

Clinical utility of a health measurement tool is influenced by a number of characteristics such as the clarity of instructions, format of the tool, time taken to complete it, purchase cost, training requirements, the effort required by the consumer or the clinician to complete it and the overall acceptability of the test to the clinician and the consumer [20,21]. As the COSMIN checklist does not contain criteria for evaluating clinical utility, criteria from the Outcome Measures Rating Form (OMRF) [20] were used to evaluate this aspect of the instrument. Where clinical utility was evaluated using qualitative research, the McMaster guidelines for critical review-qualitative studies (version 2.0) [22], as well as guidelines for appraising the trustworthiness of qualitative studies [23] were used to evaluate the strength of study methods and the transferability of the findings.

#### Evaluation of the quality of the instrument

The quality of the PC-PART's measurement properties was assessed using quality criteria developed by Terwee et al. [24]. Terwee et al. provide explicit design, methods and outcome quality criteria for eight measurement properties: content validity, internal consistency, criterion validity, construct validity, reproducibility (reliability and agreement), floor and ceiling effects, responsiveness and interpretability. Quality criteria for each of these properties were developed based on consensus of opinion, and designed to be used as "rules-ofthumb". The rating for each measurement property is assigned either: "+" (positive) for a positive rating when study methods are sound; "?" (indeterminate) when there is a positive or negative rating but doubtful study methods or design; "-" (negative) when there is a negative quality finding using sound study methods and design or "0" (no information available).

# Results

The electronic database searches yielded 796 articles. After removing duplicates, the remaining 492 articles were independently assessed for inclusion, resulting in three studies included for review. Reference lists of retrieved articles yielded two Victorian Government contracted research reports available online. Two further unpublished studies, provided by the HART and PC-PART developer, were eligible for review. A total of seven studies were identified for review, each examining at least one measurement property of the HART or PC-PART. Of the seven included studies, three investigated inter-rater reliability [25-27]; three examined content validity [10,28,29]; two investigated construct validity through hypothesis testing [30]; two evaluated responsiveness [28,30]; and three explored clinical utility [28-30]. Details of the purpose, methods, patient sample and conclusions are provided in Table I.

#### **Terminology**

In this review, an assumption of consistency in content, concept and structure between the HART and PC-PART is made, based on inspection of both instruments and communication with the developer. Therefore, reporting in this systematic review uses the name "HART" or "PC-PART" interchangeably, according to the instrument's name when the research was conducted. Similarly, the terms "activity limitation" (AL) and "participation restriction" (PR) are used when discussing research that was published following publication of the ICF in 2001. The terms "disability" and "handicap" are used when discussing research that was published up to the year 2000.

#### External validity of the studies

The COSMIN checklist contains eight criteria for evaluating the generalizability of quantitative studies. Six of the seven studies included in the review contained a quantitative component that could be evaluated. The number of criteria met by each study ranged from three [10] to eight [28] and are shown in Table I.

Samples in these studies came from a wide range of health settings in Canada and Australia and the majority were comprised of older adults. Sample size relevant to study purpose differed across studies. There was variable reporting of patient sample characteristics and the handling of missing data across studies. The absence of reporting on specific COSMIN criteria in the manuscripts resulted in some lower COSMIN scores, but overall ratings were sound for generalizability.

In qualitative research, one component of trustworthiness of data is "transferability". Transferability relates to whether findings can be transferred to other situations and is ensured through adequate descriptions of sample and setting [22]. Transferability of the three reviewed qualitative studies exploring clinical utility varied. The study by Barbara & Whiteford [29] demonstrated transferability of findings to relatively novice occupational therapists working in regional acute aged care in-patient settings. Smith et al. [28,30] demonstrated transferability of their findings to Melbourne based in-patient, outpatient and community rehabilitation multidisciplinary clinicians, and Darzins et al. [28] demonstrated transferability of their findings to

Table I. Summary of study purpose, methods and conclusions; COSMIN generalizability requirements met for each study.

uay harb	table it. Summany of study purpose, incurous and conclusions, Confi		, tribanity	in generalization tequirements into tot each stary	ioi cacii study.		:	-			,
			Methods				Patient sam	Patient sample characteristics	STICS	Conclusions	No or
											COS- MIN general- izability
			Clinician raters.	Clinician	(i) Data analysis (ii) Handling	Sample		Age (yrs) Mean S	Sex	Overall	require- ments
	Study design	Setting	participants	description	missing data	selection	n	(a)	M/F Population		met/8a
Development and content validity of the HART.	Item generation, iterative tests with experts, clinicians and consumers.		1 Geriatrician Developers 4 OTs of the HAR Experience clinicians.	Developers of the HART. Experienced clinicians.	(i) Descriptive statistics Convenience sample (ii) NR	ss Convenience sample	~100	N.	NR NR	HART is a client-centred, comprehensive and practical tool that is acceptable to users and	es .
Pilot in metropolitan hospital to confirm content and utility.	Descriptive-user training, six week trial of HART with varied client groups.	Large acute care hospital, Hamilton, Ontario, Canada.	11 OTs	NR	(i) Descriptive (ii) See below <sup>b</sup>	Consecutive inpatients referred to OT for d/c plan-ning.	50	89	F = Neuro, 65% Orth, Onc, Psych, Rehab. Gen Med.	clients during d/c planning.	∞
Pilot in rural hospital & community to explore use in rural settings.	_	Rural hospital, Long term care, Patient homes, Iroquois Falls, Ontario, Canada	3 OTs	Developers of the HART. Experienced clinicians.	(i) Descriptive statistics (ii) NR	Convenience sample to ensure variety of issues.	26	(33–96)	NR NR		ιν
Describe change in AL and personal care PR during inpatient rehabilitation.	Consecutive case series with repeated measures.	One 28 bed rehabilitation ward, one 28 bed GEM ward in Melbourne, Australia.	OTs assigned to the wards.	Experienced clinicians, trained in use of the FIM and HART.	(i) Mean FIM and HART scores on a/d and d/c, charted weekly. (ii) NR.	Consecutive series from both wards.	Total = 36 Rehab. = 20 GEM = 16	Rehab = $75$ (57–97) GEM = $79$	NR General medicine, Ortho pedic, Neurology patients.	Trajectories of change in AL and personal care PR differ markedly in some patients (in 22% of this sample).	9
Explore clinical utility of the HART.	Semi-structured focus group discussions.	Inpatient, outpatient and community rehabilitation programs in Melbourne,	60 clinicians represen-ting 17 clinical programs.	Multidisciplinary clinicians, trained to use the HART.	Thematic analysis of focus group discussions.	n/a	n/a	n/a	n/a n/a	HART covers all relevant ADL, clarifies important risk areas, aids hand-over between in & out-patient services.	Frans- ferability of quali- tative studies ad- dressed in text.
Explore if BI, SMAF and HART show true change in clinical status. Establish if AL and personal care PR are different con- structs.	Completion of a/d and d/c assessments using BI (all teams) and SMAF (9 teams) or HART (5 teams) by health team members.	Inpatient rehabilitation sites (GEM or Rehabilitation specific units) from 7 Victorian regional health services, Australia.	All clinicians from 14 health teams across 9 sites.	All members of the multidis- cipl. health team received ≥ 2 hrs formal training to use HART or SMAF. All had previous experience using BI.	All members (i) comparison of of the multidischange scores, scatcipl, health team terplots between BI received ≥ 2 hrs and SMAF/HART formal training scores.  SMAF. All had of BI Axs, 6% of previous SMAF Axs, Hand of BI Axs, 6% of experience SMAF Axs, Hanusing BI. dling NR.	Consecutive - case series [ of patients in 11 of 14 in-patient rehabilitation settings.	Patients with a/d and d/c Axs, HART (n = 131) SMAF (n = 182); BI (n = 313)	d/c group P = 77, Non-d/c group = 80 (21–100).	NR Cross section of diagnostic groups. See below:	Cross section AL and personal of diagnostic care PR are different constructs.  See AL data cannot below: be used to predict personal care PR. HART and SMAF are sensitive to meaningful change.	∞
										(C	(Continued)

			Methods				Patient s	Patient sample characteristics	teristics		Conclusions	No of
	Study design	Sertino	Clinician raters,	Clinician	(i) Data analysis (ii) Handling missino data	Sample selection	F	Age (yrs) Mean (Ranoe)	Sex M/F	Population	Overall findings	COS- MIN general- izability require- ments
Examine the content and the the HART and SMAF in inpatient rehabilitation settings.	Focus groups discussions & discussions & individual interviews, with thematic analysis.	Inpatient rehabilitation sites (GEM or Rehab specific units) from 7 Victorian regional health services.	Fatterpairs All clinicians from 14 h ealth teams across 9 sites.	Focus groups Focus groups Focus groups Clinicians from each health team. Individual interviews occurred × 2.	(i) Thematic analysis focus group, interview data. (ii) Missing data in 6% of HART Axs, 34% of SMAF Axs. Handling NR.		n/a	n/a		n/a	HART covers all relevant areas of ADL. Provides good checklist for d/c planning and prioritizing intervention. Content reflected usual	
Investigate clinical utility of the HART in acute aged care setting using qualitative methods.	Individual indepth interviews with thematic analysis using phenomenological perspective.	Acute aged care inpatient setting in NSW, Australia.	4 OTs from one regional health. service	Purposeful (i) Ther sampling, interpretaria: want to participate, can attend training, (ii) NR can complete 6 HART Axs.	(i) Thematic analysis of n/a interviews.	of n/a	n/a	n/a	n/a	n/a	OTIs reported that HART addressed complexity of patients' reasons for a/d and issues needing resolution for d/c.	ferability of qualitative studies ad-dressed in text.
To examine the inter-rater reliability of the PC-PART in a rehabilitation setting.	PC-PART Axs by health team members com- pared to those done within 3 days by the researcher.	Subacute in patient rehabilitation setting in Melbourne Australia.	1 research OT paired with 1 other health team member (3 OT, 6 PT, 3 S/W, 2 SP)	Members of health team with varying expertise with PC-PART.	(i) Unweighted Kappa (x) for each item, summarized by each HART domain, then overall score.	Consecutive in-patient ad within a 6 week study period (n = 66).	25	68.2 (44-85) (SD 11.3)	H = 16	Musculoskel- etal  (n = 9), Cir- culatory (n = 6), Neu- nogical (n = 5), Respiratory (n = 2), Infectious disease (n = 1), Infectious disease (n = 1), Infectious disease (n = 1), Infectious	Musculoskel- Unweighted etal Kappa (κ) for: (n = 9), Cir- Clothing (0.45) culatory Hygiene (0.59) (n = 6), Neu- Nutrition (0.47) rological Mobility (0.78) (n = 2), Residence (0.15) (n = 2), Respiratory Safety (0.43) Infectious Supports (NR) disease Total score (0.65) (n = 1), Injury (n = 5),	<u></u>

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												0 2	COS- MIN
												SS	general- izability
				Clinician		(i) Data analysis			Age (yrs)			I	require-
				raters,	Clinician	(ii) Handling	Sample		Mean	Sex	0	Overall	ments
Study Pu	Purpose	Study design	Setting	participants	description	missing data	selection	n	(e)	M/F Popu	Population f	findings I	met/8a
Darzins et al. To test the	o test the	Two independent Geriatric Day	Geriatric Day	2 OTs	One	(i) Unweighted κ for	Consecutive	48	NR	NR NR	1	Unweighted к	4
[25] in	inter-rater	raters	Hospital, Hamilton,		experienced	each item, summa- outpatients	outpatients				y.	for:	
Unpubli re	Unpubli reliability of the administered t	administered the	administered the Ontario, Canada.		with HART and		referred to OT.	, .				Clothing (0.61)	
shed study H	ART in a geriatric	HART within			clinical practice,	HART domain.					, 11	Hygiene (0.46)	
̈́σ	day hospital setting. 2 weeks of one	2 weeks of one			one novice.						7	Nutrition (0.71)	
		another.				(ii) No reference to					~	Mobility (0.34)	
						missing items.					I	Residence (0.64)	
											S	Safety (0.79)	
											S	Supports (0.71)	
-		- -		E		0 - 1 - 44.77	:	C I	100		,		ı
laylor et al. To test the	o test the	I wo indep.	Aged Care Assess-	3 O Is,	One experi-	(1) Unweighted K for	Consecutive	20	/6(3/-93) M =	M = NK	_	Unweighted k for	`
[26] in	inter-rater	raters	ment Team and		enced with	each item, summa- referrals to	referrals to	$(2 \times 25)$		17	_	OT1/2; OT1/3:	
Unpublished re	Unpublished reliability of the	administered	Community Aids		HART, all	rized by each	each agency.	for		F = 33	0	Clothing (1.00; 1.00)	
study H	ART in two com-	HART within 1	and Equipment		experienced	HART domain.		analysis)			, 1	Hyraiana (0.73:	
	unity based health	munity based health week of the other. Program, Perth,	Program, Perth,		clinicians.						1 0	11)glette (0.7.3; 0.80)	
20	care settings.	One	Australia.								2 4	, ou)	
		rater was the indep.	Ė								4	Nutrition (0.65;	
		seeson of both									0	0.78)	
		settings				(ii) There were no miss-	-8				N	Mobility (0.84; 0.82)	
						ing data.					I	Residence (0.78; 1.00)	
											S	Safety (0.65; 1.00)	
											0, 0	Supports (0.69;	

"The COSMIN checklist generalizability requirements: description of age, sex, important disease characteristics, setting, countries where study was conducted, language used, participant selection described adequately, a/d, admission; AL, activity limitation; Ax, assessment; BI, Barthel Index; d/c, discharge; FIM, Functional Independence Measure; GEM, geriatric evaluation and management; Gen Med, general medicine; Neuro, neurology; Onc, oncology; Orth, orthopaedic; OT, occupational therapist; PR, participation restriction; Psych, psychiatry; PT, physiotherapist; Rehab, rehabilitation; S/W, social worker; NR, not reported; SMAF, Functional Autonomy Measuring Scale; SR, speech pathologist.

"Other" rehabilitation (includes arthritis, pain, cardiac, pulmonary, musculoskeletal, geriatric management), orthopaedic (fractured hip or pelvis, joint replacement, other fractures), amputation (upper, lower, or percentage of missing responses acceptable.

<sup>b</sup>18 incomplete assessments due to precipitous discharge or ward transfer, reasons for other missing data not provided. Cases with missing data removed from analysis. multiple limb), neurology (stroke, head injury, MS, parkinsonism, polyneuropathy, other neurological). health care team members in Victorian metropolitan and rural in-patient geriatric and rehabilitation health care settings.

#### Study quality (by measurement property) Reliability

Reliability is the extent to which scores on instrument items are the same on repeated occasions for patients who are stable between measurements under several conditions: using different sets of items from the same health measurement instrument (internal consistency); over time (test-retest); by different persons on the same occasion (inter-rater); or by the same person on different occasions (intra-rater) [17]. Studies included in this review evaluated inter-rater reliability only.

Inter-rater reliability Table II summarizes the methodological quality of the three studies exploring inter-rater reliability of scores on the HART/PC-PART in different aged care settings.

Use of Kappa (κ) to measure agreement between raters on the HART/PC-PART items was appropriate as items on the HART were scored as dichotomous variables ("OK" or "Not OK") [31]. These scores were then summarized by domain. The study by Taylor et al. [26], met 10 of 11 COSMIN checklist design requirements, demonstrating strong methods. The weakest methodological score came from Turner et al. [27], meeting only six design requirements. This study had a small sample, various levels of understanding of the PC-PART items amongst the raters, questionable similarity in test conditions between occasions of assessment and failed to report the management of missing data. All studies used at least two independent administrations of the PC-PART; an acceptable

period between administrations of the assessment; and appropriate statistical analyses.

Validity is defined as the degree to which an instrument measures the construct(s) it purports to measure [31]. This is especially important in health settings where it is frequently impossible to make a direct observation of the intended construct [31]. Different types of validity include content and face validity, construct validity (or hypothesis testing), structural validity, cross-cultural validity and criterion validity (concurrent and predictive) [17]. Studies included in this review investigated content and construct validity (hypothesis testing).

**Content validity** Content validity is the degree to which the content of an instrument is an adequate reflection of the construct to be measured [17]. Each study investigating content validity of the HART met four of the five COSMIN checklist design requirements (see Table III).

Despite variation in the quality in the reporting of study methods between the studies, and evidence of some study design flaws, there was relatively strong evidence that overall the HART items (i) measured relevant aspects of personal care handicap needed for discharge planning, (ii) were relevant to the study populations, (iii) were relevant to the purpose of establishing readiness for discharge and prioritizing discharge planning interventions and (iv) together, comprehensively reflected the target construct of "areas of occupational performance essential for community living".

**Construct validity (hypothesis testing)** Construct validity is the degree to which the scores of an instrument are consistent

Table II. Inter-rater reliability - summary of COSMIN checklist design requirements met for each study.

Study	Missing data	3. Adequate sample size?	4. At least two	Between administrations:	9. Similar test conditions	10. Absence of	COSMIN design
	1. Reported?	sample size:	measurements? (No.)	adillilistrations:	for both	important flaws	requirements
	2. Handling explained?		5. Independent administrations?	6. Time?	measurements? <sup>a</sup>	in study methods?	met/11
	1			7. Patients stable?		11. Statistical	
				8. Interval appropriate?		methods appropriate?	
Darzins et al. [25]	1. Yes (none)	48-probably	4. Yes (2)	6. Within 14 days	a. Yes	10. No – 1 pair of raters	8
	2. n/a	Adequate	5. Yes	7. Not reported	b. Yes	11. Yes	
				8. Yes	c. Yes		
Taylor et al. [26]	1. Yes (none)	50-analysis	4. Yes (2)	6. Within 7 days	a. Yes	10. Yes	10
	2. n/a	completed for two groups of	5. Yes	7. Yes	b. Yes	11. Yes	
		25, therefore inadequate		8. Yes	c. Yes		
Turner et al. [27]	1. No	25-inadequate	4. Yes (2)	6. Within 3 days	a. Yes	10. No - small	6
	2. No		5. Yes	7. Yes	b. Yes	sample, varied	d
				8. Yes	c. Not reported	PC-PART training acros raters,	SS
						11. Yes	

Refer to Table I for summary of methods and findings for each study.

a, administration; b, setting; c, instructions

Table III. Content Validity - summary of COSMIN design requirements met (includes face validity).

Table III. Content vand	ity – summary of COSMIIN desi	Table III. Content vandity – summary of COSMIN design requirements met (includes face vandity)	validity).			
		Assessment of whether all items:	ether all items:		1	
	1. Measure relevant aspects of the target construct?	2. Are relevant to the study population?	3. Are relevant to the purpose of the	4. Together, comprehensively reflect	5. Absence of study	COSMIN design
Study			measurement tool?	the target construct?	design flaws?	requirements met /5
Vertesi et al. [10]	Yes – The HART was designed to measure Handicap based on the ICIDH framework. The HART was designed to provide information about personal care Handicap relevant community living. HART was found to "provide a means to empower occupational therapists to provide client-centred care with regards to personal-care Handicap" (p. 126)	Yes – Positive feedback from respondents indicated "all aspects of their daily routines were addressed" (p. 126). During development content experts, OTs, other health professionals and consumers were consulted in item generation phase. Items were tested with 'nearly 100' clients with varying disabilities residing in the community.	Yes – "The HART provided "a comprehensive assessment that addresses both clients' function and the support system available in their living environment." (p. 126).	Yes – "Discharge from hospital was better planned as all problem areas were addressed, which ensured no significant personal care handicaps were overlooked" (p. 126). All items addressed areas of occupational performance that are essential for community living.	No – Lack of specific detail of sample characteristics. At the hospital site the HART was administered just prior to discharge resulting in lower than expected prevalence of, and variability in Personal Care Handicaps observed.	4
Darzins et al. [28]	Yes – HART items cover all relevant aspects of personal care participation restriction. HART acknowledges social and environmental issues. HART does not address impairment, medical intervention, quality of life or patient satisfaction.	Yes – HART provides a "complete and objective picture" (p. 72) of the patient's situation. This aids communication with the family. It is useful for patients where decisions between home and residential placement is unclear	Yes – The HART provides a structured way to measure and establish readiness for discharge and helps to streamline discharge planning.	Yes – The HART provides a whole picture of the patient's living situation. HART was more comprehensive than other outcome measures being used at the time of the study.	No – Reporting of study methods lacked rigour. There was procedural rigour during data collection, but inability to determine if the thematic analysis was inductive, and inability to audit the analysis using the set criteria, undermining potential value of the findings.	4
Barbara & Whiteford [25	Barbara & Whiteford [29] Yes – The assessment was reported to be a comprehensive personal care participation restriction assessment. Participants found the HART thorough and items were relevant to the issues needing to be addressed for discharge planning.	Yes – "The HART is a context sensitive tool that addresses the complex needs of older patients [in acute care settings]." (p. 17). Wording of items in the HART had a North American sound which was difficult for older Australian patients, but the simple OK/NOT OK scoring was well received by all therapists.	Yes – The HART aided normal clinical reasoning in the acute care setting and "addressed the complexity of clients' reasons for admission and issues that needed to be resolved for discharge" (p. 24). The HART's process of guiding decisions and options for discharge planning was seen as a strength of the tool.	Yes – All participants reported that the HART is a comprehensive personal care PR assessment tool. The HART provided a useful global picture of how the client was managing at home.	No – This study was not specifically designed to test content validity.	4

Refer to Table I for summary of study methods and results for each study.

COSMIN design requirements met /10	N	v
<ol> <li>Design and statistical methods adequate?</li> </ol>	Yes – Visual graphs of scores on both measures weekly from a/d to d/c. Spearman's rho correlation between change scores on each measure (r = 0.59).	No – Scatterplots were provided without calculating the strength and statistical significance of the correlations to support the visual representation of no/poor correlation between HART and BI scores.
9. Absence of important flaws in study design or methods?	No – Inadequate detail in hypotheses set a- <i>priori</i> .	No – Inadequate detail in hypotheses set a-priori.
7. Description of comparator instrument adequate? 8. Properties described?	7. Yes – FIM described No – Inadequate in detail. es Acasurement a-priori. properties of the FIM described in detail. (p. 66)	7. Yes – BI described in No – Inadequate Smith et al. (2001) detail in hypotheses set 8. Yes – described in a-priori. (p. 67)
5. Direction of correlations specified? 6. Magnitude of correlations specified?	5. Yes – Inverse relationship between FIM and HART scores 6. No – not stated	5. No – not stated 6. No – not stated
4. Hypotheses formulated a-priori?	Yes – H <sub>0</sub> ; a tight relationship between patients' FIM scores and HART scores exists, indicating one measure can be used as a proxy of the other.  H; the relationship between FIM and HART scores is limited or variable, indicating use of one instrument is insufficient to reflect patient outcomes (p. 69).	Yes – H <sub>0</sub> : there will be a correlation between Activity Limitation (B1) score and Personal Care Participation Restriction (HART) score at a'd and dc within an inpatient rehabilitation setting.
3. Sample size adequate?	Not justified. n = 36 (GEM = 16; Rehab. = 20)	Yes-131 complete sets of data for HART and BI
Percentage of 3. Sample sizenssing items given? adequate?      Handling missing data?	1. Not reported 2. Not reported	Darzins et al. [28] 1. Yes – HART (6%), BI (9%) 2. Yes – cases with missing data excluded from analysis.
Study	Smith et al. [30]	Darzins et al. [28]

Refer to Table I for a summary of study methods and results for each study. a/d = admission; d/c = discharge;  $H_0$  = Null hypothesis;  $H_1$  = alternate hypothesis.

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Study	<ol> <li>Percentage of missing items given?</li> </ol>	3. Sample size adequate?	Longitudinal design		Requirements for hypothesis testing (where no gold standard is available)	ıypothesis gold standard	13. Absence of important flaws in study design or	Testing of hypotheses  14. Statistical design and methods adequate?	COSMIN design requirements
	2. Handling missing data?		At least two measurements?     Time interval stated?	6. Interim occurrences described? 7. Proportion of patients changed?	8. A-priori hypotheses about expected change scores? 9. Expected direction of correlations? 10. Magnitude of expected	Comparator instrument: 11. Adequate description? 12. Properties described?			met/14
Smith et al. [30]	1. NR 2. NR	3. Not justified. n = 36 GEM = 16 Rehab. = 20	4. Yes 5. Yes – On a/d, then weekly until d/c.	6. No 7. Yes – fewer PRs at d/c (lower HART scores).	8. Yes – H <sub>0</sub> : AL (FIM) scores will show parallel change to PR (HART) scores from a/d to d/c.	11. Yes 12. Yes (FIM)	13. No – Small sample. More details of sample, hypotheses, and focus in statistical analyses needed.	14. Yes – Association between FIM and HART change scores was r = 0.59. In rehab setting: Mean HART score at a/d = 15 (Range: 2–35) and on d/c = 2 (Range 0–8).  On GEM unit: Mean HART con a/d = 15 (Pages 1.32)	∞
Darzins et al. [28] 1. Yes HART SMAF BI (99, 2. Yes miss exch ana)	Darzins et al. [28] 1. Yes  HART (6%)  Sets of data for 5. Yes  SMAF (34%)  BI (9%)  2. Yes – complete 4. Yes  HART  (LOS  BI (9%)  SMAF  2. Yes – cases with (n = 131).  missing data excluded from analysis.	3. Yes – Complete 4. Yes sets of data for 5. Yes HART (LO (n = 131). SMAF (n = 182).	4. Yes 5. Yes – a/d and d/c (LOS could vary).	6. No 7. Yes – fewer PRs at d/c (lower HART scores).	PR (higher HART scores) expected at a/d than at d/c.  10. No  6. No  8. Yes – H <sub>0</sub> ; there 11. Yes 13. No – 8 could vary). at d/c (lower change in AL (B1) and comp change in PR HART scores).  AL (B1) and comp comp change in PR (HART) from and S a/d to d/c in not p an inpatient rehabilitation setting.  9. Yes – H <sub>0</sub> ; there will be a stronger relationship between AL and PR at d/c than at a/d.	11. Yes 12. Yes (BI)	13. No – a-priori hypotheses needed to be more specific. Direct comparison between HART and SMAF was not possible due to study design.	There was no testing of difference between mean HART scores from a/d to d/c.  14. No – Scatterplots showed the nature of associations between PR and AL measures, but statistical tests not used to show magnitude of the associations. Proportionate change from a/d to d/c was compared between BI and HART – but categorizations of scores into 6 categories to enable direct comparison of change between BI and HART was not evidence-based.	10

Disability & Rehabilitation

	ria			ned
	Utility criteria met /9		<b>6</b>	(Continued)
- 1	9. Absence of Utility important study met /9 flaws?	No – Gaps in reporting of some study methods and data analysis procedures undermined potential strength of the transferability and truckworthiness of the findings.	No – Thematic analysis used to analyse focus group discussions lacked auditability. Not possible to discern if analysis was inductive, undermining data trustworthiness.	
	8. Clinical usefulness of information	Yes – Useful when setting therapy goals with patients. The tool structured rather than replaced what was already being done. Supports clinical reasoning process. Some concern over ability to correctly score some items in the hospital setting.	Yes – HART viewed as a good checklist for discharge planning, useful for structuring family meetings, useful for assessment and management of 'complex' patients, promoted consistency of info.	
	7. Acceptability to clinician and patient	Yes – HART viewed as complimentary to current assess- ment. Conversa- tional approach empowering to the patient and carer, asking for their individual perspectives. Provides prompts for new users. Records what therapy is achieving.	Yes – HART viewed positively by OTs and PTs. Good supplement to current discipline specific assessments by structuring rather than replacing existing work. It empowered the patient.	
wcett (2007).	6. Effort required	Yes – Easy to use & complete HART. Relatively easy to integrate into current practice.	Yes – Simple to use once familiar with the assessment. Initially perceived as intimidating and lengthy.	
m Law (2004) and Fa	5. Examiner qualifications & training	Yes – Formal HART training was provided and viewed as necessary <sup>a</sup> . It took approx. 10 assessments after training to feel confident to use HART effectively. Required training to judge risk level.	Yes – Formal HART training was provided and viewed as necessary and valued to enable effective administration <sup>a</sup> .	
o criteria collated fro	3. Time to complete 4. Cost	3. Yes – "Variable" but "not too long". HART did not add to overall assessment time. In-patient group had more concern about time taken. 4. No – Not Rated	3. No – Not specifically addressed. 4. No – Not rated	
findings according to	2. Format of administration	Yes – Good structure to assessment including both patient & carer input and options for observation. Therapists wanted more room on summary sheet for recording goals, action plans, and patient ID.	Yes – Therapists who (incorrectly) used only the HART checklist later realized the value of completing the full worksheet, which allowed recording of the reasoning for assigned scores.	
Table VI. Clinical utility – summary of findings according to criteria collated from Law (2004) and Fawcett (2007).	<ol> <li>Clarity of instructions</li> </ol>	Yes – Straight- forward wording.	Yes – Questions put simply. Some items needed to be rephrased to be understood by the patient.	
Table VI. Clinical	Study	Smith et al. [30]	Darzins et al. [28]	

Table VI. (Continued).	nued).								
Barbara et al. [29] No - Mixed	No - Mixed	Yes – The com-	3. Yes – Time	Yes – Formal	Yes - Required	Yes - HART	Yes – HART	No – Small	9
	responses to	bination of client	varied between	HART training	organization	placed patient &	provided structure	sample lacked	
	wording of	interview, care-	participants.	was provided. Par-	by therapist to	families central	for discussion and	diversity, induc-	
	HART items-	giver interview and	HART took	ticipants viewed	speak to patient	to assessment	focus for interven-	tive analysis	
	perceived by	task observation	longer than	access to specific	and carer, but	process, it	tions to aid patient	processes lacked	
	one therapist to	was viewed posi-	standard initial	HART training as	this was per-	facilitated family	discharge. Scoring	auditability, weak	
	sound American	tively. Simple OK/	assessment but	desirable <sup>a</sup> .	ceived to have	discussion about	system enabled	strategies used	
	(i.e. using "ok").	Not OK scoring	was balanced		better outcomes	how patient	therapists to use	to reduce. These	
		system was viewed	by usefulness of		for patients.	and family were	established clinical	undermined	
		positively as simple	the information			managing with	reasoning processes.	strength in trans-	
		and easy to use	obtained.			patient's living	Some items are best	ferability and	
		in a time-limited	4. No - Not rated			situation. HART	addressed in the	trustworthiness	
		situation.				facilitated clini-	home environment.	of the findings.	
						cal reasoning.			
						Therapists felt			
						empowered to			
						discuss sensitive			
						issues.			

Oualified health professionals can administer the PC-PART. Formal training is not a requirement for using the PC-PART. Training is self-guided using the PC-PART manual & DVD. Yes = positive rating; No = Not Reported(NR) or Negative rating. Refer to Table I for a summary of the methods and results for each study.

with hypotheses, for instance with regard to internal relationships, relationships to scores on other instruments, or differences between relevant groups, based on the assumption that the instrument is a valid measure of the construct to be measured [17].

The two studies providing evidence of construct validity of the HART [28,30] met 6 and 5 of 10 COSMIN design requirements (see Table IV). The main limitations were that there was no *a-priori* justification for the sample size in either study, and although *a-priori* hypotheses were set, they were not sufficiently detailed. The FIM and HART score correlations observed in these studies provided some evidence that the HART and FIM may measure different constructs.

#### Responsiveness

Responsiveness is the ability of an instrument to detect withinperson change over time in the construct to be measured [17]. The two studies providing evidence of responsiveness of the HART [28,30] met 10 and 8 of 14 COSMIN design requirements (see Table V). One strength of the study by Smith et al. was the weekly measurement of patients' change in both HART and FIM scores between admission and discharge. All patients in the sample showed improvement in their HART scores between admission and discharge, while eight patients (22%) showed no appreciable change in their FIM score between admission and discharge. This provided some evidence in support of responsiveness of the HART in subacute inpatient settings. In the study by Darzins et al., there was no visible correlation between BI and HART change scores between admission and discharge on scatter plots. One weakness of this study was that it was not possible to make direct comparisons between change scores on similar measures used in this study.

# Clinical utility

Clinical utility refers to the degree to which an assessment can provide useful clinical information, is acceptable to users and consumers, and can facilitate data collection [20,21,32]. The three qualitative studies exploring clinical utility of the HART met 6 or 7 of the eight set criteria [28-30] (see Table VI). Overall, participants in all studies were positive about the format and usefulness of the information obtained by the HART, each providing different perspectives about the benefits of the patient interview, informant interview, and structured observation components to the assessment. Initially, the HART seemed to be a lengthy assessment that became faster to administer with practice. Formal training to use the PC-PART is not currently required, however, in each of the reported studies at least two hours of formal training was provided. In all studies, participants expressed the desire for longer formal training sessions to enable a clearer understanding of the concepts within the tool, the purpose of the tool and the reasoning process used during administration of the HART. Assessing degree of risk was reported to be difficult by clinicians, supporting the need for specific training. The HART was viewed as acceptable to both patient and clinician by being client centred, empowering to both and allowing clear communication of the issues related to community living. Focus group

Disability & Rehabilitation

Overall quality rating 0 0 0 Quality rating individual studies 0,+ 0,3 ∼: 0 0 0 0 0 (Agreement, Reliability) (Agreement, Reliability) Predictive: No evidence (Agreement, Reliability) 3. Barbara &Whiteford 1. Darzins et al. [25] 1. Darzins et al. [28] 2. Vertesi et al. [10] 2. Darzins et al. [28] 3. Turner et al. [27] Darzins et al. [28] No evidence found. No evidence found No evidence found 1. Smith et al. [30] 2. Taylor et al. [26] 1. Smith et al. [30] No. of studies Study providing Concurrent: No evidence found evidence [29] punoj punoj n \*0 0 7 3 7 0 0 + Factor analyses performed on adequate sample size (7\*# items and ≥100) AND Chronbach's alpha Doubtful design or method OR (MIC not defined AND no convincing arguments that agreement Clear description of above-mentioned aspects is lacking OR only target population involved OR - SDC or SDC > MIC OR MIC = or inside LOA OR RR < 1.96 OR AUC < 0.70, despite adequate + Convincing arguments that gold standard is "gold" AND correlation with gold standard ≥0.70. + Specific hypotheses formulated AND at least 75% of results in accordance with set hypotheses. + Mean and SD scores presented of at least four relevant subgroups of patients and MIC defined. + Clear description of measurement aim, target population, concepts that were being measured, + MIC< SDC or MIC outside the LOA OR convincing arguments that agreement is acceptable. - > 15% of respondents achieved highest or lowest possible scores despite adequate design and item selection AND target population and (investigators or experts) involved in the item No convincing arguments gold standard is "gold" OR doubtful design/method. Less than 75% of hypotheses confirmed, despite adequate design and methods. ? Doubtful design or method OR less than four subgroups OR no MIC defined. - MIC > SDC OR MIC = or inside LOA, despite adequate design and method. - Correlation with gold standard < 0.70 despite adequate design and method. + SDC or SDC< MIC OR MIC outside LOA OR RR > 1.96 OR AUC ≥ 0.70. calculated per dimension AND Chronbach's alpha between 0.7 and 0.95. Chronbach's alpha <0.70 or >0.95, despite adequate design and method.  $+ \le 15\%$  of respondents achieved highest or lowest possible scores; - ICC or weighted  $\kappa < 0.70$  despite adequate design and method. ? Doubtful design or method (e.g. time interval not mentioned). Table VII. Quality ratings for the PC-PART using criteria provided by Terwee et al. [24]. Minimum quality standards provided by Terwee et al. [24] No factor analysis OR doubtful design or method. ? Doubtful design or method (e.g. no hypotheses) No target population involvement. ? Doubtful design or method. Doubtful design or method. + ICC or weighted  $\kappa \ge 0.70$ . doubtful design/method. design and methods. is acceptable) Agreement: selection. Reliability: Internal consistency (Hypothesis testing) Construct validity Criterion Validity Floor and ceiling Content validity Reproducibility Responsiveness Interpretability Measurement property effects

AUC, area under the curve; ICC, intra class correlation coefficient; LOA, limits of agreement; MIC, minimal important change; RR, relative risk; SDC, smallest detectable change.  $^*0$  = No information found.

participants from Darzins et al. [28] reported that PC-PART items were not useful for patients who were high functioning or who were already in residential care or supported accommodation. It was best used when there was uncertainty about a person's ability to live in the community.

#### Instrument quality

Synthesis of the results from all included studies enabled an overall rating of the PC-PART's measurement properties. Table VII shows the quality ratings assigned to each studied measurement property using the criteria provided by Terwee et al. (see Table VII). Content validity was the only property to receive an overall positive rating, with all other studied properties receiving an overall indeterminate rating related to doubtful design or methods.

For inter-rater reliability, Taylor et al. [26] reported κ scores of at least 0.70 for four domains using one pair of raters and 0.70 for all domains using the other pair of raters. The study by Darzins et al. [25] obtained κ scores of at least 0.70 for three HART domains. The study by Turner et al. [27] obtained κ scores of at least 0.70 for one domain and provided strong arguments to explain the low κ scores relating to the low prevalence of participation restrictions across most domains within the sample. The particularly low  $\kappa$  score for the domain of "safety" ( $\kappa = 0.15$ ), yet high percentage agreement (94.4%) may have occurred because of the small sample size as well as the low prevalence of "Not OK's" (participation restrictions) within the sample across most domains. No limits of agreement (LOA) analyses were performed in any study. Reproducibility of the "low," "medium" or "high" risk ratings for items scored with "Not OK" on the PC-PART were not tested in any study.

### Discussion

This systematic review identified seven studies investigating the measurement properties of the PC-PART. The critical analysis of the measurement properties of the instrument allowed us to identify those properties that require further investigation. The seven studies included in this systematic review represent a relatively small body of research investigating the PC-PART. Using established criteria, we found sufficient evidence to support content validity of the PC-PART, substantial evidence to support clinical utility and inconclusive evidence to support reproducibility, construct validity and responsiveness. There was no information upon which to judge internal consistency, criterion validity, structural validity and interpretability.

#### **External validity**

Knowledge of the generalizability of each quantitative study and transferability of each qualitative study in this review is important for determining how applicable the findings are to clinical settings. Overall, there was good evidence to support generalizability of the findings to aged care in-patient and outpatient, urban and rural, acute and subacute health settings [10,25,26]. However, the PC-PART was designed for use in any adult health care setting where assessment of the

patient's ability to live in the community occurs [9]. This is not specific to the adult's age or diagnosis. Examples of other settings where validation studies of the PC-PART could occur include supported accommodation or transitional living program settings, community based aged care assessment settings and emergency department settings.

#### Inter-rater reliability

We found some evidence to support inter-rater reliability from three studies, but overall the evidence remains inconclusive due to doubtful methods and reporting in each study. The low  $\kappa$  score obtained for the "safety" domain in the study by Turner et al. [27] may reflect subjectivity in rating these items and the absence of training regarding item scoring conventions. The therapist is required to make judgements about peoples' ability to cope with unexpected or unusual demands, which may involve a safety risk. Information available to make judgements about people's safety may be limited and also subject to the assessor's own values about hazards and risks, leaving them open to variation in scoring. In contrast, other domains such as "mobility," contain items that are more easily observable: the highest  $\kappa$ (0.78) was obtained in this domain. The absence of formal training to use the HART in the study by Turner et al. may reflect clinical reality and therefore the level of agreement that could be expected in such circumstances. κ scores for the study by Taylor et al. [26] were relatively high ( $\kappa = 0.63$ – 1.00). Assessors using the HART in this latter study were all trained in the tool's purpose, administration and scoring. All were occupational therapists who had worked together clinically for several years in aged care settings. Although all score data were gathered from independent raters in this study, similar work experience and team work may influence patterns of clinical reasoning and may have strengthened their agreement. These results indicate that training can improve inter-observer agreement on the PC-PART items.

Researchers in each study assessed reliability using κ for each of the seven domains contained in the PC-PART. Intraclass correlation coefficients – Agreement (ICC<sub>agreement</sub>) and LOA for the total PC-PART scores were not calculated for any of these studies. It would be possible to treat the total PC-PART score as a continuous variable as the score represents the total number of participation restrictions obtained on the assessment (0–43). The ICC and LOA would have provided an estimate of reliability of the total score taking into account the magnitude of difference between assessors on PC-PART scores for each patient. Using the ICC also allows missing data, the number of assessors, and systematic bias between assessors to be taken into account [31]. These analyses would have provided an estimate of the PC-PART's ability to differentiate among people.

# Validity

# Content validity

Whilst there was good evidence to support content validity of the PC-PART in the settings used for each of three studies as a measure of PADL and IADL participation related to living in the community, this still represents a relatively small body of research. Content validity is fundamentally important for a clinically targeted measure such as the PC-PART [31] and therefore these positive results justify further investigation of the PC-PART's measurement properties in different health care settings.

#### **Construct validity**

Some investigation of construct validity was provided by two studies and both studies concluded that the HART measures a different construct to the FIM and the BI. The FIM and the BI measure performance in PADL by scoring what the person is able to perform on their own; if the person uses adaptive equipment or requires assistance to perform the activities involved in the assessment, they obtain lower scores. The PC-PART measures performance in PADL and IADL by scoring what the person is able to complete using available supports (adaptive equipment or assistance). Scores are not impacted by the use of supports. This represents a difference in theoretical constructs between the assessments. The FIM and BI measure change in performance at the level of the person whereas the PC-PART measures change in performance that may come about when changing environmental factors. This difference can be compared to the differences between performance at an activity level and performance at a participation level using the ICF framework [6]. The results observed in the reviewed studies that support differences in construct between the BI/ FIM and the PC-PART appear valid, but stronger study methods and reporting are required to establish a true difference in construct between such measures.

#### Responsiveness

Mokkink et al. [19] defined responsiveness as the ability of an instrument to detect change over time in the construct to be measured. They explain that the difference between crosssectional (construct and criterion) validity and responsiveness was that validity refers to the validity of a single score and that responsiveness refers to the validity of a change score. This is why the standards for the evaluation of responsiveness are similar to those of construct and criterion validity. The main difference is that the a-priori hypotheses for responsiveness should focus on the change score. Therefore, the methods used in the studies by Darzins et al. [28] and Smith et al. [30] were largely valid, however the results were compromised by the small sample in one study [30] and lack of specific a-priori hypotheses and adequate statistical analyses in both studies. However, preliminary evidence from these studies does indicate that the PC-PART shows promise as a responsive instrument in acute and subacute adult health settings and that further investigation of responsiveness is warranted using larger samples in a range of clinical settings using sound methods.

#### Clinical utility

Clinical utility has one of the strongest influences on actual use of an outcome measure in a clinical situation [32]. One important issue that was highlighted [28] related to formal training to use the PC-PART to ensure clinicians understood important concepts intrinsic to the tool. It was evident there was a lack of understanding amongst clinicians about the distinction between the assessment of a person's individual abilities (activity/limitation) and what the person does using available supports (participation/restriction) [6]. This lack of conceptual knowledge may jeopardize the validity of PC-PART assessments scores, as these are fundamental concepts underlying the assessment that impact how items are scored. This highlights the need for an investigation of whether formal training for administering the PC-PART influences the validity of responses. If formal training is found to be important, the usefulness, feasibility and cost of implementing training would also need to be evaluated as an aspect of clinical utility of the tool. The findings provide an overall positive impression of the clinical utility of the PC-PART that needs to be further tested in a range of clinical settings, using sound methods and reporting.

#### Instrument quality

Rating the quality of the instrument using Terwee et al. [24] criteria depends on both the amount of research conducted and the adequacy of study reporting. New measures or those that have not been studied widely may have many indeterminate ratings, not because they are poor measures, but because measurement properties have not yet been studied. In addition, poorly reported validation studies lead to low ratings for measures that are not necessarily poor in design or performance [24].

There were some studies where, in the reviewers' opinion, there was poor reporting of what may have been sound methods. For example, most studies obtained a lower rating for not reporting the handling of missing data. If not reported, it is not possible to determine whether they were handled appropriately. On the other hand, failure to set specific and detailed a-priori hypotheses when testing construct validity and responsiveness, and not including LOA when testing agreement as part of reproducibility, are examples of flaws that could be observed within the publications and that appropriately led to some indeterminate ratings on the Terwee et al. criteria.

#### Limitations

One potential source of bias in a systematic review is that of reviewer bias related to positive expectations by those conducting the review. To minimize this potential source of bias, objective review structures containing set criteria for evaluation were used for each step of the critical review process. In addition, two reviewers independently critiqued each study using the criteria, and then discussed their findings to reach consensus on the ratings. Another limitation of this review is the possible under-estimation of the strength of evidence to support the measurement properties of the PC-PART. This may have arisen in instances where evidence to support a measurement property of the PC-PART existed, but inadequate and alternative ways of reporting methods, analyses, or results meant that the evidence could not be accepted as presented. In this review, we assigned equal weighting to each of the methodological criteria in the COSMIN checklist. It is likely that certain criteria are more important to the establishment of a particular measurement property than others. It is difficult to know whether this is likely to have resulted in under- or over-estimation of conclusions drawn from this review.

#### **Future research**

Several areas for future investigation of the measurement properties of the PC-PART have been highlighted by this systematic review. The PC-PART aims to measure PADL and IADL participation [9] using the concept of participation contained in the ICF [6]. Testing of the conceptual foundations of the tool may be undertaken by linking the concepts of the PC-PART to ICF Activities and Participation codes using Cieza's established linking rules [33]. This may provide evidence of construct validity of the PC-PART from a theoretical perspective.

Further investigation of construct validity through hypothesis testing is warranted in different health care contexts where decisions about community living are made. Future studies will require clear *a-priori* hypotheses about the direction and magnitude of expected correlations between PC-PART item scores and other measures. Similarly, investigation of responsiveness will need to incorporate *a-priori* hypotheses about the expected direction and magnitude of change scores of the PC-PART, and the correlation of change scores between measures [18,24].

Further testing of the PC-PART's structural validity is required. Methods incorporating Classical Test Theory (Factor analysis) may be used to investigate its structural validity [31]. The instrument is already divided into seven domains, but the structural validity of these domains has not been confirmed.

Fully-powered inter-rater reliability studies are warranted in a range of patient populations using at least two independent raters, and applying unweighted  $\kappa$  measure of agreement at the individual item level, LOA analysis, and ICC scores for the total PC-PART score [18,24,31]. No study has tested the reproducibility of the risk ratings that are assigned to items deemed "Not OK", and this should be done to establish if the risk ratings may be used.

There were no studies of the predictive criterion validity of the PC-PART. It would be important to health service provision and resources across a range of patient populations to understand the nature of the relationship between PC-PART item scores and outcomes such as discharge destination from in-patient health care settings. In community settings, it may be possible to identify the need for particular services based on specific PC-PART scores. This requires further testing in a range of health care settings.

Clinical utility of the PC-PART should be further investigated using combined quantitative and qualitative research methods if it is to be used in different clinical contexts to those already tested [21].

#### **Conclusions**

The PC-PART shows promise as a clinically relevant assessment of PADL and IADL participation restrictions related to "living in the community". This is relevant for decision making about admission or discharge from health care settings. This

systematic review revealed good evidence to support content validity of the PC-PART. Although there is some evidence to support clinical utility, reproducibility, construct validity and responsiveness in various health care settings, these properties require further testing using sound methods and comprehensive reporting in a range of health settings with different patient populations. Properties not yet studied, such as structural validity and criterion validity require investigation.

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D. Mobility

1. Mobility

6. Hazards

F. Residence

Appendix I. Individual item content of the PC-PART.

- 24. Terwee CB, Bot SD, de Boer MR, van der Windt DA, Knol DL, Dekker J, Bouter LM, de Vet HC. Quality criteria were proposed for measurement properties of health status questionnaires. J Clin Epidemiol
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#### **Appendix**

A. Clothing

1. Dress: top

1. D1033. top	1. 1/10011114
2. Dress: bottom	2. Bed
3. Dress: footwear	3. Falls
4. Selection of clothing	4. Steps
5. Laundry	5. Outside
B. Hygiene	6. Diving
1. Toilet: transfer	7. Transport
2. Bladder control	8. Wandering
3. Bowel control	9. Orientation
4. Groom: hair	E. Safety
5. Groom: teeth	1. Medications
6. Groom: shave/menstruation	2. Substance Abuse
7. Bathing	3. Illness
8. Bath transfer	4. Emergency help
C. Nutrition	5. Smoking

3. Meal: plan 1. Money Management 4. Meal: make 2. Security 5. Groceries 3. Personal Information 6. Food: restriction 4. Shopping

7. Stove 5. Temperature 8. Spoiled food G. Supports 1. Adequate?

2. Stability/can cope

1. Eat: weight

2. Eat: choke

## **Evidence Available Since Publication of the Systematic Review**

Since publication of this systematic review, one further study examining measurement properties of the PC-PART has been published. This study evaluated inter-rater reliability and clinical utility of the PC-PART for inpatient rehabilitation (Radia-George, Imms, & Taylor, 2014). The systematic review published in 2013 reported some evidence to support inter-rater reliability from three studies. However, evidence about the PC-PART's reliability, overall, remained inconclusive because of doubtful methods and reporting in each study.

The later study by Radia-George et al. (2014) was a well-constructed study, which met all eight generalisability requirements and all 11 design requirements for an inter-rater reliability study, according to the COSMIN checklist. Table 3.1 displays the COSMIN generalisability requirements met for this study. Table 3.2 displays the COSMIN checklist inter-rater reliability design requirements met by this later study (shaded), in addition to those examined in the 2013 published systematic review.

The setting for this later reliability study was an in-patient rehabilitation ward in a publicly funded hospital in an outer metropolitan region located in Australia. Four occupational therapists with a mean of 7 years of experience (*SD*=2.0), plus the occupational therapist researcher were the raters. All had training in use of the PC-PART and completed at least 10 PC-PART assessments. The initial PC-PART assessment was completed by the treating therapist within three days of admission. The research therapist was blinded to the rating of the treating therapists. The second assessment occurred within one working day of the treating therapist's assessment.

Table 3.1. Summary of study purpose, methods and conclusions; COSMIN generalisability requirements met for available studies since systematic review publication.

No of COSMIN	Generalisability	Requirements	met /8	8																		
Conclusions aNo	Population Overall findings Ge	Rec	mei	Total PC-PART score	ICC = .91	Domain ICCs range	=.77 to .84 (except	Residence ICC=.38)	Domain PC-PART	score LOA:	Group of OTs=narrow	Indiv. OTs =wide	Total PC-PART score	LOA:	Group OTs (-1.3, 0.05)	Indiv. OTs (-9.6, 8.20)	Percentage agreement	>85% for 31 items, not	able to calculate for 4	PC-PART items rated	same for all patients	hy all raters
	Population			Stroke (27)	Post	fracture	(25), Post	hip- or	knee-joint	replace-	ment (21),	Other (23)	,									
	Sex	M/F		M=42	F=54																	
tics	Age (yrs)	Mean	(Kange)	73	(range	NR)	SD=12															
characteris	и			96	(n=100)	sufficient	to show	ICC=.90	for total	score	with	SE=.25										
Patient Sample characteristics	Sample	selection		Consecutive	series of	admissions to	rehabilitation	wards.														
	i. Data Analysis	ii. Handling	MISSING UATA	i. ICC; LOA;	Cohen's Kappa;	percentage	agreement.	ii. There were	no missing data.	•												
	Clinician	description		All clinical	OTs from	rehabilitation	ward eligible	if trained or	willing to be	trained in use	of PC-PART.											
	Clinician	raters,	participants	4 clinical OTs	plus 1 indep	research OT																
	Setting			Inpatient adult	rehabilitation	wards of public	outer	metropolitan	hospital,	Australia.												
Methods	Study design			PC-PART	Axs by	clinical OTs	within 3 days	of a/d. Indep	research OT	rater within 1	working day.											
Purpose				To test inter-	rater	reliability of	PC-PART in	rehabilitation	setting.	)												
Study				Radia-	George et	al (2014)	Peer-	reviewed	journal	article												

Abbreviations: OT= Occupational Therapist; NR=Not Reported; a/d=admission; d/c=discharge; Ax=Assessment; ICC=Intra Class Correlation Coefficient; LOA=Limits of Agreement; SD=Standard Deviation; SE=Standard Error.

\* The COSMIN checklist generalisability requirements: Description of age, sex, important disease characteristics, setting, countries where study was conducted, language used, participant selection described adequately, percentage of missing responses acceptable.

Table 3.2. Inter-rater reliability - summary of COSMIN checklist design requirements met for each study included in the systematic review, including evidence available since publication (shaded row).

Study	Missing data	<ol><li>Adequate sample</li></ol>	4. At least two	Between administrations:	9. Similar test	<ol><li>Absence of important</li></ol>	COSMIN
	<ol> <li>Reported?</li> </ol>	size?	measurements? (No.)	6. Time?	conditions for both	flaws in study methods?	Design
	<ol><li>Handling</li></ol>		<ol><li>Independent</li></ol>	7. Patients stable?	measurements? <sup>a</sup>	11. Statistical methods	Requirements
	explained?		administrations?	8. Interval appropriate?		appropriate?	met /11
Darzins.	1. Yes (none)	48 - probably	4. Yes (2)	6. Within 14 days	a. Yes	10. No - 1 pair of raters	8
et al.	2. n/a	adequate	5. Yes	7. Not reported	b. Yes	11. Yes	
(1996)				8. Yes	c. Yes		
Taylor et	1. Yes (none)	50 - analysis	4. Yes (2)	6. Within 7 days	a. Yes	10. Yes	10
al. (1998)	2. n/a	completed for two	5. Yes	7. Yes	b. Yes	11. Yes	
		groups of 25,		8. Yes	c. Yes		
		therefore inadequate					
Turner et	1. No	25 - inadequate	4. Yes (2)	6. Within 3 days	a. Yes	10. No - small sample,	9
al. (2009)	2. No		5. Yes	7. Yes	b. Yes	varied PC-PART training	
				8. Yes	<ul> <li>c. Not reported</li> </ul>	across raters,	
						11. Yes	
<sup>b</sup> Radia-	1. None	96 pairs of	4. Yes (2)	6. Within 1 working day	a. Yes	10. Yes	111
George et	2. n/a	observations-	5. Yes	7. Yes	b. Yes	11. Yes	
al. (2014)		adequate		8. Yes	c. Yes		

<sup>a</sup> a=adminstration; b=setting; c= instructions
<sup>b</sup> shaded row summarises evidence available since systematic review publication.

Analyses included Cohen's Kappa; percentage agreement; intra-class correlation coefficient (ICC; Model 2,1) representing relative agreement; and limits of agreement, representing absolute agreement. This analysis occurred between the research therapist and each treating therapist and between the research therapist and all therapists, combined. A sample size of 100 patients and 4 treating occupational therapists in addition to the research therapist was calculated as sufficient to demonstrate an ICC of .90 for the total score with standard error set at 0.25. Patient participants are described in Table 3.1.

Overall findings from this study included absolute agreement for PC-PART total scores between the researcher and all therapists (limits of agreement = -1.3, 0.5), and individual therapists (limits of agreement = -9.6, 8.2). Absolute agreement for PC-PART domain scores between the researcher and all therapists showed narrow limits of agreement for all domains, centred around zero (range -0.5, 0.6). Absolute agreement for PC-PART domain scores between the researcher and individual therapists displayed wider limits of agreement. In contrast, overall relative agreement for total PC-PART scores was high (ICC=.91) with good to very good agreement (ICC>.77) for PC-PART domains, except residence for which agreement was poor (ICC=.38). Inter-rater agreement for individual items was moderate to good with 31 of the 43 items achieving >85% agreement. Kappa statistics could not be calculated for some items due to lack of variability in scores across the sample.

The study also evaluated clinical utility from the perspective of the time taken to administer the PC-PART. The instrument took a mean of 26.5 minutes to complete (*SD*=10.96). Although this is useful information, a comprehensive evaluation of clinical

utility was not undertaken. Therefore, a separate clinical utility table was not completed for this additional information.

This additional inter-rater reliability study suggested that the PC-PART in its current form has adequate reliability for use with aggregate data from individual patients. Although group-level reliability was high, inter-rater reliability for evaluating individual patients was relatively low. Applying the quality criteria used in the systematic review (Terwee et al., 2007), a positive rating has been assigned for agreement and inter-rater reliability, supporting the PC-PART's use in rehabilitation settings when aggregate data are needed, but not for use with individual patient data (see Table 3.3). It would be useful to gain insight about influences on the instrument's relatively low reliability when used with individuals so that these may be addressed in future revisions of the instrument.

Table 3.3. Updated quality ratings for the PC-PART using criteria provided by Terwee et al. (2007) including evidence available since publication (shaded).

•		,			
Measurement Property	Minimum quality standards provided by Terwee et al. (2007)	No. of studies found.	Study providing evidence	Quality rating individual studies	Overall quality rating
Content Validity	+ Clear description of measurement aim, target population, concepts that were being measured, item selection AND target population and (investigators or experts) involved in the item selection; ? Clear description of above-mentioned aspects is lacking OR only target population involved OR doubtful design/method; - No target population involvement.	8	1. Darzins <i>et al.</i> (2002) 2. Vertesi <i>et al.</i> (2000) 3. Barbara & Whiteford (2005)	+ + +	+
Internal Consistency	+ Factor analyses performed on adequate sample size (7*#items and ≥100) AND Chronbach's alpha calculated per dimension AND Chronbach's alpha between 0.7 and 0.95; ? No factor analysis OR doubtful design or method; — Chronbach's alpha <0.70 or >0.95, despite adequate design and method.	$0_{ m e}$	No evidence found.	0	0
Criterion Validity	+ Convincing arguments that gold standard is "gold" AND correlation with gold standard ≥ 0.70; ? No convincing arguments gold standard is "gold" OR doubtful design/method; - Correlation with gold standard <0.70 despite adequate design and method.	0	Concurrent: No evidence found Predictive: No evidence found	0	0
Construct Validity (Hypothesis testing)	+ Specific hypotheses formulated AND at least 75% of results in accordance with set hypotheses; ? Doubtful design or method (eg no hypotheses); - Less than 75% of hypotheses confirmed, despite adequate design and methods.	2	1. Smith et al. (2001) 2. Darzins et al. (2002)	<i>i</i>	ė
Reproducibility	Agreement:  + MIC< SDC or MIC outside the LOA OR convincing arguments that agreement is acceptable; ? Doubtful design or method OR (MIC not defined AND no convincing arguments that agreement is acceptable);  - MIC_SDC OR MIC = or inside LOA, despite adequate design and method.  + ICC or weighted Kappa ≥ 0.70; ? Doubtful design or method (e.g. time interval not mentioned); - ICC or weighted Kappa < 0.70 despite adequate design and method.	ф 4	1.Darzins et al. (2002) (Agreement, Reliability) 2. Taylor et al. (1998) (Agreement, Reliability) 3. Turner et al. (2009) (Agreement, Reliability) 4. Radia-George et al. (2014) (Agreement, Reliability)	0, ? 0, + 7, ? +, +	c+ +
Responsiveness	+ SDC or SDC< MIC OR MIC outside LOA OR RR > 1.96 OR AUC ≥ 0.70; ? Doubtful design or method; - SDC or SDC≥MIC OR MIC = or inside LOA OR RR≤1.96 OR AUC<0.70, despite adequate design and methods.	2	1. Smith et al. (2001) 2. Darzins et al. (2002)	? ?	ċ
Floor and Ceiling effects	+ ≤ 15% of respondents achieved highest or lowest possible scores; ? Doubtful design or method; −> 15% of respondents achieved highest or lowest possible scores despite adequate design and methods.	0	No evidence found	0	0
Interpretability	+ Mean and SD scores presented of at least four relevant subgroups of patients and MIC defined; ? Doubtful design or method OR less than four subgroups OR no MIC defined.	0	No evidence found	0	0

<sup>a</sup>0= No information found MIC= Minimal Important Change; SDC=Smallest Detectable Change; LOA= Limits of Agreement; ICC= Intra-class Correlation Coefficient; RR=Relative Risk; AUC=Area under the Curve

## **Specific Research Objectives**

As stated in chapter 2, the broad purpose of the research presented in this thesis was to develop a body of evidence about the measurement properties and clinical utility of the PC-PART for use with inpatient rehabilitation service-users. This systematic review achieved the first broad research objective for this body of research. The second broad research objective was to design and conduct a series of studies to investigate the measurement properties and clinical utility of the PC-PART for use with inpatient rehabilitation service-users. To accomplish this second broad research objective, specific research objectives for the remaining studies were needed.

Evidence from the systematic review highlighted areas where further research was required to investigate the PC-PART's measurement properties and clinical utility to establish its value as a measure of participation restrictions in ADL required for community life. Of note, evidence from the updated systematic review supported adequate reliability for use of the PC-PART with grouped data in a rehabilitation setting. Priorities for further PC-PART validation and clinical utility research, which were evident from identified gaps in existing research, were investigation of its structural validity, construct validity, criterion validity, responsiveness and clinical utility for specific practice contexts. It was also identified that evidence was required to explore the PC-PART's measurement construct as a measure of participation restrictions. This is central to the purpose of the PC-PART instrument. Linking of the PC-PART's content to ICF categories had not previously been completed. It was considered this would provide additional information about the PC-PART's content,

relative to the international, standardised language of the ICF, and would illuminate the domains covered by the PC-PART.

When this doctoral research commenced, the PC-PART was being used as a secondary outcome measure in a large randomised controlled trial (RCT), funded by the Australian National Health and Medical Research Council (N. F. Taylor et al., 2010). The trial recruited 996 participants from the inpatient rehabilitation department of a large publicly funded health service in Melbourne, Australia, to investigate the impact of additional allied health services on rehabilitation length of stay and patient outcomes. Occupational therapists working across two settings involved in the trial were asked to complete the PC-PART with RCT participants both at admission and again just prior to discharge, as part of the data collection procedures for the trial. Data were collected between July 2010 and January, 2012. Access to the RCT data for secondary data analysis, enabled several objectives of this doctoral research to be achieved (see Appendix E for the relevant ethics clearance letters). As the validation studies for this thesis used existing data, development of specific research objectives were limited to the scope possible within the methods used to collect the data, and the nature and limits of the available data. The opportunity also arose to invite occupational therapists who had used the PC-PART to gather data for the RCT, to participate in a study about their perceptions of the instrument.

Consideration was given to the gaps identified in existing evidence about the measurement properties and clinical utility of the PC-PART, the ongoing reliability study, and the opportunity to gain access to a large inpatient rehabilitation data set including individual PC-PART item data, when developing the specific research

objectives for this body of doctoral research. The specific research objectives, listed in the sequence in which their corresponding study is presented in this thesis, were to:

- Investigate the theoretical concept and measurement of participation restriction, as measured by the PC-PART through:
  - a. Linking content of the PC-PART to ICF categories to identify ICF components and domains covered by the PC-PART;
  - b. Comparing the scale properties of the PC-PART to those of an accepted measure of activity limitation;
- 2. Explore occupational therapists' perceptions of the clinical utility of the PC-PART when used in an in-patient rehabilitation context;
- 3. Evaluate the internal construct validity of the PC-PART;
- 4. Use hypothesis testing to evaluate construct validity, criterion validity and responsiveness of the PC-PART for inpatient rehabilitation.

## **Chapter 3 - Conclusions**

The published systematic review and subsequent update elucidated known available evidence about the PC-PART's measurement properties and clinical utility for specific clinical settings. Gaps in evidence were highlighted, particularly in relation to validity, responsiveness and clinical utility of the PC-PART. To address these knowledge gaps, specific research objectives for this body of research were listed in the order in which they are addressed by separate studies in this thesis.

#### **Chapter 4. Measurement Construct of the PC-PART**

#### Introduction

The first specific research objective identified for this body of research was to investigate the theoretical concept and measurement of participation restriction, as measured by the PC-PART. This was undertaken through (1) linking content of the PC-PART to ICF categories to identify ICF components and domains covered by the PC-PART, and (2) comparing the scale properties of the PC-PART to those of an accepted measure of activity limitation. The paper presented in this chapter describes research addressing this objective. The FIM<sup>TM</sup>, known as a measure of activity limitations (Uniform Data Systems for Medical Rehabilitation, 2014), was used as the comparison instrument. The following manuscript, Paper 2, has been submitted for peer-reviewed publication. Following the manuscript is a short conclusion, connecting the contribution of this paper to the overall objectives of the thesis.

## Paper 2: Investigation of activity limitation and participation restriction constructs

Darzins, S., Imms, C., Di Stefano, M. (under review). Measurement of activity limitations and participation restrictions: Examination of ICF-linked content and scale properties of the PC-PART and FIM<sup>TM</sup> instruments, *Disability & Rehabilitation*, SciMago Journal Rank: Q1 (Medicine); SJR: 0.88; Journal Impact Factor 2013: 1.837; 5-Year Impact Factor: 1.973

## Measurement of activity limitations and participation restrictions:

# Examination of ICF-linked content and scale properties of the $\mbox{FIM}^{\mbox{\scriptsize TM}}$ and PC-PART instruments.

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*Key Words*: International Classification of Functioning Disability and Health, ICF, Content Validity, PC-PART, Activities of Daily Living, Measurement, Linking studies.

#### **Abstract**

*Purpose:* To explore the operationalization of activity and participation-related measurement constructs through comparison of item phrasing, item response categories and scoring (scale properties) for two separate instruments targeting activities of daily living.

*Method:* Personal Care Participation Assessment and Resource Tool (PC-PART) item content was linked to ICF categories using established linking rules. Previously reported ICF-linked FIM<sup>TM</sup> content categories and ICF-linked PC-PART content categories were compared to identify common ICF categories between the instruments. Scale properties of both instruments were compared using a patient scenario to explore the instruments' separate measurement constructs.

*Results:* The PC-PART and FIM<sup>TM</sup> shared 15 of the 53 level two ICF-linked categories identified across both instruments. Examination of the instruments' scale properties for items with overlapping ICF content, and exploration through a patient scenario, provided supportive evidence that the instruments measure different constructs.

Conclusions: While the PC-PART and FIM<sup>TM</sup> share common ICF-linked content, they measure separate constructs. Measurement construct was influenced by the instruments' scale properties. The FIM<sup>TM</sup> was observed to measure activity limitations and the PC-PART measured participation restrictions. Scrutiny of instruments' scale properties in addition to item content is critical in the operationalization of activity and participation-related measurement constructs.

#### Introduction

The Personal Care Participation Assessment and Resource Tool (PC-PART)<sup>1</sup>, formerly the Handicap Assessment and Resource Tool (HART)<sup>2</sup>, was developed to identify people's unmet needs in accomplishing activities of daily living (ADL) required for community life. Unmet needs are those that persist in people's living environments despite their own efforts, use of assistive devices and available supports or assistance from others. These unmet needs are termed ADL participation restrictions<sup>1</sup>. This type of information is helpful to health care teams when making decisions about people's admission or discharge from health care settings<sup>3</sup>. The PC-PART has been used in acute hospitals, sub-acute inpatient, rehabilitation inpatient, and community settings<sup>2,4-9</sup>. Evidence supports the PC-PART's content validity for clinical use, and there are encouraging results for clinical utility, construct validity and reliability in acute and subacute inpatient health care settings<sup>10-12</sup>.

The HART was developed in 1994<sup>2</sup>. The aim of the instrument was to correspond conceptually to the measurement of handicap within the framework of the International Classification of Impairment, Disability and Handicap (ICIDH)<sup>13</sup>. With the introduction of the International Classification of Functioning, Disability and Health (ICF) in 2001, the HART was renamed the Personal Care Participation Assessment and Resource Tool (PC-PART)<sup>1</sup>, to coincide with the newer ICF terminology. In the ICF, the term *participation restriction* replaced the term *handicap*, and is defined as "problems an individual may experience in involvement in life situations" (p10)<sup>14</sup>. The PC-PART remained essentially unchanged from the HART, except for changes to its presentation, layout and small adjustments to phrasing of some items<sup>1</sup>.

The biopsychosocial conceptual framework and terminology of the ICF has enabled an international standard classification system and language, across health disciplines and departments, for understanding and communicating individuals' health, functioning and disability<sup>14</sup>. Examination of discipline-specific concepts and domains of practice using ICF concepts and language may allow explicit identification and reporting of practice domains and treatment outcomes that can be communicated across professions<sup>15-19</sup>. The universal language of the ICF potentially enables scholarly and professional communication about broad aspects of disability and health, across disciplines, organisations, governments and nations<sup>20</sup>. Interdisciplinary research and improved clinical care, health policy and management may then be stimulated<sup>15,20</sup>.

The ICF classifies human functioning in the presence of a health condition, at different levels. The levels include body functions and structures, activities (individual), and participation (society). The ability of individuals to function is presented as a dynamic interaction between elements of these domains and is influenced by contextual factors including environmental and personal factors<sup>14</sup>. The ICF<sup>14</sup> defines activity as "the execution of a task or action by an individual" (p. 14) and participation as "involvement in a life situation" (p.14). The ICF suggests that the activities and participation component of the classification system can be used to denote activities, participation, or both and suggests four options for making this distinction: 1) divide activity and participation domains and do not allow for any overlap; 2) allow for partial overlap between activity and participation domains; 3) operationalize participation as broad categories within the domains and activity as the more detailed categories, with either partial or no overlap; and 4) allow for complete overlap in the domains considered to be activity and participation<sup>14</sup>.

To enable the ICF classification system to capture descriptive information about functioning and disability in each domain of the *activities* and *participation* component, the ICF advocated use of *capacity* and *performance* qualifiers<sup>14</sup>. The *capacity* qualifier "describes an individual's abilities to execute a task or an action.... to indicate the highest probable level of functioning that a person may reach in a given domain at a given moment" <sup>14</sup>(p. 15). This qualifier may be used to indicate *activity limitations*. The *performance* qualifier "describes what an individual does in his or her current environment" <sup>14</sup>(p. 15). This qualifier may be used to indicate *participation restrictions*. The gap between *capacity* and *performance* reflects the influence of environments and personal factors on performance. Within the ICF it is suggested that because individuals' environments include a societal context, *performance* could also be understood as 'involvement in a life situation <sup>14</sup>.

The only possible indicator of participation within the activities and participation component of the ICF is attained through coding the performance qualifier<sup>14</sup>. Use of the performance qualifier within the ICF taps an objective 'doing' aspect of participation/performance. However, 'participation' should not automatically be equated with 'performance' Participation has an additional subjective component, such as the person's sense, or feeling of involvement, inclusion or engagement in life situations, which is not captured when measuring 'performance' alone <sup>14,21-23</sup>.

Definitions for activity and participation concepts and guidelines for their operationalization provided by the ICF are ambiguous<sup>22-26</sup>. Consensus has not yet been reached on a definition for, and methods to operationalize the participation construct<sup>24</sup>, or how to distinguish activity from participation<sup>22,23,27-31</sup>. Although this ambiguity and

lack of consensus has made operationalization and measurement of the participation concept challenging, participation-related outcomes for health care service-users are considered central to health care <sup>24,32,33</sup>. To manage the ambiguity in the operationalization of participation-related constructs, one convention for researchers has been to present their own interpretation and rationale<sup>22</sup>.

Development of linking rules by Cieza et al. <sup>34,35</sup> has provided a standardised procedure to link the meaningful concepts contained within outcome measures to their corresponding ICF categories. This method has primarily been used for content comparison and analysis of different measures, such as quality of life and functional outcome measures<sup>36</sup>. Measures developed prior to establishment of the ICF have also been linked to establish their content validity in accordance with the ICF <sup>17</sup>. By linking meaningful concepts contained within the PC-PART to ICF categories, it is possible to establish the extent to which PC-PART content is reflected in the ICF framework.

To achieve useful measurement of the effects of health interventions it is essential for health care providers and researchers to select outcome instruments that accurately measure the specific intended outcomes of such interventions <sup>33,37</sup>. Some researchers have used the ICF-linked content of various measures to determine whether instruments of interest measure activity or participation-related constructs <sup>22,26,38-40</sup>. However, one view is that examining instruments' content provides only some of the required information about the constructs they measure. Knowing an instruments' ICF-linked content is useful for selecting measures that target outcomes clinicians and researchers seek. However, distinguishing activity from participation-related measures requires observation and examination of instruments' item phrasing, response categories

and scoring (together, named *scale properties* in this paper) to differentiate the construct measured <sup>41-43</sup>. We assert that it is primarily instruments' scale properties, rather than item content, that differentiates the construct being measured.

The aim of this present study was to determine whether a distinction could be made between measurement of activity limitations and participation restrictions by examining and comparing the PC-PART and FIM instruments' ICF-linked content, their respective scale properties and clinical interpretation of scores. Such a distinction may advance understanding about one aspect in the differentiation between activity and participation-related outcomes.

Several basic personal and instrumental activities of daily living instruments could have been used as comparison instruments to the PC-PART in this study. Potential instruments vary in their length, the extent of their coverage of activities of daily living (ADL), their intentions for use with patients from specific impairment groups and their use by different health professionals. The FIM<sup>44</sup> was chosen as a comparison assessment for the PC-PART in this study because it is reported as an assessment of activity limitations and need for assistance (burden of care) in basic life activities<sup>45</sup>, as opposed to the measurement of participation restrictions, intended by the PC-PART. The FIM has well documented measurement properties<sup>46</sup>, and it is well known and widely used in rehabilitation settings worldwide<sup>46,47</sup>. The FIM is also mandated for use in subacute health settings as part of activity-based funding models in Australia<sup>48</sup>. At face value, the FIM and PC-PART appear different as the FIM covers motor and cognitive personal ADL tasks and the PC-PART covers broader personal and

instrumental ADL tasks. However, for this study, it was necessary to explore the distinctions between the instruments' scale properties in their commonly shared content.

#### Methods

This descriptive study involved five stages. First, meaningful concepts from the PC-PART were linked to the ICF using established linking rules<sup>34,35</sup>. Second, peer-reviewed literature was searched to identify existing studies linking FIM content to the ICF. Third, ICF-linked PC-PART and FIM categories were compared to confirm overlapping content between the instruments. Fourth, the scale properties of both instruments were examined to identify the nature of the information gathered by items with overlapping content. Lastly, application of both instruments to a patient scenario was used to further explore interpretation of the instruments' scores and their measurement constructs. The patient scenario and instrument scores were prepared by an experienced geriatrician and a rehabilitation clinician who were independent to this study and who practised at a large metropolitan publicly funded hospital in Melbourne, Australia. The clinicians were familiar with operationalization of both instruments and were asked to provide instrument scores and patient characteristics that were typical of patients in their rehabilitation wards.

## **Instruments**

## PC-PART

The PC-PART has 43 items covering seven domains: clothing, hygiene, nutrition, mobility, safety, residence, and supports. Item responses are *OK by self* (patients manage activity alone with or without aids in their living environments), *OK with help* 

(patients manage activity with help from others in their living environments), or *Not OK* (patients do not manage the activity in their living environments despite their own efforts, use of aids and use of available support from others). Both OK by self and OK with help are scored 0 (no participation restriction present), and Not OK is scored 1 (participation restriction is present). Each Not OK represents an ADL participation restriction. The total PC-PART score is the frequency of Not OKs, with a possible score of 0 (no participation restrictions) to 43 (the most participation restrictions possible for this instrument). The PC-PART is typically completed by an occupational therapist using a structured interview format and structured observations if needed. It includes input from both the patient and a key informant if needed. A key informant is usually a carer, family member or paid carer (see Appendix B for example items). In clinical settings where it may not be possible to observe patients in their living environments, the identified presence or absence of participation restrictions arising from completion of the PC-PART constitute reasoned judgements about patients' expected functioning in their living environments. These judgements are based on discussions with the patient and their key informants, clinically based observations of patients' abilities, as well as clinicians' knowledge and previous experience.

#### **FIM**

The FIM consists of 18 items from motor (13 items) and cognitive (5 items) domains. These include performance in self-care, sphincter control, mobility, communication, social interaction, problem solving and memory. Each FIM item is rated on a 7-point scale, where 1 represents complete dependence and the need for total

assistance and 7 represents complete independence. Scores range from 18 (complete dependence on all items) to 126 (complete independence on all items)<sup>45</sup>.

#### Literature search

Medline and CINAHL databases were searched to locate studies linking FIM content to the ICF. Search terms included *Functional Independence Measure*, *FIM* or *ICF* in the title, abstract or text, and *link\* to the ICF* in the paper's text. Only papers reporting on studies linking meaningful concepts from the FIM instrument to ICF categories at level 2 or 3 were included; using established linking rules (discussed below); and papers where it was possible to specifically identify FIM-linked ICF categories in studies where several instruments were linked to the ICF. All other papers were excluded.

## Linking procedures

#### PC-PART

Two researchers independently linked categories from the ICF to meaningful concepts contained within individual PC-PART items, according to published linking rules<sup>34,35</sup>. ICF categories were assigned to the third level, where possible. Items not specifically meeting level three descriptions were coded at level two. Percentage agreement between researchers' assigned codes was calculated. Disagreements were resolved through discussion between the two researchers. A third independent researcher arbitrated the final decision if disagreement persisted. The agreed ICF-linked PC-PART data were also summarised at the second ICF category level to enable comparison to the ICF-linked FIM data.

#### **FIM**

The ICF-linked FIM content was extracted from the identified studies. As it was possible that the FIM would be linked differently in separate studies, decision rules were established to enable the authors to agree on a common set of ICF-linked categories for the FIM. These rules were: (1) if the majority of studies identified the same ICF-linked category, this category was accepted, and (2) if the minority of studies identified an ICF-linked category for a specific FIM meaningful concept, two researchers from the present study independently linked this FIM concept to the ICF, using the updated ICF linking rules<sup>34,35</sup>, the ICF<sup>14</sup>, and the FIM training manual as reference materials<sup>45</sup>. Disagreements were resolved through discussion between the two researchers. A third researcher arbitrated the final decision if disagreement persisted.

#### Comparisons between PC-PART and FIM

Comparison of level two ICF-linked PC-PART and FIM categories was used to identify common content between the PC-PART and the FIM instruments. Next, scale properties of each instrument were examined to identify the nature of their respective item phrasing, item response categories and scoring. Then, a patient scenario was constructed (see methods), to reflect commonly observed clinical problems encountered by patients in an inpatient rehabilitation setting. The scenario was used to examine the type of information provided by each instrument. Finally, the instruments' scale properties and clinical information derived from each instrument were examined to explore differences in the constructs measured by each instrument.

#### Findings/Results

## Linking PC-PART to the ICF

A total of 77 meaningful concepts were identified from the 43 PC-PART items. Seventy three of these meaningful concepts (96%) linked to both level 2 and 3 ICF unique categories and are shown in Table 1 (part A), as follows: body functions (12 categories); activities and participation (46 categories); and environmental factors (15 categories). Four concepts (4%) could not be linked to the ICF. Forty seven level 2 ICF categories were identified: body functions (8 categories); activities and participation (25 categories); and environmental factors (14 categories). The percentage agreement between independent researchers on ICF-linked categories for each *PC-PART item* was 93% (indicating agreement on at least one ICF category for each PC-PART item, at least to level 2, or agreement on a 'not classified' rating). The percentage agreement between independent researchers on ICF-linked categories for identified *meaningful concepts* within the PC-PART items was 84% (indicating agreement on at least one ICF category for each meaningful concept, at least to level 2, or agreement on a 'not classified' concept rating). In both cases, 100% agreement was reached through discussion with a third independent researcher.

Table 1. Summary of linked PC-PART and FIM<sup>TM</sup> content to ICF categories (Part A and B), with comparison between the instruments (Part C). Shaded rows denote common ICF-linked content between PC-PART and FIM<sup>TM</sup> instruments.

Part A:	Fart A: ICF categories linked to PC-PART content (to level 2&3, then level 2 categories)	ntent (to level 2&	3, then leve	2 categories)		Part B: S linking F 2 ICF cat	Part B: Summary of studies linking FIM <sup>TM</sup> to ICF (to level 2 ICF categories) <sup>a</sup>	tudies (to level	Part C: Comparison of PC-PART & FIM <sup>TM</sup> ICF linked content (at category level 2)	mparison T & T linked category
ICF category level 2 and 3	Label	No. times PC-PART concept linked up to level 3 category	ICF category level 2 only	Label	No. times PC-PART concept linked to level 2 category	Grill et al. 2006 [51]	Schepers et al. 2007 [50]	Laxe et al. 2012 [49]	Agreed ICF- linked FIM <sup>TM</sup> content <sup>b</sup>	PC- PART content
Body Functions           b114         Orie           b1140         Orie           b1141         Orie           b1142         Orie	Orientation to time Orientation to time Orientation to place Orientation to place	- 2 2 -	b114	Orientation functions	9					Y
b1266	Confidence	. 0	b126	Temperament and personality functions	7					*
b144 b164 b1641	Memory functions Higher level cognitive functions (about food restrictions; about cooking hazards; about food safety; awareness/knowledge of risks associated with smoking) Organisation and planning	4 0 –	b144 b164	Memory functions Higher level cognitive functions	4 01	<b>&gt;</b>	<b>&gt;</b>	<b>&gt;</b>	<b>&gt;</b> -	> >
b5105 b5253 b530 b6202	Swallowing Faecal continence Weight maintenance functions		b510 b525 b530 b620	Ingestion functions Defecation functions Weight maintenance functions Urination functions		z > >	z > >	>> z	>> >	>>>>
Activitie d1	Activities and Participation  d1 Learning and applying knowledge	1		CITIZENDI TERROTORIO	4	z	z		Z	
d175 d179	Applying knowledge (solving problems – sources of assistance) Applying knowledge nec (food	7 7	d175	Applying knowledge Applying knowledge nec (food	1 2	Y	<b>X</b>	Y	Y	<b>&gt; &gt;</b>
d2302	restrictions; personal details) Completing daily routine (washing clothes)	ı —	d230	restrictions; personal details) Carrying out daily routine	ı —	<b>*</b>	Z	Z	Z	· >
d240 d2400 d2401 d2402	Handling stress and other Handling responsibilities Handling stress Handling crisis		d240	Handling stress and other	4					<b>&gt;</b>
d310 d315	Communicating with-receiving verbal messages Communicating with – receiving nonverbal messages					<b>&gt; &gt;</b>	z z	× ×	<b>&gt; &gt;</b>	
d329	Communicating receiving other spec/unspec					Z	Y	Z	Z	

d330	Speaking					Y	z	Υ	Y	
d335	Producing non-verbal messages					Y		Y	Y	
d349	Communicating producing other					z	Y	Z	Z	
	sbec/unspec									
d410	Changing basic body position	2	d410	Changing basic body position	2	Y	Y	Y	Y	<b>\</b>
	(getting in/out of bath or shower; in/out bed)									
d420	Transferring oneself					Y	X	>	X	
d429	Changing and maintaining body					z	Y	Z	Z	
	position other spec/unspec									
d450	Walking	1	d450	Walking	_	Υ	Y	Y	¥	Y
d4551	Climbing	1	d455	Moving around		Y	Y	Y	Y	Y
d460	Moving around in different locations	_	d460	Moving around in different locations	9					Y
d4600	Moving around within the home									
d4601	Moving around within buildings	_								
	other than home									
d4602	Moving around outside the home and other buildings	3								
d465	Moving around using equipment	2	d465	Moving around using	2	Y	Y	Y	Y	Y
				equipment						
d470	Using transportation	2	d470	Using transportation	2					Y
d475	Driving	2	d475	Driving	3					Y
d4751	Driving motorised vehicles	1								
d5100	Washing body parts (hair, body)	2	d510	Washing oneself	4	Y	Y	Y	Y	Y
d5101	Washing whole body	1								
d5102	Drying oneself									
d5201	Caring for teeth	_	d520	Caring for body parts	2	Y	Y	Y	Y	Y
d5202	Caring for hair	_								
d5300	Regulating urination (includes all aspects of task)	2	d530	Toileting	4	7	<b>&gt;</b>	Y	Y	Y
d5301	Regulating defecation (includes all									
	aspects of task)									
d5302	Menstrual care	1								
d5400	Putting on clothes	2	d540	Dressing	7	Y	Y	Y	Y	Y
d5401	Taking off clothes	2								
d5402	Putting on footwear									
d5403	Taking off footwear	1								
d5404	Choosing appropriate clothing	1								
d550	Eating		d550	Eating		> ;	<b>&gt;</b> ;	<b>&gt;</b> ;	<b>&gt;</b> :	<b>&gt;</b> :
d560	Drinking	1	d560	Drinking		Υ .	Z	Y	Y	Y
d5700	Ensuring one's physical comfort	1	d570	Looking after one's health	5					Y

Part A: I(	rari A.: 1CF categories illiked to FC-FAR1 colltent (to tevel 2&5), then tevel 2 categories)	itent (to level 28	c3, then level	2 categories)		Part B: Summary linking FIM <sup>TM</sup> to I 2 ICF categories) <sup>a</sup>	Part B: Summary of studies linking FIM <sup>TM</sup> to ICF (to level 2 ICF categories) <sup>a</sup>	udies (to level	Part C: Comparison of PC-PART & FIM TM ICF linked content (at category level 2)	omparis RT & F linked t categoi
ICF category level 2 and 3	Label	No. times PC-PART concept linked up to level 3 category	ICF category level 2 only	Label	No. times PC-PART concept linked to level 2 category	Grill et al. 2006 [51]	Schepers et al. 2007 [50]	Laxe et al. 2012 [49]	Agreed ICF- linked FIM <sup>TM</sup> content <sup>b</sup>	PC- PART content
d5702	Maintaining ones health (prevent ill health; taking medication; avoid alcohol/substance abuse)	4								
d620	Acquisition of goods and services (meals)	-	d620	Acquisition of goods and services	5	Z	Z	Y	Z	×
d6200 d6201	Shopping Gathering daily necessities	2 2								
d6300	Preparing simple meals (includes	2	d630	Preparing meals	4					Y
d6301	Preparing complex meals (includes plan & organise)	2								
d6400	Washing and drying clothes/garments	-	d640	Doing housework	2					7
d6403	Using household appliances	1								
d650 d710	Caring for household objects Basic interpersonal interactions		d650	Caring for household objects	_	Y	Z	Y	Y	<b>&gt;</b>
d729	General interpersonal interactions, other specified and unspecified					Z	*	z	z	
098p	Basic economic transactions	1	098p	Basic economic transactions	1					Y
d865	Complex economic transactions	-	d865	Complex economic transactions	1					Y
d8700	Personal economic resources	1	d870	Economic self-sufficiency	1					Y
Environm	Environmental Factors									
e1100	Food (alcohol)	-	e110	Products or substances for personal consumption	3					X
e1101	Drugs	2		1						
e115	Products and technology for personal	_	e115	Products and technology for	1					Y
e155	Design, construction and building	2	e155	Design, construction and	2					Υ

	for private use			technology of buildings for		
				private use		
e310	Immediate family	з	e310	Immediate family	3	Y
e315	Extended family	Э	e315	Extended family	3	Y
e320	Friends	3	e320	Friends	3	Y
e325	Acquaintances, peers, colleagues,	3	e325	Acquaintances, peers,	3	Y
	neighbours and community members			colleagues, neighbours and		
				community members		
e330	People in positions of authority	2	e330	People in positions of authority	2	Y
e335	People in subordinate positions	2	e335	People in subordinate positions	2	Y
e340	Personal care providers and personal	2	e340	Personal care providers and	2	¥
	assistants			personal assistants		
e355	Health professionals	2	e355	Health professionals	2	Y
e360	Other professionals	-	e360	Other professionals		Y
e5450	Civil protection services	_	e545	Civil protection services,		Y
				systems and policies		
e5800	Health services	-	e580	Health systems, services and		Υ
Not	Avoid burning pots, counter or self	-			1	
covered						
	Avoid falls	1			-	
	Safe driving	1				
	Repeated use of emergency help	1				

<sup>a</sup>Y indicates concept rated as present; N indicates concept rated as not present.

<sup>b</sup>After application of these decision rules: (1) if at least two of the studies identified the same ICF category, this category was accepted; (2) if only one study identified a particular ICF category for a specific FIM meaningful concept, two researchers from the present study independently linked this FIM<sup>TM</sup> concept to the ICF, using the updated ICF linking rules, the ICF, and the FIM<sup>TM</sup> training manual as reference materials. Disagreements were resolved through discussion between the two researchers. A third researcher arbitrated the final decision if disagreement persisted.

## Linking FIM<sup>TM</sup> to ICF.

Of the 62 papers identified in the literature search, three met the inclusion criteria by linking FIM content to level 2 ICF categories<sup>49-51</sup>. No retrieved studies linked FIM content to level 3 ICF categories. Reference list searches of the three identified papers did not reveal any further studies linking FIM content to the ICF. The three identified studies reported variations in their assigned ICF categories, shown in Table 1, Part B. All three studies reported that if an item contained more than one meaningful concept, each concept was linked to the ICF. All studies aimed to specify the most precise ICF category for each concept at the second level of the classification. Two studies<sup>50,51</sup> used the 2002 published linking rules<sup>34</sup> and used two independent raters to perform the linking. A third rater arbitrated persistent disagreement between the raters. One study<sup>49</sup> used the updated 2005 linking rules<sup>35</sup> and two independent raters, who were trained how to conduct ICF linking at the ICF Research Branch in Munich, Germany. Two of the three studies reported Kappa measures of agreement between raters. Grill et al.<sup>51</sup> achieved a Kappa statistic of 0.90 (95%CI 0.71,1.0) and Laxe et al. 49 achieved a Kappa statistic of 0.83 (95%CI 0.77, 0.83), although this was a combined value which included linking to ICF categories for additional instruments. Table 1, Part C, column one, displays the agreed ICF-linked FIM content for the 21 meaningful concepts contained within the FIM in this present study: body functions (4 categories) and activities and participation (17 categories).

#### **Comparisons between PC-PART and FIM**

The PC-PART and FIM shared 15 of the 53 combined level two ICF-linked categories across both instruments: body functions (4 categories); activity and participation (11 categories); and environmental factors (0 categories), as displayed in Table 1, Part C, and highlighted by the shaded areas. Overlap in the activities and participation domains occurred across the following ICF chapters: learning and applying knowledge (1 category); mobility (4 categories); and self care (6 categories).

Two ICF categories that contained overlapping PC-PART and FIM content, are used as examples in Table 2, to display specific instrument scale properties including: item phrasing, response categories, and scoring. The PC-PART and FIM instruments demonstrated different procedural formats, item phrasing, response formats, categories and scoring. Differences between the instruments' scale properties and their clinical interpretation of scores were observed.

Table 2. Examples of PC-PART and FIM<sup>TM</sup> items with overlapping ICF-linked content: Item phrasing and procedures; response categories and corresponding scores.

	Instruments' item phrasing and procedures.			
ovorlopping ICE			control of the contro	
overlapping ICF- linked categories b/w PC-PART &			categories and corresponding scores.	
FIM.				
	PC-PART [1]	$FIM^{IM}$ [45]	PC-PART	$\mathbf{FIM}^{\mathrm{LM}}$
d410-Changing	Item B8: Bath transfers:	Item K: Transfers (bath/shower):	OK by self = 0.	No helper:
basic body	Ask patient: Do you get in/out of the shower/bath?	Observation includes getting into and out of bath or	Patient manages	Complete independence $= 7$ .
position	Ask key informant: Doesget in/out of the shower/bath?	shower.	activity alone with	No help, no devices, safely and
•	Standardised task: Get in/out of shower/bath.		or without aids in	timely;
	Item D2: Bed:	Item I: Transfers (bed/chair/wheelchair):	his/her living	Modified independence $= 6$ .
	Ask patient: Do you get in/out of bed?	Observation includes all aspects of transferring to	environment;	Assistive device, safely or
	Ask key informant: Doesget in/out of bed?	and from bed, chair, and wheelchair, or coming to	OK with $help = 0$ .	timeliness issues;
	Standardised task: Observe patient get in/out of bed.	standing position, if walking is typical mode of	Patient manages	Helper:
		locomotion.	activity with help	Supervision = 5.
d540-Dressing	Item A1: Dressing top	Item D: Dressing – upper body:	from others, and	Supervision, set-up or standby
	Ask patient: Do you get your top dressed?	Observation includes dressing/undressing above	this help is available	prompting;
	Ask key informant: Doesget his/her top dressed?	waist, and applying/removing prosthesis or orthosis	in his/her living	$Minimal\ contact\ assistance = 4.$
	Standardised task: Observe patient take top off and put	when applicable.	environment;	Patient does 75% or more of
	back on.		Not $OK = 1$ .	effort;
	Item A2: Dressing bottom	Item E: Dressing – lower body:	Patient does not	Moderate contact
	Ask patient: Do you get your pants/skirt on?	Observation includes dressing and undressing from	manage the activity	assistance = 3.
	Ask key informant: Doesget his/her pants/skirt on?	waist down and applying and removing prosthesis	in their living	Patient does 50-74% of effort;
	Standardised task: Observe patient put on pants/skirt.	or orthosis when applicable. Includes applying and	environment despite	Maximum contact
	Item A3: Dressing footwear	removing several pieces of clothing, includes	his/her own efforts,	assistance = 2.
	Ask patient: Do you get your socks, shoes, slippers on?	obtaining clothing from drawers/closet. Includes	use of aids and help	Patient does 25-49% of effort;
	Ask key informant: Doesget his/her socks, shoes,	underpants, slacks or skirt, socks, shoes.	from available	Total assistance $= 1$ .
	slippers on?		support from others.	Patient does less than 25% of
	Standardised task: Observe patient take shoes and socks			effort.
	off and then put back on.			
	Item A4: Dressing – selection appropriate for			
	environment.			
	Ask patient: Do you get dressed appropriately for the			
	weather?			
	Ask key informant: Doesget dressed appropriately for the weather?			
	Standardised task: Discuss what patient wears in			
	different weather conditions.			

#### Scale properties

Item phrasing provides the content of interest in each measure. The PC-PART is administered by questioning the patient and their key informant(s), and provides options for structured patient observation, if needed, to verify the information gathered. In contrast, FIM administration primarily requires structured observations of patient abilities to determine their level of dependence on a helper for completion of the task.

Response categories in the PC-PART are selected (scored) using integrated verbal information from the patient and key informant, observational information, as well as the availability, provision and stability of needed supports (environmental factors). Response categories are dichotomous providing item scores that indicate presence or absence of unmet needs. The FIM scores are chosen on the basis of the need/use of assistive devices and incremental levels of support required from a helper to complete each assessed task across seven levels of dependence. Use of an assistive device by the patient to achieve a task (item) outcome is scored as a level of dependence on the FIM.

#### Clinical interpretation of scores

The patient scenario used for this study is shown in Table 3, and contextualises use of the FIM and PC-PART instruments. It contains clinically relevant biopsychosocial details of the patient as well as FIM and PC-PART admission and discharge scores for the common ICF-linked content. Full admission and discharge PC-PART and FIM scores are provided in Appendix A.

Table 3. Patient scenario contextualising PC-PART and FIM<sup>TM</sup> scores at admission and discharge from inpatient rehabilitation for items with overlapping ICF-linked content.

## PC-PART score was 0. She had no participation restrictions for shower and bed transfers, bathing, mobility, toileting, dressing, and stairs as a personal care attendant Subsequently, she modified her goals so that she could return home. A personal care attendant was arranged to provide showering assistance three times a week. She A hand-shower and slide board for the shower were obtained. At discharge she still required contact supervision with dressing upper and lower body; bed, toilet and shower transfers, and stairs. She required supervision and set-up with bathing, problem-solving and memory operations. At discharge, her FIM<sup>TM</sup> score was 96. The they would manage all other required areas at home (i.e. meal preparation, shopping, laundry, money management, transportation). They hoped that her functioning realised that if her husband was to supervise toileting transfers, and was to help with dressing she could return home, and came to accept this solution. Her husband uneven path, a shower over the bath and a separate toilet. Installation of a handrail at the front steps, and grab bars in the shower, bathroom and toilet was arranged transportation and getting to appointments, money management, and managing her medications was also arranged, resulting in no participation restrictions in these independent. She was transferred to rehabilitation with left hemiparesis, left sided inattention and constructional apraxia. Admission PC-PART assessment showed or her husband provided the needed supports for these tasks. Assistance for managing laundry, meal planning and preparation, acquiring groceries, other shopping, A 73 year old woman admitted to hospital with right middle cerebral artery territory infarction. Before this both she and her husband were in good health and fully was willing and able to provide this assistance and was taught how to assist her with mobility, transfers and dressing. The woman, her husband and family agreed would continue to improve after discharge. Prior to discharge, the occupational therapist assessed her home, and noted three front steps and one rear step with an 24 participation restrictions and the FIM<sup>TM</sup> score was 74 (Appendix A). Scores on both instruments for items with common ICF-linked content are shown below Her inpatient rehabilitation goals were to regain independence in self-care and domestic activities of daily living, but she could not achieve independence. areas. Although she was restricted from driving at discharge, her husband and family agreed to drive her where she wanted and needed to go Patient scenario<sup>a</sup>

MI.	ritem Fitem			Corresponding	. STORE INT	
		a/d <sup>d</sup>	g/c	FIM <sup>TM</sup> item	a/d	d/c
	D9. Orientation: Remember appointments.	0	0	R. Memory	4	\$
	D8. Wandering: Avoid getting lost.	0	0			
	F3. Provide basic personal information.	0	0			
	E1. Manage medications.	0	0			
b510 - Ingestion functions C2. Eat an	C2. Eat and drink without coughing or choking.	0	0	A. Eating	5	9
b525 - Defecation functions B3. Bowel	B3. Bowel control/management.	0	0	H. Bowel management	5	7
b620 - Urination functions B2. Bladd	B2. Bladder control/management.	0	0	G. Bladder management	5	7
d175 - Applying knowledge F3. Provid	F3. Provide basic personal information.	0	0	Q. Problem solving	4	5
	B8. Get in/out of bath or shower.	1	0	K. Bath/shower transfers	3	4
	D2. Get in/out of bed.	1	0	I. Bed/chair transfer	3	4
d450 - Walking D3. Get ar	D3. Get around without falling.	_	0	L. Walking	3	9
d455 - Moving around - stairs D4. Manag	D4. Manage steps/stairs.	1	0	M. Stairs	2	4
	D1. Mobility indoors.		0	L. Walking	3	9
	D5. Mobility outdoors.	_	0			
d510 - Washing oneself B7. Get w	B7. Get washed/dried.		0	C. Bathing	3	5

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Table	222

Common ICF categories	Corresponding	PC-PA	PC-PART score <sup>b</sup> :	Corresponding	$FIM^{TM}$ score <sup>c</sup> :	ore <sup>c</sup> :
between PC-PART & FIM <sup>TM</sup> . PC-PART item	PC-PART item	$a/d^d$	d/ce	$FIM^{TM}$ item	a/d	d/c
d520 - Caring for body parts	B4. Grooming hair.	0	0	B. Grooming	4	9
	B5. Grooming teeth.	0	0			
d530 - Toileting	B1. Use toilet.	1	0	F. Toileting	3	4
d540 - Dressing	A1. Dressing: Top dressed/undressed.	1	0	D. Dress upper body	3	4
	A2. Dressing: Bottom (pants/skirt) on/off.	1	0	E. Dress lower body	3	4
	A3. Dressing: Footwear on/off.	1	0			
d550 - Eating	C2. Eat and drink without coughing or choking.	0	0	A. Eating	5	9
d560 - Drinking	C2. Eat and drink without coughing or choking.	0	0	A. Eating	5	9

<sup>a</sup> Patient scenario was constructed from typical FIM<sup>TM</sup> and PC-PART scores of patients in rehabilitation wards within a large outer metropolitan publicly funded hospital in Melbourne,

Australia.

<sup>b</sup> 0=OK by self or OK with help (no participation restriction); 1=Not OK (participation restriction present).

<sup>c</sup> 1= Total assistance; 2=Maximum contact assistance; 3=Moderate contact assistance; 4=Minimal contact assistance; 5=Supervision; 6=Modified independence; 7=Complete independence.

<sup>d</sup> Admission

<sup>e</sup> Discharge

Examination of the information elicited from both instruments revealed different clinical information arising from items that contained overlapping ICF-linked content. In the clinical setting the PC-PART provided information about what is expected to be accomplished in the patients' living environment and the identification of anticipated unmet needs. The FIM elicited information about the patient's level of independent performance onspecific activities in the clinical setting

Examination and clinical interpretation of change scores on both instruments in areas that contained overlapping ICF-linked content revealed observable and clinically relevant differences between the instruments. At discharge, PC-PART scores indicated no participation restrictions in activities of daily living required for community life for the overlapping content. That is, the participation restrictions experienced at admission (n=11) had been eliminated at discharge from inpatient rehabilitation (n=0) This change in score was brought about by the woman's improved physical functioning during her rehabilitation and success of interventions targeted at providing needed supports in her living environment. The PC-PART score at discharge indicated the woman was expected to be able to return to her living environment without any unmet needs in activities of daily living that she would require for community life. Changes in FIM scores from admission to discharge indicated that the woman had improved in her cognition, mobility, transfers, and basic self care activities during rehabilitation on all 17 items. The scores indicated there were nine areas in which she remained dependent on others for assistance at discharge.

#### Discussion

The patient scenario highlighted differences in the scale properties, score patterns and clinical interpretation of scores for the PC-PART and FIM ICF-linked matching items, between admission and discharge. For items with overlapping content, the two instruments appear to elicit different, but related information. The instruments therefore appear to measure different, but related constructs. At admission, the instruments showed the presence of several activity limitations and participation restrictions. At discharge, FIM scores were higher on all items, and demonstrated some improvement in physical and cognitive functioning, although dependence on a helper for assistance in some activities, remained. This is the primary clinical information that could be derived from the FIM. The PC-PART showed resolution of all participation restrictions at discharge. This arose because of the modifying effect of available supports within the woman's environment, enabling accomplishment of her ADL, and this was integral to PC-PART item scores. The changed PC-PART scores reflected the effects of the interventions applied during inpatient rehabilitation to ensure provision of suitable environmental supports for the woman in her living environment, prior to discharge, to enable her to return there at discharge. Thus, in the case scenario, improvement in the woman's functioning, measured by the FIM alone, provided some of the relevant information about the degree to which the inpatient rehabilitation program as a whole, prepared her to return to her living environment. The PC-PART provided different, yet clinically relevant, information, about the extent of anticipated unmet needs the woman would experience in her living environment. It was use of PC-PART and FIM information, together, that provided more comprehensive measurement of the woman's functioning in activities of daily living required for community life.

When the PC-PART is used in settings where there is no opportunity to observe patients' living environments, judgements need to be made about whether the individual will be able to function in their living environments at discharge. In these situations, it is possible that patients and their key informants may provide inaccurate information or form incorrect judgements about patients' functioning in their living environments. The extent to which these potential errors of judgement occur relates to the ecological validity of the PC-PART and would be a useful area of future research.

In this present study, the FIM and PC-PART's scale properties appeared to elicit differences in the type of information gathered, and consequently, the construct being measured, even for overlapping content between the instruments. Measures eliciting information about an individual's ability, level of difficulty or level of dependence in performing tasks, without inclusion of the modifying effects of the environment in the instrument's scale properties, seem to measure the activity construct. Therefore, the FIM, with scale properties capturing patients' level of dependence and need for assistance, seems to measure the 'problem' dimension of activity: activity limitations. Measures eliciting information about performance of tasks in natural environments and that include influences of the environment on performance in the instrument's scale properties, seem to measure a performance aspect of the participation construct. The PC-PART, with scale properties capturing the persons' need for assistance, their use of assistive devices and available supports in the living environment to identify unmet needs, into its measurement and scoring, seems to measure the 'problem' dimension of the performance aspect of the participation construct: participation restriction. Other authors support the notion that participation-related measures need to capture and integrate the transaction between the person, the task and the environment within the

instrument<sup>30,32,43,52,53</sup>. Influences of the physical and social environment on accomplishment of each ADL task need to be considered when the patient requires assistance to complete an ADL task. Adequacy of available assistive devices and personal supports may be informed by whether they are: available, accessible, affordable, able to be accommodated and acceptable<sup>54</sup>. Thus, overall adequacy of available supports may be evaluated with the patient and key informant to inform scoring of PC-PART items in this situation as either 'OK with Help" or "Not OK".

Authors who have advocated differentiating activity and participation related constructs by partitioning the life areas chapters within the activities and participation component of the ICF have categorised instruments according to their corresponding content<sup>22,61</sup>. However, the same authors recognise there is a lack of consensus about how life area chapters should be partitioned<sup>22</sup>. This lack of consensus would be expected to result in a lack of consistency in measurement by clinicians and researchers, and between institutions and countries, preventing valid activity and participation measurement comparisons<sup>62</sup>. Authors who focus on instrument content to differentiate activity and participation-related measures have argued that instruments containing content from the mobility, self care and domestic life chapters of the ICF, such as the PC-PART and FIM, measure the activity construct, not the participation construct <sup>22,39,63</sup>. One view that has been asserted seems to be that a community-based societal context is central to measures of participation. Further, content from the self care and domestic life chapters of the ICF do not include community-based societal contexts and therefore would not be included in measures of participation<sup>22,39,63</sup>. This argument is not valid for people for whom accomplishment of self care and domestic life activities within their home-based life situations are a major and important source of personal meaning and is

their main life situation<sup>30,64,65</sup>. Easily identifiable examples may be found amongst children and older adults, but examples are not limited to these groups. Asserting that participation-related measures require the instrument to include items targeting community-based societal engagement is likely to result in measurement that fails to capture meaningful participation for some groups in our societies. This development would not fit with the WHO's ideal that the ICF is relevant for describing health and health-related states for all people<sup>14</sup>.

The nature of instruments' scale properties as an important aspect in differentiating measurement of activity and participation-related constructs does not seem to have been part of the discussion in peer reviewed literature about operationalization of the activity and participation constructs. This may be because the notion is obvious and therefore discussion is not required, or alternatively, because this notion has largely been overlooked. In 2003, Perenboom and Chorus promoted scale factors as the main decisive factor when differentiating activity from participationrelated measures<sup>41</sup>. Other authors have rarely emphasized their importance, although there are some examples. In one study, an instrument's physical functioning items were sorted into discrete activity and participation domains by their content using factor analysis, but unexpected groupings of items that were difficult to explain emerged. Scaling properties were briefly mentioned as possible contributors to the findings. Items using a perceived difficulty scale converged primarily on the activity domain and items using a perceived limitations in performance of daily life behaviours scale, converging on the participation domain<sup>27</sup>. The same authors later found evidence that clear distinctions between activity and participation sub-domains of the ICF could not be identified, according to item content<sup>28</sup>. In these studies, the instruments' response scales

were described, but were not examined as having significant influence on items' convergence on either activity or participation domains. Another paper described dimensions in the measurement of participation including the types of questions and response categories included, such as those addressing frequency, limitation, satisfaction, and assistance<sup>39</sup>. One further paper recognised the importance of examining the aspect of participation measured by a participation instrument, including item contexts and response options, to define and bound the aspects of participation measured<sup>26</sup>. Thus, examination of instruments' scale properties in the differentiation of measurement construct is not a new concept, but seems to have been discussed by relatively few and has not gained prominence in the discussion about differentiation of activity and participation-related measures. In addition, examining scale properties has not generally formed part of the operationalization strategies observed in activity and participation-related measurement research.

Linking of meaningful concepts within the PC-PART instrument to ICF categories confirmed that almost all PC-PART content could be linked to the ICF. The majority of PC-PART content was contained in the activities and participation component of the ICF. Environmental factors were also identified as a major aspect of the PC-PART's content. The linking process also illuminated aspects of the PC-PART's content that linked to body functions categories. This is an interesting outcome, given the purpose of the instrument is to focus on accomplishment of activities of daily living required for community life, not on body functions. One possible explanation for this may be that the phrasing of some items inappropriately focused on body functions, when the intention of the instrument was to gather information about management of an aspect of daily living. For example, the phrasing of item D9 (orientation: do you

remember your appointments?) was linked to the ICF code b144 (memory functions). An alternative wording of the item could be 'Do you get to your appointments on the right day and time?' which focuses on the accomplishment of an activity, rather than a specific body function. Revision of item phrasing in line with the intention of the instrument to focus on accomplishment of activities of daily living required for community life may improve reliability and validity of the instrument.

Three separate studies linking the FIM to level two ICF categories arrived at different conclusions. Some variation in outcome may have arisen because two studies used linking rules established in 2002<sup>34,50,51</sup> and one study used the updated linking rules<sup>35,49</sup>. The updated linking rules advise researchers to avoid use of the 'other specified/unspecified' categories, by using a broader definitive category<sup>35</sup>. This difference was observed between studies. It is also apparent there were different interpretations of the data made between research groups, despite their use of established linking rules and peer review processes. This result highlights that the linking process includes an element of subjective interpretation about meaningful concepts within an instrument and their corresponding ICF categories. The need for use of clear linking rules and independent peer review is emphasized, but despite best efforts, even this can lead to minor variations in outcomes between studies and is acknowledged as a potential limitation in this present study.

### **Conclusions**

This study examined ICF-linked meaningful concepts within the PC-PART and the FIM<sup>TM</sup> instruments and identified overlapping content between the instruments across body functions, mobility and self care domains of the activity and participation

component of the ICF. Examination of the two instruments' scale properties (item phrasing, response categories and scoring) for items containing common content between the measures showed that the instruments elicit different information and therefore measure different constructs. The PC-PART measures participation restrictions and the FIM<sup>TM</sup> measures activity limitations. Measurement of participation-related constructs includes the modifying influences of the person's social and physical environment. The results of this research support the hypothesis that instruments scale properties are critical in differentiating measurement of activity from participation related constructs. Focus on instruments' item content, rather than scale properties, as a way to differentiate activity from participation related measurement, provides only some of the information required to make this distinction. Examination of an instrument's scale properties in addition to its content is necessary when identifying the construct it measures

### **Declaration of Interest**

SD was the recipient of an Australian Postgraduate Award scholarship during this study, which contributed to her doctoral research program. SD is a Director of Darzins Consulting Pty. Ltd., which operates using the business name *The PART Group. The PART Group* distributes the PC-PART assessment. Darzins Consulting Pty Ltd is not financing this manuscript nor had any role in approving the final manuscript. During the last six years (January 2009-2015) SD has not received reimbursements, fees, funding or salary associated with sales of PC-PART products, from Darzins Consulting Pty. Ltd. SD does not hold and is not applying for any patents relating to the contents of this manuscript. All other authors declare that they have no competing interests.

# Appendices

Appendix A. Complete PC-PART and FIM<sup>TM</sup> scores at admission and discharge from inpatient rehabilitation, for patient scenario.

PC-PART items:	PC-PART		FIM <sup>TM</sup> items	FIM <sup>TM</sup>	FIM <sup>TM</sup>
	admission	discharge		admission	discharge
A1. Dressing: Top	1	0	A. Eating	5	6
A2. Dressing: Bottom	1	0	B. Grooming	4	6
A3. Dressing: Footwear	1	0	C. Bathing	3	5
A4. Select clothes appropriate to	0	0	D. Dress upper body	3	4
environment					
A5. Laundry	1	0	E. Dress lower body	3	4
B1. Toileting	1	0	F. Toileting	3	4
B2. Bladder control/management	0	0	G. Bladder management	5	7
B3. Bowel control/management	0	0	H. Bowel management	5	7
B4. Grooming: Hair	0	0	I. Bed/chair transfer	3	4
B5. Grooming: Teeth	0	0	J. Toilet transfer	3	4
B6. Grooming: Shaving/menstruation	NA=0	NA=0	K. Bath/shower transfer	3	4
B7. Bathing	1	0	L. Walking	3	6
B8. Bath/shower transfers	1	0	M. Stairs	2	4
C1. Eating: Weight management	0	0	N. Comprehension	7	7
C2. Eating: Choking/coughing	0	0	O. Expression	7	7
C3. Meal planning	1	0	P. Social interaction	7	7
C4. Meal preparation	1	0	Q. Problem solving	4	5
C5. Acquire groceries	1	0	R. Memory	4	5
C6. Manage food restrictions	0	0	TOTAL SCORE <sup>b</sup>	74	96
C7. Use stove	0	0			
C8. Avoid spoiled food	0	0			
D1. Mobility in the home	1	0			
D2. Bed transfers	1	0			
D3. Avoid falls	1	0			
D4. Manage steps/stairs	1	0			
D5. Outdoor mobility	1	0			
D6. Driving	1	1			
D7. Transportation	1	0			
D8. Wandering: Avoid getting lost	0	0			
D9. Orientation: Remember appointments	1	0			
E1. Manage medications	1	0			
E2. Avoid alcohol/substance misuse	0	0			
E3. Illness/crisis management	1	0			
E4. Avoid repeated need for emergency	0	0			
help					
E5. Avoid smoking safety hazards	0	0			
E6. Home free of hazards	0	0			
F1. Money management	1	0			
F2. Manage home security	0	0			
F3. Basic personal information	0	0			
F4. Shopping for personal/household items	1	0			
F5. Manage temperature in living	0	0			
environment					
G1. Adequate supports	1	0			
G2. Stability of supports	1	0			
TOTAL SCORE <sup>a</sup>	24	1			

<sup>&</sup>lt;sup>a</sup> PC-PART score range: 43=most participation restrictions possible on the scale, 0=no participation restrictions.

<sup>&</sup>lt;sup>b</sup> FIM<sup>TM</sup> score range: 18=complete dependence on all items, 126=complete independence on all items.

Appendix B: Example of four items from the PC-PART instrument.

Item Label	Question to patient	Question to key informant	Observation <sup>a</sup>	Standard task (done with usual help)	Global response and score
Dressing Do you get top your top		Doesget his/her top dressed?	Top adequately dressed?	Take off top and put it back on.	OK by self [0]
dressed?	OK with Help [0]				
					Not OK [1]
Mobility Do you get around in your home OK?	Doesget	N/A	Mobilise	OK by self [0]	
		around in the home OK?		around objects in the room.	OK with Help [0]
	nome ore:		in the room.	Not OK [1]	
Groceries Do you get your groceries?	Doesget his/her groceries?	Adequate groceries present?	Clarify situation through discussion.	OK by self [0]	
				OK with Help [0]	
				Not OK [1]	
Laundry Do you get your clothes laundered regularly?	Doesget	Absence of	Clarify	OK by self [0]	
	2	clothes laundered	dirty laundry?	situation through discussion.	OK with Help [0]
	laundered	regularly?			Not OK [1]

<sup>&</sup>lt;sup>a</sup> When observations are not possible within a clinical setting, situation needs to be clarified through discussion.

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# **Chapter 4 - Conclusions**

This study fulfilled the first specific research objective for this body of research which was to investigate the theoretical concept and measurement of participation restriction, as measured by the PC-PART. This was achieved through (a) linking content of the PC-PART to ICF categories to identify ICF components and domains covered by the PC-PART, and (b) comparing the scale properties of the PC-PART to those of an accepted measure of activity limitation.

Almost all of the meaningful concepts within the PC-PART linked to the body functions and structures, activities and participation, and environmental factors components of the ICF. Given the intention of the PC-PART is to measure participation restrictions, the PC-PART items that linked to the body functions and structures and environmental factors components of the ICF could be rephrased so that the items target the activities and participation component of the ICF. This change may facilitate alignment of all PC-PART items to the purpose of the instrument as a measure targeting participation restrictions.

The study concluded that measurement of participation-related constructs includes not only the content of the items, but also the modifying influences of the person's social and physical environment in its scores. Thus, instruments' scale properties may be critical in differentiating measurement of activity from participation-related constructs. Theoretical validation of the PC-PART's measurement construct provided a basis for developing theoretical expectations about the instrument's scores in various clinical scenarios, and how it may be used in clinical settings. Thus, confirmation of the measurement construct of the PC-PART as a measure of

participation restriction, was important in providing a foundation for developing hypotheses for further validation of the instrument and for exploring its clinical utility.

The measurement of both activity limitation and participation restrictions in activities of daily living required for community life may provide more comprehensive measurement of rehabilitation outcomes than independent measurement of either construct. This study highlighted the importance of understanding the type of information gathered by specific instruments. Subtle differences in the scale properties of instruments may result in differences in the type of information gathered, and subsequently, in the construct being measured. This understanding is critical in both research and in clinical practice to ensure instruments are selected that correctly measure the construct(s) of interest.

# Chapter 5. Clinical Utility of the PC-PART for Inpatient Rehabilitation

#### Introduction

Following the previously described exploration of the theoretical construct of the PC-PART, this next study addressed the second specific research objective for this body of research. The objective was to explore occupational therapists' perceptions of the clinical utility of the PC-PART when used for inpatient rehabilitation. Although clinical utility of the PC-PART has been explored in the past (Barbara & Whiteford, 2005; P Darzins, Bremner, & Smith, 2002; R. Smith et al., 2001), the reported studies were negatively impacted by small sample size in relation to methods used, and limited reporting of their methods. As a result, the evidence about clinical utility of the PC-PART in the studied settings remained inconclusive.

The opportunity arose to conduct a study with occupational therapists who had used the PC-PART to collect data for the randomised controlled trial described in Chapter three. Gathering insights about occupational therapists' perceptions of the PC-PART instrument was used to gain a deeper understanding of the strengths and limitations of the instrument as well as factors that impede or promote its continued use in clinical practice. This exploratory study was also used to elucidate aspects of the PC-PART's use that may promote or impede reliability and validity of responses and scores on the instrument. The findings were expected to provide useful insights that could be applied in any subsequent revision of the instrument.

In this chapter the methods used to study clinical utility of the PC-PART are described, as well as the philosophical assumptions underlying the research. Aspects of the study methods already described in detail in the manuscript are not repeated in this introduction. The manuscript, submitted for publication in a peer-reviewed journal, is presented. Following the inserted manuscript, conclusions from this study are presented, linking the findings to the broad objectives of the doctoral research.

# **Study Aim**

The aim of this descriptive study was to explore perceptions of occupational therapists who had used the PC-PART, regarding its clinical utility for inpatient rehabilitation, and aspects of the instrument that promote or impede the PC-PART's routine use as a clinical assessment. A mixed methods approach was adopted to: gather therapists' views about pre-defined aspects of clinical utility in relation to the PC-PART's use in rehabilitation; provide a mechanism to explore their views in depth; explore other factors that may be important to clinical utility of the instrument; and provide deep understanding of the factors influencing the PC-PART's use in that setting.

# **Mixed Methods Research Design**

Mixed methods research uses both quantitative and qualitative research methods to address research aims. One benefit of mixed methods research is that the strength of one research method may offset weaknesses of the other (Creswell & Plano Clark, 2011; Teddlie & Tashakkori, 2011) when use of either quantitative or qualitative methods alone may not answer the research question. Qualitative methods may extend

or provide deeper understanding of quantitative data if used after a quantitative phase of data collection (Patton, 2002). Creswell and Plano Clark (2011) assert that mixed methods research "combines methods, a philosophy and a research design orientation" (p. 5). Researchers collect and analyse both qualitative and quantitative data and may give priority to one or to both types of data (Creswell & Plano Clark, 2011). Both qualitative and quantitative procedures may be combined into specific research designs that dictate plans for conducting studies. This may include mixing, integrating or linking qualitative and quantitative data contemporaneously or by merging or combining them in sequence, having one develop from the other, or embedding one within the other (Creswell & Plano Clark, 2011). Researchers frame the procedures from within philosophical world views, in other words, frameworks of ideas and attitudes about the world (Creswell & Plano Clark, 2011).

### **Research Methods in this Study**

An explanatory sequential mixed methods design was used in this study to explore PC-PART users' perceptions about the clinical utility of the PC-PART instrument in a rehabilitation setting. This design consisted of two distinct phases: A quantitative phase followed by a qualitative phase (Creswell & Plano Clark, 2011; Patton, 2002; Teddlie & Tashakkori, 2011). Use of questionnaires and focus group discussions are common data gathering methods for exploring the subjective experiences of, and for obtaining rich data from participants (Mortenson & Oliffe, 2009).

The quantitative phase included a survey questionnaire that gathered numeric and text data. The use of a questionnaire offered an efficient way of collecting data by using

a series of structured questions that participants responded to about aspects of clinical utility, eliciting responses, which could be gathered and summarised (see Appendix F). Questionnaires frequently yield broad responses from target populations that can be further clarified and explored through focus group discussion (Creswell & Plano Clark, 2011; Schofield & Knauss, 2010; Teddlie & Tashakkori, 2011).

The qualitative phase included a focus group, which permitted the gathering of spoken data, which was later transcribed to text data. The questionnaire data informed the development of the focus group discussion schedule used in this second phase (see Appendix F). This process effectively connected the two phases of the study (Creswell & Plano Clark, 2011). Focus groups enable in-depth discussions and are used to elicit knowledge, attitudes and beliefs within a group, to generate hypotheses and to clarify quantitative study findings. Interaction among participants is the strength of the focus group method, as group members stimulate each other to comment and question, resulting in the gathering of rich data (Davidson, Halcomb, & Gholizadeh, 2010; Liamputtong, 2011). A focus group has several important features: It enables in-depth discussion and involves a relatively small number of people; it is focused on a specific area of interest that allows participants to discuss the topic in detail; it relies on interaction between participants to explore and clarify their points of view; it is facilitated by a moderator whose role is to obtain good and accurate information; and the participants usually have shared social and cultural experiences or shared particular areas of concern (Liamputtong, 2011). This second phase of the study involved thematic analysis of data from multiple sources and provided in-depth and extended understanding of the initial results obtained from the quantitative phase (Creswell & Plano Clark, 2011; Morgan, 1998). Documents supporting the procedures applied in this study are included in Appendix F (e.g. questionnaire, focus group schedule, ethics clearances, participant information and consent forms, advertisement).

# **Philosophical Assumptions**

Philosophical assumptions in mixed methods research consist of a set of beliefs or assumptions that shape research processes and conduct of the inquiry (Creswell & Plano Clark, 2011; Lincoln & Guba, 2000). Knowledge of, and articulation of these assumptions is important, to provide understanding of how these may influence the research. Part of articulating philosophical assumptions involves acknowledging and describing the researcher's worldview(s) and relating this to specific procedures in a mixed methods project (Creswell & Plano Clark, 2011). More than one worldview, or paradigm may be used in a mixed methods study (Creswell & Plano Clark, 2011; Teddlie & Tashakkori, 2011). The selection of multiple world views relates to the type of mixed methods design used (Creswell & Plano Clark, 2011).

# Adopted Worldview/Paradigm

When a mixed methods study commences with a questionnaire, the researcher implicitly uses a post-positivist worldview (Creswell, 2011; Creswell & Plano Clark, 2011). Post-positivism serves as the primary underpinning of quantitative research (Ponterotto, 2005). This perspective has elements of being reductionist, logical, empirical and cause and effect oriented towards phenomena that can be studied, identified and generalised (Creswell, 2013; Patton, 2002). It proposes an impartial, detached and unbiased researcher role (Creswell & Plano Clark, 2011; Ponterotto, 2005). A post-positivist worldview informed the start of this study with the use of pre-

defined *clinical utility* variables (Laver Fawcett, 2007; Law & Baum, 2005), that were then embedded into questionnaire items, and tested (Creswell & Plano Clark, 2011).

In the qualitative phase of the study, the implementation of a qualitative focus group method to extend and explain the questionnaire results, meant that the researcher's worldview shifted to more of a constructivist perspective (Creswell, 2011; Creswell & Plano Clark, 2011). A constructivist perspective is typically associated with qualitative approaches and is based on meaning and understanding of phenomena, which is formed through the subjective views of participants (Creswell, 2013; Patton, 2002). Participants speak about meanings and understandings that are shaped by their social interactions and personal histories (Creswell & Plano Clark, 2011; Lincoln & Guba, 2000). The constructivist position upholds meaning as something hidden that needs to be brought to the surface by means of deep reflection (Ponterotto, 2005). Meaning can also be inspired by researcher-participant interactive dialogue (Ponterotto, 2005). Constructivist researchers focus on people's specific living and working environments to understand their cultural and historical contexts (Creswell, 2013). A characteristic that distinguishes constructivism is the interaction between the researcher and the participants, with the aim of constructing findings from their interactive dialogue and interpretation (Lincoln & Guba, 2000; Ponterotto, 2005). In this type of investigation, research and analysis is moulded from individual perspectives through to broader patterns and ultimately to broader understandings (Creswell & Plano Clark, 2011). A constructivist view recognises participants' multiple realities and thus, researchers provide quotes to illustrate their different perspectives (Creswell & Plano Clark, 2011). Creswell (2013) states that constructivist "researchers recognise that their own background shapes their interpretation, and they position themselves in the research to acknowledge how their interpretation flows from their own personal, cultural, historical experiences." (p25).

# **Mixed Methods Data Analysis**

Mixed methods data analysis involves combining, connecting or integrating quantitative and qualitative data analysis strategies (Teddlie & Tashakkori, 2011). For this study, quantitative numeric data were summarised into tables using descriptive statistics. Qualitative data were analysed using inductive thematic analysis. This involved preparing and organising the data for analysis into text units, reading the text data several times as a whole to become *close* and immersed in the data, describing, classifying and interpreting data into codes, categories of codes, and finally, themes (Creswell, 2013). Typically, researchers systematically reduce qualitative data to codes by assigning codes to units of information. Patterns are found amongst the coded data and categories, or labels are assigned to these groups of codes. Further abstraction of the categories occurs to identify themes (Creswell, 2013; Onwuegbuzie & Combs, 2010). Themes are broad units of information that consist of several codes aggregated to form a common idea (Creswell, 2013). Interpretation involves making sense of the data, or learning lessons, abstracting out beyond the codes and themes to the larger meaning of the data (Creswell, 2013). In this case, interpretation was used to inform future revisions of the PC-PART to enhance its clinical utility for inpatient rehabilitation.

# Position of the researcher in this study.

There are three main aspects to consider regarding my position in this research.

First, I have an interest in the PC-PART. This created potential for me to hold bias in

favour of the instrument. I used strategies to manage this potential bias such as avoidance of involvement in direct recruitment and data collection procedures with participants, inclusion of an independent focus group moderator, involvement of independent co-researchers in the data analysis phase to identify potential bias. In addition, I held regular reflective discussions with other researchers about the data analysis process and the findings. Second, I positioned myself in the research as an expert learner. The reason for this is that while I am familiar with the PC-PART content, I am not familiar with the in-patient rehabilitation environment at the research site. Therefore I positioned myself as a learner about participants' experience of reality with respect to use of the PC-PART. I share an occupational therapy background with participants, which affords common theoretical foundations of practice. Third, I value the use of valid, standardised outcome measures in clinical practice and hold the belief they are necessary for measuring the benefit of occupational therapy services on service-users' lives. I have an interest in exploring both strengths and limitations of the PC-PART as a clinically useful, valid, reliable and responsive measure for use in clinical settings to enable measurement of meaningful problems experienced by serviceusers. A balanced understanding of both strengths and limitations of the instrument on these dimensions is important for understanding the need for further development and validation of the instrument.

# Position of participants in this study.

My assumptions were that the occupational therapist participants would understand the concepts underpinning the PC-PART instrument, such as participation restriction. I assumed the participants would have good knowledge of how to use the

instrument having used it routinely in an inpatient rehabilitation setting. I assumed that therapists were time poor, with little time to complete assessments of service-users' functioning. I was concerned therapists may be suspicious of my intended plans for this research because of my interest in the instrument. My response to these perspectives during data analysis was to be intentionally reflective in my reactions to, and personal interpretations of, the data.

# Paper 3: Clinical Utility of the PC-PART

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# PERSONAL CARE PARTICIPATION ASSESSMENT AND RESOURCE

### TOOL: CLINICAL UTILITY FOR INPATIENT REHABILITATION.

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# **Key Words**

Activities of Daily Living; Outcome Measures; Clinical Assessment Tools; International Classification of Functioning Disability and Health, ICF,

### Abstract

Background. Evidence supports validity of the Personal Care-Participation

Assessment and Resource Tool (PC-PART) but clinical utility remains unverified.

Purpose. Investigate occupational therapists' perceptions about the PC-PART's clinical utility for inpatient rehabilitation. Method. Using mixed methods, occupational therapists who had used the PC-PART as part of a research study in an inpatient rehabilitation setting completed a questionnaire (n=9) and participated in a focus group (n=6) to explore their perspectives about its clinical utility. Quantitative data were summarised and qualitative data analysed using inductive thematic analysis. Findings.

Quantitative data highlighted both positive and negative aspects of the PC-PART's clinical utility. Five themes emerged from the qualitative data: nature of information gathered; familiarity with the instrument; perceived time and effort; item phrasing, interpretation and presentation; and external influences on clinical use. Implications.

The PC-PART was perceived to support gathering of clinically useful information, helpful to intervention and discharge planning. Recommendations for improving some item phrasing, operational definitions, and instructions were identified. Although

standardized assessments were valued, use in routine practice was challenging, requiring a knowledge translation strategy.

#### Introduction

The purpose of the Personal Care-Participation Assessment and Resource Tool (PC-PART) is to identify adults' unmet needs in accomplishing activities of daily living (ADL) required for community life (P. Darzins, 2004; Vertesi, Darzins, Lowe, McEvoy, & Edwards, 2000). Specifically, it aims to identify unmet needs that persist in individuals' living environments despite their own efforts, use of assistive devices, and available supports or assistance from others (P. Darzins, 2004). In the language of the International Classification of Functioning, Disability and Health (ICF) *unmet needs* may be termed *participation restrictions* (World Health Organisation, 2001). The purpose of using the PC-PART for inpatient rehabilitation is to aid (a) identification of participation restrictions in ADL presenting as barriers to community living upon discharge, (b) prioritisation of interventions to resolve ADL participation restriction, and (c) measurement of change in ADL participation restrictions at specified time-points, such as at admission and discharge from inpatient rehabilitation.

The PC-PART has 43 items across the domains of *Clothing, Hygiene, Nutrition, Mobility, Safety, Residence,* and *Supports* (P. Darzins, 2004; Vertesi, et al., 2000). The items are listed in Appendix A. The assessment is administered using a combination of client interview, key informant interview and task observation, as needed. Items are scored as either *OK by self* (clients manage the activity alone with or without assistive devices in their living environments), *OK with help* (clients manage the activity with help from others in their living environments), or *Not OK* (clients do not manage the

activity in their living environments despite their own efforts, use of assistive devices and help from others). Both *OK by self* and *OK with help* are scored 0 (*no* participation restriction present), and *Not OK* is scored 1 (participation restriction *is* present), forming a dichotomous scale. Each *Not OK* response represents an ADL participation restriction that may be addressed through intervention. Conventional clinical scoring is the total number of *Not OK* scores for an individual client (range 0-43; see Appendix B for sample items).

A recent systematic review of the PC-PART's measurement properties found positive evidence supporting its' content validity and promising support for its' clinical utility in various settings (S. Darzins, Imms, & Di Stefano, 2013). Clinical utility refers to many factors, including the degree to which an instrument provides appropriate and useful information for client clinical management, is practical for the particular setting and is acceptable to users and consumers (Laver Fawcett, 2007; Law, 2004; Law, King, & Russell, 2005; Smart, 2006). Developers of measures may overlook investigating a tool's clinical utility because it is not a measurement property. However, clinical utility is cited as an important influence on instruments' use in clinical practice (Law, et al., 2005). Subsequent to the systematic review (S. Darzins, et al., 2013), validation research provided support for the PC-PART's inter-rater reliability (Radia-George, Imms, & Taylor, 2014) and internal construct validity, evaluated using Rasch analysis (S. Darzins, Imms, Di Stefano, Taylor, & Pallant, 2014).

Although evidence exists supporting use of valid, standardized assessments relevant to occupational therapy practice, their use by occupational therapists remains low across various clinical contexts (Bowman, 2006; Pilegaard, Pilegaard, Birn, &

Kristensen, 2014; Pumpa, Cahill, & Carey, 2015; Stapleton & McBrearty, 2009).

Specifically, high prevalence of non-standardized assessment of clients' occupational performance in personal and instrumental activities of daily living in stroke rehabilitation settings has been reported, despite their availability (Kitsos, Harris, Pollack, & Hubbard, 2011; Koh, Hoffmann, Bennett, & McKenna, 2009). Commonly cited barriers to the use of valid standardized measures include time restraints, lack of training and lack of access to the assessments (Barbara & Whiteford, 2005; Bowman & Llewellyn, 2002; Koh, et al., 2009; Pumpa, et al., 2015; Radia-George, et al., 2014; Stapleton & McBrearty, 2009).

In Australia, standardized measures such as the FIM<sup>TM</sup> (Uniform Data Systems for Medical Rehabilitation [UDSMR], 2014) are routinely used in inpatient rehabilitation settings to measure clients' level of dependence in basic ADL-related mobility and cognitive tasks, in accordance with government requirements (Australian Institute of Health and Welfare [AIHW], 2015). In the language of the ICF, the FIM<sup>TM</sup> measures activity limitations (UDSMR, 2014; WHO, 2001). This type of instrument is important for measuring changes in clients' level of dependence over time but does not measure clients' participation restrictions in accomplishing ADL required for community life. Measurement of both clients' activity limitations *and* participation restrictions are important in inpatient rehabilitation contexts to produce a comprehensive and clinically meaningful picture of clients' overall functioning in ADL required for community life.

Given this context, it was considered necessary to explore occupational therapists' perceptions about the clinical utility of the PC-PART for use in inpatient

rehabilitation, to promote understanding about barriers and facilitates to its use. Therapists' judgements about clinical utility of specific assessments are based on perceptions of usefulness of the information gathered, time and cost required to administer the assessment, instructions, ease of use and acceptability of the assessment to the client, and to the therapist (Law, 1987). These judgements are formed from experiences. Incorporation of qualitative methods, to collect participants' subjective views and opinions, is appropriate for the investigation of clinical utility of an instrument. Survey and/or focus group methods have previously been used to investigate clinical utility (Cameron et al., 2001; Gustafsson, Mitchell, Fleming, & Price, 2012; Gustafsson, Turpin, & Dorman, 2010; Toomey, Nicholson, & Carswell, 1995; Wressle, Marcusson, & Henriksson, 2002).

Three qualitative studies have already explored clinical utility of the original version of the PC-PART, the Handicap Assessment and Resource Tool (HART) (Barbara & Whiteford, 2005; P. Darzins, Bremner, & Smith, 2002; Smith et al., 2001) drawing positive conclusions about its' utility for rehabilitation and acute hospital settings. It is noted that the PC-PART and HART contain the same items, with the PC-PART including changes to presentation style and minor rephrasing of some items (Darzins, 2004). Each prior study had important limitations in study design, sampling, and reporting, impacting on transferability and trustworthiness of the findings (S. Darzins, et al., 2013). Thus, clinical utility of the PC-PART is not yet established. We aimed to explore occupational therapist user perceptions of the PC-PART's clinical utility for inpatient rehabilitation, including aspects that promoted or impeded its' routine use as a clinical assessment.

#### Method

# **Study Design**

An explanatory, sequential, mixed methods design was used. First, both quantitative and qualitative questionnaire data were gathered and summarised. These data were extended and enriched using focus-group methods to gather in-depth qualitative data (Creswell & Plano Clark, 2011; Liamputtong, 2011; Schofield & Knauss, 2010; Teddlie & Tashakkori, 2011). Both methods were given equal priority in addressing research aims (Creswell & Plano Clark, 2011).

# **Participants**

Potential participants were all occupational therapists from a large metropolitan health service in Australia with experience completing the PC-PART for adult inpatient rehabilitation (n = 25). This service had previously used the PC-PART in a clinical trial and inter-rater reliability study (Radia-George, et al., 2014; Taylor et al., 2010). The inpatient rehabilitation service provided multidisciplinary rehabilitation for clients with primarily orthopaedic, neurological or other health problems, such as cardiac, pulmonary, or deconditioning health conditions. Length of stay was, on average, 21 days. Relevant health service and university human research ethics committees approved the study and all participants provided written consent.

### **Ouestionnaire**

Formal construction, critique, external review, revision and pilot-testing methods were applied for questionnaire development (Schofield & Knauss, 2010).

Items were structured to collect both quantitative and qualitative data using criteria provided by Law (Law, 2004) and Fawcett (Laver Fawcett, 2007). Criteria included: time taken and effort needed to complete the assessment; type and completeness of gathered information; phrasing of items; response and scoring options; item layout and ordering; assessment cost; acceptability to patients and key informants/carers; and training. Additional items were: involvement of key informants during information gathering; and options provided for client observation and standard observable tasks.

Operational definitions for each aspect of clinical utility criteria were provided (see Table 1). Participants were asked to rate and comment on the *influence* of each criterion on the PC-PART's clinical utility across five categories: *large negative*, *small negative*, *no influence*, *small positive* and *large positive*. One global question elicited a rating of the PC-PART's overall clinical utility using a 10 cm visual analogue scale, using the following anchors: *extremely poor* (0) and *excellent* (10).

Table 1. Operational definitions of clinical utility criteria used in the study.

Clinical utility criteria	Operational Definitions
Time taken	Time taken to gather relevant information and complete the assessment.
Effort required	Physical and cognitive effort required of the therapist to complete the assessment.
Type of gathered information	Relevance of the information gathered to the clinical construct being measured (i.e. problems managing essential personal and instrumental activities of daily living).
Completeness of gathered information	Extent to which the questions cover all relevant areas of the clinical construct being measured (i.e. essential personal and instrumental activities of daily living).
Phrasing of the questions	Language, expressions or words used in the questions. How the questions are put to the person and their key informant(s).
Question response options and scoring	Response choices, or categories, available for each question and their corresponding scores (where applicable).
Layout	Layout of the questions and the assessment worksheet (e.g. separate columns for each informant, columns for observations and standardised tasks, and spaces for writing; the booklet format; coloured sections).
Ordering of items	Sequence of the questions in relation to clinical information needs and therapist clinical reasoning.
Assessment cost	Influence of the cost of the assessment on its clinical utility.

Acceptability to clients and key informants	How suitable and satisfactory the assessment is perceived to be to clients and to key informants (e.g. carers, family members, other health professionals).
Training requirements	Adequacy of current training methods and requirements for use of the

# Focus group

A 90-minute audio-recorded focus group followed a pre-planned schedule of discussion topics, derived from questionnaire data. The experienced moderator and note-taker were both expert occupational therapists and independent from any relationship with participants or the PC-PART. Immediately following the focus group, the moderator and note-taker recorded and discussed their reflections on the discussion. This was audio-recorded. Both audio-recordings were transcribed, verbatim. The moderator and note-taker reported that all participants talked freely and that saturation of discussion topics was reached within the group.

## **Data Analysis**

Qualitative questionnaire data were summarised using descriptive statistics.

Qualitative data, including written qualitative questionnaire responses, audiorecordings, transcriptions of focus group data and reflections, were analysed using
inductive thematic analysis. All authors were involved in various stages of the analysis.

First, SD (first author) and CRG (fourth author) listened separately to the audiorecordings and read the transcripts to gain a sense of the data as a whole. Next, opencoding of all written and transcribed data was manually completed by SD to label 'what
was said' as either positive, negative, clinical reasoning, agreement, disagreement or
suggestion for change. CRG and MDS (third author) independently reviewed the

coding with an average of 97% agreement. Consensus occurred after discussion between SD, CRG and MDS.

SD assigned numeric codes and sub-codes to all clinical utility criteria used in the questionnaire to form clinical utility categories, along with their corresponding definitions. SD categorised all open-coded qualitative data using these numeric codes. Additional categories, numeric codes and corresponding definitions were created where open-coded data could not be categorised using existing codes. Coding was independently reviewed by MDS achieving 99% agreement in code assignment, and full agreement after discussion with SD. SD grouped the coded data by numeric code. This was independently reviewed by MDS. Abstraction of grouped, coded data by SD identified key themes emerging within and across categories. This was independently reviewed by MDS and CI (second author), with consensus reached through discussion. All participants were offered the opportunity to provide feedback through a 'member checking' process, however, none took up the offer.

## **Findings**

## **Participant Characteristics**

Nine occupational therapists completed the questionnaire. Six of these also participated in the focus group (see Table 2 for participant characteristics). The nine participants had completed an average of 45 PC-PART assessments with clients as part of an earlier randomised controlled trial (RCT). Two participants reported continued use of the PC-PART following the RCT. Participants' overall rating of the PC-PART's clinical utility for inpatient rehabilitation was 5.4 on the 10 centimetre visual analogue

scale. All viewed standardized assessments as important to clinical practice and used them for inpatient rehabilitation.

Table 2. Participant characteristics (n=9).

Professional characteristics					
Age in years: Mean (SD, Range)	30.3 (10.2, 2	,			
Number of years practising OT: Mean (SD, Range)	7.4 (8.7, 2-2	9)			
Number of years practising in a	5.3 (8.1, 1-2	5)			
rehabilitation setting: Mean (SD,					
Range)					
Highest qualification (number of participants)	Bachelor of	OT (8); Master	of OT (1)		
Use of the PC-PART					
Number of PC-PARTs completed	45 (22.8, 10	-45)			
during RCT: Mean (SD, Range)					
Estimated time taken to complete PC-	25 (10.9, 10	-45)			
PART in minutes: Mean (SD, Range)	5 4 (1 4 2 4	7.7			
VAS rating of overall clinical utility of the PC-PART (range 0-10): Mean	5.4 (1.4, 3.4	-1.1)			
(SD, Range)					
Type of training used to learn to use			_	_	
the PC-PART - participants could	Users	Training	Peer	Peer	Shown by
choose more than one (number of	manual	DVD (1)	discussion <sup>a</sup> (6)	review	colleague (1)
participants)	(7)	(1)	(0)	(3)	. ,
Use of PC-PART following the RCT	Not at all	Seldom	Occasional		Routine
(number of participants)	(7)	(1)	(1)		(0)
Use of Standardised Assessments					
Frequency participants currently use standardised assessments in a					Almost
rehabilitation setting (number of	Never (0)	Seldom (0)	Often (4)		always (5)
participants)					arways (5)
Frequency participants had used					A 1
standardised assessments in past work	Never (1)	Seldom (4)	Often (3)		Almost
settings (number of participants)					always (1)
Participants' views about perceived	Not	Some-what	Moderately		Very
importance of standardised	important	important	important		important
assessments (number of participants)	(0)	(2)	(5)		(2)
Standardised assessments used by	Functional I	ndependence M	Measure (FIM)	(9)	
participants for inpatient rehabilitation		State Exam (N			
(number of participants)	Rowland Ur	niversal Demen	tia Assessment	Scale (RU	JDAS) (6)
	Barthel Inde				
	Cognistat (4				
		OT Cognitive	*		
		ıman Occupatio	•	`	OST) (1)
SD=Standard Deviation; OT=Occupational		ognitive Assess			G . 11 1 m

SD=Standard Deviation; OT=Occupational Therapy; VAS=Visual Analogue Scale; RCT=Randomised Controlled Trial <sup>a</sup> Informal discussion, not part of a formal training session.

# **Questionnaire responses**

Tables 3 and 4 summarise participants' responses to the clinical utility questionnaire. The type and completeness of information gathered, involvement of key informants, inclusion of opportunity to observe clients, assessment layout and the rating options were viewed as positively influencing clinical utility. Time and effort to complete the assessment, as well as cost and phrasing of items negatively influenced therapists' views of clinical utility. Item phrasing was perceived to have low acceptability to clients and key informants, while type and completeness of information gathered were perceived to have high acceptability.

Table 3. Participant ratings about characteristics of the PC-PART and their influence on the PC-PART's overall clinical utility (n=9).

		Infl	uence on clinical	lutility	
Characteristic	Large negative	Small negative	No influence	Small positive	Large positive
1. Time taken to gather information	1	5	3	-	-
2. Effort needed to gather information	1	5	3	-	-
3. Type of information gathered	-	-	3	4	2
4. Completeness of information		1	1	5	2
5. Phrasing of questions	1	5	2	1	-
6. Rating options for each item	1	1	1	5	1
7. Layout of the instrument	-	-	4	3	2
8. Ordering of questions in the instrument (n=8, missing=1)	-	-	4	4	_
9. Involvement of key informants	-	-	2	4	3
10. Patient observation options given	-	-	2	5	2
11. Standard task options given	-	-	4	4	1
12. Cost of the assessment	5	1	3	_	_

Table 4. Participants' perceived acceptability of the PC-PART to clients and key informants (n=8, missing=1)

		Pe	rceived a	cceptabil	lity	
Aspect of the PC-PART being rated		To client	S	To k	ey inforr	nants
	Low	Med	High	Low	Med	High
a. The length of the assessment	1	5	2	-	7	1
b. The types of questions asked	-	4	4	-	4	4
c. The phrasing of the questions	5	3	-	2	5	1
d. The extent to which the assessment covers all the main activities a person needs to do to live at home	-	3	5	-	3	5
e. Involving others as part of the information gathering process	-	5	2	-	3	4
f. The extent to which the assessment picks up problems someone might be having with everyday life	-	7	1	1	4	3

### **Themes**

Five themes related to participants' perceptions of the PC-PART's clinical utility for inpatient rehabilitation were identified from qualitative data: nature of information gathered; instrument familiarity; perceived time and effort; item phrasing, interpretation and presentation; and external influences on clinical use. Quotes from individual questionnaire participants are labelled Q1-Q9, and focus group participants, F1-F6.

## Nature of information gathered.

The PC-PART was perceived to comprehensively cover all aspects of activities of daily living and to support clinical reasoning: "it was quite thorough too...so you didn't have to think about anything additional...you could run through it quite easily" [F6] and "it prompted you to look at areas you might forget or leave out at times...and gave you a whole kind of picture" [F4]. One participant also commented "the [PC-PART] questions may act as a trigger for

more [detailed] investigation and assessment" [F2] and "should sort of confirm your clinical reasoning around what the areas are to work on and what people are actually managing well" [F2]. The assessment provided useful information for discharge-related goal setting: "it really helped with goal-setting with us, so when you summarised....it was a red flag....if someone got a not okay... essentially we needed to work on it [before discharge]" [F1].

The degree to which the PC-PART covered similar information gathered by the occupational therapists' locally developed, non-standardized initial assessment was discussed, with comments such as: "It's similar to our initial assessment but you come out of it with a score, so it's just that objective measure, which is nice ... so that was really good" [F1].

Triangulation of information gathered through involvement of key informants, such as family members, was perceived to be useful and promote understanding of clients' issues. Questionnaire responses included.... "carers can answer if the client is unsure" [Q1] and that it is "definitely useful to consult key informants as quite often there would be a discrepancy between what the client and carer reports...which gave us areas we needed to focus on for discharge...and encouraged interaction with other team members if unsure of certain items" [Q2]. Options for client observation were perceived to be 'mostly helpful' as a basic prompt, but weren't always required for scoring. One questionnaire respondent noted... "some of [the observations] were not applicable in the hospital setting and would need to be done in the home environment, and this [was] not possible when used as part of an initial assessment [of inpatients]" [Q2]. Another

I quite like the difference, using the self-report, [the person's] understanding of what they can do, but also their key informants or their family members, and then obviously our observations....so that gave me really good insight into actually, their cognitive capacities [F5].

Participants expressed concern that the nature of the PC-PART's response categories and scoring may lack sensitivity to small changes in clients' level of dependence compared to other assessments, and how this would be interpreted...."assessments like the FIM or Barthel use that ...to justify why people are in rehab for four weeks, whereas people with [responses of] *OK with help* and then *OK with help* at the end [of inpatient rehabilitation], then they'd say well, why were they here for four weeks?" [F5].

Inclusion of different item phrasing for clients, key informants, and standard observations was viewed positively. For example....this "made me think more about how I was asking the questions differently according to who I was talking to" [F5]. Another gave the example: "In one instance I used the specific questions and examples [standard observation/tasks] and that really brought out the specific answers from the key informants, actually asking them specific questions, the way it's phrased here, so that really helped [the man and his wife to provide needed information]" [F4].

## Familiarity with the instrument.

Participants articulated varied levels of familiarity with the PC-PART's purpose and method of completion and some expressed difficulty shifting conceptually from scoring FIM items to scoring PC-PART items... "being strongly FIM oriented here, I

was confused about the difference between FIM and this different assessment [PC-PART] and how to rate items" [F3]. Some participants used the summary score sheet to conduct the assessment, rather than the fully phrased worksheet containing prompts, and viewed the summary sheet as inadequate if used alone. They said "we had to go back [to check the worksheet] to find out what it says for each item" [F5].

One participant was uncertain if it was acceptable to clarify clients' responses through paraphrasing..."I'd want to go back to the training, to understand if the intent of the creator is to use exact wording or whether it is OK to modify your language to the situation" [F2]. Participants were unsure if key informants were always required in the PC-PART assessment. One participant said "in rehab there are often patients who are [competent] where no information from key informants is required, therefore if it is required as part of the PC-PART assessment [to include a key informant], this would unnecessarily increase the time and effort needed to complete the assessment" [F6].

Questionnaire respondents reported using various methods to familiarise themselves with the PC-PART (Table 2). In addition to the research-focused training, eight questionnaire respondents perceived the need for PC-PART users to have one to two hours of formal training. Focus group participants supported the need for formal training addressing test purpose, individual item meanings, administering and scoring. They explained "some therapists missed out on training" [F6] and "when you don't get the training you make your own interpretation on how to fill in the form, so that makes a difference to everybody about how you complete the assessment" [F2]. This same participant went on to explain they had to hold discussions to "reassess how we were

using the assessment because we were disagreeing on the result of whether the patient had improved or stayed the same" [F2].

## Perceived time and effort.

Perceptions about the time and effort required to complete the PC-PART seemed to be influenced by: the complexity of clients' situations; participants' views about PC-PART use in addition to the usual initial assessment; their comfort level using the instrument and the nature of information collected.

The complexity of clients' situations and their cognitive state influenced participants' views of the time and effort required to complete the PC-PART...

I find it can take up to an hour just to interview a client, depending on how well they answer and all the factors, and then a phone call to a family member could take anywhere from 10 to 20 minutes....if you have a cognitively intact, 'switched on' client you might get both done in 30 minutes [F2].

Some participants perceived the need to interview a key informant, despite the client being cognitively intact, as unnecessarily increasing assessment completion time. For example..."it's not uncommon in rehab (sic?) to get patients who are completely on the ball and there's no need to source additional information, so....if you are doing that, that is going to increase the time factor to what you are doing" [F6].

Perceptions about the PC-PART, and how it fits into existing clinical information gathering procedures influenced perceptions about required time and effort

for completion. The PC-PART was perceived by some participants to duplicate information already gathered by the occupational therapy initial assessment and to take approximately the same time to complete. Questionnaire participants commented that completing the PC-PART during the research project "increased time on [our] workload in addition to other assessment and therapy time" [Q1].

Participants also perceived that assessment item phrasing impacted on completion reporting:

It took a little bit of effort because we weren't happy with the wording....if you were really happy with exactly how it was and you could just go in and do it, then it wouldn't take as much time and it wouldn't take as much effort as well [F1]

Perceived time and effort were also influenced by participants' expectations about the nature of information collected. They commented that assessment information is gathered over time in rehabilitation settings: "I don't think you could ever expect to be always doing your initial assessment in 20 to 25 minutes.....with things like cognition and that kind of thing, I don't think you could ever properly assess it by just asking questions of someone" [F4], and "our guidelines are that we have up to a week to finish our initial assessment" [F3]. Another participant added a comment to contextualise how the PC-PART might fit into this process, saying "I don't think changing from our current initial assessment to [the PC-PART) would change that process.....that might be your initial data gathering but there's always going to be [other specific assessments] you're doing in addition to that" [F6]. These comments highlight the importance of clarity about the purpose and nature of the information being

collected, and how this impacts on time and effort expended to gather the necessary information.

A favourable view about time and effort was also expressed: the PC-PART "may be less time-consuming if incorporated as part of [the] initial assessment" [Q2] and that "this should be your initial assessment except for the extra little bits that your [initial] assessment gathers that maybe this doesn't" [F1].

## Item phrasing, interpretation and presentation.

Phrasing of some items was thought to impact negatively on rapport building with clients and key informants, with one participant stating "you need to be very mindful about how you use the wording that's put in here to make sure that you maintain a clinical, or you know, a rapport with the patient" [F2]. Some items were viewed as ambiguously phrased, negatively influencing clients' understanding of the questions, with one participant saying "I often had to ask subsequent questions" [F1].

Interpretation of some items' meaning was perceived to be difficult, especially for therapists who used the FIM. A lack of detailed operational definitions for items on the PC-PART worksheet contributed to their confusion:

For the item 'Do you use the toilet OK?'... this was confusing.....we were wondering are we talking about FIM toileting, pants up and down, or are we talking about getting on and off the toilet?....there's no prompt...the prompt is 'not soiled'...so then are we talking about continence? [F1].

Participants expressed initial difficulty interpreting the meaning of the PC-PART's response categories. However, once familiar, therapists reported these "really helped with goal setting and helped [clients] be able to assess their own abilities" [F1]. The presence of a PC-PART score at the end of the assessment was also described as beneficial to interpretation of the extent of clients' support needs because otherwise, "if you are doing an initial assessment you don't have this clear [score], you just have a space to write the answer whether they're independent with A, B or C" [F1].

Overall layout and presentation of the instrument were viewed favourably, with one questionnaire respondent reporting "the sequence of questions was appropriate" [Q1]. One focus group participant said "the thing that strikes me most is I like the presentation of it, I think it was very easy to administer in the different colours and comes in a booklet" [F4]. Another said there was "enough space to [write on] it" [F1]. The same participant offered a suggestion for improvement saying "we probably would want to be able to document our goals directly related to this assessment....if this was to substitute our initial assessment we'd want [space to write] a goal and a treatment plan" [F1].

## External influences on clinical use.

Participants reported discontinuing use of the PC-PART because of their perceptions about duplication of information gathering, lack of perceived need or requirement to alter current information gathering practices, cost and existing institutional structures. One participant said "it looks at similar occupational performance issues to [the] initial assessment which I have to complete, so [there is] no reason or time to complete the PC-PART" [Q4]. The need to purchase the

PC-PART in order to use it was perceived as an additional negative influence on continued use of the PC-PART. Therapists perceived pressure in a cost-sensitive health environment to minimise spending, with one participant saying "the appeal of buying an assessment when we have demonstrated we can complete a similar kind of assessment at no cost, or at a lower cost, is obviously going to impact upon any decision to use it" [F6].

The PC-PART was also perceived not to conform to existing institutional structures for record-keeping: "We weren't filing [PC-PARTs] in the medical history but we would like to, so obviously it needs to be medical record friendly...so that would need to be considered" [F1]. However, some participants articulated how the PC-PART could be incorporated into their usual practice suggesting "it might have been more relevant if it was actually used within that discharge plan" [F6] and "it's about using the tool to aid assessment data gathering and discharge planning" [F1].

### **Discussion**

A mixed methods approach including a questionnaire followed by a focus group discussion provided detailed insights into occupational therapists' views about the clinical utility of the PC-PART for inpatient rehabilitation. Overall, clinical utility of the PC-PART was rated as moderate and aspects were identified for improvement. Methodological rigour and trustworthiness of the findings were enhanced by triangulation of data collection methods, use of an independent moderator and observer to conduct the focus group, achievement of saturation within the focus group discussion, peer review during the data analysis and maintenance of an audit trail.

Participants' familiarity with the PC-PART's purpose and method for completion influenced their views about its clinical utility. Those who felt familiar with the purpose and completion methods discussed how the assessment assisted clinical reasoning and provided useful information for problem identification, goal setting and intervention planning. Those who felt less familiar with the purpose of the PC-PART made comments reflecting their difficulty discriminating between the measurement construct of the FIM<sup>TM</sup> versus the PC-PART, and difficulty with procedural aspects when conducting the assessment. Therapists' difficulty discriminating the construct measured by the PC-PART could compromise validity of PC-PART item responses and therefore, assessment scores. Other research exploring challenges to measuring outcomes in occupational therapy had similar findings (Bowman, 2006). This highlights the need for therapists to recognise differences in the purpose and nature of the information gathered from various clinical assessments. (e.g. activity limitations [level of dependence] versus participation restrictions [unmet needs]) to ensure intended constructs are measured (Madden, Fortune, Cheeseman, Mpofu, & Bundy, 2013).

Lack of familiarity with the PC-PART instrument also negatively influenced therapists' perceptions about the time and effort required to complete the assessment. Participants supported attendance at training to develop confidence and efficiency using the instrument in the manner intended by the developer. This is consistent with Bowman (2006), who reported therapists expressed a need for support and supervision to facilitate routine measurement of clinical outcomes. Thus, we inferred that formal training seems both clinically valuable and an important enhancement of reliability and validity of item responses. Past studies investigating clinical utility of the PC-PART have drawn similar conclusions about therapists' perceived need for training (Barbara &

Whiteford, 2005; Smith, et al., 2001). A further Australian study found that formal training in the use of specific outcome measures increases the proportion of occupational therapists who use standardized outcome measures (Cook, McCluskey, & Bowman, 2007). Investigating the benefits of formal training for therapists in use of the PC-PART, versus a self-directed learning approach, may provide valuable evidence about the effect of training on reliability and validity of item responses and efficiency of the instrument's use. This would indicate whether investment of therapists' time, effort and resources to undertake formal PC-PART training is worthwhile.

The main barrier to using the PC-PART was the perception that it duplicated information from the locally developed departmental occupational therapy initial assessment. Participants believed using the PC-PART would add unnecessary time, effort and cost to their assessments. On the other hand, the PC-PART was also perceived to support therapists' clinical reasoning by comprehensively collecting the information needed for intervention and discharge planning important to clients' activities of daily living required for community life. So, while the PC-PART was perceived to gather clinically useful information, barriers existed to using the instrument routinely. Consistent with past research (Barbara & Whiteford, 2005; Radia-George, et al., 2014; Smith, et al., 2001), some participants could anticipate incorporating the PC-PART into the initial assessment to obtain the benefit of including standardized measurement into practice. However, as previously reported, the introduction and inclusion of standardized assessment and measurement, as part of routine occupational therapy practice has been challenging (Barbara & Whiteford, 2005; Bowman, 2006; Colquhoun, Letts, Law, MacDermid, & Missiuna, 2012; Kitsos, et al., 2011; Koh, et al., 2009; Pilegaard, et al., 2014; Stapleton & McBrearty, 2009).

Changing health care professionals' behaviour to reflect best practice has been identified as an important challenge for health care systems: there is a need for translation of evidence into practice using knowledge translation strategies (Graham et al., 2006; Grimshaw, Eccles, Lavis, Hill, & Squires, 2012; Squires, Sullivan, Eccles, Worswick, & Grimshaw, 2014; Walker, Fisher, Korner-Bitensky, McCluskey, & Carey, 2013). Knowledge translation has been described as ensuring stakeholders know about, and use, research evidence to inform decision-making in healthcare (Grimshaw, et al., 2012). Knowledge translation strategies can include interventions such as provision of printed materials; educational workshops; training leaders who are 'knowledge brokers' within an organisation; tailored interventions within a particular setting to improve professional practice; and educational outreach by trained persons who meet and work with providers to change practices (Grimshaw, et al., 2012). A recent overview of systematic reviews suggested that there is no compelling evidence that multifaceted interventions are more effective than single-component interventions in creating behaviour change (Squires, et al., 2014). It has been suggested that knowledge translation strategies are likely to be more successful if they are informed by an assessment of the specific barriers and facilitators within a given context (Grimshaw, et al., 2012; Walker, et al., 2013). Thus, understanding occupational therapists' perceptions about factors that promote or impede use of the PC-PART for inpatient rehabilitation is useful to this process of change.

A popularised organisational change formula (Beckhard & Harris, 1987; Dannemiller & Jacobs, 1992), proposed that change in practices (C) will occur when the product of employees' dissatisfaction with the present situation (D), their vision of what is possible (V), and their first steps towards reaching their vision (F) are greater than

their resistance to change (R) (i.e.  $C = D \times V \times F > R$ ). If any of these elements is absent or very low (i.e. close to zero), change will not occur, as the resistance to change will not be overcome. Consideration of this formula in conjunction with what is known about knowledge translation strategies suggests that enhancing occupational therapists' use of standardized assessments will require organisational vision about the purpose and value of such assessments in practice (V), along with support to facilitate their use (F). In addition, therapists and the organisation must be dissatisfied with current practice (D). In the present study, therapists' level of dissatisfaction with current initial assessment practices seemed low, suggesting little likelihood of overcoming resistance to change in practice. This simple conceptual formula may provide a useful structure for identifying where knowledge translation strategies may be targeted within an organisation to create behaviour change, for example, targeting therapists' level of dissatisfaction with current assessment practices.

Occupational therapists need to select assessments that measure anticipated changes in occupational performance as a result of our services. Participants in this present study were concerned that the PC-PART may not be sensitive to clients' change in their level of individual functioning during the course of inpatient rehabilitation and may not therefore, pick up activity-level improvements made by clients as a result of occupational therapy services. However, change in clients' individual abilities and need for assistance in self-care related mobility and cognition (activity limitations) were already measured during inpatient rehabilitation using the FIM<sup>TM</sup>, which has been validated for this purpose (UDSMR, 2014). The PC-PART was designed to measure ADL participation restrictions, or unmet needs. Reduction in ADL participation restrictions may arise during rehabilitation from occupational therapy services such as

arranging family or community supports, provision of adaptive equipment, and making environmental adjustments that enable clients to accomplish ADL required for community life. Benefits of these services on outcomes for clients are not directly measured using typically applied standardized assessments in inpatient rehabilitation settings, such as the FIM<sup>TM</sup>. Inpatient rehabilitation services focus on both restoration of individuals' functioning and substitution of function to enable discharge of clients to community living environments. It is therefore important to provide clarity for therapists of the conceptual difference between instruments that measure activity limitations, such as the FIM<sup>TM</sup>, and participation restrictions, such as the PC-PART. The type of information gathered by the PC-PART is unique, and complimentary to instruments such as the FIM<sup>TM</sup>. This is relevant not only to occupational therapists, but to health care teams, as it can provide information identified as important to discharge planning from inpatient settings (Moats, 2007; New, Cameron, Olver, & Stoelwinder, 2013; Shepperd et al., 2010).

Participants in this study were critical of the phrasing of some PC-PART items to the extent that it impacted on the acceptability of the instrument to therapists, clients and key informants. They provided specific, useful feedback and recommendations for improvements to instructions, operational definitions and item phrasing. It is anticipated that improvements in these areas would have a positive impact on therapists' perceptions about the time and effort required to administer the assessment, as there would be less time wasted trying to interpret the items. Such improvements may also reduce the time required for formal training of therapists. This is an area for further PC-PART instrument development and investigation.

One limitation of this study was the relatively small proportion (9/25) of participants from the eligible therapist population. However, all participants were experienced using the PC-PART, having completed at least 10 assessments and were able to provide varied, candid and useful insights about the instrument's use to the point of saturation in the focus group discussion. It is acknowledged that the views of non-participants could have differed to those of participants. One further limitation of this research was that most participants had used the PC-PART as part of a clinical trial and not purely for clinical purposes and therefore, most participants provided insights from this perspective.

### Conclusion

A mixed methods approach obtained rich data about one group of occupational therapists' perceptions of the clinical utility of the PC-PART for inpatient rehabilitation. The therapists perceived the PC-PART to be a moderately clinically useful aid to goal setting and discharge planning, by comprehensively measuring clients' participation restrictions in activities of daily living required for community life. Refinements to phrasing of some questions, providing operational definitions for items and scoring instructions on the worksheet, were viewed as necessary to make the assessment more acceptable and reduce, but not eliminate, the need for training. Training needs to emphasise the PC-PART's conceptual difference to other commonly used outcome measures in rehabilitation settings. Therapists' views that the PC-PART was time consuming to administer, duplicated their existing departmental initial assessment and was therefore, redundant, highlighted challenges associated with incorporating validated assessments into existing clinical assessment practices. Incorporation of the PC-PART into routine practice may require a knowledge translation strategy.

## **Key Messages**

- The PC-PART provides moderately clinically useful and comprehensive information about clients' participation restrictions in activities of daily living required for community life.
- Use of clinical utility criteria and a mixed method study design were effective means to identify potential refinements to the PC-PART that may enhance its practical use.
- Integration of standardized assessments into routine practice, such as the PC-PART,
   presented challenges, highlighting the need for a knowledge translation strategy to
   enhance routine use.

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### **Declaration Of Interest**

SD was the recipient of an Australian Postgraduate Award scholarship during this study, which contributed to her doctoral research program. SD is a Director of Darzins Consulting Pty. Ltd., which operates using the business name *The PART* 

Group. The PART Group distributes the PC-PART assessment. Darzins Consulting Pty Ltd is not financing this study or manuscript nor had any role in approving the final manuscript. During the last six years (January 2009-2015) SD has not received reimbursements, fees, funding or salary associated with sales of PC-PART products, from Darzins Consulting Pty. Ltd. SD does not hold and is not applying for any patents relating to the contents of this manuscript. All other authors declare that they have no competing interests.

# **Appendix A:**

## PC-PART individual items.

1 0 111111 11141114441 1001110.	
A. Clothing	D. Mobility
1. Dress: top	1. Mobility
2. Dress: bottom	2. Bed
3. Dress: footwear	3. Falls
4. Selection of clothing	4. Steps
5. Laundry	5. Outside
B. Hygiene	6. Driving
1. Toilet: transfer	7. Transport
2. Bladder control	8. Wandering
3. Bowel control	9. Orientation
4. Groom: hair	E. Safety
5. Groom: teeth	1. Medications
6. Groom: shave/menstruation	2. Substance Abuse
7. Bathing	3. Illness
8. Bath transfer	4. Emergency help
C. Nutrition	5. Smoking
1. Eat: weight	6. Hazards
2. Eat: choke	F. Residence
3. Meal: plan	<ol> <li>Money Management</li> </ol>
4. Meal: make	2. Security
5. Groceries	3. Personal Information
6. Food: restriction	4. Shopping
7. Stove	5. Temperature
<ol><li>Spoiled Food</li></ol>	G. Supports
	1. Adequate?
	2. Can cope? Stable?

Item Label	Question to patient	Question to key informant	<b>Observation</b> <sup>a</sup>	Standard task <sup>a</sup> (done with usual help)	Global response and score
Dressing	Do you get	Doesget	Top	Take off top and	OK by self [0]
top	your top dressed?	his/her top dressed?	adequately dressed?	put it back on.	OK with Help [0]
					Not OK [1]
Mobility	Do you get	Doesget	N/A	Mobilise around	OK by self [0]
(indoors)	around in your home	around in the home OK?		objects in the room.	OK with Help [0]
	OK?				Not OK [1]
Groceries	Do you get	Doesget	Adequate	Clarify situation	OK by self [0]
	your groceries?	his/her groceries?	groceries present?	through discussion.	OK with Help [0]
	Brownies.	grocerres.	present.	<b>4.150 4.</b> 5510111	Not OK [1]
Laundry	Do you get	Doesget	Absence of	Clarify situation	OK by self [0]
	your clothes laundered	clothes laundered	dirty laundry?	through discussion.	OK with Help [0]
	regularly?	regularly?		albeablett.	Not OK [1]

<sup>&</sup>lt;sup>a</sup>When observations are not possible within a clinical setting, situation needs to be clarified through discussion.

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## **Chapter 5 - Conclusions**

This study addressed the second specific research objective for this thesis, obtaining perceptions of one group of occupational therapists about clinical utility of the PC-PART for inpatient rehabilitation. Therapists' uptake of the PC-PART for clinical use following the research was low, resulting in limited experience of the PC-PART as a clinically used instrument in the sample. Valuable information was still obtained and can inform revision of the instrument to further enhance its clinical utility.

An updated summary of evidence about clinical utility of the PC-PART is provided in Table 5.1 (refer to shaded cells). Strong methods were used in this study, with an absence of important design flaws. Four of the eight clinical utility quality criteria were not endorsed. As discussed in the manuscript, these were: Item phrasing, time required to complete the assessment, cost and effort needed to complete the assessment.

Despite limited transferability of the findings due to limited sample diversity, this study did contribute useful evidence about the PC-PART's clinical utility for inpatient rehabilitation. It highlighted some of the challenges when incorporating standardised assessments into clinical practice. The insights gained from this study were useful for considering potential sources of measurement error and factors impacting on validity of PC-PART scores. For example, it was helpful to know that some therapists may not have recognised clinical differences in the information obtained by the FIM<sup>TM</sup> compared to the PC-PART, and may have misinterpreted the meaning of some PC-PART items. This type of knowledge was useful when analysing scores of individual items in the next study, evaluation of the internal construct validity of the PC-PART.

Table 5.1. Clinical utility - Summary of criteria met for each study included in the systematic review, plus findings from this present study (shaded row).

		•	'n	'n	'n	•	•			
I	Study	1. Clarity of instructions	2. Format of administration	3. Time to complete 4. Cost	5. Examiner qualifications & training	6. Effort required	7. Acceptability to clinician and patient	8. Clinical usefulness of information	9. Absence of important study flaws?	Utility criteria met /9
	Smith et al. (2001)	Yes-Straight- forward wording.	Yes-Good structure to assessment including both patient & carer input and options for observation.  Therapists wanted more room on summary sheet for recording goals, action plans, discharge plans and patient ID.	3. Yes-'Variable' but 'not too long'. HART did not add to overall assessment time. In-patient group had more concern about time taken. 4. No-Not Rated	Yes-*Formal HART training was provided and viewed as necessary. It took approx. 10 assessments after training to feel confident to use HART effectively. Required training to judge risk level.	Yes-Easy to use & complete HART. Relatively easy to integrate into current practice.	Yes-HART viewed as complimentary to current assessment. Conversational approach empowering to the patient and carer, asking for their individual perspectives. Provides prompts for new users Records what therapy is achieving.	Yes-Useful when setting therapy goals with patients. The tool structured rather than replaced what was already being done. Supports clinical reasoning process. Some concern over ability to correctly score some items in the hospital setting.	No - Gaps in reporting of some study methods and data analysis procedures undermined potential strength of the transferability and trustworthiness of the findings.	٢
l	Darzins et al. (2002)	Yes- Questions put simply. Some items needed to be rephrased to be understood by the patient.	Yes-Therapists who (incorrectly) used only the HART checklist later realised the value of completing the full worksheet, which allowed recording of the reasoning for assigned scores.	3. No-Not specifically addressed. 4. No-Not Rated	Yes. <sup>a</sup> Formal HART training was provided and viewed as necessary and valued to enable effective administration.	Yes-Simple to use once familiar with the assessment. Initially perceived as intimidating and lengthy.	Yes- HART viewed positively by OTs and PTs. Good supplement to current discipline specific assessments by structuring rather than replacing existing work. It empowered the patient.	Yes- HART viewed as a good checklist for discharge planning, useful for structuring family meetings, useful for assessment and management of complex' patients, promoted consistency of info.	No - Thematic analysis used to analyse focus group discussions lacked auditability. Not possible to discern if analysis was inductive, undermining data trustworthiness.	9
l l	Barbara et al. (2005)	No-Mixed responses to wording of HART items -perceived by one therapist to sound American (ie using "ok").	Yes-The combination of client interview, caregiver interview and task observation was viewed positively. Simple OK/Not OK scoring system was viewed positively as simple and easy to use in a time-limited situation.	3. Yes-Time varied between participants. HART took longer than standard initial assessment but was balanced by usefulness of the information obtained.	Yes-*Formal HART training was provided. Participants viewed access to specific HART training as desirable.	Yes-Required organization by therapist to speak to patient and carer, but this was perceived to have better outcomes for patients.	Yes-HART placed patient & families central to assessment process, it facilitated family discussion about how patient and family were managing with patient's living situation. HART facilitated clinical reasoning. Therapists felt empowered to discuss sensitive issues.	Yes-HART provided structure for discussion and focus for interventions to aid patient discharge. Scoring system enabled therapists to use established clinical reasoning processes. Some items are best addressed in the home environment.	No – Small sample lacked diversity, inductive analysis processes lacked auditability, weak strategies used to reduce. These undermined strength in transferability and trustworthiness of the findings.	9
209	Darzins No- et al. item (for sub- amb mission) phra diffi inter mea	No-Some items have ambiguous phrasing, difficulty interpreting meaning of some items.	Yes-The 3. No- combination of viewec service-user probler perspective, key duplica informant initial perspective and task assess observation viewed 4. No- positively. OK/Not as unn OK response cost. options viewed positively.	3. No-Time viewed as problematic if duplicating initial assessment. 4. No –Viewed as unnecessary cost.	Yes- <sup>a</sup> Formal training viewed as necessary and valued to enable accurate administration.	No-Effort too high if unfamiliar and if duplication of initial assessment.	Yes-Acceptable to both clinicians and clients, overall. Supports clinical reasoning, gathers clinically useful information and is comprehensive assessment, aids intervention and discharge planning.	Yes- provided structure for discussion and focus for interventions to aid patient discharge. Scoring system enabled therapists to use established clinical reasoning processes.	Yes – sound methods, inductive analysis, findings trustworthy for the group.  However, low transferability to other settings due to lack of diversity in sample.	S

<sup>a</sup> Qualified health professionals can administer the PC-PART. Formal training is not a requirement for using the PC-PART. Training is self-guided using the PC-PART manual & DVD. Abbreviations: Yes=positive rating; No=Not Reported (NR) or Negative rating.

## **Chapter 6. Internal Construct Validity of the PC-PART**

#### Introduction

This chapter addresses the third specific research objective in this body of research, which was to evaluate the internal construct validity of the PC-PART. As described in chapter two, CTT and IRT approaches to the evaluation of internal construct validity of health measurement scales have been used extensively in health research. In this chapter, advantages and disadvantages of using either CTT or IRT to evaluate internal construct validity of the PC-PART are discussed. A rationale for choosing Rasch analysis, as the preferred method, is given and an overview of Rasch analysis provided. The published manuscript is then presented, followed by a brief discussion about the contribution of this study to the overall aim of the validation research

## **Advantages of CTT Methods**

One advantage of CTT methods for evaluating internal validity of a scale is the familiarity of many researchers with CTT concepts. Researchers who have taken an interest in measurement and scale properties are likely to have encountered CTT with many currently available health measurement scales being developed using methods based on CTT (DeVellis, 2006). Another advantage is the broad access of researchers to statistical programs, aligned to CTT that are routinely used for performing procedures such as factor analysis and calculating coefficient alpha (DeVellis, 2006). Another potential advantage is that CTT is suited to particular instruments, such as those that add together scores from several items that are intended to contribute equally to the

same construct. By having several items tap the underlying construct, errors associated with each individual item have a relatively low effect on the scale's reliability (DeVellis, 2006). One further possible advantage is that items in a scale need only relate moderately to the underlying construct to produce favourable reliability scores (DeVellis, 2006). Thus, if scores from a health measurement scale have interval-level scale properties, then CTT methods may be appropriate for testing measurement properties and may be completed using readily available statistical programs.

## **Disadvantages of CTT Methods**

There are a number of problems with the assumptions of CTT and with scales constructed using CTT methods as outlined below.

1. Sample dependency: One disadvantage of CTT methods is that item and scale statistics only apply to groups of participants who completed the test (Cano & Hobart, 2011; Streiner et al., 2015). One implication of sample dependency is that "different samples with different variances will not yield equivalent data or data that can easily be compared across samples" (DeVellis, 2006, p. S58). This means that it is necessary to re-establish measurement properties of a scale if it is to be used with a different group of people or if items were altered, or a shorter version of the scale is to be developed (Streiner et al., 2015). It is also the case that the reliability and validity estimates of a scale are dependent on homogeneity of the sample. Another implication is that it is not possible to separate out the attributes of the people completing the scale from the properties of the scale (Streiner et al., 2015). There is a circular dependency in that the scores on an instrument depend on how much of the construct people in the sample have, while how much they have depends on the norms of the scale. For example, the

item-total correlations are dependent on the variance of the sample's scores and given a more, or less, homogeneous sample, these correlations will change.

- 2. Assumptions of item equivalence: In CTT it is assumed that each item contributes equally to the final score. However, both item statistics and clinical judgement inform us that some items provide a stronger indicator of the attribute than others, but there is no way to effectively build this into a scale (Streiner et al., 2015). For example, if a person scores five *Not OK*s on five items on the PC-PART, in CTT we would have to assume that a different person who scores five *Not OK*s on five different items, would have the same level of ADL participation restriction as the other person. We know from our clinical judgement that this cannot be assumed. Even though we know that people with different amounts of ADL participation restriction will likely respond negatively to different items in a scale, with CTT, it is impossible to predict how a person will respond on any given item if the items differ in their tendency to tap ADL participation restriction (the construct being measured). Summing the item scores to create a total score also assumes that all of the items are measured on the same interval scale. This assumption is deceptive because item scores are more likely to be ordinal rather than interval, and should therefore not be added together. For example, it cannot be assumed that the distance between response categories of OK by self or OK with help and Not OK are equal, nor that the amount of ADL participation restriction is equal from one item to the next (Cano & Hobart, 2011).
- 3. Assumptions of the standard error of measurement (SEM): In CTT we make the assumption that the error of measurement is the same at all places on the scale. This is not correct (Cano & Hobart, 2011). If the scores on a scale for a given sample are

relatively normally distributed, then more people will score in the middle range of values and because the sample size is larger there, the standard error of measurement (SEM) is smallest in the middle range of scores. The SEM increases towards the higher and lower score range. However, in CTT there is no summary statistic to capture SEM at each point along the range of scores of a scale. Also, once SEM is calculated, it is assumed to be the same for every individual, when it must be higher for people at the higher and lower scores than those in the middle range of scores (Feldt, Steffan, & Gupta, 1985). Another consideration is that the SEM for a given individual is dependent on the distribution of scores for that particular sample, and therefore it is dependent on the other people's scores in the sample. This is counter-intuitive, as how much a person's score changes on retesting because of sampling error (what SEM reflects) is a function of the individual, not other members of the sample (Streiner et al., 2015).

- 4. *Problems equating tests:* With CTT it is very difficult to equate scores a person receives on different versions of a test. This poses a particular problem for longitudinal studies because over time scales are revised with new sets of norms and people could be administered different versions of a test. The usual approach to equating scores in this situation is to compute a standardised *z* score or to use percentile equating, but this assumes that scores on all of the tests are normally distributed, which is improbable (Streiner et al., 2015).
- 5. Superficial similarities between items: Another disadvantage of CTT methods for evaluating internal validity of a scale is that the scales frequently contain many items and the items frequently appear similar. Superficial similarities between items can occur as a result of the significant effort required to generate items that correlate

strongly (DeVellis, 2006). This can result in a mixture of items that includes the construct of interest as well as superficial features that are not of interest. Thus, Devellis (2006) stated that "CTT methods have difficulty differentiating between common themes across items that are important to the trait [i.e. construct] of interest and common themes of this more superficial type" (p. S58).

# **Advantages of IRT Methods**

IRT has many advantages over CTT methods at a theoretical and practical level:

- 1. *Interval level measurement*. From the theoretical viewpoint, scales arising from IRT analysis have interval-level measurement properties. This means that objective measurement of change over time can be computed using parametric statistics. It is from the one-parameter Rasch model that interval-level measurement is achieved and from which person and item parameters can be separated (Bond & Fox, 2007).
- 2. Correct estimate of measurement error. Also from a theoretical standpoint, measurement error is more correctly estimated using IRT rather than CTT methods. In IRT, error values vary according to the respondent's score, whereas in CTT there is one value for the reliability and the SEM, which pertains to all respondents, irrespective of where they fall on the scale (Streiner et al., 2015).
- 3. *Test-free measurement*: From the practical view, one IRT method, Rasch analysis, allows for test-free measurement which means that people can be compared on a construct or attribute even if they respond to different items within a scale (Crocker & Algina, 1986). For example, from a set of 30 items measuring physical mobility ranging from complete immobility, to unrestricted pain-free movement, a person who responds

to an item indicating they can walk 100 metres on flat ground is assumed to have responded positively to all items indicating lower levels of mobility (e.g. being able to walk 10 metres on flat ground). If the person responds negatively to being able to walk 100 metres uphill, then it is assumed the person would not answer positively to an item reflecting more difficult, or higher levels of physical mobility. Knowing this, it is not necessary to administer all items to all people, only those items that straddle the point where the person switches from answering in one direction to answering in the other direction. That point places the person at a specific level along the *physical mobility* continuum. That point can be compared directly from one person to another person who was given a different subset of items. This form of testing is called adaptive testing and has been widely used in achievement testing, so that people at different levels can be given different items, yet be placed on the same scale (Velozo et al., 2008). Adaptive computerised testing has been adopted over recent years for some scales measuring function and disability across the lifespan (Coster et al., 2004; Haley et al., 2009; Hart, Mioduski, Werneke, & Stratford, 2006; Jette, Haley, Ni, Olarsch, & Moed, 2008; Velozo et al., 2008).

4. Flexibility in item response categories. Assessments yielding dichotomous and ordinal-level data may be analysed using IRT methods to produce interval-level measurement. Unlike the application of CTT, with IRT it is possible to have items with different responses within the same scale since the score assigned to each item is a function of its difficulty level and not the raw response. This gives the test developer flexibility in designing questions rather than being locked into the same response format (Streiner et al., 2015).

## **Disadvantages of IRT Methods**

There are some potential disadvantages of IRT methods, and/or situations where IRT may not be appropriate.

- 1. Assumptions of invariance: One of the purported advantages of IRT is that item characteristics are independent to the sample from which they were derived. This has been shown at a theoretical level, but studies have found differences from one population or test condition to another, suggesting that invariance does not necessarily hold (Nilsson & Tennant, 2011). In the context of educational tests, where IRT methods were first used, the populations being assessed may be considered relatively homogeneous. However, clinical populations are typically more heterogeneous, so that issues such as clinical context and the nature of the specific sample may affect item parameters (Streiner et al., 2015).
- 2. Assumption of unidimensionality: One consequence of the assumption of unidimensionality is that IRT cannot be used to construct indices. Thus, it would be erroneous to use IRT to construct indices, for example, of quality of life, symptom checklists and other tools, where the items themselves define the construct, rather than being manifestations of an underlying latent construct (Streiner, 2003a; Streiner et al., 2015). Further, IRT cannot be used when the underlying construct is itself multifaceted and complex. In this situation subscale scores cannot be summed to make a *global* scale.

Some researchers argue that participation, as defined by the WHO, is a non-hierarchical and multidimensional construct (Dijkers, 2010; Whiteneck & Dijkers,

2009). That is, participation may be made up of varied and unrelated aspects of involvement in a life situation and therefore, IRT methods may not be appropriate in the evaluation of participation measures. The same researchers propose an approach to the measurement of participation-related constructs that are suitable for multidimensional indexes (Dijkers, 2010). In such an approach, emphasis is on clinical meaningfulness of the measure. Items within the measure are not expected to be correlated as they are selected to reflect two or more behaviours or characteristics that together, define the latent concept of interest (Dijkers, 2010; Feinstein, 1983). The items are termed causal indicators (Streiner, 2003a) and each indicator item is relevant and important to the overall score. Instruments composed of unrelated items can be thought of as *indexes*, rather than scales (Streiner, 2003a). A frequently used example is the Apgar test (Apgar, 1953), which quantifies the survival potential of a newborn based on six vital signs that are not correlated. Items are chosen to be heterogeneous and to reflect all significant factors affecting the concept of interest (de Vet, Terwee, & Bouter, 2003). Ease of use is a prime consideration and face validity is important in selecting items and evaluating the measure as a whole (Dijkers, 2010). Items are not weighted in calculating an index total score. Streiner (2003b) has argued that health status questionnaires are either unidimensional scales or multidimensional indexes, and in both situations, validation approaches may be applied to their development and evaluation, but using different methods.

The argument against use of IRT methods for measures of the participation experience seems valid, especially given the notion that participation experiences encompass different environmental contexts of functioning, such as school, work and home, as well as different domains of functioning such as self care, domestic life,

relationships, community, civic and social life. For a participation-related measure to satisfy the measurement requirements of a unidimensional construct, it seems likely, then, that the measure may need to focus on a specific aspect of the participation, or participation restriction experience. For example, either people's attendance or their experience of involvement (Imms et al., 2016) in specific life activities, could be considered for measurement. Thus, a measure of participation restriction may need to focus on a specific life situation and/or one dimension of the participation construct to meet the assumptions for measuring a unidimensional construct.

## Rationale for Application of IRT Methods to the PC-PART

The PC-PART was confirmed theoretically, as a measure of participation restriction in ADL required for community life, in the theoretical validation study described in Chapter four. The instrument focuses on the accomplishment of activities from the mobility, self care and domestic life domains of the activities and participation component of the ICF, and is therefore relatively limited in scope. It therefore seemed possible that the PC-PART may measure a single construct and that scores may identify people as experiencing more (higher levels of) or less (lower levels of) participation restriction. Participation restrictions across several essential ADL required for community life may be moderately correlated with one another. This may be especially so where a person's level of functioning with one activity, such as mobility indoors, might be expected to have a moderate association with functioning in another activity, such as toileting, or bathing, or getting in/out of bed. In addition, because the PC-PART item responses are dichotomous and scores produce ordinal-level data, the instrument was suited to IRT rather than CTT test validation methods. Thus, with consideration of

all of these factors, methods aligned to IRT to test internal construct validity of the PC-PART were favoured. Specifically, use of Rasch methods were chosen for the evaluation.

## **Overview of Rasch Analysis**

Rasch methods test if dichotomous responses from a set of items within an instrument can be summed together, to provide a total score. The Rasch model is a 1-parameter model within the framework of Item Response Theory (IRT) models (Rasch, 1960; Velozo et al., 2012). The model involves testing *fit* of an instrument's scale to the Rasch model, a mathematical measurement model, developed in 1960 by Georg Rasch, a mathematician from Denmark (Rasch, 1960; Tennant & Conaghan, 2007).

Descriptions of the assumptions underlying Rasch analysis and what Rasch analysis does, are available in many texts, but a succinct description was provided by Velozo et al., (2012), as follows:

[Rasch analysis] assumes that the proportion of individuals who respond correctly to an item is a function of *person ability* and *item difficulty*. Rasch analysis examines whether each item fits the [construct] being measured and calibrates scale items along a hierarchy, matching item difficulty to person ability. Item difficulty and person ability estimates are log transformed and converted to an interval measure called a logit (log odds unit), with a mean item difficulty arbitrarily set at zero. Easier items are assigned negative difficulty estimates and more difficult items are assigned progressively positive difficulty estimates. Each item is assigned an error estimate for the logit difficulty estimate based on

how well the item and person fit the model. The relationship between item difficulty, person ability and item discrimination is graphically represented by an S shaped item characteristic curve in which the slope represents item discrimination." (p. S155)

The Rasch model therefore satisfies many of the requirements of objective measurement put forward by Thurstone in the 1920s and early 1930s, such as unidimensionality, linearity, sample-free calibration and test-free measurement (1926, 1928, 1931). An important aspect of Rasch analysis is that it ensures scales are unidimensional (if they show adequate fit to the Rasch model), a fundamental requirement of internal construct validity (Streiner et al., 2015).

Rasch modelling has been applied in educational contexts for several decades and has gained popularity in the validation of health measurement scales over the past two decades, particularly in rehabilitation and in the measurement of quality of life (Silverstein, Fisher, Kilgore, Harley, & Harvey, 1992; Silverstein, Kilmore, Fisher, & Harvey, 1991; Tennant & Conaghan, 2007; Tennant et al., 2004). Many patient reported outcome measures used in health care and health care research focus on attributes that are not directly measurable, such as pain, quality of life or, in the case of the PC-PART, participation restriction in ADL required for community life. These measures may give a total score of the construct being measured. Most outcome measures used in health care have been developed as ordinal-level scales. Total ordinal scores derived from scales developed in this way indicate some rank on a perceived underlying construct. Ordinal-level score data precludes use of parametric statistical operations (Svensson, 2001). Although non-parametric tests are available, and may be used with ordinal-level

data, calculation of change scores and *effect sizes* in clinical trial analyses requires normally distributed, interval level measurement. Rasch analysis enables conversion of ordinal-level data into linear, interval-level data, if adequate fit to the Rasch model is satisfied (Tennant & Conaghan, 2007). Of note, Rasch analysis has previously been applied to measures of both personal and instrumental activities of daily living (Clemson et al., 2009; Coster et al., 2004; das Nair, Moreton, & Lincoln, 2011; de Morton, Keating, & Davidson, 2008; Finlayson, Mallinson, & Barbosa, 2005; Glenny, Stolee, Thompson, & Husted, 2012; Linacre, Heinemann, Wright, & Granger, 1994; Ostir et al., 2006). Tennant and Conaghan (2007) list ways that Rasch analysis can be applied, such as when:

- 1. Developing a new scale;
- 2. Reviewing measurement properties of an existing ordinal scale;
- 3. Testing the dimensional structure of ordinal scales, and whether sets of items from different scales can be joined together to form a higher-order scale that fits the Rasch model;
- 4. Constructing item banks as the basis of *computer adaptive testing*, to calibrate items so that a person's level on a construct can be measured using a subset of the total pool of items; and
- 5. There is a need to calculate change scores from ordinal scales. (p. 1359)

Dichotomous versions of the Rasch model (two item response categories) (Rasch, 1960), and polytomous versions (more than two item response categories), such as the partial credit model (Master, 1982) and rating scale model (Andrich, 1978), are available. In both versions, the hierarchy in response patterns achieved for a set of

items, when item scores are designed to be summed together, are tested against expectations of the model. When the observed response pattern coincides with, or closely matches the expected response pattern, the items are considered to fit the Rasch measurement model and comprise a unidimensional scale. This is similar to a type of Guttman scaling, based on probability principles (Tennant & Conaghan, 2007). In Guttman scaling, there is an expectation of a strict hierarchical order of items from low to high levels of the construct being measured (e.g. from low to high levels of participation restriction). For example, if a rehabilitation service-user (using a dichotomous response) affirms an item on the PC-PART, representing an activity deemed to indicate a certain level of participation restriction in ADL required for community life, then all the items below that activity on the scale should also be affirmed. However, the Rasch model is based on a stochastic model that is slightly less strict than Guttman scaling and articulates that if an activity indicating a high level of the construct is affirmed, for example, participation restriction in ADL required for community life, then there is a high *probability* that activities indicating lower levels of the same construct will also be affirmed (Tennant & Conaghan, 2007, p. 1358).

The Rasch model assumes that the probability of a person affirming an item is a logistic function of the relative distance between the person's location parameter, or level of the attribute, for example, participation restriction, and the item location parameter, or level of participation restriction expressed by the item, and *only* a function of that difference (Tennant & Conaghan, 2007, pp. 1358-1359). Fitting data to the Rasch model places both item and person parameter estimates on the same log-odds units (logit) scale, and it is this that provides the linear transformation of the raw score to Rasch-derived interval level measurement (Pallant & Tennant, 2007, p. 3).

## **Application of Rasch Analysis**

Statistical procedures are used to indicate the extent that observed data from the scales fit expectations of the Rasch model. Thus, it is the model that defines measurement. Therefore data are *fitted* to the model to see if they meet the model's expectations (Pallant & Tennant, 2007). These analyses are undertaken using proprietary software such as WINSTEPS (Linacre, 2012), RUMM2030 (Andrich, Sheridan, & Luo, 2012) or ConQuest (Adams, Wu, & Wilson, 2012). Although each program tests whether the response patterns observed in the data match the theoretical patterns expected by the model, the individual programs report findings in varying ways. In this study RUMM 2030 software was used. Fit to the Rasch model was evaluated using the methods described below.

## Overall fit.

Overall fit statistics provide a summary of overall fit of the scale to the Rasch model. In RUMM2030 three overall fit statistics are considered:

- 1. An *item-trait* interaction chi-square interaction fit statistic. This is calculated using an alpha value set at 0.05, with a Bonferroni adjustment for the number of items (0.05/number of items in the scale) (Bland & Altman, 1995). A significant chi-square statistic indicates "that the hierarchical ordering of the items varies across the [construct], thus compromising the required property of invariance" (Pallant & Tennant, 2007, p. 5);
- 2. Summary item-person interaction fit residual statistic for *items*; and
- 3. Summary item-person interaction fit residual statistic for *persons*.

For both (2) and (3), above, Pallant and Tennant (2007) explain that the "item-person interaction statistics [are] transformed to approximate a *z* score, representing a standardised normal distribution" (p. 5). Also, if both *persons* and *items* fit the model, a mean near to zero and a standard deviation of one would be observed (Pallant & Tennant, 2007). The standard deviation (*SD*) of the estimated means for *items* and for *persons* would have a value of one for a perfect fit, and should not deviate above 1.5. Values above 1.5 indicate the presence of misfitting *items* or *persons* which require further investigation (Pallant & Tennant, 2007).

## Suitability of item response categories.

Individual items with more than two response categories are called polytomous items. The Rasch model holds the expectation that within a set of polytomous items, the response categories are defined and *function* in the same way for each item (Pallant & Tennant, 2007). The term *function* in this context means that the distances between the transition points across response categories are the same across all items. These transition points are called thresholds. Thresholds identify a point between adjacent response categories for a given item where either response category is equally probable (Pallant & Tennant, 2007). A likelihood ratio test determines whether this is the case, indicating whether the thresholds for each item are *ordered* or *disordered*. All items are expected to have *ordered* response thresholds, thus consecutive thresholds are expected to demonstrate an increase of the underlying construct (Pallant & Tennant, 2007). Where this does not happen, thresholds are considered *disordered*. *Disordered* thresholds occur when respondents do not consistently discriminate between the item response categories relative to the level of the construct being measured (Pallant &

Tennant, 2007). This can typically occur when labelling of response categories is confusing or ambiguous or when there are too many response categories. *Disordered* thresholds are usually resolved by reducing the number of response categories in the items (Pallant & Tennant, 2007).

### Individual item fit.

RUMM2030 provides individual item-fit statistics in addition to overall item fit statistics. These enable checking for individual item *misfit* in the scale, which may contribute to reducing overall fit of the scale to the Rasch model. Individual item fit residual statistics are calculated to identify if individually observed item scores deviate from their expected values, summed over all persons (Pallant & Tennant, 2007). Individual item fit residuals of between  $\pm$  2.5 indicate adequate fit to the model. The chi-square probability value associated with each item fit residual should be statistically non-significant. Bonferroni corrections are applied to the chi-squared p value to make adjustments for multiple testing (Bland & Altman, 1995; Pallant & Tennant, 2007).

## Individual person fit.

Examination of person fit is important because respondents who have residual scores outside an acceptable range may cause significant item misfit (Pallant & Tennant, 2007). If unexpected person responses are not investigated to find out why some people may have responded to items differently to others, scales may be discarded inappropriately during the validation process (Pallant & Tennant, 2007). According to Pallant and Tennant, this seems to be more of an issue in respondent-completed instruments and less of an issue with clinician-administered instruments. Removal of

misfitting persons from the analysis may improve the scale's internal construct validity but may compromise external construct validity of the scale for the respondent group (Pallant & Tennant, 2007).

## Internal consistency reliability.

Internal consistency reliability reflects the strength with which the measure is able to reliably differentiate respondents with differing levels of the construct being measured. An estimation of the internal consistency reliability of the scale in Rasch analysis is the Person Separation Index (PSI). The PSI relies on respondents' logit scale estimates to calculate reliability (Tennant & Conaghan, 2007). The PSI estimates the spread of persons across the measured variable (Bond & Fox, 2007). Values for PSI exceeding 0.70 indicate acceptable internal consistency of a scale for use with population scores. Values for PSI exceeding 0.85 are considered acceptable for use with individuals' scores (Tennant & Conaghan, 2007).

## Differential Item Functioning (DIF).

Differential item functioning (DIF) can potentially violate the required property of invariance. DIF occurs when specified groups within the sample that are expected to behave similarly, for example males and females, actually respond differently to an individual item, despite equal levels of the construct being measured (Tennant & Conaghan, 2007). Two types of DIF may be identified: Uniform and Non-uniform DIF. Uniform DIF occurs when one group (e.g. females), shows a systematic difference to another group (e.g. males), in their responses to a specific item, across all levels of the construct being measured. Non-uniform DIF occurs when there are non-systematic

differences between groups in their responses to a specific item, across all levels of the construct being measured. The absence of DIF indicates that an item works invariantly across the sub-groups examined (e.g. gender and age) and the probability of endorsement of the item is conditional on the construct alone (Tennant & Conaghan, 2007). If one gender or age group displayed a different probability of affirming the item (for items with dichotomous response categories) then this item would be considered to display DIF, violating the requirement of invariance (Tennant & Conaghan, 2007).

To test for the presence of DIF, analysis of variance between scores for the subgroups (e.g. males and females) across all levels of the construct are computed. A significant Bonferroni adjusted *p*-value is indicative of Uniform or Non-Uniform DIF between the scores across all levels of the construct for identified groups (Pallant & Tennant, 2007). Uniform DIF may be remedied by splitting the file by group, and separately calibrating the item for each group. Non-uniform DIF cannot be resolved. A series of complex tests may be used to investigate the magnitude of the effects of DIF. When an item shows evidence of DIF, biasing influences on the scale can be checked. This is carried out by comparing the person estimates derived from all items in the scale with those derived from the items not showing DIF (Tennant & Pallant, 2007). The estimates at the individual person level can be inspected to see the extent of difference. If person estimates differ by less than 0.5 of a logit, which has been defined as a trivial impact (Wright & Panchapakesan, 1969), then there is little influence of DIF on the scale and no further action needs to be taken (Tennant & Pallant, 2007; Teresi, 2006).

When investigating evidence of DIF for PC-PART items, the specified groups are gender and age. However, not all PC-PART items may be expected to have the same

probability of men and women affirming them, even though both men and women may have the same level of ADL participation restriction. There may be variation between men and women on some items if traditional gender divisions of roles within the home prevail (e.g. laundry, shopping, meal preparation). Similarly, there are PC-PART items that seem more likely to be affirmed with increasing age, such as bladder and bowel control. Therefore, evidence of DIF during Rasch analysis needed to be evaluated and judged using statistical evidence as well as clinical reasoning about what would be expected in the population.

## Local response dependency.

The Rasch model holds the assumption that items have local independence. This requires that the response to any one item is not dependent on the response to any other item. This assumption is tested through inspection of the residual correlation matrix from the principal components analysis (PCA) of the residuals. No association between residuals for individual items provides evidence that items are independent of one another, and this is labelled *local item independence* (E. Smith, 2002). Local item independence across items in a scale supports unidimensionality of the scale (E. Smith, 2002). High positive correlation between individual item residuals provides evidence that responses to those items are dependent on response to other items, and is labelled *local item dependence*. Presence of local item dependence may inflate internal reliability of the scale and may indicate item redundancy (Tennant & Conaghan, 2007). High negative correlations between item residuals may indicate multidimensionality. In accordance with other studies, local dependency between item pairs in this present research was considered to be present for residual correlation values exceeding 0.2 (de

Morton et al., 2008; La Porta, Caselli, Susassi, Cavallini, & Tennant, 2012; Linacre, 2002).

If item dependence is detected between pairs of items, it may be necessary to form a *combined item* by joining the locally dependent items together in the analysis as though they are one item and re-evaluating the scale. Re-evaluation of the scale that includes the combined item should be undertaken to determine the effect on PSI. If the effect on PSI is negligible, then inclusion of both items is not considered to artificially alter PSI, however, it does indicate that one of the items is redundant in the scale. If PSI is altered by the subtest, one item should be removed (E. Smith, 2002).

## Dimensionality of the scale.

One essential expectation of the Rasch model is of scale unidimensionality. Unidimensionality may be assessed using the Principal Components Analysis (PCA) on the residual correlations among the items. The PCA residuals are used to identify subsets of items with high positive or negative correlations on the first un-rotated Principal Components factor. A series of paired *t*-tests are undertaken to compare the magnitude of difference between person estimates for the two opposing sets of items. The percentage of paired *t*-tests outside of the range +/- 1.96 is computed (E. Smith, 2002). Unidimensionality is supported if 5% or less of the paired *t*-tests are statistically significant at *p*=.05 level of significance, as determined by the calculated range of the 95% confidence interval of the estimated proportion of significant tests. According to Smith (2002), this approach is sufficiently robust to detect multidimensionality. This method for evaluating unidimensionality has also been adopted by others (Hagquist, Bruce, & Gustavsson, 2009; Tennant & Conaghan, 2007; Tennant & Pallant, 2006).

## Targeting of items.

In clinical practice, a well-targeted measure requires that items target different levels of the construct intended for measurement in the populations in which they are used, without floor or ceiling effects (Hagquist et al., 2009; Pallant & Tennant, 2007). In Rasch analysis software, the item with average difficulty for the scale is always centred on zero logits (Tennant & Conaghan, 2007). In a well-targeted scale the mean logit value for persons would also approximate zero. If a positive mean logit value for persons is obtained, this indicates that the whole sample is located at a higher-than-average level of the construct being measured. A negative mean logit value for persons would suggest the sample as a whole is located as a lower-than-average level of the construct (Tennant & Conaghan, 2007). If many persons have logit values at the margins, then arguably, the scale is not properly targeted (Pallant & Tennant, 2007).

Targeting can be viewed using a person-item threshold distribution map, which displays the spread of items relative to the level of the construct being measured in the persons within the sample. A well-targeted scale shows the items spanning the full range of individual person scores, and importantly, displays items that capture people at high and low levels of the construct. Demonstrating that the scale identifies people at high and low levels of the construct indicates a lack of ceiling and floor effects within the scale. A scale showing a ceiling or floor effect may indicate the need for new items to be developed for the scale, in the attempt to measure persons with very high or low levels of the construct, if that is important for the construct being measured.

## Improving the scale construct

Where statistical tests reveal failures to meet Rasch assumptions and therefore show poor fit of the scale to the Rasch model, the scale can be modified and reevaluated to determine if the scale's internal construct validity can be improved.

Attempts to refine a scale involves progression through several iterations of the Rasch analysis (Bourke-Taylor, Pallant, & Law, 2013; La Porta et al., 2012; Shea, Tennant, & Pallant, 2009). Each iteration is conducted to evaluate the effect of one action on the fit of the scale to the Rasch model, and each iteration is dependent on the outcome of the immediately preceding analysis. Throughout the refinement process, misfitting items are removed and combined items are constructed where local response dependency is present. The endpoint for each stage of the analysis is the point where further refinement does not improve the scale's fit to the Rasch model.

Where scales demonstrate adequate fit to the Rasch model, and the assumptions of the model are upheld, interval-level conversion scores for the scales may be computed from the Rasch-derived interval-level item location scores. Conversion scores enhance ease of use of the scale in clinical practice. A commonly used scale is a 0 to 100 scale.

The next published paper describes use of Rasch analysis with PC-PART data to evaluate its internal construct validity and refinements to the scales within the instrument. Documents supporting ethical clearance for the procedures used, are located in Appendix E.

## Paper 4: Internal Construct Validity of the PC-PART

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## **RESEARCH ARTICLE**

**Open Access** 

# Evaluation of the internal construct validity of the Personal Care Participation Assessment and Resource Tool (PC-PART) using Rasch analysis

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#### **Abstract**

**Background:** The Personal Care Participation Assessment and Resource Tool (PC-PART) is a 43-item, clinician-administered assessment, designed to identify patients' unmet needs (participation restrictions) in activities of daily living (ADL) required for community life. This information is important for identifying problems that need addressing to enable, for example, discharge from inpatient settings to community living. The objective of this study was to evaluate internal construct validity of the PC-PART using Rasch methods.

**Methods:** Fit to the Rasch model was evaluated for 41 PC-PART items, assessing threshold ordering, overall model fit, individual item fit, person fit, internal consistency, Differential Item Functioning (DIF), targeting of items and dimensionality. Data used in this research were taken from admission data from a randomised controlled trial conducted at two publically funded inpatient rehabilitation units in Melbourne, Australia, with 996 participants (63% women; mean age 74 years) and with various impairment types.

**Results:** PC-PART items assessed as one scale, and original PC-PART domains evaluated as separate scales, demonstrated poor fit to the Rasch model. Adequate fit to the Rasch model was achieved in two newly formed PC-PART scales: *Self-Care* (16 items) and *Domestic Life* (14 items). Both scales were unidimensional, had acceptable internal consistency (PSI =0.85, 0.76, respectively) and well-targeted items.

**Conclusions:** Rasch analysis did not support conventional summation of all PC-PART item scores to create a total score. However, internal construct validity of the newly formed PC-PART scales, *Self-Care* and *Domestic Life*, was supported. Their Rasch-derived scores provided interval-level measurement enabling summation of scores to form a total score on each scale. These scales may assist clinicians, managers and researchers in rehabilitation settings to assess and measure changes in ADL participation restrictions relevant to community living.

**Trial registration:** Data used in this research were gathered during a registered randomised controlled trial: Australian and New Zealand Clinical Trials Registry ACTRN12609000973213. Ethics committee approval was gained for secondary analysis of data for this study.

**Keywords:** Rehabilitation, Activities of daily living, Outcome assessment, Validation studies, Construct validity, World Health Organisation, Participation

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#### **Background**

Participation is described in the International Classification of Functioning, Disability and Health (ICF) as a person's involvement in a life situation. Participation restrictions are described as problems a person may have in their involvement in a life situation [1]. Activities are described as execution of tasks or actions by a person. Activity limitations are difficulties a person may have in executing activities [1]. Much has been said about the ICF's lack of clarity in these definitions and the difficulties operationalizing these concepts [2-5]. To date, there is no consensus about the definition of the concept of participation (restriction), nor the measurement of participation (restriction) [4].

There is division amongst researchers as to whether Self Care and Domestic Life tasks classified within the ICF belong to the activity or to the participation construct [2,6]. Such allocations have generally been made according to content of the categories within these domains. The distinction between measurement of constructs that are more closely aligned to activity (limitation) versus participation (restriction) may depend not only on the content of the items within an instrument, but also on the metric used in the measure [3]. Measures eliciting information about an individual's ability, level of difficulty, level of dependence in performing tasks, without inclusion of the modifying effects of the environment in the metric, are more closely aligned to the measurement of activity (limitation). Measures eliciting information about actual performance of, and satisfaction with, tasks in environments where they occur, and which include in the metric, influences of the environment and health condition on performance and satisfaction, are more closely aligned to the measurement of participation (restriction) [3].

The Personal Care Participation Assessment and Resource Tool (PC-PART) records the transaction between the person, their health condition and environmental factors operating in the person's living situation, resulting in measurement of the person's met and unmet ADL needs in their living situation (life situation). It is important to measure both met and unmet ADL needs in order to understand the nature and extent of problems people experience accomplishing both self care and domestic life activities of daily living required for community life, and their involvement in community living as a citizen. Unmet ADL needs, as measured by the PC-PART, are aligned to the construct of participation restriction and are therefore named ADL participation restrictions.

The PC-PART is divided into 43 items across seven domains: *Clothing*; *Hygiene*; *Nutrition*; *Mobility*; *Safety*; *Residence*; and *Supports*. It is a clinician-administered assessment and uses a structured interview format to gather information and item responses from the person and if necessary, key informant(s). Item responses are:

OK by self (patient manages activity alone with or without aids and appliances in the living environment), OK with help (patient manages activity with help from others, and this help is available in the living environment), or Not OK (patient does not manage the activity in the living environment despite their own efforts, use of aids and appliances and help from available support from others). Both OK by self and OK with help are scored 0, and *Not OK* is scored 1, forming a dichotomy. Each Not OK represents an ADL participation restriction and provides a target for intervention. The final domain, supports, consists of two questions addressing the adequacy and stability of available supports, with responses OK and Not OK. Conventional overall scoring of the PC-PART involves summation of *Not OK* responses to produce a total score, producing ordinal data.

There is an important and clinically relevant distinction between the PC-PART and other ADL measures. Commonly used ADL instruments in Australia, such as the FIM [7] and Barthel Index (BI) [8] measure a person's capabilities and their individual level of independence/dependence in self care activities of daily living and mobility. These are therefore measures of activity (limitations). While this is clinically important information to gather, such ADL measures stop short of measuring actual accomplishment of activities of daily living in the person's living environment. This is because they do not incorporate into the measurement, the availability and stability of specifically needed assistance to the person in their living environment. This latter information is clinically relevant. For example, for discharge planning, it is the aim of health services to address people's ADL needs required for community living before returning people to live in the community. The PC-PART was designed to achieve this.

There are other ADL measures that specifically address supports, resources or assistance (environmental barriers and facilitators) as part of their responses and scoring, including the Assessment of Living Skills and Resources-Revised 2 (ALSAR-R2) [9], Assessment of Life Habits (LIFE-H) [10], Craig Handicap Assessment and Reporting Technique (CHART) [11] and the Functional Autonomy Measurement System (SMAF) [12]. However, the ALSAR-R2, LIFE-H and CHART cover broader areas of functioning than the PC-PART (such as education, work and leisure) and therefore have application in different environments from the PC-PART. The SMAF was developed for the measurement of care needs in older adults in order to allocate community services or chronic care beds [12]. It was not developed for use with younger people. While the SMAF covers essential self care and domestic life activities of daily living, it differs from the PC-PART in that it also includes items focused on body functions (e.g. vision, speaking, hearing, memory). Each instrument described above varies in the way it incorporates the availability and the need for supports, resources or assistance into the instrument's scoring. The PC-PART is the only instrument we are aware of that specifically targets the transaction between the person, the activity and the available supports in the person's living environment to record participation restrictions in those activities of daily living required for community life.

The PC-PART has demonstrated content validity [13] and good inter-rater reliability for grouped data [14-16], but its internal validity has not been subjected to rigorous evaluation [15]. Whether it is valid to sum PC-PART item scores has not been tested. For clinicians, health-service managers and researchers to have confidence in any measurement instrument, and the scores derived from it, evidence of internal and external validity of the instrument is required. Therefore, the aim of the current study was to evaluate the internal construct validity of the PC-PART to address this gap in the tool's validation, and to refine the instrument, if necessary, using Rasch methods [17].

#### **Methods**

#### Design

This was an instrument validation study. Methods based in Item Response Theory have increasingly been used to evaluate psychometric properties of health measures, and have been applied to both personal and instrumental ADL instruments [18-22]. The Rasch model is a oneparameter model within the Item Response Theory framework [23,24]. It involves formal rigorous psychometric testing of a scale against a mathematical measurement model by testing the scale's fit to the Rasch model [17,25,26]. The model asserts that scale item scores can only be appropriately summed to provide a total score if the scale is unidimensional. If items satisfy expectations of the Rasch model, the analysis enables transformation of the scale's ordinal raw scores to interval-level measurement [26,27]. Methods based in Classical Test Theory (CTT), such as Factor Analysis and Confirmatory Factor Analysis, were not appropriate for this study because PC-PART items violate assumptions that scale items have interval-level properties [24].

## **Participants**

This study involved secondary analysis of data from 996 adult inpatient rehabilitation participants in Melbourne, Australia, enrolled in a trial of standard versus augmented therapy (ACTRN12609000973213) [28]. The PC-PART was administered as an outcome measure at admission to, and at discharge from the inpatient rehabilitation unit. Participants were included in the trial if they were aged 18 years or older, were admitted for rehabilitation to one of two government-funded hospital facilities and consented to participate in the trial. Patients were excluded if they were

admitted for geriatric evaluation and management, or if they were already enrolled in another intervention trial. The rehabilitation setting provided therapeutic intervention and multi-disciplinary management.

Participants' admission PC-PART data were used in this study. The PC-PART was administered by an occupational therapist blinded to group allocation. The occupational therapist completed PC-PART assessments using a combination of patient interview, key informant interview and task observation. The occupational therapist assessor was provided with standardized education in the use of the PC-PART prior to commencement of data collection. This consisted of a one-hour training session with an occupational therapist experienced in use of the PC-PART. In addition, the PC-PART manual [29] and DVD [30] were made available.

This secondary analysis of trial data was approved by Human Research and Ethics Committees at Eastern Health (E58/0910) and La Trobe University (FHEC10/14).

#### Data analysis

Rasch modelling procedures consistent with established guidelines were adopted [25-27,31,32], using RUMM 2030 software [33]. For a 41-item scale, a sample size of 250 for well-targeted items, or 820 for poorly-targeted items, provides 99% confidence that person estimates are definitive [34]. Therefore, the sample of 996 in the current study was adequate.

Analysis methods and criteria applied to tests of fit to the Rasch model included assessment of (1) overall fit to the Rasch model; (2) item response format; (3) individual item fit; (4) individual person fit; (5) Differential Item Functioning (DIF); (6) internal consistency; (7) local dependency among items; (8) dimensionality of the scale, and (9) targeting of items.

In large samples and with scales involving large numbers of items, the chi-square statistic may not be a reliable indicator of fit to the Rasch model. Therefore, in this study, other fit statistics were used. Overall fit to the model was observed using Fit Residual values, with a Fit Residual Standard Deviation value exceeding 1.5 suggesting possible misfit. To assess fit of individual items and persons to the scale, it was expected that the individual item and person Fit Residual values should fall within the range of  $\pm 1.5$  [27].

Problems with an item's response format were indicated by the presence of disordered thresholds. A threshold is the point between two response categories where either response is equally probable. Inconsistent use of item response categories results in disordered thresholds. Presence of disordered thresholds indicated the need to reduce the number of response categories [25,27].

Differential Item Functioning (DIF) occurs when different groups within the same sample (e.g. men and women) respond differently to an item despite having equal levels

of the underlying trait. Both uniform (systematic) and non-uniform (not systematic) DIF by age and sex were examined. Items displaying DIF were evaluated for their clinical importance to the scale versus the potential for improvement of the internal validity of the scale resulting from their removal [27]. The Person Separation Index (PSI) provided an indication of the internal consistency of the scale and the power of the scale to discriminate amongst persons with different levels of the trait. A value of at least 0.7 was considered acceptable [25].

Local dependency between item-pairs was considered to exist when the response to one item was dependent on the response to another item, revealing between-item residual correlations matrix values above 0.2. Item-pairs showing local dependency above 0.2 were examined for potential item-redundancy using clinical judgement. Items were further examined to identify if retaining both items inflated the scale's PSI value. This was assessed by forming 'subtests', joining locally dependent item pairs, to absorb the effect of the dependent items on PSI [25]. If the PSI value then changed by more than +/- 0.1, consideration was then given to removal of one of the locally dependent items from the scale.

To test dimensionality of the scales, items with strongest positive and negative loadings from the first component of the Principal Components Analysis of the standardised residuals were used in a series of independent t-tests to test the null hypothesis of no difference in the individual person location scores between the two sets of items. If fewer than 5% of the t-tests showed statistically significant differences, or the lower bound value of the associated 95% confidence interval was 5% or lower, then the scale was considered unidimensional [26,31,35].

Targeting of items in the scale was checked with a person-item map to evaluate if there were sufficient items to measure the full extent of clinically relevant ADL participation restrictions among persons, without ceiling effects [25,27]. Floor effects were not considered relevant in this evaluation, as clinical teams are more concerned about addressing the presence of ADL participation restrictions, rather than the absence of participation restrictions prior to discharge from the hospital setting.

Rasch analysis was conducted in three stages on 41 PC-PART items listed in Table 1, column 1. The two *Supports* items were excluded from all analyses as they were considered to be global items, measuring a different construct to the remaining PC-PART items. During Stage one of the analysis, the 41 items were analysed as one scale, consistent with the recommended scoring protocol. The alternative three-category item response options (0 = OK by self, 1 = OK with help and 2 = Not OK) were also evaluated to determine if they were appropriate for use, instead of the existing two-category item response options (0 = OK by self, 0 = OK with help and 1 = Not OK). In Stage two of the

analysis, fit to the Rasch model was evaluated for the six original PC-PART domains (*Clothing, Hygiene, Nutrition, Mobility, Safety* and *Residence*) using the two and three-category response options just described.

Stage three of the analysis involved forming alternative PC-PART item groupings using the ICF as the theoretical framework a-priori to further analysis. PC-PART items were linked to ICF categories using Cieza's linking rules [36,37]. Most items aligned to either the Self-Care or Domestic Life chapter of the ICF activities and participation component [1]. Items that aligned to other ICF chapters, such as mobility, were assigned to either the Self-Care or Domestic Life item group based on the activity context of the mobility item. Self-Care items corresponded to personal ADL activities, for example, bathing, toileting, dressing and eating. Domestic Life items corresponded to broader instrumental ADL activities needed for community living, for example, shopping, transportation, laundry and food preparation. The newly formed Self-Care and Domestic Life item groups were then evaluated for their fit to the Rasch model.

#### **Results**

#### **Participants**

Participants' mean (SD) age was 73.9 (12.8) years, with a minimum of 22 years and a maximum of 102 years and 631 (63%) were women. A total of 581 (58%) participants were admitted with an orthopaedic impairment, 203 (20%) with neurological impairment and 212 (21%) with other disabling impairments. Prior to admission, 94% of participants had been living in their own homes, while 3% lived in 'low-level' residential care facilities. These admission data are typical of Australian inpatient rehabilitation settings [38]. Complete admission PC-PART data were available for 958 (96%) of the 996 participants.

Table 2 displays results from the three-staged analysis.

#### Stage 1. One scale containing 41 PC-PART items

During stage 1(a) of the analysis, when assessed using the three response categories (0,1,2), 27 of the 41 PC-PART items showed disordered thresholds, suggesting the need to collapse the response categories to form a dichotomous scale (0,0,1).

In stage 1(b) of the analysis using the dichotomous scale, there was evidence of overall item misfit, with the overall item fit residual standard deviation (SD) being 2.14 ( $\geq$ 1.5), and the presence of three misfitting items. There were 11 misfitting persons. Internal consistency of the scale was high (PSI = 0.91). There was evidence of uniform DIF by age (three items) and sex (four items) and non-uniform DIF by sex (one item). Local item dependency was observed for 39 item-pairs. The scale was not unidimensional, with the lower bound 95% CI of the proportion of significant t-tests (5.7%) being above the critical value of 5%.

1. Original PC-PARTdomains and items	2. Items included in the Rasch-derived scales	Rasch-derived scales	3. Items not included in
	(a) Self Care	(b) Domestic Life	the Rasch-derived scales.
A. Clothing	וס ונפווס	14 (61115)	
A1 Manage dressing: top (upper body)	>		
A2 Manage dressing: bottom (lower body)	`		
A3 Getting socks & shoes on/off	>		
A4 Select clothing appropriate for weather	>		
A5 Managing laundry		>	
B. Hygiene			
B1 Manage toileting	>		
B2 Bladder control/keeping pants dry			>
B3 Bowel control/keeping pants unsoiled			`
B4 Washing hair			`
B5 Cleaning teeth	>		
B6 Manage shaving/menstruation			`
B7 Washing self	>		
B8 Getting in & out of bath/shower	`		
C. Nutrition			
C1 Maintaining usual weight			`
C2 Eat without choking/coughing			`
C3 Planning meals		`	
C4 Preparing meals		`	
C5 Acquiring groceries		`	
C6 Managing food restrictions	`		
C7 Using the stove		`	
C8 Avoiding spoiled food	>		
D. Mobility			
D1 Moving around inside the home	>		
D2 Getting in & out of bed	>		
D3 Move around without falling	`		
D4 Managing steps/stairs	`		
D5 Moving around outdoors		>	
D6 Driving safely			`

D7 Getting to/from appointments	`	
D8 Wandering (remember where to go without getting lost)		>
D9 Orientation (remembering appointments)		>
E. Safety		
E1 Managing medications	>	
E2 Avoiding alcohol/substance overuse	>	
E3 Coping with minor illness/crisis		
E4 Coping without repeated emergency help	>	
E5 Managing safety hazards when smoking		>
E6 Home free of hazards		>
F. Residence		
F1 Managing money	>	
F2 Managing home security	>	
F3 Using basic personal Information	>	
F4 Shopping for personal/household needs	>	
F5 Keep cool in Summer /warm in Winter		
G. Supports		
G1 Adequacy of supports from others		>
G2 Stability of supports from others		>

Table 2 Mod	el fit fo	r the three-	Table 2 Model fit for the three-staged Rasch analysis	analysis ( $n = 958$ in each analysis)	n analysis)							
Subscale	No. of items	response categories	Overall model fit <sup>a</sup>	Overall Item fit residual (SD) <sup>b</sup>	Overall Person fit residual (SD) <sup>b</sup>	No. of items with disordered thresholds	No of misfitting items <sup>c</sup>	No of Imisfitting persons <sup>c</sup>	PSI <sup>d</sup> Item uniff non DIF	Items with uniform/non-uniform DIF	No. of item- pairs with response dependency <sup>e</sup>	Dimensionality  (% of significant
									(a)	(b) by sex		t-tests) <sup>f</sup>
Stage 1. All PC-PART items as one scale	-PART ite	ems as one s	cale									
(a) All original items	14	012	$\chi^2 = 2003.85$ , df (369),	-0.07 (2.84)	-0.46 (1.23)	27	9 (D6 C1 E6	21 (	0.93 (a)	(a) B2 D6 E2/ -	48	11.5%
			$p < .001$ , $(\alpha = .001)$				C5 E1 F4 E2 D7 C7)		@ S	(b) A5 B6 B7 C3 D9/ –		(95% CI 10.1-12.9%)
(b) All original items	4	001	$\chi^2 = 1743.19$ , df (369),	-0.47 (2.14)	-0.54 (1.03)	NA <sup>9</sup>	3 (D6 D7 C1)	11	0.91 (a)	(a) B2 D6 E2/ -	39	7.1%
			$p < .001$ , ( $\alpha = .001$ )						⊕ Q	(b) A5 B6 B7 C4/ E3		(95% CI 5.7-8.5%)
(c) Removal of 6	5 35	100	$\chi^2 = 693.50,$	-0.46 (1.80)	-0.52 (0.87)	V ∀N	0	9	0.88 (a)	(a) B2 E2/ –	2	7.52%
items			at (234), $p < .001$ , ( $\alpha = .001$ )						(q)	C4/ -		(95% CI 6.1-8.9%)
Stage 2. Original PC-PART domains	al PC-PA	RT domains										
Clothing	ſΟ	001	$\chi^2 = 316.31$ , df (15), $p < .001$ , ( $\alpha = .01$ )	-0.81, (4.23)	-0.34, (0.60)	<b>∀</b> Z	1 (A5)	0	0.54 (a) -/ (b) A5	(a) -/ - (b) A5/ -	<del>-</del>	- ا
Hygiene	∞	1000	$X^2 = 384.92$ , df (39), $p < .001$ , ( $\alpha = .006$ )	-1.03 (1.99)	-0.75 (0.86)	¥Z	0	0	0.68 (a) (b)	(a) B2/ – (b) –/ B2 B6	_	1.98%
Mobility	0	1000	$X^2 = 539.17$ , df (54), $p < .001$ , ( $\alpha = .006$ )	-1.51 (3.38)	-0.42 (0.48)	¥ Z	2 (D6 D7)	0	0.68 (a) (b)	(a) D3 D6/ – (b) –/ –	2	1.67%
Nutrition	∞	1000	$X^2 = 413.10,$ df (48), $p < .001, (\alpha = .006)$	-1.04 (3.05)	-0.53 (0.71)	¥ Z	2 (C1 C5)	0	0.49 (a) (b)	(a) -/ C6 (b) C3/ -	0	4.92%
Residence	2	001	$\chi^2 = 189.26$ , df (5), p < .001, ( $\alpha = .01$ )	-3.18 (2.9)	-0.59 (0.50)	<b>∢</b> Z	0	0	-0.31 (a) -/	(a) -/ - (b) -/ F3	0	<u>-</u> ا
Safety	9	001	$X^2 = 109.40$ , df (23), $p < .001$ , ( $\alpha = .008$ )	-0.44 (2.62)	-0.25 (0.48)	<b>∀</b>	0	0	-0.46 (a) (b)	(a) E2/ – (b) –/ –	0	%00.0

Table 2 Model fit for the three-staged Rasch analysis (n = 958 in each analysis) (Continued)

	14.61%	(95% CI 13.2%-16.0%)	8.56%	(95% CI 7.2%-9.9%)	4.18%		5.16%	(95% CI 4.8-7.5%)
	<del>,</del>	9 -	ω	9)	4		9	≎ 4
	1		7		0		0	
	(a) B2/ –	(b) B6/ -	(a) E2/ –	(b) A5 C4/ -	(a) -/-	- /- (q)	(a) E2/ –	(b) A5 C4/ -
	0.87		0.79		0.85		0.76	
	2		0		0		0	
	3 (C1 C2 2	B2)	2 (D6 E6) 0		0		0	
	Ϋ́		Ϋ́		Ϋ́		Ϋ́	
	-0.51 (0.77)		-0.50 (0.81)		-0.46 (0.62)		-0.45 (0.63)	
estic Life' scales	-0.64 (2.33)		-0.77 (2.48)		-0.86 (1.87)		-0.57 (2.02)	
Stage 3. PC-PART items separated into 'Self Care' and 'Domestic Life' scales	$\chi^2 = 987.96$ ,	df (184), $p < .001$ , ( $\alpha = .002$ )	$\chi^2 = 1058.02,$	df (162), $p < .001$ , ( $\alpha = .002$ )	$\chi^2 = 360.64,$	df (91), p < .001, ( $\alpha$ = .003)		df (91), p < .001, ( $\alpha$ = .004)
separated	100		100		100		100	
T items	23		18		16		14	
Stage 3. PC-PAF	(a) All self	care items	All domestic	life items	(b) Refined Self 16	Care scale	Refined	domestic life scale

 $SD = Standard Deviation, PSI = Person Separation Index, DIF = Differential Item Functioning, <math>\chi^2 = chi$  square, df = degrees of freedom, p = probability value, <math>a = Bonferroni adjusted alpha level, CI = Confidence Interval.

<sup>a</sup>non significant chi-square item-trait interaction statistic is evidence of overall model fit.

Plean-Person Fir Residual SD ≤1.5 is evidence of overall item/person fit.

\*Chalvidual item or person Fir Residual values of ≤2.5 are evidence of item/person fit.

\*Chalvidual item or person Fir Residual values of ≤2.5 are evidence of item/person fit.

\*Plean pairs with Residual correlation values of r ≥0.2 deemed to have local item dependency.

\*Values ≤5% considered evidence of a unidimensional scale (95% CI only presented when the proportion of significant t-tests exceeded 5%).

\*Not Applicable - only one threshold for items with two response categories.

\*Insufficient items and response categories to produce minimum scores for meaningful results.

Attempts were made to refine the scale to achieve unidimensionality and fit of the scale to the Rasch model in stage 1(c) of the analysis. With removal of six misfitting items, the overall item fit residual standard deviation (SD) was reduced to 1.8. While there were no misfitting items and PSI was acceptable (0.88), there was evidence of uniform DIF by age (two items) and sex (one item) and there were five item-pairs with local dependency. Additionally, the scale was not unidimensional, with the lower bound 95%CI value on the proportion of significant t-tests being 6.1%. A decision was made to move to Stage 2 of the analysis.

#### Stage 2. Original PC-PART domains

Rasch analysis of six original PC-PART domains using the three response categories (0,1,2) revealed disordered thresholds for all six domains. Therefore, the response categories were collapsed to the original dichotomous responses (0,0,1) and the Rasch analysis was repeated. While four domains had sufficient items to test dimensionality and appeared to be unidimensional, overall fit to the Rasch model was poor. All six domains showed inflated item fit residual SDs (range 1.99 to 4.23). Item misfit was detected in three of the six domains. PSI values in all domains were below the critical value of 0.7. Uniform DIF by age was present for Hygiene (one item), Mobility (two items), and Safety (one item), and by sex for Clothing (one item) and Nutrition (one item). Nonuniform DIF by age was present for Nutrition (one item) and by sex for Hygiene (two items) and Residence (one item). There was local item response dependency for Clothing (one item-pair), Hygiene (one item-pair) and Mobility (two item-pairs). Fit to the Rasch model deteriorated further through attempts to refine the original domain scales by deleting misfitting items. Therefore the decision was made to move to Stage 3 of the analysis.

## Stage 3. PC-PART items separated into 'Self-Care' and 'Domestic Life' scales

Stage 3(a). Rasch analysis was conducted on the proposed Self-Care (23 items) and Domestic Life (18 items) scales using the dichotomous item response categories (0,0,1). The 23 Self-Care items showed evidence of misfit (Item Fit Resid. SD = 2.33), with three misfitting items and two misfitting persons. The PSI was acceptable (PSI = 0.87). Only uniform DIF was present for one item by age and one item by sex. Local item response dependency was present for 11 item pairs. The scale failed the test for unidimensionality. Analysis of the 18 Domestic Life items revealed overall misfit (Item Fit Resid. SD = 2.48), with two misfitting items and no misfitting persons. PSI was acceptable (PSI = 0.79). Uniform DIF was present for one item by age and two items by sex. There was evidence of local

item response dependency for seven item-pairs. The scale failed the test for unidimensionality.

Stage 3(b). Refinement of the Self-Care scale involved deletion of seven misfitting or redundant items. Although the resultant Self-Care scale containing 16 items showed slightly elevated overall item fit residual statistics (Item Fit Resid. SD =1.87), there was no individual item misfit and no misfitting persons. The PSI (0.85) was acceptable. There was no evidence of DIF by age or sex. There was no local item response dependency and the scale was shown to be unidimensional. The 16 Self-Care scale items in the refined scale are shown in Table 1, column 2a. Refinement of the Domestic Life scale involved deletion of four items and creation of one subtest between items showing local dependency. The refined scale, containing 14 items, had no misfitting items or persons. The PSI (0.76) was acceptable. There was uniform DIF by sex for items 'laundry' and 'meal preparation', with women scoring higher than men; and by age for the item 'avoiding alcohol/substance abuse', with younger patients showing higher scores than older patients. There was no local item dependency. The scale was shown to be unidimensional with the lower bound 95%CI of the percentage of significant t-tests being 4.8%. The 14 Domestic Life scale items on the refined scale are shown in Table 1, column 2b.

Item-location maps for the refined *Self-Care* and *Domestic Life* scales (Figures 1 and 2) suggested items were well targeted, demonstrating sufficient item spread across the full range of person location scores on both scales, without ceiling effects. Higher scores on the *Self-Care* and *Domestic Life* scales indicated higher (worse) levels of *Self-Care* and *Domestic Life* ADL participation restriction.

## Combined self-care and domestic life scales

Dimensionality testing was completed including all 30 items from the resultant *Self-Care* and *Domestic Life* scales in one analysis. This scale failed the test for unidimensionality, with the 95% CI for the percentage of significant t-tests ranging from 5.8% to 8.6%. Therefore summation of *Self-Care* and *Domestic Life* scale scores to form a total PC-PART score was not supported.

#### **Conversion scores**

Adjusted conversion scores were computed from the Rasch-derived logit scores on the refined *Self-Care* and *Domestic Life* scales, using a 0 to 100 scale, with higher scores indicating higher levels of participation restriction. This enabled conversion of raw ordinal scores from the scales to interval level measurement. For practical purposes, a converted score is dependent on all items in the scales being answered. The mean *Self-Care* admission converted score was 42.0 (N = 958;

LOCATI	ON PERSONS	ITEMS [locations]
5.0	00	
4.0	00	
3.0	00	
2.0	000	   F5-Keep cool in summer/warm in winter 
	00000000	C8-Avoid spoiled food
1.0	00000000	C6-Managing food restrictions
0.0	000000000000000000	   E3-Coping with minor illness/crisis
	000000000000000000	
-1.0	0000000000000	B5-Cleaning teeth
-2.0	0000000000	A4-Select clothing appropriate for weather  A1-Manage dressing: top (upper body)  D2-Getting in & out of bed  B1-Manage toileting B8-Getting in/out bath/shower
-3.0	0000000	D3-Move around without falling
		A2-Dressing:bottom(lower body) A3-Shoes&socks on/off
-4.0	00000000	B7-Washing self   
	00000000000	   D1-Moving around in home D4-Managing steps/stairs 
-5.0		
	00000000000	
-6.0		<u> </u>

**Figure 1 Item map for the PC-PART Self Care scale.** Location values for persons are on the left (o =6 Persons). Relative difficulty of items is displayed on the right. Items at higher location scores represent activities that are Not OK for relatively few people; only people with higher levels of ADL participation restriction are rated 'Not OK' on these items. These are 'easier' items for most people to manage. Items at lower location scores represent activities that are Not OK for relatively many people; people with lower levels of ADL participation restriction are rated NOT OK on these items. These are 'harder' items for most people to manage.

SD = 22.3; Range 0,100) and the mean *Domestic Life* admission converted score was 38.5 (N = 957; SD = 20.4; Range 0,100). These scores represented between 6/7 and 4/5 ADL participation restrictions (raw scores) on the scales, respectively.

## Discussion

Rigorous psychometric analysis was used to examine the internal construct validity of the PC-PART in order to enhance empirical development of the tool [15]. Rasch analysis demonstrated that it is inappropriate to sum all

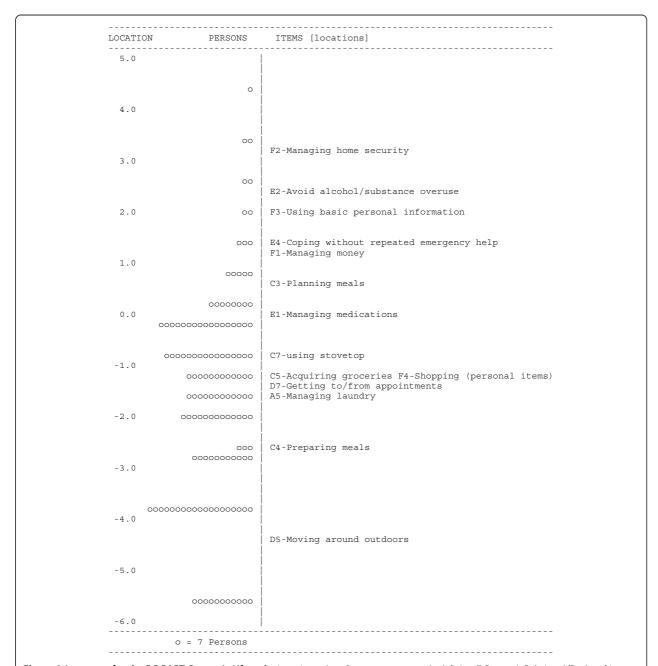


Figure 2 Item map for the PC-PART Domestic Life scale. Location values for persons are on the left (o =7 Persons). Relative difficulty of items are displayed on the right. Items at higher location scores represent activities that are Not OK for relatively few people; only people with higher levels of ADL participation restriction are rated Not OK on these items. These are 'easier' items for most people to manage. Items at lower location scores represent activities that are Not OK for relatively many people; people with lower levels of ADL participation restriction are rated NOT OK on these items. These are 'harder' items for most people to manage.

items in the original PC-PART item set to produce a total score, and that the six original PC-PART domains did not form psychometrically sound scales. Use of Rasch methods generated evidence supporting the internal construct validity of the newly formed PC-PART Self-Care (16 items) and Domestic Life (14 items) scales as measures of Self Care and Domestic Life ADL participation restriction. These were

shown to be unidimensional scales. The total raw scores on each scale may be matched to corresponding Rasch-derived conversion scores on a 0 to 100 scale, for use as interval-level measurement (conversion scores available from the corresponding author).

Frequently used and researched self care and domestic life ADL measures [7,8,39] typically measure patients' level

of dependence (i.e. activity limitations). One shortcoming of this approach is that decisions about whether patients are ready for discharge from inpatient settings depends not only on what patients can or cannot do for themselves, but how they will complete self care and domestic life ADL in their real living environment with the supports that are available; in other words whether or not there will be unmet self-care and domestic life ADL needs (participation restrictions) [40,41]. The PC-PART Self-Care and Domestic Life scales address this limitation through the measurement of ADL participation restrictions. These scales may be used alongside existing measures of ADL in/dependence, to enable more complete and useful measurement of patients' ADL functioning for community life. Such measurement of ADL functioning may enable existing barriers to patients' discharge to community living to be identified and addressed [41,42]. In this way, the PC-PART scales may assist decision-making by health care team, consistent with the original purpose of the PC-PART [13,29].

The PC-PART Self-Care and Domestic Life scales may have potential to aid health care system management. The patterns and the extent of ADL participation restrictions experienced by specific patient populations, as well as the extent of care required by family, friends and neighbours in providing support to those who need it, is an inadequately described phenomenon [43,44]. The PC-PART scales may enable identification and documentation of unmet ADL needs that arise from inadequate and/or unstable supply of both formal and informal supports intended to enable people to accomplish essential selfcare and domestic life activities in their community living environments. Support with self-care activities (e.g. toileting, showering, and dressing) and domestic life activities (e.g. shopping, cooking, transport, and household tasks) is commonly provided by a combination of both formal and informal supports including family, neighbours, friends and paid or volunteer services [45]. Use of the PC-PART scales may assist clinicians, managers and researchers to quantify the extent of informal supports that help people accomplish their essential activities of daily living. The involvement of patients and their key informants in the PC-PART assessment may enable identification of the types of supports and resources most needed in communities by specific patient groups, as well as identification of existing service gaps. Recent literature highlights the importance of involving patients and carers in identifying the types of supports that would be of greatest assistance to them in easing carer strain [43-46].

The PC-PART scales provide interval level measurement, which may be used to measure the magnitude of change in patients' levels of ADL participation restriction. This may make it possible to investigate the efficiency of clinical interventions and community services that seek to reduce ADL participation restrictions. This may be of significance

for outcome-based payment systems. In Australia, the most recent payment system incorporates measurement of functioning across a limited number of domains, focusing on measuring activity limitations, and this may not be adequate for complex rehabilitation [41]. Madden et al. reported there is a need for an ICF-linked standardised measure within case-mix systems, and that including information about broad aspects of functioning increases the proportion of the variance explained in health care costs [41]. The PC-PART may be an appropriate measure for this purpose.

One of the strengths of this study was the use of Rasch analysis to provide a detailed analysis of not only the PC-PART items, but also the item response categories [24,25]. Analysis of the PC-PART's item response categories supported use of the dichotomous response categories of the PC-PART items. These response categories are consistent with the overall purpose of the instrument, which is to identify and document the presence of ADL participation restrictions in activities of daily living required for community life.

The presence of uniform DIF by age in the *Domestic Life* scale for 'avoiding alcohol/substance overuse' and by sex for 'managing laundry' and 'meal preparation' suggested influences on scores associated with age and sex, respectively. While it is usual to delete items that demonstrate DIF, these items were retained because they were deemed to be clinically relevant to the scale and the observed DIF could be clinically explained. Further validation of the scales would provide additional evidence about the appropriateness of retaining these items.

An inter-rater reliability study of the PC-PART conducted in the same rehabilitation centres, using the same therapists to collect PC-PART data, with an independent sample of patients, showed a high level of inter-rater agreement, with an intra-class correlation coefficient of 0.91 (95% CI 0.88 to 0.93) for grouped PC-PART data [16]. Hence, it is unlikely that potential measurement error during data collection influenced the results of this present study.

Of the original PC-PART items, 13 showed misfit during the Rasch scale refinement process, and were excluded from the newly formed PC-PART *Self Care* and *Domestic Life* scales. However, it is still possible that some of these items may be clinically relevant as part of an assessment of ADL participation restrictions for community living. Some of the excluded items may not have had health consequences if left unmanaged, or they may have addressed different constructs to ADL participation restriction, or the aspect of ADL participation restriction covered by the item was already addressed by another item. Some items may have contained ambiguous phrasing resulting in misinterpretation by therapists.

Further investigation of the measurement properties of the PC-PART *Self-Care* and *Domestic Life* scales, including their convergent and divergent validity, longitudinal validity and criterion validity, would guide judgement regarding their utility. Specifically, investigation concerning possible cut-point scores on the PC-PART *Self-Care* and *Domestic Life* scales to indicate the critical value for inpatient care versus community living (including supported living), would provide clinically relevant information.

#### **Conclusions**

This study generated evidence supporting the internal construct validity of the PC-PART *Self-Care* and *Domestic Life* scales as valid, unidimensional scales for inpatients receiving rehabilitation, allowing summation of scores on each scale. Rasch-derived conversion scores enable interval-level measurement, appropriate for parametric analyses of grouped data. The scales may be useful to clinical practice, clinical research and to health care system managers. Further validation research of the scales to confirm their utility is recommended.

#### Abbreviations

ADL: Activities of Daily Living; DIF: Differential Item Functioning; ICF: International Classification of Functioning, Disability and Health; PC-PART: Personal Care-Participation Assessment and Resource Tool; PSI: Person Separation Index; RCT: Randomised Controlled Trial.

#### Competing interests

Susan Darzīns is a Director of Darzins Consulting Pty. Ltd., which operates using the business name 'The PART Group'. The PART Group distributes the PC-PART assessment. The author of the PC-PART has a direct relationship to Susan Darzins. Darzins Consulting Pty Ltd is not financing this research or this manuscript. During the last five years (January 2009–2014) Susan Darzins has not received reimbursements, fees, funding or salary associated with sales of PC-PART products, from Darzins Consulting Pty. Ltd. Susan Darzins does not hold and is not applying for any patents relating to the contents of this manuscript. All other authors declare that they have no competing interests.

#### Authors' contributions

SD designed the study, completed the data entry, performed all statistical analyses, wrote, edited and formatted the manuscript for submission. CI assisted in design of the study, provided consultation and supervision on data analyses and contributed to the editing of the manuscript. MDS assisted in design of the study, provided consultation and supervision on data analyses and contributed to the editing of the manuscript. NT provided the study data, assisted in design of the study and contributed to the editing of the manuscript. JP provided training in Rasch analysis, statistical consultation on the data analysis and assisted with editing of the methods and results of the manuscript. All authors read and approved the final manuscript.

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## **Chapter 6 - Conclusions**

The third specific research objective for this thesis, to evaluate the internal construct validity of the PC-PART instrument, was achieved by this study. Internal validity of the PC-PART is critical to its use in clinical settings as a descriptive, discriminative and evaluative measure of participation restrictions in ADL required for community life. Use of Rasch methods in this study provided evidence that the PC-PART contains two unidimensional scales that fit the Rasch model: *Self Care* and *Domestic Life*. The items in each of the two final scales are shown in Appendix G. In all remaining chapters of the thesis, the PC-PART instrument as a whole is referred to as the PC-PART. The labels *Self Care* scale and *Domestic Life* scale will be used when referring specifically to the individual PC-PART scales identified from the Rasch analysis.

This study met all COSMIN generalisability requirements (see Table 6.1) and design criteria for structural validity and IRT methods (see Table 6.2). Conversion tables enabling raw *Self Care* and *Domestic Life* scale scores to be converted to Raschderived scale scores were made available to those requesting them, but were not included in the published paper, pending future possible revision of the items and further testing of the scales. The conversion tables are provided in Appendix G of this thesis.

Item maps for the *Self Care* and *Domestic Life* scales demonstrated that both scales discriminated between people with different levels of participation restriction without floor or ceiling effects. For the *Self Care* scale, 144 (15.0%) and 56 (5.8%)

inpatients scored the lowest and highest possible scores, respectively. For the *Domestic Life* scale, 21 (2.2%) and 66 (6.9%) inpatients scored the lowest and highest possible scores, respectively. These results are within the accepted floor and ceiling effect criteria (i.e. ≤15% of participants obtaining the highest or lowest scale score from a sample of at least 50 people) published by Terwee et al. (2007), with the Self Care scale at the limits of acceptability for floor effects. Floor effects for the PC-PART scales are not clinically problematic as zero scores represent no participation restrictions, and therefore, no unmet needs requiring intervention.

Overall, these results indicate acceptable ability of both scales to discriminate between people at different levels of participation restriction requiring intervention. The results also indicate that the scales may be responsive, as people's change in participation restrictions in either direction on the scales, can be measured. The scales would not have utility in populations who do not experience participation restrictions in ADL required for community life, for example, residents living in high-level care environments where all ADL needs are met by paid carers.

Table 6.1. Summary of study purpose, methods and conclusions; COSMIN generalisability requirements met for this study.

Furpose	oose Methods	spo					Fatient Sample characteristics	pie charact	eristics			Conclusions	No of COSMIN Generalis-ability Requirements
	Study	Study design	Setting	Clinician raters, participants	Clinician description	i. Data Analysis ii. Handling Missing data	Sample selection	и	Age (yrs) Mean (Range)	Sex M/F	Population (impairment)	Overall findings	
Evalı			Inpatient	Occupational	All clinical	i. Rasch	All adult	966=u	74	M=365	Orthopaedic	Two scales fit	8
interr			adult	Therapists	OTs from	analysis and	participants		(22-102)	F=631	=581 (58%)	the Rasch	
const			rehabilitation	involved in	rehabilitatio	modelling on	included in				Neurological	model:	
validity	ity using Rasch		wards of	collection of	n wards	admission PC-	RCT of				=203 (20%)	Self Care	
of the	S		government-	RCT data	eligible if	PART item data	standard				Other	(n=16 items)	
PC-	Н	RUMM2030	funded	including	trained in	ii. Only	versus				disabling	Domestic Life	
PAR			hospital,	PC-PART at	nse of	inclusion of	augmented				=212(21%)	(n=14 items)	
			Melbourne,	admission	PC-PART.	complete	therapy.						
			Australia.	and discharge		PC-PART data							
				n~25		sets $n=958$ .							

Abbreviations: PC-PART=Personal Care Participation Assessment and Resource Tool; RCT=Randomised Controlled Trial; OT= Occupational Therapist; M=Male; F=Female

"The COSMIN checklist generalisability requirements: Description of age, sex, important disease characteristics, setting, countries where study was conducted, language used, participant selection described adequately, percentage of missing responses acceptable.

Table 6.2. Structural (internal construct) validity and IRT - summary of COSMIN checklist design requirements met.

	Structural validity					IRT				
Study	1. Scale based on reflective model, items expected to be manifestation of same underlying construct?	Missing data 2. Reported? 3. Handling explained?	4. Sample size adequate? 5. Absence of important flaws in study design or methods?	Statistical methods 6. for CTT, factor analysis performed? OR 7. for IRT, tests for unidimensionality of items performed?	No. of the 6 COSMIN design requirements met.	Was IRT model used adequately described?	2. Was computer software used adequately described?	3. Was method of estimation used adequately described	4. Were assumptions for estimating parameters of IRT model checked?	COSMIN design requirements met /4
Darzins et al., 2014	l. Yes.	2. Yes 3. Yes	4. Yes 5. Yes	6. Not applicable 7. Yes	9	1. Yes – One parameter Logistic Model	2. Yes RUM2030	3. Yes— RUMM2030 which uses weighted likelihood person estimation methods as default setting.	4. Yes – Item fit, Individual person fit, Internal consistency, DIF Local dependence, Dimensionality	4

IRT=Item Response Theory; CTT=Classical Test Theory; COSMIN=COnsensus-based Standards for the selection of health Measurement INstruments; DIF=Differential Item Functioning.

Item misfit observed during the Rasch analysis is relevant to ongoing validation of the PC-PART instrument. It may be possible that poorly targeted items or ambiguous phrasing of some items was associated with misfit of some items in the final scales. For example, the deleted item D6: Do you drive a car safely? was not phrased in a way that matched its response categories of OK by self, OK with help, or Not OK, and was not phrased to address the participation aspect of driving. While driving may be an important aspect of IADL for community living, a more appropriate measure of participation restriction may be to address whether a person is able to get to the places they need to go, either independently, or with help. This latter concept seems to be achieved with the retention of item D7: Do you get to and from your appointments? The items C1: Have you kept your usual weight?; C2: Do you eat and drink without coughing or choking?; D8: When you go out, do you remember where to go and get there without getting lost?; and D9: Do you remember your appointments? appeared more closely matched to the ICF component of body functions and structures. As phrased, these items may not target participation restrictions associated with problems in the body function and structure related to the item. Indeed, content of these items was linked to the body functions and structures component of the ICF, as previously described in Chapter 4, Table 1. Similarly, item *E6: Is your home free of hazards?* was linked to the environmental factors component of the ICF, and as phrased, this item does not target participation restriction. If these items were rephrased in a revised version of the PC-PART, further evaluation of their inclusion in the scales, and of internal validity of the instrument, could occur in a prospective study, using the revised PC-PART items.

There were 13 PC-PART items that were not included in the final Rasch derived scales, and scores for these items cannot be included in the calculation of Self Care and Domestic Life scale scores. It is recommended that if the PC-PART is used for research purposes, or in clinical situations to measure change in total Self Care and Domestic Life scores over time, then only Self Care and Domestic Life scale item scores should be used. When the PC-PART instrument is used with individual service-users for intervention and discharge planning, some of these 13 items may still be relevant to identify individualised problems relevant to community living. Examples are the items B2: Bladder control and B3: Bowel control. Despite the Self Care scale's inclusion of item B1: Toileting, these other items may also be relevant to individualised discharge planning. It may be premature to dispense with items containing clinically important information that were not included in the revised scales, especially as some items were identified in the clinical utility study as needing to be rephrased to aid their interpretation. Rephrasing may also enhance reliability of these items. Future evaluation of revised items' fit within the structure of the PC-PART scales is therefore appropriate. There are two PC-PART items, G1 and G2, which address the adequacy and sustainability of available supports in the living environment. These items were not entered into the Rasch analysis but may also continue to be used clinically as individual items.

Explanations for the observed DIF within the *Domestic Life* scale were briefly provided in the publication. DIF by *age* was found for the item *E2: Alcohol and substance abuse*, with younger patients demonstrating higher participation restriction scores than older patients. Further considerations as to the cause of DIF for this item are provided here. First, this item was rated as posing a participation restriction for a

relatively small number of patients (n=34) from the total sample of 996 patients. It may be that substance use and alcohol intake of younger patients, when identified, is viewed as more problematic than for older patients. It is also possible that younger patients consume higher levels of recreational drugs and alcohol than older patients, and may therefore be more likely to experience an impact on their everyday functioning as a result. One further possibility is that when substance abuse is identified as a problem for a patient, it may impact on a younger person's involvement in their life situation more than an older person's life situation. These possibilities are speculative and require further investigation.

DIF by sex was found for the items A5: Laundry and C3: Meal planning, with women experiencing higher participation restrictions than men. It is possible that within this predominantly older participant group, traditional roles within the home may prevail. Hence, women may experience higher levels of participation restriction than men, in roles such as laundry and meal planning, as these may be roles that are predominantly undertaken by women. If men's roles did not normally include managing laundry and meal planning within the home, then any difficulties men experience performing these roles may not be identified as participation restrictions, as long as the usual supports for these activities remain. Hence, it was decided that these items would remain in the Domestic Life scale as they are important activities and score differences could be clinically explained.

The *Domestic Life* scale, while meeting the requirements of a unidimensional scale during the Rasch analysis, did not demonstrate strong unidimensional properties.

This finding may relate to the range of activities that make up *Domestic Life* activities (aligned to IADL) that while contributing to one overall construct, are relatively varied

and complex. This activity range contrasts with the *Self Care* activities, which have less variability and also less complexity (aligned with PADL). This interpretation is consistent with other studies that have identified IADL as more complex, varied and difficult to accomplish than PADL (Coster et al., 2004; Njegovan, Man-Son-Hing, Mitchell, & Molnar, 2001; Stineman et al., 2012; Whiteneck & Dijkers, 2009). If IADL are more complex in nature than PADL, they may provide more opportunities for variation in how they are carried out. Hence, it may be that the internal consistency of a *Domestic Life* scale is justifiably lower than that of a *Self Care* scale, as observed in this study.

New evidence generated in this present study supported the internal construct validity of the Rasch-derived *Self Care* and *Domestic Life* scales for use with grouped data. This evidence enabled further exploration of the scales' validity and responsiveness for measuring participation restrictions in ADL amongst rehabilitation inpatients during an episode of rehabilitation. The final specific research objective of this body of research was to use hypothesis testing to evaluate construct validity, criterion validity and responsiveness of the PC-PART (*Self Care* and *Domestic Life* scales) for inpatient rehabilitation, which is reported in Chapter 7.

# Chapter 7. Construct Validity, Criterion Validity and Responsiveness of the PC-PART

#### Introduction

The final study in this body of research addressed the fourth specific research objective, which was to use hypothesis testing to evaluate construct validity, criterion validity and responsiveness of the PC-PART for inpatient rehabilitation. The published paper presented in this chapter describes this research. Given evidence supported internal construct validity of the Self Care and Domestic Life scales in the previous study, these same scales were used in this next study. For this next study hypotheses were formulated and tested concerning expected scores on the Self Care and Domestic *Life* scales compared to other measures collected during inpatient rehabilitation. COSMIN checklist criteria (see Appendix C) for hypothesis testing (Box F), criterion validity (Box H) and responsiveness (Box I), respectively, were used to aid design of the study methods. Formulation of hypotheses for this study was informed by evidence obtained from the study exploring the theoretical validation of the PC-PART measurement construct (chapter 4), as well as clinical knowledge and experience. Data used for the statistical analyses came from the RCT previously described (Peiris, Shields, Brusco, Watts, & Taylor, 2013a, 2013b; N. F. Taylor et al., 2010). Documents supporting ethical clearance for the procedures used, are located in Appendix E. Following the published paper, the final section of this chapter discusses the contribution of this study to the body of research contained in this thesis.

# **Hypothesis Testing (Construct Validity)**

The COSMIN checklist criteria for hypothesis-testing specify that it is important that detailed hypotheses are formulated before data are examined and the hypotheses are tested. The hypotheses should be specified in the methods section of a manuscript. This is to avoid the potential bias of retrospectively finding explanations for certain results, rather than concluding the instrument lacks validity for the purpose for which it was used (Mokkink, Terwee, et al., 2010a). The hypotheses should relate to expected between-group differences in instrument scores based on clinical or demographic groupings, as well as expected correlations between scores on the instrument and scores on other instruments. Hypotheses should specify expected relative magnitude and direction of correlations, based on the construct being tested. There is no specified limit to the number of hypotheses that should be tested. Indeed, the amount of evidence gathered about construct validity of an instrument increases as more hypotheses, that are specific, are tested (Mokkink, Terwee, et al., 2010a). Mokkink et al. (2010a) asserted that it is important that measurement properties of comparison instruments are described or that references are provided to studies in which they are described. Tests of statistical significance and their associated probability values should be avoided when testing hypotheses about correlations between instruments' scores because this is not relevant (Mokkink, Terwee, et al., 2010a, p. 34). It is also more relevant whether differences between groups are of the nature expected, than whether observed differences are statistically significant (Mokkink, Terwee, et al., 2010a).

# **Criterion Validity**

COSMIN checklist criteria for evaluating criterion validity, which includes predictive and concurrent validity, require a criterion that can reasonably be considered as a gold standard (Mokkink, Terwee, et al., 2010a). A gold standard reflects a true state and is "a criterion measure that is already established or assumed to be valid" (Portney & Watkins, 2009, p. 84). In this particular study, discharge destination was used as a gold standard variable, being collapsed into a dichotomous discharge outcome of home or supported living environment versus transfer to inpatient acute or transitional care. Transitional care involved continued inpatient care for either lower intensity rehabilitation activities or to await placement in residential care facilities. Of note is that "the COSMIN panel reached consensus that no gold standard exist[s] for HR-PRO instruments" except "when a shortened version of an instrument is compared to the original long version" (Mokkink, Terwee, et al., 2010a, p. 38). The gold standard in this particular study was considered to be valid, as it is an objectively observable outcome of the rehabilitation process, rather than a different instrument. Mokkink et al. (2010a) assert that "when the instrument scores are continuous and scores on the gold standard is dichotomous the area under the receiver operating characteristic (ROC) curve is the preferred method" (p. 38) for evaluating the instrument's ability to discriminate. In this case, the focus was on the scales' abilities to discriminate between patients discharged to home or community living environments, versus those transferred to acute or transitional care (Mokkink, Terwee, et al., 2010a).

Evaluation of predictive validity of the PC-PART instrument may not be relevant as it is unlikely the instrument would be used, for example, at admission, to

predict future discharge destination. PC-PART assessments administered by the therapist to aid discharge planning, are completed with the discharge destination in mind. Therefore, it does not seem practical, nor logical, to evaluate predictive validity of the PC-PART, which would involve the PC-PART being completed by an assessor who is blind to the discharge destination. It is, however, helpful to know that the PC-PART instrument scores are able to discriminate between those who return to community living, and those who do not, and to establish cut points for discharge scores to community living. This may inform therapists whether service-users are ready, or not, for discharge to community living.

# Responsiveness

Responsiveness is viewed as a different measurement property to validity in the COSMIN checklist (Mokkink, Terwee, et al., 2010a). The only real difference between responsiveness, construct validity and criterion validity, is that construct and criterion validity are cross-sectional, referring to validity of one single score, and responsiveness "refers to the validity of a change score" (Mokkink, Terwee, et al., 2010c, p. 748).

Thus, evaluation of responsiveness requires at least two measurements over a time. The quality standards for responsiveness in the COSMIN checklist are similar to the quality standards for construct and criterion validity (Mokkink, Terwee, et al., 2010a). To know whether changes in scores are expected, there should be some description of what occurred between the measurements and the period of time (Mokkink, Terwee, et al., 2010a). For this present study, a description of the intervention was published in a RCT protocol (N. F. Taylor et al., 2010). Some evidence should be provided that a proportion of the people under study improved or deteriorated on the construct to be measured,

otherwise it is difficult to know afterwards if the people did not change or whether it was the instrument that was not responsive to actual change (Mokkink, Terwee, et al., 2010a, p. 40). Relevant to this study, outcomes of the RCT indicated that participants demonstrated clinically meaningful change across a range of outcomes and parameters (Peiris et al., 2013a, 2013b). The hypotheses should articulate "expected mean differences between changes in groups or expected correlations between changes in [instrument scores] and changes in other variables" (Mokkink, Terwee, et al., 2010a, pp. 40-41). The hypotheses may focus on the relative magnitude of correlations in change scores with other variables (Mokkink, Terwee, et al., 2010a, p. 41). Many of the same criteria apply to responsiveness as for hypothesis testing, with respect to expected number of, and nature of, hypotheses, comparator measures and the avoidance of examining statistical significance of differences between groups.

During development of the COSMIN checklist, the COSMIN consensus panel considered that effect sizes were not appropriate measures of responsiveness (Mokkink, Terwee, Knol, et al., 2010). The panel considered that effect sizes measure the magnitude of an intervention rather than the quality of the measurement instrument. Also, the paired t-test was considered not to be appropriate because it measures statistically significant change, rather than clinically meaningful change (Mokkink, Terwee, et al., 2010a). It is noted that in this present study, effect sizes of FIM<sup>TM</sup> and PC-PART scores between admission and discharge were calculated, but it was the relative magnitude of the effect sizes between the measures, over time, that was of interest, not the actual effect size of change scores on any single instrument.

# Paper 5: Responsiveness, Construct and Criterion Validity of the PC-PART

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RESEARCH Open Access



# Responsiveness, construct and criterion validity of the Personal Care-Participation Assessment and Resource Tool (PC-PART)

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#### **Abstract**

**Background:** The Personal Care-Participation Assessment and Resource Tool (PC-PART) was designed to measure participation restrictions in activities of daily living required for community life. Rasch analysis has confirmed that the PC-PART contains two unidimensional scales providing interval-level measurement: the *Self Care* and *Domestic Life* scales. This study investigated validity and responsiveness of these PC-PART scales using the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) approach.

**Methods:** Thirteen hypotheses about *Self Care* and *Domestic Life* scale scores were established prior to conducting the analyses. Data from a prospective randomized controlled trial of additional (weekend) inpatient rehabilitation in Melbourne, Australia, were used. The 996 participants had a mean (SD) age of 74 (13) years and were admitted with orthopaedic (n = 581), neurological (n = 203) or other disabling impairments (n = 212). *Self Care* and *Domestic Life* scores were compared to functional independence (FIM), comorbidity (Charlson Comorbidity Index), whether activities of daily living goals were met, and discharge destination.

**Results:** Low to moderate correlations between FIM and PC-PART scales' scores supported hypotheses that the PC-PART measures a different construct from functional independence: *Self Care*  $r_s$  -0.52(95 % CI -.46 to -.57) and *Domestic Life*  $r_s$  -0.32(95 % CI -.25 to -.38). The scales had low to moderate discriminative ability for discharge destination, with the area under the curve for *Self Care*, 0.70 (95 % CI 0.62-0.78), and *Domestic Life*, 0.72 (95 % CI 0.64-0.80). The discharge to community living cut-off scores for *Self Care*: 5.50 (sensitivity .83, specificity .53) and *Domestic Life*: 7.50 (sensitivity .75, specificity .60), represented patients having no participation restrictions. Change scores from admission to discharge demonstrated larger effect sizes for the *Self Care* (1.67) and *Domestic Life* (1.50) scales than for the FIM (1.10), supporting hypotheses about responsiveness. Ten of the 13 hypotheses were supported.

**Conclusions:** This study provided evidence supporting construct validity, criterion validity and responsiveness of the PC-PART *Self Care* and *Domestic Life* scales for inpatient rehabilitation. Clinicians, managers and researchers who wish to measure the patterns and extent of people's participation restrictions in activities of daily living and the associated burden of care, before and/or after intervention, can be somewhat confident about the PC-PART's validity and responsiveness for this purpose.

**Trial registration:** Data used in this research were gathered during a registered randomized controlled trial: Australian and New Zealand Clinical Trials Registry ACTRN12609000973213.

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#### **Background**

Rehabilitation aims to improve activity performance and address barriers to patients' participation in their life situations [1–3]. Rehabilitation services assist patients to adapt to challenges they face in their daily life as a result of their impairments. Participation is a key outcome of rehabilitation programmes [2, 4].

The International Classification of Functioning, Disability and Health (ICF) [5] is a commonly used framework in rehabilitation that informs assessment and measurement of patients' functioning and health outcomes [6, 7]. The functioning and disability aspect of the ICF framework provides three separate constructs (impairments, activities, participation). However, only two components are described: one for impairments, and one for activities and participation, combined [5]. Researchers have commented on the lack of clarity in the interpretation of, and operationalization of the activity and participation concepts within the ICF framework [3, 7-11]. In particular, there is lack of consensus on interpretation of the definition for, and measurement of, participation-related constructs [7, 8, 10]. It seems accepted that measures eliciting information about an individual's ability, level of difficulty or level of dependence in performing tasks, without inclusion of the modifying effects of the environment in the instrument's metric, measure activity limitations [2, 3, 7]. With respect to measurement of participation restrictions, one view is that measures eliciting information about performance of tasks in natural environments and that include influences of the environment on performance in the instrument's metric, measure participation restrictions [2-4, 12, 13].

The Personal Care-Participation Assessment and Resource Tool (PC-PART) [14–16] was designed to measure the presence or absence of participation restrictions experienced by individuals in self care and domestic activities of daily living (ADL) required for community life. It systematically identifies unmet ADL needs which persist in individuals' living environments despite their own efforts, use of assistive devices, and supports or assistance from others [14, 16]. The PC-PART provides one conceptual perspective on the measurement of participation restriction in self care and domestic life domains.

The PC-PART differs from commonly used ADL instruments, such as the FIM [17, 18] and the Barthel Index (BI) [19], in a fundamentally important way. The FIM and BI measure patients' level of dependence in self care and mobility, rating their abilities and their need for assistance or adaptive equipment or both. They can be considered to measure activity limitations [2]. Such instruments are not able to capture what ADL will actually be accomplished. The PC-PART differs in that it measures both the need for assistance or equipment and

whether any required assistance is available and is provided in the patients' living environment. Such information is critical, for example, for discharge planning from inpatient settings [20–23] and for admission decisions in emergency departments [24, 25].

The COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) is an internationally recognised framework, developed through international consensus of experts in the measurement of health status outcomes [26–28]. The COSMIN checklist provides a framework of criteria for rating the methodological quality of research investigating the reliability, validity, responsiveness and interpretability of health measurement instruments. [27, 29]. It can also guide the development of rigorous methods to investigate measurement properties of health related outcome measures [29].

A systematic review of the measurement properties of the PC-PART using the COSMIN checklist showed that PC-PART items demonstrated good content validity [16, 30]. Other aspects of the instrument's validity could not be confirmed from the systematic review. Subsequent research has demonstrated that the PC-PART has good inter-rater reliability for group applications but not for individual applications, such as in the clinical setting [31]. Using Rasch methods, a further study generated evidence supporting internal validity of 30 of the original 43 items, when grouped into separate Self Care (16 items) and Domestic Life (14 items) scales [32]. The objective of this present study was to evaluate the construct validity, criterion validity and responsiveness of the Rasch-derived Self Care and Domestic Life scales in an adult inpatient rehabilitation setting.

#### **Methods**

#### Design

This is an instrument validation study guided by the COSMIN framework, involving secondary analysis of existing data from a prospective randomized controlled trial (RCT). The RCT investigated what effect providing additional Saturday rehabilitation during inpatient rehabilitation had on functional independence, quality of life and length of stay, compared to 5 days per week of rehabilitation [33–35].

#### **Participants**

Participants were the 996 adults enrolled in the trial, conducted in two public hospital multidisciplinary inpatient rehabilitation units in Melbourne, Australia. Participants with orthopaedic (e.g. fractures, elective joint replacements), neurological (e.g. stroke, multiple sclerosis, Parkinson's disease) or other disabling condition (e.g. cardiac, pulmonary, deconditioning) were included. Patients were not excluded if their primary language was different from English or if they had

reduced cognition, but were excluded if they were admitted for 'Geriatric Evaluation and Management' (otherwise known as slow stream rehabilitation) or if they were enrolled in another trial. Patients are typically accepted for inpatient rehabilitation if assessed as being able to participate actively in rehabilitation with the expectation they will improve sufficiently to return to community living [33]. Ethics approval for this study, involving secondary analysis of the RCT data, was received from University and Health Service Human Research Ethics Committees. Participants gave written informed consent to take part in the RCT.

#### Measures

Data from all measures used in the RCT were available for this study and these are detailed elsewhere [33]. Hypotheses for this present study were generated prior to all analyses with knowledge of the available measures used for the RCT. Only data from measures relevant to the hypotheses for this present study were used.

The PC-PART was administered to gather data for the RCT at admission (baseline) and again at discharge from inpatient rehabilitation. It was administered by occupational therapists using a combination of patient interview, key informant interview and task observation (see Appendix A: Table 8 for item examples). Prior to commencement of data collection the occupational therapist assessors were provided with standardized education in the use of the PC-PART. This consisted of a one-hour training session. In addition, the occupational therapists were provided the PC-PART manual [14] and a recorded audiovidual presentation [15].

The PC-PART assessment was administered to identify participants' existing participation restrictions in ADL in their discharge living environments. Items were scored as either OK by self (patients will manage the activity alone with or without aids in their living environments), OK with help (patients will manage the activity with help from others, and this help is available and provided in their living environments), or Not OK (patients will not manage the activity in their living environments despite their own efforts, use of aids and help from available support from others). Both OK by self and OK with help were scored 0 (no participation restriction present), and Not OK was scored 1 (participation restriction was present). Each Not OK represented an ADL participation restriction. These item response categories were shown to be valid using Rasch analysis [32]. When used clinically, the raw score for each scale is the total number of Not OK scores observed for an individual patient, with a range of possible scores of 0-16 (Self Care) and 0-14 (Domestic Life). Rasch-derived conversion scores for each scale use a 0-100 scale, where 0 reflects no ADL participation restriction and 100 represents complete

ADL participation restriction. *Self Care* and *Domestic Life* scale total scores cannot be combined to form an overall PC-PART score [32].

Rasch-derived scores for the 16 *Self Care* scale items and 14 *Domestic Life* scale items were used for all analyses in this present study [32]. To aid clinical interpretation where relevant, Rasch-derived scores were related back to corresponding total raw *Self Care* and *Domestic Life* scores using a conversion table [32].

The FIM [36] consists of 18 items from motor (13 items) and cognitive (5 items) domains. Each item is rated on a 7-point scale, where 1 represents complete dependence and the need for total assistance and 7 represents complete independence. Scores range from 18 (complete dependence on all items) to 126 (complete independence on all items) [37]. Items cover activities such as eating, grooming, bathing, dressing, toileting, sphincter control, , transfers, locomotion, communication and social cognition. There is evidence from studies conducted in the past two decades across several countries and different patient populations, supporting reliability, validity and responsiveness of the FIM as a measure of disability for patients receiving rehabilitation [38]. Thus, the FIM was viewed as a suitable comparison instrument for the PC-PART. It is a measure of activity limitations according to ICF concepts and terminology [5, 39]. It has sufficient similarity in the content of its domains to the PC-PART, to generate hypotheses reflecting expected convergence and divergence between their scores at admission and discharge from inpatient rehabilitation. The FIM was administered as part of routine care by FIM trained assessors, including physiotherapists and occupational therapists. It was scored during multidisciplinary team meetings at admission (baseline) and at discharge from inpatient rehabilitation. At both points, the FIM was completed on a separate occasion to the PC-PART.

The Charlson Comorbidity Index [40] was selected as the best available measure used in the RCT to enable testing of hypotheses about the PC-PART's scores related to the level of patients' co-morbidity. The sum of the index score, adjusted for age, is an indicator of disease burden and an estimator of mortality [40]. It provided a mechanism to quantify the severity of a patient's overall state of ill-health, given the number and seriousness of health conditions experienced. The index has been widely used and validated in population studies [41], but it is recognized that some conditions (e.g. rheumatological disease) are less accurately coded [42]. The score was calculated at admission.

ADL discharge goals were established by the patients and treating occupational therapists at admission. This information was gathered for the RCT but not with the structured approach of goal attainment scaling.

Achievement of ADL goals was measured and recorded at discharge from inpatient rehabilitation by the treating occupational therapist as being either met/unmet. Partially met goals were categorized as unmet.

Patients' discharge destinations, that is, patients' living situations immediately following discharge from inpatient rehabilitation were categorised as home (usual place of residence), low-level residential care, high-level residential care, acute hospital transfer, or transitional care. The transitional care program involved continued inpatient care for either lower intensity rehabilitation activities or to await placement in residential care facilities.

#### Analysis

#### COSMIN checklist

The COSMIN checklist provided criteria for evaluating construct validity, criterion validity and responsiveness. In this study all design criteria were addressed [29, 43].

#### **Construct validity**

COSMIN stipulates that construct validity is the degree to which the scores of health related outcome instruments are consistent with hypotheses formulated prior to data analysis, based on the assumption that the instrument measures the construct of interest [27]. In accordance with COSMIN's recommendations, construct validity was evaluated by five hypotheses of expected mean score differences between impairment groups, and expected correlations between PC-PART scores and FIM and Charlson Comorbidity Index scores [29]. The hypotheses and statistical test criteria used are presented in Table 1.

#### Criterion Validity

COSMIN stipulates that criterion validity is the degree to which the scores of a health related patient reported outcomes instrument are an adequate reflection of a suitable *gold standard* [27]. In this case, the objectively observable dichotomous *gold standard* outcome was discharge destination (community living at home or in residential care versus inpatient acute or transitional care), reflecting an overall aim of rehabilitation to prepare patients for community living. Criterion validity was tested using three hypotheses, in accordance with COSMIN recommendedations. The hypotheses are presented in Table 1.

Receiver-Operator Characteristic curve data were used to estimate cut-off scores at discharge for the *Self Care* and *Domestic Life* scales that may discriminate patients discharged home or to residential care from those transferred to acute hospital or transitional care. Consideration was given to balancing sensitivity and specificity of the scales' scores.

#### Responsiveness

COSMIN stipulates that responsiveness is the ability of an instrument to detect change over time when change has occurred [27]. In accordance with COSMIN's recommendations, responsiveness was evaluated with five hypotheses about the relationship between change scores on the PC-PART and FIM and predicted magnitudes of effect sizes of each measure between admission and discharge (see Table 1).

#### Data analysis

Data were analyzed using IBM SPSS Statistics (Version 21.0.0) software. Missing study data were removed from analyses using pairwise methods in all analyses. According to the COSMIN rating scale [46], a sample size for testing measurement properties of  $n \ge 100$ , is considered excellent; from n = 50-99 is good; from n = 30-49 is fair; and n < 30 is poor. It was expected that sample sizes, per analysis, using the RCT data (n = 996) would be excellent for evaluating construct validity, criterion validity and responsiveness of the Rasch-derived Self Care and Domestic Life scales.

#### Results

The 996 participants had a mean (SD) age of 74 (13) years, and 631 (63%) were women (see Table 2). There were 581 (58%) participants admitted with an orthopaedic diagnosis, 203 (20%) with a neurological diagnosis and 212 (21%) with other disabling impairments. Mean (SD) length of stay in the rehabilitation unit was 21 (16) nights. Most participants (93%) were living at home prior to their acute hospital admission. Of the 7% of participants not living at home prior to admission, 2% (n = 27) lived in low-level residential care (LLC), 2% (n = 23) lived in 'other' accommodation, and 2% (n = 19) had missing data for this variable. Participants from LLC or 'other' accommodation (n = 50) showed average (median) improvement of 18 points on the FIM from admission to discharge.

Approximately 10 % of discharge PC-PART data for both Self Care and Domestic Life scales were missing (see Table 2). There were a number of these patients for whom most discharge PC-PART individual item data were available, but for whom Self Care scores (n = 64) and Domestic Life scores (n = 59) could not be calculated because there was between one and three missing values for individual items in the scale. To use a Rasch-derived scale and its associated conversion table, all items in the scale need to be completed to produce a valid score. There were 34 patients (3 % of the sample) with no discharge PC-PART data. Patients with no discharge PC-PART data (n = 34) had similar mean age (74 yrs, SD = 15, 95 % CI 67-81), length of stay (20 nights, SD = 21, 95 % CI 16-41), admission Self Care scale scores (Mean = 48.0, SD = 25.1, 95 % CI 40.7-63.4) and Domestic Life scale scores

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Construct	Hypothesis number	Hypotheses about Self Care	Hypotheses about Domestic Life	Rationale	Test Criteria used
Construct	-	At admission, there will be a large negative correlation between Self Care scores and FIM total scores, for the whole sample.	At admission there will be a moderate negative correlation between <i>Domestic Life</i> scores and FIM total scores for the whole sample.	Higher correlations expected between Self Care scale and FIM than between Domestic Life and FIM. Self Care scale contains more items with content directly related to the FIM than Domestic Life scale and appears to measure same construct at high levels of functioning (i.e. 'OK by self' on the PC-PART and scores of 6-7 on the FIM).	Magnitude of correlation coefficient $(s_i)^3$ , $t_i \ge .5 = large$ , $t_s$ .3 to $.49 = moderate$ , $t_s$ .1 to $.29 = small [44]$ .
	2	At admission, there will be a large negative correlation between Self Care scores and FIM total scores, irrespective of sex, age and major impairment groups	At admission, there will be a a moderate negative correlation between <i>Domestic Life</i> scores and FIM total scores, irrespective of sex, age and major impairment groups.		
	м	There will be a moderate positive correlation between admission Self Care and Charlson Comorbidity Index scores.	There will be a moderate positive correlation between admission Domestic Life scores and Charlson Comorbidity Index scores.	Patients with high co-morbidity expected to have more ADL activity limitations and more support needs than patients with low comorbidity. More support needs expected to be more difficult to satisfy, resulting in higher levels of ADL participation restriction than for those with low comorbidity.	
	4	On admission, there will be no observed differences in Self Care participation restriction scores between patient impairment groups.	On admission, there will be no observed differences in <i>Domestic Life</i> participation restriction scores between patient impairment groups.	Differences in scores between impairment groups not expected because PC-PART measurement records interactions between persons, tasks and environment. Scores not based on patients' impairments or diagnoses.	Admission <i>Self Care</i> and <i>Domestic Life</i> Mean ± 95 % Cl scores for each impairment group.
	rv.	Self Care mean discharge scores will be lower for patients who attained their ADL goals than for patients who did not attain their ADL goals by at least one participation restriction on the Self Care scale.	Domestic Life scale mean discharge scores will be lower for patients who achieved their ADL goals than for patients who did not achieve their ADL goals by at least one participation restriction on the Domestic Life scale.	Patients' inpatient rehabilitation ADL goals focused on optimising independence in self-care and domestic life activities of daily living and arranging zappropriate supports to enable discharge to the community. Achievement of ADL goals therefore expected to correspond to low <i>Self Care</i> and <i>Domestic Life</i> participation restriction (unmet needs) scores.	Mean difference in 1 Raschderived participation restriction scores. Self Care = 6.3 Domestic Life = 6.9. Differences assessed using 95 % CI mean estimates.
Criterion	o	Self Care scales will discriminate between those patients discharged to 'home or residential care' versus patients discharged to 'acute hospital or transitional care.'	Domestic Life scales will discriminate between those patients discharged to 'home or residential care' versus patients discharged to 'acute hospital or transitional care'	'Gold standard' of 'discharge destination'is the criterion for estimating the probability that Self Care and Domestic Life scale scores are an accurate reflection of discharge destination. Theoretical expectation is thappatients discharged to community living situation (home, low- or high-level residential care) will have resolved ADL participation restrictions. Patients discharged to acute hospital or transitional care are likely to have unresolved ADL participation restrictions.	Area under the curve (AUC) range is 1.0 (perfect discrimination) to .5 (no discrimination): >,9 = high; .7 to .9 = moderate; >,5 to .69 = low; .5 = none [45]

 Table 1
 Methods: Hypotheses, criteria and rationale used to test construct validity, criterion validity and responsiveness (Continued)

Patients discharged home or to residential Patients discharged home or to residential care will have mean scores on the discharge Self Care scale reflecting less than discharge Domestic Life scale reflecting less than discharge ADL participation restrictions.  Patients discharged to acure hospital care  Patients discharged to acure hospital care
rations dischalged to acute hospital care or transitional care will have mean scores on the discharge <i>Domestic Life</i> scale reflecting three or more ADL participation restrictions.
There will be a low to moderate negative correlation between change scores on the Domestic Life scale and the FIM change score across the whole sample.
There will be a low to moderate negative correlation between change scores on the Domestic Life scale and the FIM change score irrespective of sex, age and major impairment groups.
The effect size observed on the Domestic Life scale and the FIM between admission and discharge will each be large, but the effect size observed on the FIM will be lower than that of the Domestic Life scale.
For patients discharged to 'home or residential care', there will be a large effect size on the <i>Domestic Life</i> scale.
The effect size on the <i>Domestic Life</i> scale for those discharged to 'acute hospital or transitional care' will be small to medium.

<sup>a</sup>Spearman correlation used to accommodate ordinal FIM data

 Table 2 Participant characteristics and study data

Gender: n (%) Age in years: mean (SD), min, max Age group: n (%)  ≤59 years 60 to 79 years ≥80 years Living at home prior to admission: n (%), missing	365 (37) 73 (13), 33, 98  57 (16) 180 (50) 128 (35)  341 (93), 12	631 (63) 75 (13), 22, 102 78 (12) 292 (46) 261 (41)	996 (100) 74 (13), 22, 102  135 (14) 472 (47) 389 (39)
min, max  Age group: n (%)  ≤59 years  60 to 79 years  ≥80 years  Living at home prior to admission:  n (%), missing	33, 98 57 (16) 180 (50) 128 (35) 341 (93), 12	22, 102 78 (12) 292 (46)	22, 102 135 (14) 472 (47)
Age group: n (%)  ≤59 years  60 to 79 years  ≥80 years  Living at home prior to admission: n (%), missing	57 (16) 180 (50) 128 (35) 341 (93), 12	78 (12) 292 (46)	135 (14) 472 (47)
≤59 years 60 to 79 years ≥80 years Living at home prior to admission: n (%), missing	180 (50) 128 (35) 341 (93), 12	292 (46)	472 (47)
60 to 79 years ≥80 years Living at home prior to admission: n (%), missing	180 (50) 128 (35) 341 (93), 12	292 (46)	472 (47)
≥80 years Living at home prior to admission:  n (%), missing	128 (35) 341 (93), 12		
Living at home prior to admission:  n (%), missing	341 (93), 12	261 (41)	389 (39)
n (%), missing			
	22 (17)	586 (93), 7	927 (93), 19
∟ength of stay <sup>a</sup> : mean (SD),	22 (17),	21 (15),	21 (16),
n, min, max, missing	359, 3, 124, 6	626, 3, 144, 5	985, 3, 144, 1
mpairment category: n (%)			
Stroke	88 (24)	72 (11)	160 (16)
Other neurological	20 (6)	23 (4)	43 (4)
Orthopaedic	171 (47)	410 (65)	581 (58)
Pain syndromes	12 (3)	31 (5)	43 (4)
Cardiac/Pulmonary	24 (7)	24 (4)	48 (5)
Other disabling impairments	50 (14)	71 (11)	121 (12)
Charlson Comorbidity Index: mode, median	0,1	0,0	0,1
Quartiles (25th ,50th ,75th)	0,1,2	0,0,1	0,1,2
min, max	0,9	0,9	0,9
PC-PART Self Care scores <sup>b</sup> :			
Admission: mean score (SD)	41.6 (24.4)	42.3 (21.0)	42.0 (22.3)
min, max, missing	0, 100, 11	0, 100, 27	0, 100, 38
Discharge: mean score (SD)	4.6 (12.1)	3.5 (11.1)	3.9 (11.5)
min, max, missing	0, 100, 42	0, 100, 58	0, 100, 100
PC-PART <i>Domestic Life</i> scores <sup>b</sup> :			
Admission: mean score (SD)	38.1 (22.5)	38.7 (19.0)	38.5 (20.4)
min, max, missing	0, 100, 11	0, 100, 28	0, 100, 39
Discharge: mean score (SD)	9.3 (17.1)	6.8 (14.3)	7.7 (15.4)
min, max, missing	0, 100, 36	0, 100 57	0, 100, 93
FIM total scores <sup>c</sup> :			
Admission: median,	86,	87,	87,
mean score (SD)	81.9 (22.2)	85.1 (17.4)	83.9 (19.3)
min, max, missing	18, 124, 0	23, 122, 1	18, 124, 1
Discharge: median,	110,	112,	111,
mean score (SD)	102.8 (21.1)	106.6 (16.0)	105.2, (18.1)
min, max, missing	18, 125, 6	18, 126, 3	18, 126, 9
Were ADL goals met at discharge?	, ,		, ,
Yes: n (%)	241 (66)	482 (76)	723 (73)
No: n (%)	100 (27)	116 (18)	216 (22)
Missing: n (%)	24 (7)	33 (5)	58 (6)
Discharge destination	.,	\-/	(-/
Home: n (%)	289 (79)	505 (80)	794 (80)

Table 2 Participant characteristics and study data (Continued)

•	Low level residential care: n (%)	10 (3)	33 (5)	43 (4)
	High level residential care: n (%)	16 (4)	20 (3)	36 (4)
	Acute hospital transfer: n (%)	10 (3)	7 (1)	17 (2)
	Transitional Care Prog. and 'other': n (%)	25 (7)	44 (7)	69 (7)
	Missing: n (%)	15 (4)	22 (4)	38 (4)

<sup>&</sup>lt;sup>a</sup>Number of nights in inpatient rehabilitation

(Mean = 38.4, SD = 19.5, 95 % CI 29.3-50.2) compared to the rest of the sample. However, their admission FIM scores (median = 72) and discharge FIM scores (median = 71) were lower compared to the rest of the sample. A higher proportion of patients with no discharge PC-PART data were discharged to acute care (33 %), compared to 2 % for the whole sample.

#### Construct validity Hypothesis 1

Table 3 shows that at admission, the large negative correlation between Self Care scores and FIM total scores,  $r_s$  = -.52 (95 % CI -.46 to-.57), and a moderate negative correlation between Domestic Life scores and FIM total scores,  $r_s = -.32$  (95 % CI -.25 to-.38), supported the hypothesis about the magnitude and direction of these correlations. However, 95 % confidence intervals of the estimates included lower correlations than expected.

#### Hypothesis 2

Correlations by sex, age, and impairment between PC-PART scales and FIM generated 16 correlation values. The magnitude of 10 correlation values were as hypothesized, but six correlation values were lower than expected

Table 3 Hypotheses 1 and 2 (construct validity): correlations between PC-PART scales and FIM at admission to inpatient rehabilitation

	Spearman correlation: r	s (95 % CI) <sup>a</sup>		Hypothesis supported? Self Care: $r_s \ge .5$ ? <sup>b</sup>
				Domestic Life: $r_s$ .30 to .49? $^b$
Whole sample	n = 956			
Self Care and FIM	.52(.46,.57)			Yes <sup>c</sup>
Domestic Life and FIM	.32(.25,.38)			Yes <sup>c</sup>
by Sex	Women n = 602	Men n = 354		
Self Care and FIM	.51(.44,.57)	.53(.44,.61)		Yes <sup>c</sup>
Domestic Life and FIM	.32(.24,.39)	.32(.22,.42)		Yes <sup>c</sup>
by Age	≤59 yrs	60 to 79 yrs	≥80 yrs	
	n = 127	n = 454	n = 375	
Self Care and FIM	.52(.35,.65)	.51(.42,.59)	.44(.34,.53)	Yes: ≤59yrs <sup>c</sup> & 60 to 79 yrs <sup>c</sup>
				No: ≥80yrs <sup>e</sup>
Domestic Life and FIM	.37(.21,.53)	.30(.21,.39)	.28(.18,.37)	Yes: ≤59yrs <sup>c, d</sup> & 60 to 79 yrs <sup>c</sup>
				No: ≥80yrs <sup>e</sup> .
by Impairment	Orthopaedic n = 561	Neurological n = 194	Other Impairments n = 201	
Self Care and FIM	.41(.33,.48)	.70(.59,.79)	.48(.35,.58)	Yes: Neurological.
				No: Orthopaedic.
				No: Other Impairment <sup>e</sup>
Domestic Life and FIM	.27(.18,.34)	.40(.26,.52)	.28(.14,.41)	Yes: Neurological <sup>c,d</sup> ,
				No: Orthopaedic <sup>e</sup> & Other Impairment <sup>e</sup>

<sup>&</sup>lt;sup>a</sup>Absolute magnitude of the negative correlation values are represented

Interval level scale 0 to 100, where 0 reflects no ADL participation restriction, 100 reflects highest level of ADL participation restriction

<sup>&</sup>lt;sup>c</sup>Ordinal scale from 18 to 126, where 18 reflects total dependence, 126 reflects total independence

bUsing Cohen's definition[44]:  $r_s = .10$  to .29 (small);  $r_s = .30$  to .49 (medium);  $r_s = .50$  to 1.0 (large)

<sup>&</sup>lt;sup>c</sup>Lower bound 95 % confidence interval suggests true value potentially lies below the range specified

<sup>&</sup>lt;sup>d</sup>Upper bound 95 % confidence interval suggests true value potentially lies above the range specified

<sup>&</sup>lt;sup>e</sup>Upper bound 95 % confidence interval suggests true value potentially lies within the range specified

for both PC-PART scales (participants aged  $\geq 80$  years; those with orthopaedic or other disabling impairments) (see Table 3). Fifteen of the 16 lower bound 95 % confidence interval estimates were lower than predicted. Two upper bound 95 % confidence interval estimates for *Domestic Life* and FIM were higher than expected (participants aged  $\leq 59$  years; those with neurological impairment).

#### Hypothesis 3

There was a negligible (< .1) to small (.10 to.29) positive correlation between admission *Self Care*,  $r_s$  = .10 (95 % CI .04-.16), and *Domestic Life*,  $r_s$  = .04 (95 % CI .02-.10) scores and Charlson Comorbidity Index scores, suggesting a negligible relationship between the PC-PART scales and degree of comorbidity. This result did not support the hypothesis of a moderate positive correlation between the variables. Post hoc analysis showed that 75 % of participants' comorbidity scores were  $\leq$ 2 and 50 % of scores were  $\leq$ 1, showing relatively low variation in scores across the sample.

#### Hypothesis 4

The hypothesis of no difference in *Self Care* and *Domestic Life* scale mean scores across impairment groups was not supported. The mean scores and 95 % confidence intervals from the group of patients with stroke [*Self Care* 56.5(95 % CI 52.5-60.5); *Domestic Life* 50.1 (95 % CI 46.4-53.8)] demonstrated higher admission scores on both PC-PART scales than patients in other impairment groups, with the closest group being patients with other neurological conditions [*Self Care* 43.0 (95 % CI 34.3-51.7); *Domestic Life* 39.3 (95 % CI 32.2-46.3)] (see Fig. 1).

#### Hypothesis 5

The mean difference in PC-PART scores between patients who attained their ADL goals and patients who did not, was 9.3 (95 % CI 6.6-12.1) for *Self Care* and 12.2 (95 % CI 9.0-15.4) for *Domestic Life* ( see Table 4). As hypothesized, these values represented a clinically relevant difference in raw scores of at least one ADL participation restriction between groups on each scale.

#### Criterion validity

#### Hypothesis 6

Both *Self Care* and *Domestic Life* scale scores demonstrated low to moderate probability of correctly differentiating between patients discharged home or residential care (n = 815) versus patients discharged to acute hospital or transitional care (n = 86). The estimated area under the curve for the *Domestic Life* scale was .72 (95 % CI: .64-.80) and for the *Self Care* scale, was .70 (95 % CI: .62-.78). This result was modest, but supported the hypothesis of an area under the curve greater than .50, representing discriminative ability greater than chance (see Fig. 2).

#### Hypothesis 7

The hypothesis that those discharged home or to residential care would have *Self Care* and *Domestic Life* discharge scores representing less than three ADL participation restrictions, was supported (see Table 5). Those discharged to community living (home, low level-, high level residential care) had discharge mean *Self Care* scores of 2.7 (95 % CI 2.2-3.3), and *Domestic Life* scores of 6.2 (95 % CI 5.3-7.0), representing raw scores of no ADL participation restrictions on each scale.

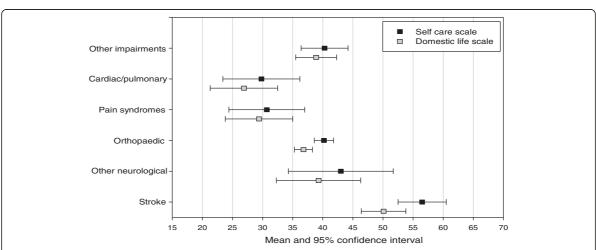


Fig. 1 Hypothesis 4 (construct validity): PC-PART Self Care and Domestic Life scores at admission for impairment groups, displaying mean and 95 % confidence interval for each group. (see separate file)

Table 4 Hypothesis 5 (construct validity): PC-PART scores and 95 % Cls at discharge for variable 'ADL goal met?'

PC-PART	ADL goal met?	No (n = 193)	Difference	Is difference > 1 ADL
scale:	Yes (n = 679)		between Means (95 % Cls)	participation restriction?
	Mean scale score (95 % CI)	Mean scale score (95 % CI)		Self Care ≥ 6.3?ªDomestic Life ≥ 6.9? ª
Self Care	1.7 (1.3-2.1)	11.0 (8.3-13.8)	9.3 (6.6-12.1)	Yes
Domestic Life	4.6 (3.8-5.3)	16.8 (13.7-19.9)	12.2 (9.0-15.4)	Yes

<sup>&</sup>lt;sup>a</sup>Value represents the mean difference between any two participation restriction scores on the 0 to 100 Rasch-derived conversion scale

#### Hypothesis 8

The hypothesis that those discharged to acute or transitional care would have *Self Care* and *Domestic Life* discharge mean scores representing three or more ADL participation restrictions, was partly supported. The 95 % confidence intervals included scores representing three ADL participation restrictions, but also included the possibility of two or one ADL participation restrictions. Those discharged to acute hospital or transitional care had discharge mean *Self Care* scores of 18.4 (95 % CI 11.5-25.3), and *Domestic Life* scores of 27.5 (95 % CI 20.1-34.8), representing raw scores of one to three ADL participation restrictions on each scale (see Table 5). Post-hoc analysis for this combined group showed that 13 of the 17 patients discharged to acute care had no discharge PC-PART data. The other

four patients discharged to acute care for whom discharge PC-PART data were available, had at least 14 Self Care participation restrictions and 12 Domestic Life participation restrictions at discharge. Of the 69 patients discharged to transitional care, 30 (44 %) had no Self Care participation restrictions and 26 (38 %) had no Domestic Life participation restrictions.

#### **Cut-off scores**

Table 6 shows potential cut-off scores for each scale at several levels of sensitivity to correctly identify patients discharged to home or to residential care. Corresponding levels of specificity for scores to correctly identify patients discharged to acute hospital or transitional care are provided. Cut-off scores of zero on both PC-PART scales reflected optimal sensitivity but specificity

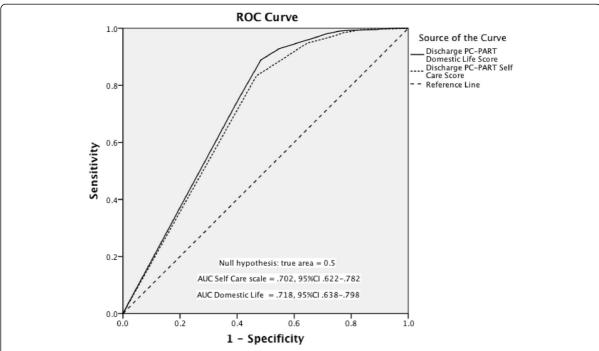


Fig. 2 Criterion validity: Area under the ROC curve (AUC) for the discharge PC-PART Self Care and Domestic Life scores, discriminating between patients discharged to home or residential care (community living) and patients discharged from inpatient rehabilitation to continued inpatient care. (see separate file)

**Table 5** Hypotheses 7 and 8 (criterion validity): PC-PART Rasch-derived scores, raw scores and 95 % CIs at discharge, by discharge destination

PC-PART scale:	Discharge to:	Rasch score:	Discharge to:	Rasch score:
	Home, LLC, HLC (n = 815)	Self Care <25?	Acute care, TCP (n = 86)	Self Care ≥25?
	Mean score (95 % CI)	Domestic Life < 33?	Mean score (95 % CI)	Domestic Life ≥ 33?
		Raw score <3 both scales?		Raw score ≥3 both scales?
Self Care:				
Rasch conversion scores	2.7 (2.2-3.3)	Yes	18.4 (11.5-25.3)	No <sup>a</sup>
Equivalent raw scores	0 (0-0)	Yes	1 (1–3)	No <sup>a</sup>
Domestic Life:				
Rasch conversion scores	6.2 (5.3-7.0)	Yes	27.5 (20.1-34.8)	No <sup>a</sup>
Equivalent raw scores	0 (0-0)	Yes	3 (1–3)	Yes <sup>b</sup>

Low-level residential care (LLC); High-level residential care (HLC); Transitional Care Program (TCP)

values were relatively low: *Self Care* 5.50 (Sensitivity, .83, Specificity, .53), and *Domestic Life* 7.50 (Sensitivity, .75, Specificity, .60).

#### Responsiveness

#### Hypothesis 9

As hypothesized, there was a low to moderate negative correlation ( $r_s \le -.49$ ) across the sample, between FIM change scores and *Self Care* change scores,  $r_s = -.40$  (95 % CI -.34 to -.45), and *Domestic Life* change scores,  $r_s = -.22$  (95 % CI -.16 to-.30) (see Table 7).

#### Hypothesis 10

Fifteen of 16 change score correlation values between the FIM and *Self Care* and *Domestic Life* scales by sex, age and major impairment groups were  $\leq$  .49, as

hypothesized (see Table 7). Participants aged  $\leq$ 59 years had a value greater than .49 on the *Self Care* scale ( $r_s$  = .56), but the lower bound 95 % CI was lower than .49, ( $r_s$  = .41). Five upper bound 95 % confidence interval estimates were higher than .49: for *Self Care* (men, participants with neurological and other impairments); and for both *Self Care* and *Domestic Life* (participants aged  $\leq$ 59 years).

#### Hypothesis 11

As hypothesized, there was a large effect size for both PC PART scales and FIM between admission and discharge with the FIM demonstrating the smallest effect size: *Self Care* scale (ES = 1.71; 95 % CI 1.60-1.82); *Domestic Life* scale (ES = 1.51; 95 % CI 1.40-1.61) and FIM (ES = 1.10; 95 % CI 1.01-1.20).

**Table 6** Criterion validity: Discharge *Self Care* and *Domestic Life* scale ROC cut-off scores and their corresponding sensitivity/specificity in identifying discharge destination

PC-PART scale	Positive	Raw scores	Sensitivity	1-Specificity	Specificity
	if ≤ to <sup>a</sup> :	represented	(true + ve)	(false + ve)	(true -ve)
Discharge Self Care score	-1.00	<0	.00	.00	1
	5.50	0	.83	.47	.53
	15.00	1	.95	.64	.46
	22.00	2	.97	.74	.26
Discharge Domestic Life score	-1.00	<0	.00	.00	1
	7.50	0	.75	.40	.60
	20.50	1	.90	.48	.52
	29.50	2	.93	.55	.45
	35.50	3	.96	.65	.35

Potential cut-off scores to optimise sensitivity and specificity of PC-PART scales for identifying patients with ADL participation restrictions who should remain as inpatients and those who may appropriately be discharged to a specified community living situation

<sup>a</sup>Positive state is discharge to home or residential care. The smallest cutoff value is the minimum observed test value minus 1, and the largest cutoff value is the maximum observed test value plus 1. All the other cutoff values are the averages of two consecutively ordered observed test values

<sup>&</sup>lt;sup>a</sup> Upper bound 95 % confidence interval suggests true value potentially lies in the range specified

<sup>&</sup>lt;sup>b</sup>Lower bound 95 % confidence interval suggests true value potentially lies below the range specified

**Table 7** Hypotheses 9 and 10 (responsiveness): correlations between PC-PART scales' change scores and FIM change scores, between admission and discharge

	Spearman correlat	tions		Hypothesis supported?
	r <sub>s</sub> (95%CI) <sup>a</sup>			$r_s \le .49?^{b}$
Whole sample	n = 891			
Self Care and FIM change scores	.40(.3445)			Yes
Domestic Life and FIM change scores	.22(.1630)			Yes
by Sex	Women n = 569	Men n = 321		
Self Care and FIM change scores	.40(.3247)	.39(.2850)		Yes: Women and Men <sup>c</sup> ,
Domestic Life and FIM change scores	.22(.1330)	.23(.1334)		Yes: Women and Men
by Age	≤59 yrs	60 to 79 yrs	≥80 yrs	
	n = 118	n = 427	n = 346	
Self Care and FIM change scores	.56(.4168)	.40(.3148)	32(.2143)	Yes: 60 to 79 yrs &≥80 yrs
				No: ≤59yrs <sup>d</sup>
Domestic Life and FIM change	.44(.2758)	.23(.1333)	14(.0224)	Yes: 60 to 79 yrs &≥80 yrs
scores				Yes: ≤59yrs <sup>c</sup>
by Impairment	Orthopaedic n = 530	Neurological n = 176	Other Impairments n = 185	
Self Care and FIM change scores	.31(.2239)	.48(.3460)	.42(.2953)	Yes: Orthopaedic.
				Yes: Neurological <sup>c</sup> & Other Impairment <sup>c</sup>
Domestic Life and FIM change scores	.19(.1028)	.21(.0635)	.24(.0938)	Yes: all groups.

<sup>&</sup>lt;sup>a</sup>Absolute magnitude of the negative correlation values are represented

#### Hypothesis 12

Patients discharged home or to residential care had a large reduction (improvement) in mean PC-PART scores from admission to discharge on the *Self Care* scale (from 40.8 to 2.7; n = 810) and the *Domestic Life* scale (from 37.3 to 6.2; n = 814). These scores represented an average improvement from six *Self Care* participation restrictions at admission to none at discharge (ES = 1.73, 95 % CI 1.62-1.85), and from three *Domestic Life* participation restrictions at admission to none at discharge (ES = 1.56, 95 % CI 1.45-1.67). As hypothesized, both observed effect sizes were > 0.8.

#### Hypothesis 13

Patients discharged to acute hospital or transitional care had a large reduction in mean PC-PART scores from admission to discharge on the *Self Care* scale (from 52.4 to 18.4; n = 63) and the *Domestic Life* scale (from 53 to 27.5; n = 63). These scores represented an average reduction of nine *Self Care* participation restrictions at admission to two at discharge (ES = 1.54, 95 % CI 1.13-1.93), and from nine *Domestic Life* participation restrictions at admission to three at discharge (*ES* = 1.22, 95 % CI 0.83-1.59). Both effect sizes and their 95 % confidence intervalswere > 0.8.

These results did not support the hypothesis of an effect size < .8 in this group.

#### **COSMIN summary**

Overall, for both *Self Care* and *Domestic Life* PC-PART scales, the number of hypotheses supported were: 3 of 5 for construct validity; 3 of 3 for criterion validity; and 4 of 5 for responsiveness. Overall 6 of 8 hypotheses about validity and 4 of 5 hypotheses about responsiveness were supported. Sample sizes for all analyses were *good* to *excellent*.

#### Discussion

This study evaluated construct validity, criterion validity and responsiveness of the PC-PART *Self Care* and *Domestic Life* scales for inpatient rehabilitation using the COSMIN framework. Overall, there was support for 10 of the 13 hypotheses.

Given that both the PC-PART and the FIM have provided evidence of reliability and validity, the lack of a strong negative correlation between the measures at admission could be interpreted as suggesting that the PC-PART measures a different construct to FIM. The FIM measures activity limitations [37]. The PC-PART scales performed in accordance with theoretical expectations,

bUsing Cohen's definition [44]:  $r_s = .10$  to .29 (small);  $r_s = .30$  to .49 (medium);  $r_s = .50$  to 1.0 (large)

<sup>&</sup>lt;sup>c</sup>Upper bound 95 % confidence interval suggests true value potentially lies above the range specified

<sup>&</sup>lt;sup>d</sup>Lower bound 95 % confidence interval suggests true value potentially lies in the range specified

supporting construct validity of the PC-PART's *Self Care* and *Domestic Life* scales as measures of ADL participation restriction.

To our knowledge, the PC-PART is the only instrument that specifically targets the transaction between people, their activity and the available supports in their living environments to record participation restrictions in activities of daily living required for community life. Other instruments seem similar, for example, the Assessment of Living Skills and Resources-Revised 2 (ALSAR-R2) [47]; Assessment of Life Habits (LIFE-H) [48]; Craig Handicap Assessment and Reporting Technique (CHART) [49]; and the Functional Autonomy Measurement System (SMAF) [50]. However, these assesments have applications in different areas of functioning than the PC-PART (e.g. performance in education, work, leisure tasks and body functions) and vary in the degree and manner in which they incorporate the need for, and availability of, supports, resources or assistance into their scoring [47-50]. The PC-PART therefore provides an important and unique contribution to health state measurement through its measurement of participation restrictions.

The relationship between comorbidity and PC-PART scores needs further investigation. Contrary to our expectations, the number and severity of comorbidities did not influence PC-PART scores (hypothesis 3). Overall, patients in this sample had relatively low comorbidity scores. Lack of variability in comorbidity scores may have affected the estimate of the correlation coefficient. It is possible that the Charlson Comorbidity Index was not sensitive to subclinical and chronic impairments that may impact people's functioning (e.g. chronic pain or rheumatological conditions) [42]. Further evidence using prospective methods gathering more detailed information about comorbidity may add to our understanding about the measurement of participation restriction as related to the number and severity of coexisting impairments.

Admission PC-PART scores were shown to be higher for patients with stroke, compared to patients from other impairment groups, showing a lack of support for hypothesis 4, which postulated no difference between impairment groups. It may be that the sudden nature of stroke onset and combination of physical and cognitive impairments associated with stroke results in more participation restrictions in the accompishment of ADL than for people with other impairments. This result suggests that the PC-PART may be sensitive to impairment type, however this premise requires testing in a specifically designed study. If PC-PART scores are shown to differ between impairment groups, then it is possible the PC-PART may be useful for identifying groups of patients who are likely to require interventions focused on

accomplishment of ADL required for community living as part of discharge planning.

The modest probability of both PC-PART scales' scores ability to accurately reflect patients' discharge destination shown in this study (hypothesis 6), seems likely to be an underestimation of their true discriminative ability. This result seems to have been influenced by the high proportion of missing PC-PART discharge data for patients discharged to acute inpatient care, as well as, a high proportion of patients with resolved participation restrictions in the transitional care group's PC-PART discharge data [45]. The acute hospital and transitional care group discharge PC-PART scores were probably not representative of the group they were intended to represent, that is, patients transferred to acute care due to ongoing problems requiring medical management. On reflection, separation of patients discharged to acute hospital and transitional care into separate groups may have provided more robust validation data. Thus, these are preliminary findings. Prospective and specifically designed investigations of the PC-PART's discriminative ability are required to produce more robust evidence about the ability of the Self Care and Domestic Life scale scores to accurately identify people who can return to community life from inpatient rehabilitation and those who continue to require inpatient

Both PC-PART scales appeared responsive. Their scores were shown to change in the direction expected when change had occurred, as indicated by other variables and instruments. Both scales demonstrated large effect sizes from rehabilitation admission to discharge. The correlation between change scores reflected a greater relative improvement in PC-PART scores than FIM scores between admission and discharge. This finding is consistent with theoretical expectations about PC-PART scores; that there should be a complete resolution of ADL participation restrictions prior to discharge home or to residential care (in residential care, the expectation is that all ADL needs are met). In contrast, it is possible for patients to be discharged to the community without complete independence scores on every FIM item, that is, without complete resolution of activity limitations, provided adequate supports are in place.

In this study, all patients' *Self Care* and *Domestic Life* scores between admission and discharge showed large effect sizes, irrespective of discharge destination. For patients discharged to home or supported living environments, the large effect size of PC-PART scores between admission and discharge supported its responsiveness. It is possible that the patients discharged to transitional care (n = 69), who had no ADL participation restrictions at discharge because they were

waiting for residential care placement, may have inflated the effect sizes for the acute and transitional inpatient care discharge group. Also, missing discharge PC-PART data for 13 of 17 patients transferred to acute care may have influenced the results by underrepresenting this group in the data. Thus, caution is advised when interpreting findings for hypothesis 13 due to limitations of the data as well as potential bias introduced during analyses. Responsiveness of the PC-PART scales should be further investigated in prospective, specifically designed studies.

One of the challenging decisions in validation research is whether to test hypotheses with the aid of structured guidelines, such as the COSMIN checklist, or whether to use more exploratory approaches. Formulating hypotheses prior to data analysis reduces the risk of bias when interpreting the results because criteria for validity are set before viewing the data. This avoids the temptation to think of alternative explanations for low correlations or no difference between groups, instead of concluding that the instrument may not be valid [27]. Limited existing validation research for the PC-PART influenced development of accurate hypotheses for this present study. The hypotheses used in this study were generated from some testing of the instrument [16, 32, 51-53], clinical knowledge and experience, combined with theoretical expectations of the instrument. The use of a more exploratory approach may have been useful for generating hypotheses for future testing, but would not have permitted the testing of evidence carried out in this study. Overall, the results of this study are positive, with the majority of hypotheses supported.

The COSMIN checklist provided a transparent, rigorous methodological structure for this research that assisted in minimizing methodological bias. It would be useful to use the COSMIN checklist to further evaluate the PC-PART scales in prospective, specifically designed research to build more evidence about the scales' validity and responsiveness.

In clinical practice the PC-PART may aid discharge planning. The derived cut-off scores of zero *Self Care* and zero *Domestic Life* participation restrictions, desirable for discharge home or to residential care living situations, intuitively match clinical reasoning. The scales may be used to identify and prioritise areas for intervention and to ensure that patients who are discharged to community living environments do not have ADL participation restrictions at the time of discharge.

The PC-PART scales may be useful for clinical practice, clinical research and health care system management. In clinical practice, they may identify the presence of participation restrictions in ADL required for community life, enabling prioritisation of intervention and

discharge planning. This may facilitate the reduction of barriers to discharge from inpatient care, which include issues of accommodation and supply of appropriate supports in community living environments [22]. In clinical research, changes that occur through interventions designed to reduce ADL participation restrictions, and their economic value, can be measured using the PC-PART scales. For the health care system, the PC-PART scales may be used to identify the nature and extent of participation restrictions experienced by populations in activities of daily living required for community life. This may aid understanding of the nature and extent of supports needed to enable people to live in the community and in turn, enable resources to be allocated where they are most needed.

#### Limitations

The retrospective use of existing data limited the scope of analysis to the type and nature of the existing variables, which were collected for a different purpose. Use of existing data also meant that specific methodological requirements for some analyses (criterion validity) were not favorable. The combined grouping of patients discharged to acute and transitional care may have resulted in an underestimation of the discriminative ability and responsiveness of the PC-PART scales. Therefore, the results of this study need to be interpreted in light of its limitations. Prospective studies could ensure more detailed, useful and specific data for comparison with PC-PART scores are gathered. Finally, testing of PC-PART scores in relation to assessments such as the ALSAR-R2, SMAF or LIFE-H, which all focus on accomplishment of some ADL as well as broader life activities, may provide opportunity for further validation research.

#### Conclusions

Overall, results of this rigorous validation study using the COSMIN checklist support the construct validity and criterion validity of the PC-PART's Self Care and Domestic Life scales for inpatient rehabilitation and show they are responsive to clinical changes, as measures of ADL participation restrictions in activities of daily living required for community life. Evidence from this study adds to existing research establishing the PC-PART scales as unidimensional interval-level measures of participation restriction. Health service clinicians, managers and researchers may confidently use the PC-PART scales to measure the pattern and extent of people's participation restrictions in activities of daily living required for community life, to gain an understanding of the burden of care associated with these needs and to aid resource allocation of services.

#### Appendix A

Table 8 Example: two items from each of the PC-PART Self Care and Domestic Life scales

Item Label	Question to patient	Question to key informant	Observation <sup>a</sup>	Standard task (done with usual help)	Global response and score
Self Care					
Dressing top	Do you get your top	Doesget his/her	Top adequately dressed?	Take off top and put	OK by self [0]
	dressed?	top dressed?		it back on.	OK with Help [0]
					Not OK [1]
Mobility	Do you get around in	Doesget around in	N/A	Mobilise around	OK by self [0]
(indoors)	your home OK?	the home OK?		objects in the room.	OK with Help [0]
					Not OK [1]
Domestic Life					
Groceries	Do you get your	Doesget his/her	Adequate groceries present?	Clarify situation	OK by self [0]
	groceries?	groceries?		through discussion.	OK with Help [0]
					Not OK [1]
Laundry	Do you get your clothes	Doesget clothes	Absence of dirty laundry?	Clarify situation	OK by self [0]
	laundered regularly?	laundered regularly?		through discussion.	OK with Help [0]
					Not OK [1]

<sup>&</sup>lt;sup>a</sup>When observations are not possible within a clinical setting, situation needs to be clarified through discussion

#### **Abbreviations**

ADL: Activities of daily living; AUC: Area under the curve; CCI: Charlson comorbidity Index; COSMIN: COnsensus-based Standards for the selection of health Measurement INstruments; ES: Effect size; FIM: Functional Independence Measure; HLC: High level care; ICF: International classification of functioning, disability and health; LLC: Low level care; PC-PART: Personal Care Participation Assessment and Resource Tool; ROC: Receiver-operator characteristic curve; TCP: Transitional care program.

#### Competing interests

Susan Darzins is a Director of Darzins Consulting Pty. Ltd., which operates using the business name 'The PART Group'. The PART Group distributes the PC-PART users' manual, assessment worksheets and training DVDs. Darzins Consulting Pty Ltd is not financing this manuscript nor had any role in approving the final manuscript. During the last five years (January 2009–2014) Susan Darzins has not received reimbursements, fees, funding or salary associated with sales of PC-PART products, from Darzins Consulting Pty. Ltd. It is possible, but unknown to what extent, Susan Darzins could benefit financially in the future from the publication of this manuscript. Susan Darzins does not hold and is not applying for any patents relating to the contents of this manuscript. All other authors declare that they have no competing interests.

#### Authors' contributions

SD conceived and designed the study and study methods, completed the data entry, performed all statistical analyses, drafted and revised the manuscript and formatted the manuscript for submission. Cl assisted in design of the study and study methods, provided consultation and supervision during data analyses and participated in revision of the manuscript. NS assisted in design of the study and study methods, provided advice on data analyses and contributed to the revision of the manuscript. NT provided access to the study data, assisted in design of the study and study methods, provided advice on data analyses and contributed to revisions of the manuscript. All authors read and approved the final manuscript.

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# **Chapter 7 - Conclusions**

This study achieved the fourth specific research objective for this body of research, which was to use hypothesis testing to evaluate construct validity, criterion validity and responsiveness of the PC-PART for inpatient rehabilitation. In this study, all eight COSMIN generalisability requirements were met (see Table 7.1) and 10 study design criteria for hypothesis testing were met (see Table 7.2). All six study design criteria for criterion validity were met (Table 7.3). All 14 study design criteria for responsiveness were met (see Table 7.4). This study contributed new evidence supporting validity and responsiveness of the PC-PART's Self Care and Domestic Life scales for inpatient rehabilitation.

Table 7.1. Summary of study purpose, methods and conclusions; COSMIN generalisability requirements met for this study.

Study	Study Purpose	Methods					Patient Sample characteristics	nple char	racteristics			Conclusions	"No of COSMIN Generalis- ability Requirements met /8
		Study design	Setting	Clinician raters, participant	Clinician description	i. Data Analysis ii. Handling Missing data	Sample selection	u	Age (yrs) Mean (Range)	Sex M/F	Population (impairment)	Overall findings	
Darzins et al., 2015	Darzins Evaluate et al., construct 2015 validity, criterion validity and responsive- ness of PC-PART for inpatient rehabilitati on	Secondary analysis of RCT data using admission and discharge measurements on selected measures	Inpatient adult rehabilitation wards of government- funded hospital, Melbourne, Australia.	Multi- disciplinary team involved in collection of RCT data including PC-PART data by OTs at admission and discharge n-25	All clinical OTs, doctors and PTs from rehabilitation wards trained in use of PC-PART.	i. Hypothesis testing- strength and direction for- Construct validity: Correlations (r,s) b/w a/d PC-PART and FIM <sup>TM</sup> scores; Mean a/d PC- PART score differences b/w impairment groups; Mean a/d PC-PART score difference b/w ADL goal attainment groups; Criterion validity: AUC and cut-off scores for d/c PC-PART scores b/w d/c groups; Responsiveness: Correlation between PC- PART and FIM <sup>TM</sup> change scores; Relative effect size on different measures.	All adult participants included in RCT of standard versus augmented therapy.	966=и	74 (22-102)	M=365 F=631	Stroke= 160 (16%); Other neuro= 43(4%) Orthopaedic= 581 (58%) Pain syndrome= 43 (4%) Cardiac/ Pulmonary= 48 (5%) Other disabling= 121 (12%)	10 of 13 hypotheses supported	∞
						ii. Missing data reported and not included in analyses							

Abbreviations: PC-PART=Personal Care Participation Assessment and Resource Tool; RCT=Randomised Controlled Trial; OT= Occupational Therapist; a/d=admission; b/w=between; d/c=discharge; PT=Physiotherapist; FIM<sup>TM</sup>=Functional Independence Measure; M=Male; F=Female; Neuro=Neurological; AUC=Area Under the Curve "The COSMIN checklist generalisability requirements: Description of age, sex, important disease characteristics, setting, countries where study was conducted, language used, participant selection described adequately, percentage of missing responses acceptable.

Table 7.2. Construct validity (hypothesis testing) - summary of COSMIN checklist design requirements met, (shaded row displays summary from this study).

1 S 01	1. Percentage of missing items	3. Sample size	4. Hypotheses formulated a priori?	5. Direction of correlations	7. Description of comparator	9. Absence of important flaws	10. Design and statistical methods adequate?	COSMIN
	ade	adequate?		specified? 6. Magnitude of	instrument adequate?	in study design or methods?	-	requirements met /10
missing data?				correlations specified?	8. Properties described?			
1. Not reported Not ju 2. Not reported N=36	Not N	Not justified. N=36	Yes – $H_o$ : A tight relationship between patients' FIM <sup>TM</sup> scores and HART	5. Yes – Inverse relationship	7. Yes – FIM <sup>TM</sup> described in detail.	No – Inadequate detail in	Yes – Visual graphs of scores on both measures weekly from a/d to d/c.	5
	(GE	(GEM = 16)	scores exists, indicating one measure	between FIM <sup>TM</sup>	8. Yes –	hypotheses set	Spearman's rho correlation between	
Reh	Reh	Rehab. =20)	can be used as a proxy of the other.	and HART scores	Measurement	a- priori.	change scores on each measure ( $r =$	
			H <sub>1</sub> : The relationship between FIM — and HART scores is limited or variable.	6. No – not stated	properties of the FIM <sup>TM</sup> described in		0.59).	
			indicating use of one instrument is		detail.			
			insufficient to reflect patient outcomes (p69).		(b.66)			
,	Yes	Yes – 131	Yes – Ho.: There will be a correlation	5. No – not stated	7. Yes – BI	No -Inadequate	No – Scatterplots were provided	9
HART (6%), BI com	com	complete sets	between Activity Limitation (BI) score	6. No – not stated	described in Smith	detail in	without calculating the strength and	
(9%) of d	of d	of data for	and Personal Care Participation		et al. (2001)	hypotheses set a	statistical significance of the	
	П	HAKI and BI	Kesulction (HAK1) score at a/d and d/c within an inpatient rehabilitation setting.		Smith et al. (2001).	-pnon.	correlations to support the visual representation of no/poor correlation	
data excluded					(p.67)		between HART and BI scores	
from analysis.								
3. Yes-	3. Y	es-	4. Yes – 5 main hypotheses set. (1) $a/d$	5. Yes	7. Yes – $FIM^{TM}$	9. Yes	10. Yes – Hypotheses formulated a-	10
con	con	complete a/d	SC and DL scores will have large –ve	6. Yes	cited as described		prior; strength and direction of	
and	and	and d/c PC-	correlation with FIM <sup>1M</sup> scores; (2) a/d		elsewhere – ref		hypotheses stated; Correlations - used	
PAI	PA	PART data	SC and DL scores will have large –ve		provided.		Spearman's r; Mean PC-PART scores	
sets	sets	sets for Self	correlation with FIM 's scores		8. Yes – reference		±95%CI between groups to indicate	
care	care	care = 858,	irrespective of age, sex & impairment		provided		difference between groups.	
o O	o i	Domestic life = 96.4	group; (3) a/d SC and DL scores will					
Ĭ	Ī	† O.	comorbidity index scores: (4) At a/d					
			there will be no difference b/w SC and					
			DL scores across impairment groups; (5)					
			SC d/c scores will be lower for those					
			who attain ADL goals.					
						200 .		

Abbreviations: a/d=admission; d/c=discharge; H<sub>o</sub>=Null hypothesis, H<sub>I</sub>=Alternate hypothesis; -ve=negative; +ve=positive; CI=Confidence Interval; SC=Self Care scale; DL=Domestic Life scale; b/w=between.

Table 7.3. Criterion validity - summary of COSMIN checklist design requirements met (shaded row displays summary from this study).

Study	1. Percentage of missing	. Percentage of missing 3. Sample size adequate?	4. Can criterion used be considered	5. Absence of	6. For continuous scores – area	COSMIN design
	items given?		reasonable gold standard?	important flaws in	under ROC curve calculated? OR requirements met /6	requirements met /6
	<ol><li>Handling missing</li></ol>			study design or	7. For dichotomous scores –	
	data?			methods?	sensitivity specificity determined?	
Darzins et	1. Yes	3. Yes-	4. Yes - discharge destination is a	5. Yes	6. Yes	9
al., 2015	2. Yes	Complete a/d and d/c PC-PART	directly measurable state.		Self Care = $.70(95\%$ CI $.6278)$	
		data sets for Self Care = $858$ ,			Domestic Life=.72(95%CI.6480)	
		Domestic Life = $864$			7. Not applicable	
Abbromotion	" o /d-o designing. d/o-disabor	POC-Description Operator Characterist	Abbarriation of Landing DO-Drawities Observed Character	for the golden and the	Maggiram and Instruments: TCD-Transi	itional Cara Dragges

Abbreviations: a/d=admission; d/c=discharge; ROC=Receiver Operator Characteristic; COSMIN=COnsensus-based Standards for the selection of health Measurement Instruments; TCP=Transitional Care Program.

Table 7.4. Responsiveness - summary of COSMIN checklist design requirements met (shaded row displays summary from this study).

Study	1. Percentage	3. Sample	Longitudinal Design:	n:	Requirements for hypothesis testing (where	is testing (where	13. Absence of important flause in	Testing of hypotheses:	COSMIN design
	items given? 2. Handling missing data?	adequate?	4. At least two measurements? 5. Time interval stated?	6. Interim occurrences described? 7. Proportion of patients changed?	8. A-priori hypotheses about expected change scores? 9. Expected direction of correlations? 10. Magnitude of expected correlations?	Comparator instrument: 11. Adequate description? 12. Properties described?	study design or methods?	adequate?	/14
Smith et al, 2001	1. NR 2. NR	3. Not justified. N=36 GEM =16 Rehab. =20	4. Yes 5. Yes - On a/d, then weekly until d/c.	6. No 7. Yes – fewer PRs at d/c (lower HART scores).	8. Yes – H <sub>0</sub> : AL (FIM <sup>TM</sup> ) scores will show parallel change to PR (HART) scores from a/d to d/c. 9. Yes – More AL (lower FIM <sup>TM</sup> scores) and PR (higher HART scores) expected at a/d than at d/c. 10. No	11. Yes 12. Yes (FIM <sup>TM</sup> )	13. No – Small sample. More details of sample, hypotheses, and focus in statistical analyses needed.	14. Yes –Association between FIM <sup>TM</sup> and HART change scores was r = 0.59. In rehab setting: Mean HART score at a/d = 15 (Range: 2.35) and on d/c = 2 (Range 0-8). On GEM unit: Mean HART on a/d=15 (Range 1-32) and on d/c= 2 (Range 0-9). There was no testing of difference between mean HART scores from a/d to d/c.	∞
Darzins et al., 2002	1. Yes HART (6%) SMAF (34%) BI (9%) 2. Yes – cases with missing data excluded from analysis.	3. Yes - Complete sets of data for HART (131) SMAF (182).	4. Yes 5. Yes – a/d and d/c (LOS could vary).	6. No 7. Yes – fewer PRs at d/c (lower HART scores).	8. Yes – Ha.: There will be a correlation between change in AL (BI) and change in PR (HART) from ad to d/c in an inpatient rehabilitation setting.  9. Yes – Ha.: There will be a stronger relationship between AL and PR at d/c than at a/d.	11. Yes 12. Yes (BI)	13. No - a-priori hypotheses needed to be more specific. Direct comparison between HART and SMAF was not possible due to study design.	14. No – Scatterplots showed the nature of associations between PR and AL measures, but statistical tests not used to show magnitude of the associations. Proportionate change from a/d to d/c was compared between BI and HART – but categorisations of scores into 6 categories to enable direct comparison of change between BI and HART was not evidence-based.	10
Darzins et al, 2015	Yes – in all tables     Yes – cases with missing data excluded from analysis	3. Yes- full a/d and d/c PC- PART data sets: SC = 858, DL = 864	4. Yes 5. Yes – a/d and d/c (mean LOS given)	6. Yes, referred to RCT paper 7. Yes – improved PR at d'c (lower SC &DL scores); Improved FIM <sup>TM</sup> score at d/c; Improved SC & DL score at d/c	8. Yes – 5 main hypotheses 9. Yes 10. Yes	11. Yes - FIM <sup>TM</sup> 12. Yes - reference given	13. Yes – Followed COSMIN study design criteria	Dazzins et 1. Yes – in all 3. Yes – 4. Yes 6. Yes, referred 8. Yes – 5 main 11. Yes – Followed 14. Yes – Correlations: Magnitude 14 and 5. Yes – a/d and 6. Yes – a main 10. Yes – COSMIN study 2. Yes – a main 10. Yes – COSMIN study 3. Yes – COSMIN study 3. Yes – COSMIN study 4. COSMIN study 4. COSMIN study 4. COSMIN study 5. Yes – a main and a magnitude of a magnitude of at a excluded 3. Yes – a main and to d/c. Improved 5. Yes – a main 11. Yes – Followed 12. Yes – COSMIN study 4. Grange scores; and a major and a majo	14

Abbreviations: a/d=admission; d/c=discharge; H<sub>o</sub>= Null hypothesis; AL=Activity Limitation; PR=Participation Restriction; SC=Self Care scale; DL=Domestic Life scale; FIM<sup>TM</sup>=Functional Independence Measure

While evidence supported validity and responsiveness of the Self Care scale and Domestic Life scale for inpatient rehabilitation, the positive results should be viewed in light of some study limitations. For example, contamination in the group of participants transferred from inpatient rehabilitation to acute or transitional care, most likely had the effect of underestimating the strength of the results. A future prospective, specifically designed study is needed to test the PC-PART scales' ability to accurately differentiate those transferred to acute care from those discharged to community living. In such a study, service-users transferred to transitional care would be excluded from analysis. Also, the PC-PART would need to be completed by a PC-PART-trained therapist who is independent to the service-users' treating therapist. During post-hoc analysis in this present study, transitional care program participants were removed from the analysis to enable examination of the AUC without their contaminating effects on the results. This post-hoc analysis demonstrated high AUC above .90 for both scales, however, removal of this group from analysis resulted in only 17 participants remaining in the acute care transfer group. This group size was insufficient for a valid analysis, but provided useful information that may inform the formulation of future hypotheses. Thus, in a future prospective, specifically designed study, it could be hypothesised that both PC-PART scales will demonstrate high AUC, greater then .90, as well as cut off scores at discharge of 0 and sensitivity and specificity values above .80, demonstrating strong ability of the scales to differentiate those discharged to community living from those transferred to acute care.

Other interesting findings in this study were that *Self Care* and *Domestic Life* scores differed between participants with different impairment types. Also the *Self Care* and *Domestic Life* scale scores were not associated with degree of comorbidity. These

were unexpected findings. Comorbidity scores using the Charlson Comorbidity Index were highly skewed, lacking variability in scores and therefore were not sensitive to smaller differences between participants. A recent Australian study found that comorbidities were associated with reduced participation in 1327 community-dwelling older men, with co-morbidity data gathered through self-report of the number of doctor-diagnosed health conditions experienced (Fairhall et al., 2014). A future prospective, carefully planned investigation of differences in *Self Care* and *Domestic Life* scale scores across impairment groups and for varying levels of co-morbidity, using a more sensitive co-morbidity measure than was used for the RCT, may provide useful guidance about the extent and types of participation restrictions experienced by different groups of rehabilitation service-users.

This final study contributed to the overall body of research in this thesis by adding new evidence supporting construct validity, criterion validity and responsiveness of the PC-PART scales for use in inpatient rehabilitation. The final chapter in this thesis provides discussion and draws conclusions about the research as a whole, its contribution to knowledge and practice in rehabilitation and future research directions.

# **Chapter 8. Overall Discussion and Conclusions**

#### Introduction

The purpose of this final chapter is to discuss the doctoral research as a whole, highlighting what knowledge has been gained about the PC-PART's validity, responsiveness and clinical utility as a measure of participation restrictions in ADL required for community life in inpatient rehabilitation. The findings are positioned within known limitations of the research. Recommended revisions to the PC-PART instrument are discussed as is the significance of the research for service-users, occupational therapists, rehabilitation and health care services and governments. Future research directions are recommended. Finally, conclusions are summarised from this body of research.

# **Discussion of Major Findings**

# Operationalisation of the participation restriction construct.

This research has made a contribution to the operationalisation of the participation restriction construct within the ICF framework (WHO, 2001). The second of five studies in this body of research, involving a theoretical examination of the PC-PART, concluded that the instrument measures participation restrictions in ADL required for community life. This theoretical examination of the PC-PART's measurement construct also highlighted the importance of understanding the type of information gathered by specific instruments, as subtle differences in instruments' item

phrasing, response categories or scoring may result in differences in the type of information gathered, and subsequently, their measurement constructs.

The role of instruments' scale properties in determining their measurement construct is an important distinction that has not been prominent in published literature about measurement. Some authors have more recently highlighted the importance of careful selection of outcome measures in clinical trials and outcomes studies to ensure the chosen measures are able to measure the construct of interest and measure meaningful changes in the construct (Coster, 2013; Imms et al., 2016; Ros Madden et al., 2013). Other research has highlighted the importance of a clear definition of the construct to be measured as a prerequisite for assessment of an instrument's validity (Ailliet et al., 2013). Notably, in a systematic review investigating measurement of the participation construct, Imms et al. (2016) identified a disconnection between intentions of researchers to measure participation and the outcome measures used in their research. It is critical that clinicians and researchers carefully scrutinise and select measures before using them. This is important so that the gathered information accurately targets the construct of interest. Otherwise, clinicians and researchers risk compromising the validity of inferences made about the effectiveness of their interventions or the outcomes of their research.

Almost all of the PC-PART's content was linked to ICF categories. This process highlighted some items that, as currently phrased, target body functions and structures and environmental factors. To be consistent with the measurement construct of the PC-PART these items should be rephrased so that they target the activities and participation component of the ICF. Identification of ICF-related content of the PC-PART instrument

enables future comparisons of the PC-PART to other instruments using the ICF's common, standardised language. Other researchers linking existing ADL measures to ICF categories have reported how this process can aid understanding about what is measured, how it is measured and how this may influence choice of instrument (Dahlgren, Sand, Larsson, Karlsson and Claesson, 2013). This type of information may be useful to leaders and managers in health and social services, policy makers in governments, and researchers during the process of selecting instruments for their respective data collection purposes.

The theoretical study in this thesis examined the activity limitation and participation restriction constructs through examination of the FIM<sup>TM</sup> and the PC-PART instruments' content and scale properties. The different scale properties between the two instruments means that they elicit related, yet clinically different information. The FIM<sup>TM</sup> assessment measures activity limitations while the PC-PART items measure participation restrictions. Evidence suggesting that the FIM<sup>TM</sup> and PC-PART measure separate constructs was also obtained during hypothesis testing. When testing hypotheses about the expected magnitude and direction of correlations between FIM<sup>TM</sup> and PC-PART instruments during inpatient rehabilitation, the lack of a strong negative correlation between the measures at admission, and the small to medium correlation between change scores from admission to discharge, provided supporting evidence that the two instruments measure separate constructs.

There appears to have been relatively little discussion in the literature about use of the capacity and performance qualifiers to measure activity limitations and participation restrictions respectively, based on information available from systematic

and integrative reviews of the ICF (Cerniauskaite et al., 2011; Jelsma, 2009; Pettersson, Pettersson, & Frisk, 2012). This present research provides a contribution to this area of knowledge and practice. The PC-PART's measurement construct is largely consistent with the description of the performance qualifier as a measure of participation restriction in the ICF, that is, "what an individual does in his or her current environment" (WHO, 2001, p. 15). The ICF indicates that the current environment includes a societal context and that performance "can also be understood as involvement in a life situation" (p. 15). Performance, as defined by the ICF, can be with or without assistive devices, and takes into account environmental factors such as the physical, societal and attitudinal context (WHO, 2001, p. 15).

In contrast to the intention of the PC-PART, activity limitations and participation restriction in the ICF are described as being "assessed against a generally accepted population standard" (WHO, 2001, p. 15). The limitation or restriction records the "discordance between the observed and the expected performance" (WHO, 2001, p. 15). In the PC-PART, there is no prescribed or expected manner in which the person accomplishes the ADL items, as this is individually determined (P Darzins, 2004). Respect for people's autonomy and preferences about the manner in which they accomplish their self care and domestic life activities is important to person-centred practice and underpins occupational therapy practice. This aspect of the ICF, which imposes an outsider's perspective on categorising performance and participation has also been criticised by others (M. Brown, 2010; Hammel et al., 2008; Magasi, Hammel, Heinemann, Whiteneck, & Bogner, 2009).

The PC-PART does not produce measurement of subjective aspects of participation restriction. It does not explicitly measure directly whether people are satisfied with the manner in which they accomplish the ADL activities in the items and it does not explicitly record a person's sense of involvement or autonomy in accomplishment of the activities. These various features have been highlighted as important to include in participation-related measures in recent literature (Cheeseman, Madden, & Bundy, 2013; Häggström & Lund, 2008; Imms et al., 2016; Maxwell, Alves, & Granlund, 2012; Whiteneck & Dijkers, 2009). Whether these are important aspects for inclusion in measures of participation restriction and in what way this information would be clinically useful, and how it would be gathered and recorded, was not the topic of this thesis. Whether the absence of a measure of these aspects in the PC-PART instrument is a limitation according to its purpose has not been explored, and could be included in future investigation of the instrument's clinical utility.

Examination of the theoretical construct of the PC-PART in this body of research specifically highlighted the importance of identifying the transaction between people, their activities and the available supports in their living environments in the measurement of participation restrictions in ADL required for community life. The measurement of participation restriction requires inclusion of the modifying effects of the environment on task accomplishment in an instrument's scale properties, that is, its item content, response categories and scoring. This perspective is consistent with other authors who have also written of the importance of incorporating the transaction between the person, their environment and their occupation in the measurement of participation-related constructs (Magasi et al., 2015; Mallinson & Hammel, 2010; Noreau & Boschen, 2010).

# Evidence supporting use of the PC-PART for inpatient rehabilitation.

Investigation of clinical utility, responsiveness, construct validity and criterion validity of the PC-PART supported its use as a comprehensive measure of participation restrictions in all areas of functioning necessary for community living, suitable for use for inpatient rehabilitation. The instrument gathers clinically meaningful information that may be used with service-users to prioritise interventions, to plan discharge and to measure change in ADL participation restrictions during an episode of inpatient rehabilitation. Robust methods were used to conduct each of the separate studies.

## Clinical utility.

Clinical utility of the PC-PART for inpatient rehabilitation was explored using mixed methods with occupational therapist users of the instrument. This study gave moderate support for clinical usefulness of the instrument for inpatient rehabilitation and but illuminated areas for revisions to some items and the worksheet to enhance the tool's ease of use. Training of therapists in use of the instrument was viewed as necessary. It was identified that the PC-PART could potentially be incorporated into routine assessment practices, although challenges to this were identified and are discussed in detail, later in this chapter.

Although this study was conducted using an appropriate research design as well as strong methods and data analysis processes, limited diversity among the participants diminished transferability of the results. This present study was the fourth study to examine clinical utility of the HART/PC-PART (Barbara & Whiteford, 2005; P Darzins et al., 2002; R. Smith et al., 2001). Compared to previous studies, this present study

used more transparent and trustworthy methods and reporting. However, when reviewing the clinical utility criteria used in the systematic review of the measurement properties of the PC-PART, the tool was found to meet fewer clinical utility criteria than reported in previous studies (i.e. 4/9 criteria met compared to 7/9, 6/9, 6/9 from previous studies) (S. Darzins, Imms, & Di Stefano, 2013). It is possible that the less favourable results of this study may have been associated with the context in which the PC-PART was used, that is, for data collection as part of the RCT within an inpatient rehabilitation setting. It was apparent that for participants, the PC-PART was used in addition to their usual assessment during the RCT, increasing their workload and effort required to complete the assessment, and also resulting in duplication of information collected from their initial clinical assessment. The context of the study may have coloured participants' perceptions of the PC-PART in a way that may not have occurred if participants had used the instrument for clinical purposes only. It may also have been possible that this study explored aspects of the PC-PART's clinical utility in more depth and detail than previous studies, and this has raised factors impacting on utility that had not previously been identified. A strong approach to future exploration of the PC-PART's clinical utility would be to gather similar data from occupational therapists from other rehabilitation sites where the PC-PART is used in practice. This would increase the diversity of the sample and enable data about facilitators and barriers to the PC-PART's use *in practice*, to be gathered. This type of study could extend the existing work and would likely provide broader perspectives and richer data, which may improve transferability.

### Internal construct validity.

Rasch analysis and modelling procedures were used on admission PC-PART data for 996 rehabilitation inpatients to evaluate internal construct validity of the PC-PART. Two unidimensional scales within the PC-PART instrument fit the Rasch model: Self Care (16 items) and Domestic Life (14 items) (refer to Appendix G). Total raw scores on each scale can be matched to corresponding Rasch-derived conversion scores on a 0-100 scale to enable use as interval-level measurement of participation restriction in *Self* Care and Domestic Life ADL required for community life. Floor and ceiling effects were within acceptable limits for both scales. Thirteen PC-PART items were not included in either of the two scales. These omitted items may continue to be used when completing a PC-PART assessment as they provide clinically relevant information. However, these items are not used to calculate the interval-level measurement of participation restriction in ADL required for community life, enabled by the Raschderived scales. Overall, the results of this study mean that the Self Care and Domestic Life scales may be used to assist clinicians, managers and researchers in rehabilitation settings to describe and evaluate changes in service-users participation restrictions in ADL relevant to community living.

The hierarchical order of items in both scales identifies the location of each item in the scale, which provides an approximate estimate of the level of participation restriction experienced. Items with higher scores (higher location) represent activities that result in participation restrictions for relatively few people. Therefore, only people with higher levels of participation restriction are rated *Not OK* on these items.

Conversely, items with lower scores (lower locations on the hierarchy) on each scale

represent activities that present more commonly experienced participation restrictions. Thus, people with lower levels of ADL participation restriction are rated *Not OK* on these items. It is noted that across both scales that more routine, mobility-related activities tended to appear at the lower end of the scales (experienced more commonly). More complex activities involving cognition, decision-making and judgment appeared at higher positions in the scales (experienced less commonly). This hierarchical ordering in the complexity of ADL activities appears consistent with other similar research investigating ordering of difficulty in PADL and IADL measures (Coster et al, 2004; Waehrens and Fisher, 2009).

In Rasch-derived scales low scores represent low levels of the construct and high scores represent high levels of the construct. Commonly, Rasch-derived scales reflect constructs such as people's *abilities*, or levels of *independence*, where low scores would reflect low levels of *ability*, or *independence* and high scores would reflect high levels of *ability* or *independence*. However, the PC-PART *Self Care* and *Domestic Life* scales' construct is that of *participation restriction* which, as this thesis has argued, is conceptually different to constructs of *ability* or *independence*. Where people have high levels of *abilities*, it could be anticipated that they would have low levels of *participation restriction*. Accordingly, low levels of *participation restriction* are reflected in low *Self Care* and *Domestic Life* scale scores and high levels of *participation restriction* are reflected in high scale scores. This conceptual difference in the construct being measured, compared to commonly measured constructs using Rasch scaling, results in a perceived reversal in scale scoring for the *Self Care* and *Domestic Life* scales.

This was the first study to examine internal construct validity of the PC-PART and provides positive evidence about the quality of the PC-PART instrument (see Table 8.1). The quality criteria developed by Terwee et al. (2007) do not provide criteria for study methods based on IRT when evaluating internal validity of an instrument. Thus, the contribution of this study to advancement of the quality of the PC-PART instrument, overall, is displayed in the summary table under the CTT based equivalent heading, *internal consistency*.

Table 8.1. Updated quality ratings for the PC-PART, following the doctoral research, using criteria provided by Terwee et al. (2007) (see shaded text for new evidence and strikethrough text for new evidence

Measurement	Minimum quality standards provided by Terwee et al. (2007)	No. of	Study providing evidence	Quality rating		Added quality
Property		studies found.		individual studies	rating prior to, and outside of, this research	rating from this research
Content Validity	+ Clear description of measurement aim, target population, concepts that were being measured, item selection AND target population and (investigators or experts) involved in the item selection; ? Clear description of above-mentioned aspects is lacking OR only target population involved OR doubtful design/method; - No target population involvement.	E.	1. Darzins <i>et al.</i> (2002) 2. Vertesi <i>et al.</i> (2000) 3. Barbara & Whiteford (2005)	+ + +	+	
Internal Consistency (Structural Validity)	+ Factor analyses performed on adequate sample size (7*#items and ≥100) AND Chronbach's alpha calculated per dimension AND Chronbach's alpha 0.7 to 0.95; ? No factor analysis OR doubtful design or method; — Chronbach's alpha <0.70 or >0.95, despite adequate design and method.	<del>0</del> ** 1	No evidence found. 1. Darzins, Imms. Di Stefano, Taylor, Pallant (2014)	0 +	0	+
Criterion Validity	+ Convincing arguments that gold standard is "gold" AND correlation with gold standard ≥ 0.70; ? No convincing arguments gold standard is "gold" OR doubtful design/method; - Correlation with gold standard <0.70 despite adequate design and method.	θ -	Concurrent: No evidence found Predictive: No evidence found 1. Darzins, Imms, Shields, Taylor (2015)	0 0 +	0	+
Construct Validity (Hypothesis testing)	+ Specific hypotheses formulated AND at least 75% of results in accordance with set hypotheses; ? Doubtful design or method (eg no hypotheses); - Less than 75% of hypotheses confirmed, despite adequate design and methods.	ભાજ	1. Smith <i>et al.</i> (2001) 2. Darzins <i>et al.</i> (2002) 3. Darzins, Imms, Shields, Taylor (2015)	6 + 6	è	+
Reproducibility		4	1. P. Darzins et al. (2002) (Agreement, Reliability) 2. Taylor et al. (1998) (Agreement, Reliability) 3. Turner et al. (2009) (Agreement, Reliability) 4. Radia-George et al. (2014)	0, ? 0	+	
Responsiveness	+ SDC or SDC< MIC OR MIC outside LOA OR RR > 1.96 OR AUC ≥ 0.70; ? Doubtful design or method; - SDC or SDC≥MIC OR MIC = or inside LOA OR RR≤1.96 OR AUC< 0.70, despite adequate design and methods.	ch co	1. Smith <i>et al.</i> (2001) 2. Darzins <i>et al.</i> (2002) 3. Darzins, Imms, Shields, Taylor (2015)	c· c· +	ć.	+
Floor and Ceiling effects	+ ≤ 15% of respondents achieved highest or lowest possible scores; ? Doubtful design or method; −> 15% of respondents achieved highest or lowest possible scores despite adequate design and methods.	0	No evidence found 1. Darzins, Imms. Di Stefano, Taylor, Pallant (2014)	Φ +	0	+
Interpretability	+ Mean and <i>SD</i> scores presented of at least four relevant subgroups of patients and MIC defined; ? Doubtful design or method OR less than four subgroups OR no MIC defined.	0	No evidence found	0	0	

<sup>\*</sup>This set of quality criteria only makes provision for methods based on CTT. Thus, research evaluating internal construct validity using Rasch methods was placed in an 'equivalent' space.

\*\*0= No information found

MIC= Minimal Important Change; SDC=Smallest Detectable Change; LOA= Limits of Agreement; ICC= Intra-class Correlation Coefficient; RR=Relative Risk; AUC=Area under the Curve

### Construct validity, criterion validity and responsiveness.

In the final study of this body of research, available RCT data were used to test hypotheses about the construct validity, criterion validity and responsiveness of the *Self Care* and *Domestic Life* scales for use in inpatient rehabilitation. Overall, results supported each of these properties. *Self Care* and *Domestic Life* scale scores at admission and discharge reflected theoretical expectations, according to the purpose of the PC-PART instrument and provided evidence to support its construct validity. The evidence demonstrated that all hypothesised correlations and group differences were in expected directions. Hypotheses that were unsupported either under- or over-estimated the magnitude of the results by a small margin. Results from this study may be useful when formulating hypotheses in future validation research investigating construct validity of the PC-PART scales for use in different settings.

The construct validation process indicated that *Self Care* and *Domestic Life* scores may be sensitive to impairment type at admission to inpatient rehabilitation: Inpatients with a diagnosis of stroke had higher scores on both scales than other groups. These impairment-based differences could be further explored to identify patterns of problems that people experience accomplishing ADL required for community life across impairment groups. This may provide clinical teams with valuable information about types of resources and interventions that would be relevant for different groups to enable resolution of their participation restrictions.

The *Self Care* and *Domestic Life* scales demonstrated moderate accuracy in differentiating patients who returned to community living from those who remained in

acute hospital, or transitional care, with cut-off scores at discharge to community living being zero for both scales. In this study, discriminative ability may have been underestimated due to contamination in the acute and transitional care group data.

Further prospective and specifically designed investigation is needed of the *Self Care* and *Domestic Life* scales' criterion validity. This would enable more control over study methods and participant groupings during the study design, data collection and data analysis phases of the research.

The Self Care and Domestic Life scales were responsive to clinically meaningful changes in inpatient rehabilitation settings, that is, resolution of ADL participation restrictions. This may occur through (1) improvement in service-users' level of independence in ADL required for community life during the inpatient rehabilitation program; and/or (2) adaptation of the living environment and arrangement of necessary assistive devices and/or supports to enable service-users to accomplish the required ADL. The ability of the Self Care and Domestic Life scales to measure this clinically relevant change is fully consistent with the purpose of the instrument. It is important to also note that a score of 0 on the Self Care or Domestic Life scale at discharge from inpatient rehabilitation relates only to the absence of participation restrictions. Further therapy may still be required to enable patients to continue to build strength, endurance and skills for specific activities to reduce their activity limitations. Change in activity limitations are evaluated using different instruments which measure this type of change.

Use of existing data for hypothesis testing limited the scope of the analyses to those that were possible using variables determined by the needs of the RCT. For example, there was no possibility of testing hypotheses about *Self Care* and *Domestic* 

*Life* scale scores compared to those from other PADL and IADL instruments, besides the FIM<sup>TM</sup>. It is also possible that unknown factors influenced the results because in secondary analyses it is not possible to control data collection parameters. It is recommended that future hypothesis testing studies use specifically designed prospective methods where the type of information gathered and data collection methods can be defined and controlled.

Responsiveness, construct validity and criterion validity of the *Self Care* and *Domestic Life* scales were evaluated using rigorous methods. The research findings support use of the PC-PART scales for inpatient rehabilitation to measure service-users' participation restrictions in ADL required for community life. The scales may be used at admission to set priorities for intervention to address participation restrictions and for discharge assessment and planning. The PC-PART scales may enable evaluation of the effectiveness and efficiency of services designed to resolve service-users ADL participation restrictions. Overall, the results of this validation study advanced knowledge about the quality of the PC-PART instrument relating to responsiveness, construct validity and criterion validity of the instrument, according to the criteria established by Terwee et al. (2007) (see Table 8.1).

### Suggested revisions to the PC-PART instrument.

It is apparent that revisions to the PC-PART instrument are needed to: enhance its acceptability to clinicians and service-users; ensure all items are phrased to measure the participation restriction construct; and improve reliability of the instrument for use with individuals. Most of these revisions are minor and are not expected to result in substantive changes to the tool. It is possible that rephrasing some items to better target

the participation restriction construct may result in changes to the tool that are more substantive. Any changes of this nature would require further validation.

The suggested revisions the PC-PART instrument are to:

- 1. Remove items identified during Rasch analysis as redundant from the worksheet (e.g. remove either the *shopping-groceries* item or the *shopping-personal* item);
- Rephrase items targeting body functions and structures and environmental factors constructs so that they align to the intended construct of participation restrictions;
- 3. Refine phrasing of items identified as ambiguous;
- 4. Include operational definitions for all items to enhance understanding;
- 5. Include instructions on the PC-PART worksheet on the process of completing the assessment and scoring of items;
- 6. Redesign the PC-PART worksheet to clearly display the separate *Self Care* and *Domestic Life* scale items separately from the additional items not included in the scales;
- 7. Include scoring information from the conversion tables on the worksheet;
- 8. Update sections of the PC-PART users' manual to reflect the changes made and include evidence from validation research about the measurement properties of the instrument.

Formal training in use of the PC-PART was identified as necessary by therapists in the clinical utility study. A study to evaluate a self-directed learning approach to

therapists' familiarisation with the PC-PART instrument compared to a formal training workshop approach would inform development of future training processes.

# PC-PART fills a measurement gap and is relevant to occupational therapy.

Identification of participation restrictions in ADL required for community life provides information highly pertinent to occupational therapy practice in inpatient rehabilitation. The role of occupational therapists in this setting is to identify and enable resolution of service-users' support needs for accomplishment of PADL and IADL in preparation for discharge to community living. Occupational therapists generally assess service-users' activity limitations in PADL in rehabilitation settings using standardised assessments such as the FIM<sup>TM</sup> or Barthel Index, and most occupational therapists informally assess functioning in IADL (Kitsos et al., 2011; Koh et al., 2009). Current evidence suggests that therapists have not typically assessed participation restrictions in PADL or IADL and have not typically used any standardised assessment of IADL functioning. Thus, although information about activity limitations in PADL is routinely gathered in inpatient rehabilitation settings, information about participation restrictions in PADL and IADL is not generally gathered (Kitsos et al., 2011; National Stroke Foundation, 2008). Consequently, inpatient rehabilitation services do not typically measure benefits of inpatient rehabilitation services on reducing service-users unmet ADL needs (Richard Madden, Marshall, & Race, 2013).

The PC-PART *Self Care* and *Domestic Life* scales have been shown, through this body of research, to provide inpatient rehabilitation settings with standardised, valid, reliable, responsive, comprehensive and clinically meaningful information about service-users' participation restrictions in PADL and IADL required for community

life. Therefore the scales are a viable option for occupational therapists' use in this setting, providing a useful addition to the occupational therapist assessment *toolkit* for inpatient rehabilitation. The scales also fill a gap in measurement for inpatient rehabilitation services, providing useful information that can add to, and complement, rather than replace, existing gathered assessment information.

Results from this body of research demonstrated that the PC-PART instrument satisfies the client centred criteria for measurement of occupational performance by occupational therapists articulated by Law, King and Russell (2005), as paraphrased in Chapter 1:

- 1. That occupational performance problems need to be identified by serviceusers and their families, not by the therapist or team. If there are issues that
  surface (safety, prevention or health maintenance) the therapist will
  communicate these concerns directly to the service-user and family (Law et
  al., 2005, p. 8). When completing PC-PART items with inpatient
  rehabilitation service-users, occupational performance problems (e.g. ADL
  participation restrictions), are identified by service-users and their families.
  The PC-PART assessment provides the structure to discuss issues related to
  safety and health maintenance with the service-user and family. Use of the
  instrument for this purpose was highlighted as a positive aspect of the PCPART during evaluation of the clinical utility of the instrument.
- 2. Evaluation of the success of occupational therapy intervention needs to focus on change in occupational performance (Law et al., 2005, p. 8). The PC-PART scales have adequate construct validity and responsiveness to measure

- success of occupational therapy interventions designed to reduce people's participation restrictions (i.e. occupational performance issues) in ADL required for community life in inpatient rehabilitation settings.
- 3. Measurement techniques need to enable service-users to have a say in evaluating the outcomes of their therapy interventions (Law et al., 2005, p.
  8). Service-users are personally involved in completion of the PC-PART items. This involvement was highlighted as a positive aspect of the PC-PART instrument during evaluation of the clinical utility of the instrument in inpatient settings.
- 4. Measurement needs to reflect the individualised nature of people's participation in occupations (Law et al., 2005, p. 8). One of the strengths of the PC-PART, highlighted as a positive feature in the clinical utility study, is that it can accommodate diversity and individualised preferences as to how ADL activities are accomplished. Its main purpose is measuring the existence and nature of unmet needs in accomplishing ADL.
- 5. Measurement should focus on both subjective and observable qualities of occupational performance in occupations (Law et al., 2005, p. 8).
  Information gathered from both self-report, key informant and by observable accomplishment of ADL is used in the process of identifying the presence of participation restrictions when using the PC-PART instrument in inpatient settings. This was highlighted as a positive aspect of the instrument during evaluation of its clinical utility, because it created opportunities for triangulation of data gathering.
- 6. Measurement of the environment is critical in helping therapists understand the influence of the person's environment on occupational performance, as

well as measuring the effects of the changing environmental conditions during the therapy process (Law et al., 2005, p. 8). This body of research has highlighted the ability of the PC-PART instrument to measure the effects of changing inpatient rehabilitation service-users' physical and social environmental conditions, on ADL participation restriction scores.

# Identified need for a knowledge translation strategy.

Participants in the clinical utility study reported that they did not incorporate the PC-PART into routine assessment practice following its use within the RCT despite their views that the PC-PART gathered clinically useful and comprehensive information and their belief in the value of using standardised assessments, generally. There may have been a variety of influencing factors associated with discontinued use of the PC-PART assessment, including participants' views about phrasing of some items, duplication of information already gathered and the length of time required to administer the assessment. Participants used a locally constructed initial assessment form for gathering information. Such forms are typically multi-purpose and cue therapists into interventions that are relevant to the facility, which standardised assessments may not. Other barriers to therapists' use of the PC-PART for clinical practice may have been associated with their practice context. In this study, participants' decisions not to use standardised assessments in favour of nonstandardised assessments, which collect similar information, is consistent with other reported studies (Kitsos et al., 2011; M. Pilegaard et al., 2014; Stapleton & McBrearty, 2009).

Although evidence supporting use of specific valid, standardised assessments exists, their use by occupational therapists remains relatively low across various clinical contexts (Bowman, 2006; M. Pilegaard et al., 2014; Pumpa, Cahill, & Carey, 2015; Stapleton & McBrearty, 2009). Commonly cited barriers to the use of valid standardised measures include time restraints, lack of training and lack of access to the assessments (Barbara & Whiteford, 2005; Bowman & Llewellyn, 2002; Koh et al., 2009; Pumpa et al., 2015; Radia-George et al., 2014; Stapleton & McBrearty, 2009). Another potential barrier to therapists' use of standardised assessments seems to be their difficulty articulating and setting measurable goals that are linked to occupational therapy interventions, resulting in difficulty selecting appropriate outcome measures related to this lack of clarity (Bowman, 2006). There is also evidence that when therapists use standardised assessments, they may frequently be used without consideration of their measurement properties (Koh et al., 2009; Pumpa et al., 2015; Stapleton & McBrearty, 2009). Given this information, it seems unlikely that minor revisions to the PC-PART instrument in itself, although required to improve its acceptability to therapists, will be sufficient in facilitating the PC-PART's routine use. A different strategy may be needed to embed use of valid, reliable instruments, such as the PC-PART, into occupational therapy assessment practices in relevant practice contexts.

Changing health care professionals' behaviour to reflect best practice has been identified as an important challenge for health care systems, with emphasis now being placed on the need for transfer of evidence into practice, known as *knowledge translation* (Graham et al., 2006; Grimshaw, Eccles, Lavis, Hill, & Squires, 2012; Squires, Sullivan, Eccles, Worswick, & Grimshaw, 2014; Walker, Fisher, Korner-Bitensky, McCluskey, & Carey, 2013). Knowledge translation has been defined as

"ensuring that stakeholders are aware of and use research evidence to inform their health and healthcare decision-making" (Grimshaw et al., 2012, p. 2). Knowledge translation strategies can include interventions such as provision of printed materials; educational workshops; training leaders who are knowledge brokers within an organisation; tailoring interventions within a particular setting to improve professional practice; and educational outreach by trained persons who meet providers in their practice setting with the intention of changing the providers' practice (Grimshaw et al., 2012). A recent overview of systematic reviews was completed by Squires et al. (2014) to evaluate the effectiveness of multifaceted knowledge transfer interventions, compared to single-component knowledge transfer interventions, in changing health care professionals' behaviour in clinical settings. The review identified no compelling evidence that multifaceted interventions are more effective than single-component interventions (Squires et al., 2014). It has been suggested that a knowledge translation strategy for health care professionals is more likely to be successful if it is first informed by identifying particular facilitators and barriers to changing practice that exist in individual organisational settings (Grimshaw et al., 2012; Upton, Stephens, Williams and Scurlock-Evans, 2014; Walker et al., 2013). Strategies that integrate structured self-reflection, consultations with peers, case study applications, dedicated staff roles such as knowledge brokers and a scholarship of practice model have been recommended for improvement in the uptake of evidence-based practice for occupational therapists (Thomas & Law, 2013; Upton et al., 2014). In the present clinical utility study, information about some barriers to the occupational therapist participants' use of the PC-PART in routine assessment practice in the rehabilitation context was obtained. However, more discussion by the focus group about barriers to implementation of the PC-PART within their organisation may have provided deeper

insights that could be used to develop a local strategy for facilitating changes in their assessment practices.

#### **Significance of Findings**

For rehabilitation service-users, reliable, valid and responsive measurement of participation restrictions in ADL required for community life, as provided by the PC-PART and demonstrated in this body of research, can ensure their unmet support needs for community living are discussed, identified and resolved prior to discharge from inpatient rehabilitation settings. This information is directly applicable to service-users' discharge goals related to community living and is not typically gathered using existing standardised assessments (Kitsos et al., 2011; Koh et al., 2009). Another potential significance for service-users is that the PC-PART promotes person-centred assessment by gathering information from both service-users and their family and carers about their support needs for community living. This process values the perspectives of all relevant stakeholders in the identification and resolution of identified participation restrictions in ADL. The assessment process also enables stakeholder engagement in decision-making about service-users' living environments and support needs upon discharge. In pressured health care environments, involvement of all stakeholders in these decisions is frequently overlooked, or believed not to be possible (Bragstad, Kirkevold, & Foss, 2014; Légaré, Ratté, Gravel, & Graham, 2008). Recent research has highlighted the importance of including service-users and their caregivers in decisions regarding support and care arrangements that meet the service-users' needs for discharge to community living (Bragstad et al., 2014; Mirzaei et al., 2013; Moats, 2007). The PC-

PART provides a structured approach to information gathering that could facilitate this practice.

For occupational therapists, use of the PC-PART enables standardised and evidence-based, valid, reliable and responsive measurement that is relevant to occupational therapy service provision in rehabilitation settings. The PC-PART Self care and Domestic life scales may be used by occupational therapists to evaluate the effectiveness and relative cost outcomes of occupational therapy services in rehabilitation settings in reducing service-users' participation restrictions in ADL required for community life. For example, effects on ADL participation restrictions arising from occupational therapy services such as home assessments, prescription of assistive devices, arranging formal and informal supports to facilitate discharge of service-users to community living situations, may be measured using the PC-PART. It is necessary for occupational therapists to evaluate these types of services so that the value of the occupational therapy role in rehabilitation teams is transparent to all. Occupational therapists have not routinely used standardised assessments to measure the benefits of their discharge-related interventions (Barras, 2005; Crennan & MacRae, 2010; Harris, James, & Snow, 2008). More attention has recently been given to investigating assessment and interventions related to discharge planning but these studies have not typically targeted measurement of participation restriction in ADL required for community life as an outcome (Lannin et al., 2007; Shepperd et al., 2010; Wales et al., 2012). The PC-PART is a suitable measure for occupational therapists to use in this context.

The PC-PART was not developed as a tool solely for occupational therapists' use. This thesis examined use of the instrument only by occupational therapists.

Therefore, investigation of the validity of PC-PART scores and its perceived clinical utility when used by other health professionals would provide valuable information about its broader use.

For *rehabilitation and health care teams*, the PC-PART, completed by occupational therapists, may be included together with existing measures used in teambased rehabilitation and health care services. The gap in measurement filled by the PC-PART enables clear, comprehensive, valid, clinically meaningful and responsive measurement that is useful to team-based decision making about service-users' preparation for discharge. The PC-PART may therefore enhance team-based rehabilitation services. Based on the findings of this research, it seems probable that service-users who are ready for discharge would have a *Self Care* and *Domestic Life* scale score at, or close to zero, however, this aspect of its utility requires further investigation. The addition of the PC-PART to routine measurement in rehabilitation settings would also enable health teams to gather evidence about the effectiveness of rehabilitation services in reducing participation restrictions related to community living.

For health care systems and governments, PC-PART Self care and Domestic life scale data can inform decisions about service delivery. This may be of significance for people responsible for health care payment policies and decisions related to inpatient rehabilitation services. In Australia, the most recent payment system for subacute services incorporates measurement of functioning across limited domains of functioning, with the focus being on measuring health care service-users' activity

limitations (Australian Government: Australian Institute of Health and Welfare [AIHW], 2015). This is not adequate for measuring the participation-related outcomes of rehabilitation (Richard Madden et al., 2013). Madden et al. (2013) reported there is a need for standardised measures within health care costing systems to be linked to the ICF components and to include information about broader aspects of functioning than is currently mandated. The additional information gained would increase the proportion of the variance explained in health care costs. The PC-PART seems well placed to make a useful contribution for this purpose given its measurement of participation restrictions, sound measurement properties and demonstrated ICF-linked content.

Both the Australian and worldwide population age group demographics are changing, with people over the age of 60 years being the fastest growing group (Australian Bureau of Statistics [ABS], 2012; World Health Organisation [WHO], 2002). The 2011 Australian census reported that one in approximately seven people were over the age of 65 years (ABS, 2012). It is projected that by 2026, approximately one in five people in Australia will be aged 65 years and over, with people over the age of 85 years constituting up to 13% of these older adults. These trends are similar to those in Canada and the United States of America (Australian Institute of Health and Welfare [AIHW], 2007). Major influences on the growing ageing population are that (a) life expectancy is increasing due to better health care and declining death rates, and (b) baby boomers are now entering their older adult years (ABS, 2012). Baby boomers are people born after World War II, between 1946 and 1964. Statistically, as age increases, the amount of assistance people need to maintain basic ADL also increases (ABS, 2012). These population trends will place significant pressure on health care systems in the decades to come as ageing populations live longer with chronic health conditions

and have increased need for assistance and supervision in self care, mobility and basic communication (ABS, 2012). Over decades to come, health care systems will need to deliver services that enable older people to live in the community for as long as possible, including appropriate community based services to address their health care and support needs (WHO, 2002). The PC-PART is a reliable, valid and responsive assessment and outcome measure that could be adopted by health care systems and used by occupational therapists with older people and their carers, in their homes or in community based health settings to structure and facilitate this process.

At a broad level, the PC-PART could provide epidemiological information about the patterns, nature and extent of unmet needs of people in accomplishing ADL required for community life. It may also be possible for this type of prevalence data to be coupled with data on the type and extent of formal and informal supports provided, to help people sustain community living. This may assist governments to form policy and for the people responsible, to make evidence-based decisions about resource allocation for community services to assist people with various health conditions to sustain community living without participation restrictions.

#### **Future Research Directions**

#### Research advancing validation of the PC-PART.

Even though this research has created further knowledge about the measurement properties of the PC-PART instrument, some further validation studies are recommended to extend this research. It would be useful to investigate inter-rater reliability of the newly identified *Self Care* and *Domestic Life* scales as existing

reliability studies have investigated reliability of the original domain scores and the total score for all PC-PART items. One possible way to investigate reliability of the *Self Care* and *Domestic Life* scales may be to gain access to existing data gathered in the inter-rater reliability study conducted by Radia-George et al. (2014). This study used a robust study design and methods to investigate inter-rater reliability of the PC-PART, making it suitable for secondary analysis. Assuming ethics clearance can be obtained, it should be possible to assess the Intra Class Correlation Coefficients (ICC) and Limits of Agreement (LOA) for items grouped together as the *Self Care* scale and *Domestic Life* scale. Such a study would be valuable and easily executed, provided access to the data is possible.

Once the recommended minor revisions to some PC-PART items and the assessment worksheet is complete, further evaluation of inter-rater reliability of revised PC-PART items is recommended. Of particular interest is whether inter-rater reliability can be enhanced by these changes. Revision of the PC-PART items may also mean that further evaluation of internal construct validity of the instrument is warranted, to enable evaluation of the fit of the revised instrument to the Rasch model. This would allow evaluation of the revised items that were previously excluded, to determine if they can be included in the *Self Care* or *Domestic Life* scales. While further evaluation of the internal construct validity of a revised version of the PC-PART instrument may be desirable, potential benefits of this research also need to be weighed against potential costs of carrying out this work. Evaluation of the PC-PART using Rasch methods requires data from individual item scores for several hundred completed PC-PART assessments. Prospective collection of this large volume of PC-PART data requires significant time and effort for clinicians and participants. Given the *Self Care* and

Domestic Life scales have shown adequate internal construct validity and may be used without changes, potential benefits of carrying out further internal validation research for the PC-PART will need to be carefully considered before undertaking this process. Data collection for this purpose could also be incorporated into the design of a bigger project.

Interpretability of the *Self Care* and *Domestic Life* scales was not specifically addressed in this doctoral research. Some evidence emerged that particular patient groups score differently on the scales. For example, rehabilitation inpatients with stroke scored higher on both scales at admission than those with other impairments and those discharged from rehabilitation to community living environments scored lower on both scales than those transferred to acute or transitional care. However, more evidence gathered prospectively to specifically address interpretability of the PC-PART scales, is recommended

# Research using the PC-PART as an outcome measure in clinical trials.

Reliability and validity of the *Self Care* and *Domestic Life* scale scores with rehabilitation inpatients are sufficient to enable researchers to use the PC-PART scales to measure the patterns and extent of people's participation restrictions in ADL required for community life in this setting. The scales may be used as an outcome measure for clinical trials designed to measure the effectiveness and relative costs of interventions designed to effect change in service-users' participation restrictions in ADL in rehabilitation settings.

### Research investigating use of the PC-PART in various settings.

It is recommended that the measurement properties and clinical utility of the *Self*Care and Domestic Life scales be further investigated related to their use in health care settings other than inpatient rehabilitation.

#### Clinical versus home environment.

When the PC-PART is used in settings where there is no opportunity to observe service-users' living environments, judgements need to be made about whether they will be able to function in their living environments at discharge. In these situations, it is possible that service-users and their key informants, who also provide information, may provide inaccurate information and may also form incorrect judgements about service-users' functioning in their living environments. This is especially pertinent to situations where service-users have a new condition, such as a recent stroke, where living in the community post-stroke will be a new experience. Therefore, there is a need to test the ecological validity of the PC-PART to determine if assessment environment influences validity of the scores. For example, it may be possible to test whether scores from a PC-PART assessment conducted in service-users' living environments produce equivalent scores to PC-PART assessments conducted in an inpatient clinical setting.

#### Community-based health care services.

It would be useful to test the measurement properties and clinical utility of the PC-PART when completed with people in their homes. The PC-PART could be used in people's homes as part of community-based health care services that focus on enabling people to live in the community, or as a secondary measure in the prevention of re-

hospitalisation. The PC-PART includes some items that relate to service-users' safety and self-neglect, which have been highlighted in recent research as important in assessments about whether older people can live independently (Douglas, Letts, Eva and Richardson, 2012; Donnelly, Brenchley, Crawford and Letts, 2014). Some items in the PC-PART have better face validity for use in people's usual living environments, than rehabilitation settings, especially if the item requires observations of performance in addition to gathering reports from both service-users and others. Some observations are only possible in the home environment, for example, the presence of groceries, spoiled or restricted foods, medications, working smoke detectors, trip hazards and door locks in the home (P Darzins, 2004). It is therefore recommended that future research in community-based health care settings prioritise testing of clinical utility and reliability of individual PC-PART item scores when completed in service-users' homes. It is anticipated that individual item reliability would be improved from reliability scores tested in inpatient settings. It is also anticipated that the acceptability of the instrument to users, service-users and carers when used in the home, would also be positive.

#### Emergency departments.

Adults aged 75 years of age or older, represent between 12%-20% of all people who present to Emergency Departments (ED) in Australia and Canada and consistently present at least twice their proportion in the general population for the same geographical areas (Aminzadeh & Dalziel, 2002; Caplan, Brown, Croker, & Doolan, 1998; Lowthian et al., 2012). Compared to younger adults, their visits are more urgent by nature; they stay for longer in the ED; and they are more likely to be admitted to inpatient care or have repeat ED visits (Aminzadeh & Dalziel, 2002; Lowthian et al.,

2012). Those at highest risk for admission following an ED visit are those who have lower scores on indices of ADL and mental status and those receiving support at home (Aminzadeh & Dalziel, 2002; Caplan, Williams, Daly, & Abraham, 2004; Wilber, Blanda, & Gerson, 2006). Some older adults who present to the ED are admitted to inpatient care because of social issues, functional decline or lack of home supports and at times when there is no need for immediate medical intervention (Moss et al., 2002). Specialised ED allied health care coordination services assist people presenting at EDs to avoid admission to inpatient care and to return to community living where possible. This is achieved through assessment of unmet support needs and by making arrangements of additional community-based supports (Arendts et al., 2012; Moss et al., 2002). This type of assessment and the effects of these interventions appear directly measurable using the PC-PART scales. Use of the PC-PART instrument in the ED may be useful in providing specialist allied health care coordination teams with a reliable, valid, standardised assessment structure for their evaluations. Research investigating the PC-PART's criterion validity, responsiveness and clinical utility in an ED setting is recommended. However, one of the perceived limitations of the PC-PART for inpatient rehabilitation from the clinical utility study was that the assessment was long. This could be problematic for time-pressured ED environments. Therefore, application of the PC-PART in the ED may enable investigation of a subset of PC-PART items that can usefully predict ED-relevant short term risks, events and outcomes such as falls and unplanned readmissions (Arendts et al., 2012).

### Acute health settings.

Investigation of the clinical utility of the Self Care and Domestic Life scales for application in acute health settings is recommended. The PC-PART may be useful in situations where clinicians require an efficient and comprehensive assessment of service-users' support needs for discharge to community living environments. Recent research investigating the effectiveness and efficiency of pre-discharge home visits in preparing service-users for discharge to community living from acute health care settings has not yet demonstrated clear benefits (Barras, 2005; Harris et al., 2008; Shepperd et al., 2010). It is not yet known who should receive a pre-discharge home visit, what should occur during the home visit, nor when this should occur (Lannin, Clemson, & McCluskey, 2011). It appears that over the past decade occupational therapists working in acute health care settings have been conducting progressively fewer pre-discharge home visits, reporting time pressure and shorter lengths of stay, as the main reasons for this (Lannin et al., 2011). This apparent trend suggests that occupational therapists have increasingly conducted pre-discharge assessments in the acute clinical setting and a need for valid, reliable and responsive measures for this purpose. Therefore, further investigation is recommended of the effectiveness and efficiency of using the PC-PART scales in acute care settings compared to usual assessment procedures or a pre-discharge home visit in: (1) identifying service-users' participation restrictions in ADL required for community life; (2) prioritising interventions needed to enable discharge; (3) achieving acceptable discharge planning processes from the perspective of service-users; and (4) ensuring service-users' support needs for ADL required for community life are met following discharge.

### **Overall Strengths and Limitations of the Research**

A major strength of this body of research was use of structures and theoretical frameworks including the PRISMA, ICF, COSMIN and clinical utility criteria to guide the research methods and analysis. These structures provided consistent reference points from which to judge the strength and limitations of methods used in separate studies and with which to evaluate results. Another strength in this research was the large number of available completed PC-PART assessments and their associated data from a separate RCT, made available for Rasch analysis and hypothesis testing.

While access to a large set of existing RCT data was beneficial for this research, there were also limitations associated with use of this data. The main limitation was using data retrospectively for a different purpose than that initially intended.

Retrospective analysis of data can introduce potential unknown bias in the results. It may have been optimal to design prospective methods for gathering PC-PART data for this research. However, collection of sufficient PC-PART data to enable Rasch analysis would have been beyond the possibilities of this doctoral research. Prospective methods for data collection and analysis do have the advantage of enabling the researcher to ensure appropriate training in use of the instrument to optimise reliability and validity of responses, and therefore of data quality. Prospective methods also allow the researcher to choose the variables for data collection to control data collection procedures and to control for potential confounding variables that may influence results of the study.

#### **Overall Conclusions**

This thesis examined the participation restriction construct, as measured by the PC-PART and reported on a body of validation and clinical utility research undertaken on the instrument. Results from the five studies undertaken provide evidence supporting the content, structural, criterion and construct validity; responsiveness; and clinical utility of the PC-PART for inpatient rehabilitation. The main conclusions are:

- 1. The PC-PART instrument's content links to ICF classification categories confirming the PC-PART's content validity in relation to the ICF framework as predominantly within the activities and participation component.
- It is necessary to examine an instrument's scale properties, that is, item
  phrasing, response categories and scoring, in addition to the instrument's content
  to identify its measurement construct.
- 3. The PC-PART operationalises the participation restriction concept contained in the ICF specifically targeting the transaction between people, their activities and the available supports in their living environments to enable the identification of participation restrictions in activities of daily living required for community life.
- 4. The PC-PART was viewed moderately positively by one group of occupational therapists as a person-centred assessment that includes clinically useful information, gathered from several sources, enabling formation of a complete picture of inpatient rehabilitation service-users' participation restrictions in ADL required for community life. Clinical utility studies in other settings would strengthen these findings.

- 5. Minor revisions to item phrasing, inclusion of operational definitions and instructions, and opportunities for formal training are recommended as methods to enhance acceptability of the instrument. Evaluation of the effect of self-directed versus formal training on reliability of item responses is recommended.
- 6. A knowledge translation strategy with clinicians and students may be required to embed use of evidence-based standardised assessments, such as the PC-PART, as part of routine assessment practice in inpatient rehabilitation settings.
- 7. The PC-PART instrument contains two unidimensional scales, which provide interval-level measurement of participation restriction in ADL required for community life: *Self Care* (16 items) and *Domestic Life* (14 items). Interval-level conversion scores on a 0-100 scale are available measuring change in ADL participation restrictions over time.
- 8. Self Care and Domestic Life scale scores at admission and discharge from inpatient rehabilitation reflect theoretical expectations, according to the purpose of the instrument, providing evidence in support of their construct validity. Further exploration of construct validity for use in different settings is warranted.
- 9. The *Self Care* and *Domestic Life* scales both demonstrate moderate ability to discriminate between service-users discharged to community living environments and those transferred to acute and transitional care from inpatient rehabilitation. Further investigation of the criterion validity of both scales is warranted using prospective design and methods.
- 10. Discharge cut-off scores on the *Self Care* and *Domestic Life* scales for service-users discharged to community living environments, from inpatient rehabilitation were found to be zero, reflecting resolution of all participation

restrictions on each scale. Further investigation of discharge cut-off scores is recommended using prospective methods as specificity of these cut-off scores was low.

- 11. The *Self Care* and *Domestic Life* scales are responsive to clinically meaningful changes in rehabilitation settings between admission and discharge, consistent with the purpose of the instrument in such settings, which is to demonstrate resolution of participation restrictions in ADL required for community life.
- 12. The *Self Care* and *Domestic Life* scales may be used in research designed to evaluate effectiveness and relative costs of interventions intending to reduce participation restrictions in ADL required for community life.
- 13. Research is recommended to build evidence about the measurement properties and clinical utility of the *Self Care* and *Domestic Life* scales' use in different health settings, such as community based health care, emergency departments and acute health care settings.
- 14. Research to investigate inter-rater reliability of the *Self Care* and *Domestic Life* scales using existing inter-rater reliability study data from Radia-George et al. (2014), is recommended if access to data and ethics approval can be obtained for the work.
- 15. Further internal validation research on the PC-PART is warranted if the benefits are likely to outweigh the costs of the validation process.

This doctoral research has made a significant contribution to occupational therapy practice and to inpatient rehabilitation service provision through its validation of the PC-PART as a measure of participation restrictions in ADL required for community life. The unique contribution of this research to current knowledge is:

- A theoretical examination of the concept and measurement of the participation restriction construct, highlighting the importance of an instrument's scale properties in determining the construct being measured;
- 2. Validation of the PC-PART's *Self Care* and *Domestic Life* scales as a means to enable more comprehensive standardised, valid, reliable and responsive measurement than is currently practised, of inpatient rehabilitation service-users' functioning and outcomes related to community living; and
- 3. Generation of evidence that supports use of the PC-PART instrument in inpatient rehabilitation settings as a valid, reliable and responsive outcome measure of clinically meaningful changes in participation restrictions in ADL required for community life.

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## **APPENDICES**

# Appendix A. International Classification of Functioning, Disability and Health (ICF): Supplementary Information.

#### Overview of the ICF.

The ICF is organised into two parts, *Functioning and Disability* and *Contextual Factors*, shown in Table A.1.

Table A.1 Overview of the International Classification of Functioning, Disability and Health (ICF).

	Part 1: Functioning	and Disability	Part 2: Contextual F	actors
Components	Body Functions	Activities and	Environmental	Personal
	and Structures	Participation	Factors	Factors
Domains	Body Functions	Life Areas	External	Internal
	<b>Body Structures</b>	(tasks, actions)	influences on	influences
			functioning and	on
			disability	functioning
				and
				disability
Constructs	Changes in body	Capacity	Facilitating or	Impact of
	functions	(Executing tasks in a	hindering impact	attributes of
	(physiological)	standard	of features of the	the person
		environment)	physical, social	
	Changes in body		and attitudinal	
	structures	Performance	world	
	(anatomical)	(Executing tasks in		
		the current		
		environment)		
Positive	Functional and	Activities	Facilitators	not
aspect	structural integrity	Participation	_	applicable
	Functioning			
Negative	Impairment	Activity limitation	Barriers/hindrance	not
aspect		Participation	S	applicable
		Restriction	_	
	Disability			

Source: World health Organisation. (2001). *International Classification of Functioning, Disability and Health (ICF)*. Geneva (p. 11)

#### Use of qualifiers to classify health-realted states.

Quantification of the problem uses a generic scale across all components: *no* problem=0; mild problem=1; moderate problem=2; severe problem=3 and complete problem=4. These numbers can be added to the coded ICF category. For example, d6200.3, may denote a severe participation restriction with shopping.

Provision is made in the ICF for different users to add other kinds of qualifiers, such as capacity and performance qualifiers to code *activities* and *participation* codes. The generic scale for both qualifiers is: *no difficulty*=0; *mild difficulty*=1; *moderate difficulty*=2; *severe difficulty*=3; *complete difficulty*=4; *not specified*=8 and *not applicable*=9. The performance qualifier occupies the first digit position after the point and the capacity qualifier occupies the second digit position after the point. For example, *d*6200.3\_ denotes a severe *restiction in performance* of shopping, while d6200. 3 denotes a severe *capacity limitation* in shopping.

#### Appendix B. PC-PART Worksheet

PLACE ID STICKER HERE PC PART PERSONAL CARE PARTICIPATION ASSESSMENT & RESOURCE TOOL INFORMANT #1 NAME RELATIONSHIP INFORMANT #2 RELATIONSHIP **ASSESSORS** PROFESSION SIGNATURE DATE NAME PROFESSION SIGNATURE DATE PROFESSION SIGNATURE NAME DATE NAME PROFESSION SIGNATURE DATE PROFESSION SIGNATURE NAME DATE PROFESSION SIGNATURE PROFESSION SIGNATURE PROFESSION SIGNATURE NAME DATE

PC PART > Personal Care Participation Assessment and Resource Tool

A. CLOTHING	SELF-REPORT	INFORMATION FROM KEY INFORMANT	OBSERVATION	IS	STANDARD TASKS (NB DONE WITH USUAL HELP)		GLOBAL SCORE
1. Dressing: Top	Do you get your top dressed?	ser Does get his/her top dressed?	Sar Property dressed?	VES NO	Take off top & put it back on.	OK NOT OK	OK BY SELF OK WITH HELP NOT OK
2. Dressing: Bottom	Do you get your pants on?	Secr. Does get his/her parts on?	Sar Pants on property?	NO NO	Check whether able to put on pants.	NOT OK	OK BY SELF OK WITH HELP NOT OK
3. Dressing: Footwear	Do you get your socks, shoes, slippers on?	SELE Does get his/her socks, shoes, slippers on?	Sacks/shoes/sippers on properly?	WES NO	Take your stoe and sock off and then put it back on.	NOT OK	OK BY SELF OK WITH HELP NOT OK
4. Selection appropriate for environment	Do you get dressed appropriately for the weather?	SKE Does get dressed appropriately?	SELF Clothes are clean and appropriate for environment?  WITH HELP NO NA NA	VES NO	It is raining and cold outside, tell me what you would wear to go out.	NOT OK	OK BY SELF OK WITH HELP NOT OK
5. Laundry	Do you get your clothes washed regularly?	SEE Does launder clothes regularly?	SELF Absence of laundry?	8 9 P	Clarify the situation through discussion.	NO TON	OK BY SELF OK WITH HELP NOT OK
B. HYGIENE	SELF-REPORT	INFORMATION FROM KEY INFORMANT	OBSERVATION	ıs	STANDARD TASKS (NB DONE WITH USUAL HELP)		GLOBAL SCORE
1. Toileting	Do you use the toilet OK?	Set Does Use the toilet OK?	SSR F Not solled?	NOT OK	Dry tollet transler, (on and off).	OK NOT OK	OK BY SELF OK WITH HELP NOT OK
2. Bladder Control	Do you have control of your bladder? If no, do you keep your pants dry?	Sets Does keep his/her partts dry?	SSE Do clothes appear dry?	MOTOW MOTOW	Clarify the situation through discussion.	OK NOT OK	OK BY SELF OK WITH HELP NOT OK
3. Bowel Control	Do you have control of your bowel? If no, do you keep your pants unsoiled?	Set Does have control of his/her bowel?	SSAF IS clothing clean?	MOTOW MOTOW	Clarify the situation through discussion.	NOT OK	OK BY SELF OK WITH HELP NOT OK
4. Grooming: Hair	(i) Do you get your hair washed?	sers Doesget his/her hair washed?	sa.F Well groomed?	NOTOW AND TOWN	If dishevelled, explore perception of this.	NOT OK	OK BY SELF OK WITH HELP NOT OK
5. Grooming: Teeth	(ii) Do you get your feetty/dentures cleaned?	sers Doesget his/her teeth/dentures cleaned?	SER Teeth not obviously diny?	MOTOW AS	if bad breath, or feeth grossly unkempt, explore perception of this.	NOT OK	OK BY SELF OK WITH HELP NOT OK
6. Grooming: shave/menstruation	Do you attend to shaving/menstruation?	SSEF Does attend to shaving/menstruation?	SGE F WITH HELP NO	11 00	If there is concern in this area, explore perception of this.	OK NOT OK	OK BY SELF OK WITH HELP NOT OK

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B. HYGIENE CONT.	SELF-REPORT		INFORMATION FROM KEY INFORMANT		OBSERVATION		STANDARD TASKS (NB DONE WITH USUAL HELP)		GLOBAL SCORE
7. Bathing	Do you get washed properly?		Does get washed properly?	SELF	Appears clean?	ж	Clarify the situation through discussion.	ж	OK BY SELF
	M	мшнегь	MT.	митн негр	ON	NOT OK		NOT OK	ОК МІТН НЕГР
		¥ ¥		N A					NOT OK
8. Bath transfers	Are you able to get in/out of the bath or shower?	SELF	ls able to get in/out of bath or shower	SELF		0	Check that can get in and out of the	ОК	OK BY SELF
	×	мшн негь	LIM .	WITH HELP		_	bathing facility.	NOT OK	ОК МТН НЕГР
		NA NA		NA NA					NOT OK
C. NUTRITION	SELF-REPORT		INFORMATION FROM KEY INFORMANT		OBSERVATION	_5,	STANDARD TASKS (NB DONE WITH USUAL HELP)		GLOBAL SCORE
1. Eating:	Have you kept your usual weight,	_	Has maintained his/her weight?	SELF	Clothes fit well?		Clarify the situation through discussion.	0K	OK BY SELF
		NO NA		NO NA		ON.		NOT OK	OK WITH HELP NOT OK
2. Eating:		SELF		SELF			Clarify the situation through discussion.	00	OK BY SELF
choking/coughing	or choking?	۵.	or choking wm	мтн негь				NOT OK	ОК МТН НЕГР
		o a		N N					NOT OK
3. Meal planning	Do you get adequate meals planned?		Does get adequate meals planned?	SELF		_	Tell me what you usually eat at the beginning,	У0	OK BY SELF
	*	WITH HELP NO	UM	WITH HELP		_	middle and end of the day?	NOT OK	ОК МТН НЕLP
		NA NA		NA					NOT OK
4. Meal preparation	Do you make or get your meals OK?		Does make or get adequate meals?	SELF		_ (	Make a drink (tea, coffee or cold drink)	0 K	OK BY SELF
	<b>X</b>	MUTH HELP	LW	MTH HELP NO			and heat up a 1000 lem.	NOT OK	ОК МТН НЕЦР
		NA		NA					NOT OK
5. Groceries	Do you get your groceries?	SELF	Does get groceries?	SELF WITH HEID	Adequate grocenies present?	YES	Clarify the situation through discussion.	90	OK BY SELF
		NA NA		N NA		2		Y C	OK WITH HELP NOT OK
6. Food-restrictions			Does understand and follow any food restrictions?	SELF	Absence of restricted foods or drinks?		Tell me about your food restrictions?	90	OK BY SELF
	ii yes, uo you undestand and ronow mem?	NO NA		MTH HELP NO NA		ON NO		NOT OK	OK WITH HELP NOT OK
7. Stove	Do you cook without burning pots, the counter		Does cook without burning pots,	SELF	Absence of burn marks on the counter top?		Turn on the left rear element (distract with a task)	У	OK BY SELF
		WITH HELP I		WITH HELP		ON ON	and then turn it off.	NOT OK	ОК МІТН НЕЦР
		NA.		NA					NOT OK
8. Spoiled food	Do you know not to eat spoiled food?	SELF	Does know not to eat spoiled food?	SELF	Absence of spoiled food?		How can you tell if food has spoiled?	Ж	OK BY SELF
	E	NO NA	Ē	NA NA		0		NOTON NOTON	OK WITH HELP NOT OK

C PART > Personal Care Participation Assessment and Resource Tool

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VEL HOOM O	Hoode Tino	THANKING THE VITY BACKT MOTTANGOTHER	MOLENIALISA		CTANDADA TANDA MA OVOTA CONTRACTOR		Tagood IA ao io
D. MUBILITY	SELT-REPURI	INFORMATION FROM REY INFORMANI	UBSERVAIION		STANDARD TASKS (NB DONE WITH USUAL HELP)		GLUBAL SCURE
1. Mobility	Do you get around in your home OK? SELF WITH HELL WITH HELL NO.	Does get around in the home OK?	SRLF NO NA		Able to mobilise around objects in the room?	NOT OK	OK BY SELF OK WITH HELP NOT OK
2. Bed	Do you get in and out of bed?	sers Does get in and out of bed?	SSB.F NOTE HELD NA		Get in and out of bed?	NOT OK	OK BY SELF OK WITH HELP NOT OK
3. Falls	Do you get around without falling?	Sears Does get around without falling?	SSE F NO MA		Clarify the situation through discussion.	NOT OK	OK BY SELF OK WITH HELP NOT OK
4. Steps or stairs	Do you get up and down steps OK?	SELF DOES get up & down steps OK?	See Home steps not grossly unsafe?  Home steps not grossly unsafe?	sie? res	If steps present, test stair mobility together with usual aid or help.	OK NOT OK	OK BY SELF OK WITH HELP NOT OK
5. Outside mobility & safety	Do you feel comfortable getting around outside alone?	SSEF Do you feel comfortable when	SSE F NA NA		Test autdoor mobility.	NOT OK	OK BY SELF OK WITH HELP NOT OK
6. Driving	Do you drive a car safely?	Ser Does drive a car safely?	SSE F WITH HELP NA		Clarify the situation through discussion.	NOT OK	OK BY SELF OK WITH HELP NOT OK
7. Transport	Do you get to and from your appointments?	sers Does get to and from his/her wm+eap appointments?	SSE F NWTH HGDP NA		Clarify the situation through discussion.	OK NOT OK	OK BY SELF OK WITH HELP NOT OK
8. Wandering	When you go out, do you remember without getting lost?	SRE When goes out, does he/she remember without getting lost? Where to go, and gets there without getting lost? Where to go, and gets there without getting lost?	SRS F NO NO NO		Describe how you would get to a familiar location.	NOT OK	OK BY SELF OK WITH HELP NOT OK
9. Orientation	Do you remember your appointments?	SELF Does remember his/her appointments?	SSE F NO NO		Describe how you keep track of your appointments.	NOT OK	OK BY SELF OK WITH HELP NOT OK
E. SAFETY	SELF-REPORT	INFORMATION FROM KEY INFORMANT	OBSERVATION		STANDARD TASKS (NB DONE WITH USUAL HELP)		GLOBAL SCORE
1. Medication use	Do you take medications; if yes, do you know what set they are and when to take them?	SELF DOSS take medications, if yes, does www.eep know what to take and when?	ser Are medications described present, wm wee with no additional prescriptions? with no additional prescriptions? we with no additional prescriptions?	resent, res	Tell me what medications you take and when you take each of them.	NOT OK	OK BY SELF OK WITH HELP NOT OK
2. Alcohol and other substance abuse	Do you live without drinking too much alcohol or with using non-prescription drugs?	ser Does live without drinking too much or using drugs?	Seare Absence of signs of alcohol/drug abuse?	drug abuse?	Clarify the situation through discussion.	NOT OK	OK BY SELF OK WITH HELP NOT OK

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3. Illness / crisis Witt	SELF-REPORT	INFORMATION FROM KEY INFORMANT	OBCEDIVATION			
			UDSERVATION	STANDARD TASKS (NB DONE WITH USUAL HELP)		GLOBAL SCORE
	With the usually available help do you with a minor illness? with a minor illness? wo	With the usually available help does  cope with a minor illness?	SELF WITH HELP NO NA	If you had a stomach upset with vorniting and diarrhoea for 24 hours, what would you do?	MOTOK	OK BY SELF OK WITH HELP NOT OK
4. Emergency help Have emit	Have you been managing without needing wm HELP emergency help repeatedly?	Doss manage without needing emergency help repeatedly?	SELF Working smoke detector present?  No No No NA	What would you do if you have a fire on your stove?  Show me how you would call the fire department?	tove? ox not ox	OK BY SELF OK WITH HELP NOT OK
5. Smoking Do v	Do you smoke without causing burns or fires?	Does smoke without causing burns or fires?	SELF Absence of burn marks from cigarettes?	Clarify the situation through discussion.	NOT OK	OK BY SELF OK WITH HELP NOT OK
6. General hazards Is yo	Is your home free of hazards? serr	Is's home free of hazards?	Star Absence of loose mats, extension conds, with Hab No	List hazards, and how they are dealt with.	MOT T OK	OK BY SELF OK WITH HELP NOT OK
F. RESIDENCE SEL	SELF-REPORT	INFORMATION FROM KEY INFORMANT	OBSERVATION	STANDARD TASKS (NB DONE WITH USUAL HELP)		GLOBAL SCORE
1. Money management Do	Do you get your bills paid? set 9 No	Does get his/her bills paid?	SELF Absence of unpaid bills?	ves Describe how your bills are paid.	MOT OK	OK BY SELF OK WITH HELP NOT OK
2. Home security Do your	Do you live without being concerned about security in the home? with wear your security in the home? No	Doss live without you being concerned about his/her security in the home?	SELF Are the doors locked?	if you hear some-one rattling at your door at night,	ght, ox NOTOK	OK BY SELF OK WITH HELP NOT OK
3. Basic personal Doy information and	Do you know your address, telephone number sets and who to contact to get help? wmn repair won your address to get help?	Does know his/her address, telephone number and who to contact to get help?	SELF IS there a phone-book/list by phone etc?	res Tell me your name, address, and how to get .  Not of your contact person.	NOT OK	OK BY SELF OK WITH HELP NOT OK
4. Shopping for personal Do needs, household items etc needs	Do you get your shopping done for personal ser- needs and household items? wmn.neta- no	Does get shopping attended to?	SELF Personal and home supplies present?	Clarify the situation through discussion.	MOT OK	OK BY SELF OK WITH HELP NOT OK
5. Temperature Do.	Do you keep warm in winter and cool in summer?	In winter does keep warm, and in summer heep cool?	SELF Appropriate temperature or clothing for season?    Man HELP   No.   No.	in? vss if it was very cold in winter, or very hot in summer, what would you do?	ner, ox	OK BY SELF OK WITH HELP NOT OK
G. SUPPORTS SEL	SELF-REPORT	INFORMATION FROM KEY INFORMANT	OBSERVATION	STANDARD TASKS (NB DONE WITH USUAL HELP)		GLOBAL SCORE
1. Adequate Do. prov.	Do you think that you have enough supports ser- provided by others? wmn werp	Do you think has enough supports provided by others?	SELF WITH HELP NO NA	Clarify through discussion and list supports, including tasks done, hours spent and times when this occurs.	NOT OK	OK BY SELF OK WITH HELP NOT OK
2. Stability - ability of Do. caregiver to cope even	Do you think that will be able to continue to do sear everything that he/she does for you now?	Can you continue to do all of the things you need to do to meet's needs?	SELF NO	ves Clarify through discussion.	NOT OK	OK BY SELF OK WITH HELP NOT OK

# summary sheet

	SELF	WITH	P W	HIGH,MED OR LOW	LIST OPTIONS FOR DEALING WITH PROBLEM	DONE (DATE)
A. CLOTHING						
1 Dress: top						
2 Dress: bottom						
3 Dress: footwear						
4 Selection of clothing						
5 Laundry						
B. HYGIENE						
1 Toilet: transfer						
2 Bladder control						
3 Bowel control						
4 Groom: hair						
5 Groom: teeth						
6 Groom: shave menst*n						
7 Bathing						
8 Bath transfer						
C. NUTRITION						
1 Eat: weight						
2 Eat: choke						
3 Meal: plan						
4 Meal: make						
5 Groceries						
6 Food: restriction						
7 Stove						
8 Spoiled food						

LIST OPTIONS FOR DEALING WITH PROBLE																										
OK OK RISK BY WITH NOT HIGH,MED SELF HELP OK OR LOW																										
NOT NO																								-		
F WITH																										
O B: B: B: AREAS OF FUNCTION SE	٨	1 Mobility	2 Bed	3 Falls	4 Steps	5 Outside	6 Driving	7 Transport	8 Wandering	9 Orientation	E. SAFETY	1 Medications	2 Substance abuse	3 Illness	4 Emergency help	5 Smoking	6 Hazards	F. RESIDENCE	1 Money management	2 Security	3 Personal information	4 Shopping	5 Temperature	G. SUPPORTS	1 Adequate	2 Stability / can cope
		DONE (DATE)	(2,140)																							
																		-								
		RISK HICHWED LIST OPTIONS FOR DEALING WITH PROBLEM OF LOW	מו מסג																							
		LIST OPTIONS FOR DEALING WITH PROBLEM	באין הנינושים אוון געוספרמע																							

NOTES:	

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#### Appendix C. COSMIN Checklist

#### **COSMIN** checklist boxes.

Mokkink, L. B., Terwee, C. B., Alonso, J., Patrick, D. L., Bouter, L. M., de Vet, H. C. W., . . . Stratford, P. W. (2015). COSMIN: COnsensus-based Standards for the selection of health Measurement INstruments. Available from: <a href="http://www.cosmin.nl">http://www.cosmin.nl</a>

Step 1. Evaluated measurement properties in the article

Internal consistency
Reliability
Measurement error
Content validity
Structural validity
Hypotheses testing
Cross-cultural validity
Criterion validity
Responsiveness
Interpretability

Step 2. Determining if the statistical method used in the article are based on CTT or IRT

В	ox General requirements for studies that applied Item Response Theory (IR	T) mod	els	•
		yes	no	?
1	Was the IRT model used adequately described? e.g. One Parameter Logistic Model (OPLM), Partial Credit Model (PCM), Graded Response Model (GRM)			
2	Was the computer software package used adequately described? e.g. RUMM2020, WINSTEPS, OPLM, MULTILOG, PARSCALE, BILOG, NLMIXED			
3	Was the method of estimation used adequately described? e.g. conditional maximum likelihood (CML), marginal maximum likelihood (MML)			
4	Were the assumptions for estimating parameters of the IRT model checked? e.g. unidimensionality, local independence, and item fit (e.g. differential item functioning (DIF))			

Step 3. Determining if a study meets the standards for good methodological quality

В	ox A. Internal consistency			
		yes	no	?
1	Does the scale consist of effect indicators, i.e. is it based on a reflective model?			
De	esign requirements	yes	no	?
2	Was the percentage of missing items given?			
3	Was there a description of how missing items were handled?			
4	Was the sample size included in the internal consistency analysis adequate?			
5	Was the unidimensionality of the scale checked? i.e. was factor analysis or IRT model applied?			
6	Was the sample size included in the unidimensionality analysis adequate?			
7	Was an internal consistency statistic calculated for each (unidimensional) (sub)scale separately?			
	Were there any important flaws in the design or methods of the study?			NA
31	utistical methods	yes	no	INA
9	for Classical Test Theory (CTT): Was Cronbach's alpha calculated?			
10				
11				
	$\chi^2$ , reliability coefficient of estimated latent trait value (index of (subject or item) separation)			

	B. Reliability: relative measures (including test-retest reliability, i -rater reliability)	nter-rat	er relia	ability a	nd
Desig	gn requirements		yes	no	?
1 2 3 4 5 6 7 8 9	Was the percentage of missing items given? Was there a description of how missing items were handled? Was the sample size included in the analysis adequate? Were at least two measurements available? Were the administrations independent? Was the time interval stated? Were patients stable in the interim period on the construct to be measured? Was the time interval appropriate? Were the test conditions similar for both measurements? e.g. type administration, environment, instructions  Were there any important flaws in the design or methods of the	oe of			
Stati	stical methods	yes	no	NA	?
11	for continuous scores: Was an intraclass correlation coefficient (ICC) calculated?				
13	for dichotomous/nominal/ordinal scores: Was kappa calculated? for ordinal scores: Was a weighted kappa calculated?				
14	for ordinal scores: Was the weighting scheme described? e.g. linear, quadratic				

3ox (	C. Measurement error: absolute measures			
Desig	nn requirements	yes	no	?
<u>)</u>	Was the percentage of missing items given? Was there a description of how missing items were handled?			
	, , , , ,			
	Were the administrations independent?			
5	Was the time interval stated?			
7	Were patients stable in the interim period on the construct to be measured?			
3	Was the time interval appropriate?			
)	Were the test conditions similar for both measurements? e.g. type of administration, environment, instructions			
	Were there any important flaws in the design or methods of the study?			,
tatis	sticai metnoas	yes	no	?
L <b>1</b>	for CTT: Was the Standard Error of Measurement (SEM), Smallest Detectable Change (SDC) or Limits of Agreement (LoA) calculated?			
	Desig	Was there a description of how missing items were handled? Was the sample size included in the analysis adequate? Were at least two measurements available? Were the administrations independent? Was the time interval stated? Were patients stable in the interim period on the construct to be measured? Was the time interval appropriate? Were the test conditions similar for both measurements? e.g. type of administration, environment, instructions  Were there any important flaws in the design or methods of the study? Statistical methods	Was the percentage of missing items given? Was there a description of how missing items were handled? Was the sample size included in the analysis adequate? Were at least two measurements available? Were the administrations independent? Was the time interval stated? Were patients stable in the interim period on the construct to be measured? Were the test conditions similar for both measurements? e.g. type of administration, environment, instructions  Were there any important flaws in the design or methods of the study? Statistical methods  Yes  To CTT: Was the Standard Error of Measurement (SEM), Smallest	Nas the percentage of missing items given? Was there a description of how missing items were handled? Was the sample size included in the analysis adequate? Were at least two measurements available? Were the administrations independent? Was the time interval stated? Were patients stable in the interim period on the construct to be measured? Were the test conditions similar for both measurements? e.g. type of administration, environment, instructions  Were there any important flaws in the design or methods of the study? Statistical methods  To CTT: Was the Standard Error of Measurement (SEM), Smallest

В	Box D. Content validity (including face validity)				
G	eneral requirements	yes	no	?	
1	Was there an assessment of whether all items refer to relevant aspects of the construct to be measured?				
2	Was there an assessment of whether all items are relevant for the study population? (e.g. age, gender, disease characteristics, country, setting)				
3	Was there an assessment of whether all items are relevant for the purpose of the measurement instrument? (discriminative, evaluative, and/or predictive)				
4	Was there an assessment of whether all items together comprehensively reflect the construct to be measured?				
5	Were there any important flaws in the design or methods of the study?				

Box E. Structural validity			
Does the scale consist of effect indicators, i.e. is it based on a reflective model?	yes	no	?
Design requirements	yes	no	?
<ul> <li>2 Was the percentage of missing items given?</li> <li>3 Was there a description of how missing items were handled?</li> <li>4 Was the sample size included in the analysis adequate?</li> <li>5 Were there any important flaws in the design or methods of the study?</li> <li>Statistical methods</li> </ul>	yes	no	NA
<ul> <li>6 for CTT: Was exploratory or confirmatory factor analysis performed?</li> <li>7 for IRT: Were IRT tests for determining the (uni-) dimensionality of the items performed?</li> </ul>			

Box F. Hypotheses testing				
Design requirements	yes	no	?	
<ul> <li>1 Was the percentage of missing items given?</li> <li>2 Was there a description of how missing items were handled?</li> <li>3 Was the sample size included in the analysis adequate?</li> <li>4 Were hypotheses regarding correlations or mean differences formulated a priori (i.e. before data collection)?</li> </ul>	yes	no	*	
5 Was the expected <i>direction</i> of correlations or mean differences included in the hypotheses?				
6 Was the expected absolute or relative <i>magnitude</i> of correlations or mean differences included in the hypotheses?				
7 for convergent validity: Was an adequate description provided of the comparator instrument(s)?				
8 for convergent validity: Were the measurement properties of the comparator instrument(s) adequately described?				
9 Were there any important flaws in the design or methods of the study? Statistical methods	yes	no	NA	
10 Were design and statistical methods adequate for the hypotheses to be tested?				

Вох	G. Cross-cultural validity			
Desi	gn requirements	yes	no	?
1 2 3 4	Was the percentage of missing items given? Was there a description of how missing items were handled? Was the sample size included in the analysis adequate? Were both the original language in which the HR-PRO instrument was developed, and the language in which the HR-PRO instrument was translated described?			
5	Was the expertise of the people involved in the translation process adequately described? e.g. expertise in the disease(s) involved, expertise in the construct to be measured, expertise in both languages			
6 7 8	Did the translators work independently from each other? Were items translated forward and backward? Was there an adequate description of how differences between the original and translated versions were resolved?			
9	Was the translation reviewed by a committee (e.g. original developers)? Was the HR-PRO instrument pre-tested (e.g. cognitive interviews) to check interpretation, cultural relevance of the translation, and ease of comprehension?			
11 12	Was the sample used in the pre-test adequately described? Were the samples similar for all characteristics except language and/or cultural background?			
13 Stati	Were there any important flaws in the design or methods of the study? stical methods	yes	no	NA
14 15	for CTT: Was confirmatory factor analysis performed? for IRT: Was differential item function (DIF) between language groups assessed?			

Box H. Criterion validity				
Design requirements	yes	no	?	
<ul> <li>1 Was the percentage of missing items given?</li> <li>2 Was there a description of how missing items were handled?</li> <li>3 Was the sample size included in the analysis adequate?</li> <li>4 Can the criterion used or employed be considered as a reasonable 'gold standard'?</li> </ul>				
5 Were there any important flaws in the design or methods of the study? Statistical methods	yes	no	NA	
6 for continuous scores: Were correlations, or the area under the receiver operating curve calculated?				
7 for dichotomous scores: Were sensitivity and specificity determined?				

7	for dichotomous scores: Were sensitivity and specificity determined?						
	· · · ·						
Во	Box I. Responsiveness						
De	sign requirements	yes	no	?			
2 3 4 5 6	Was the percentage of missing items given? Was there a description of how missing items were handled? Was the sample size included in the analysis adequate? Was a longitudinal design with at least two measurement used? Was the time interval stated? If anything occurred in the interim period (e.g. intervention, other relevant events), was it adequately described? Was a proportion of the patients changed (i.e. improvement or						
	deterioration)?						
De	sign requirements for hypotheses testing	yes	no	?			
Fo	r constructs for which a gold standard was not available:						
8	Were hypotheses about changes in scores formulated a priori (i.e. before data collection)?			*			
		yes	no	NA			
9	Was the expected <i>direction</i> of correlations or mean differences of the change scores of HR-PRO instruments included in these hypotheses?						
10	Were the expected absolute or relative <i>magnitude</i> of correlations or mean differences of the change scores of HR-PRO instruments included in these hypotheses?						
11 12	Was an adequate description provided of the comparator instrument(s)?						
13 Sto	Were there any important flaws in the design or methods of the study? ntistical methods	yes	no	NA			
14	Were design and statistical methods adequate for the hypotheses to be tested?						
Design requirement for comparison to a gold standard		yes	no	?			
Fo	r constructs for which a gold standard was available:						
15 16 <i>Sta</i>		yes	no	NA			

17	for continuous scores: Were correlations between change scores, or the area under the Receiver Operator Curve (ROC) curve calculated?		
18	for dichotomous scales: Were sensitivity and specificity (changed versus not changed) determined?		

Вс	x J. Interpretability			
		yes	no	?
1	Was the percentage of missing items given?			
2	Was there a description of how missing items were handled?			
3	Was the sample size included in the analysis adequate?			
4	Was the distribution of the (total) scores in the study sample described?			
5	Was the percentage of the respondents who had the lowest possible (total) score described?			
6	Was the percentage of the respondents who had the highest possible (total) score described?			
7	Were scores and change scores (i.e. means and SD) presented for relevant (sub)			
	groups? e.g. for normative groups, subgroups of patients, or the general population			
8	Was the minimal important change (MIC) or the minimal important difference (MID) determined?			
9	Were there any important flaws in the design or methods of the study?			

#### Step 4: Determining the Generalisability of the results

В	ox Gene	eralisability box	_		
		ne sample in which the HR-PRO instrument was evaluated adequately bed? In terms of:	yes	no	NA
	1 2 3	median or mean age (with standard deviation or range)? distribution of sex? important disease characteristics (e.g. severity, status, duration) and description of treatment?			
	4	setting(s) in which the study was conducted? e.g. general population, primary care or hospital/rehabilitation care			
7		countries in which the study was conducted? language in which the HR-PRO instrument was evaluated? ne method used to select patients adequately described? e.g. nience, consecutive, or random			
8	Was tl	ne percentage of missing responses (response rate) acceptable?	yes	no	?

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Journal - Author: Mokkink, L et al.

The COSMIN study reached international consensus on taxonomy.

**Journal - Article Title:** terminology, and definitions of measurement properties for health-related

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definitions in my PhD thesis.

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No

If not, is the author involved

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#### **Appendix D. Outcome Measures Rating Form**

#### **OUTCOME MEASURES RATING FORM**

# CANCHILD CENTRE FOR DISABILITY RESEARCH INSTITUTE OF APPLIED HEALTH SCIENCES, MCMASTER UNIVERSITY 1400 MAIN STREET WEST, ROOM 408 HAMILTON, ONTARIO,CANADA L8S 1C7 Fax (905) 522-6095

lawm@mcmaster.ca

To be u	sed with: Outcome Measures	Rating Form Guidelines (CanChild,2004)
Name an	d initials of measure:	
Author(s)	:	
Source a	nd year published:	
Date of re	eview:	
Name of	Reviewer:	
1. FOC	US	
a. Fo	ocus of measurement – Using Body Functions	the ICF framework are the physiological functions of body systems(includes psychological functions)
	Body Structures	are anatomical parts of the body such as organs, limbs, and their components
	Activities and Participation	Activity is the execution of a task or action by an individual. Participation is involvement in a life situation.
	Environmental Factors	make up the physical, social and attitudinal environment in which people live and conduct their lives.
© CanChi	ld, August 2004	1

b. Attribute(s) being measured – Check as many as apply. This list is based on attributes cited in the ICF, 2001: WHO.

#### **Body Functions**

Global Mental Functions		
<ul><li>□ consciousness</li><li>□ orientation</li><li>□ sleep</li></ul>	□ intellectual □ global psychosocial	□ temperament and personality □ energy and drive
Specific Mental Functions		
<ul><li>□ attention</li><li>□ memory</li><li>□ psychomotor</li><li>□ calculation</li></ul>	<ul><li>□ thought</li><li>□ higher level cognitive</li><li>□ perceptual</li></ul>	<ul> <li>mental functions of language</li> <li>experience of self and time</li> <li>mental function of sequencing complex measurements</li> </ul>
Sensory Functions and Pair	1	
□ seeing and related	□ hearing and vestibular	
Voice and Speech Function	s	
□ voice □ articulation	□ fluency and rhythm of spee □ alternative vocalization	ch
Functions of the Cardiovase Immunological and Respira		
<ul><li>□ cardiovascular</li><li>□ haematological and immunological systems</li></ul>	<ul> <li>□ respiratory system</li> <li>□ additional functions and se cardiovascular and respiration</li> </ul>	
Functions of the Digestive,	Metabolic and Endocrine Sy	stems
□ related to the digestive system	□ related to metabolism and t	the endocrine system
Genitourinary and Reprodu	ctive Functions	
□ urinary	□ genital and reproductive	
Neuromuscular and Movem	ent-Related Functions	
Joints and Bones	<ul><li>□ mobility of joint</li><li>□ stability of joint</li></ul>	□ mobility of bone
Muscle	<ul><li>□ muscle power</li><li>□ muscle tone</li></ul>	□ muscle endurance
Movement	<ul> <li>motor reflex</li> <li>involuntary movement reaction</li> <li>control of voluntary movement</li> </ul>	<ul> <li>involuntary movement</li> <li>sensations related to muscle and movement</li> <li>gait patterns</li> </ul>

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Functions of the Skin and F	Related Structures	
Skin	<ul><li>□ protection</li><li>□ repair</li></ul>	<ul><li>□ other functions</li><li>□ sensations</li></ul>
Hair	□ function of the hair	
Nails	□ function of nails	
Body Structures		
Structures of the Nervous S	System	
□ brain	□ spinal cord and related structures	
<ul><li>□ meninges</li><li>□ parasympathetic nervous system</li></ul>	□ sympathetic nervous syste	em
The Eye, Ear and Related S	tructures	
□ eye socket	□ around eye	□ middle ear
□ eyeball	□ external ear	□ inner ear
Structures Involved in Voic	e and Speech	
□ nose	□ pharynx	
□ mouth	□ larynx	
Structures of the Cardiovas	scular, Immunological and R	espiratory Systems
Cardiovascular System	□ heart	□ veins
	□ arteries	□ capillaries
Immune System	□ lymphatic vessels	□ lymphatic nodes
	□ thymus	□ spleen
	□ bone marrow	
Respiratory System	□ trachea	□ lungs
	□ thoracic cage	□ muscles of respiration
Structures Related to the D	igestive, Metabolic and End	ocrine Systems
□ salivary glands	□ pancreas	□ intestines
□ oesophagus	□ liver	□ endocrine glands
□ stomach	□ gall bladder	
	enitourinary and Reproduct	•
□ urinary system	□ pelvic floor	□ reproductive system

Structures Related to Mover	ment	
<ul> <li>□ head and neck</li> <li>□ upper extremity</li> <li>□ additional musculoskeletal structures related to movem</li> </ul>	<ul><li>□ shoulder region</li><li>□ trunk</li><li>ent</li></ul>	<ul><li>□ lower extremity</li><li>□ pelvic region</li></ul>
Skin and Related Structures	<b>:</b>	
□ skin □ nails	□ skin and glands □ hair	
Activities and Participation	<u>on</u>	
Learning and Applying Kno	wledge	
Purposeful Sensory Experiences	□ watching □ listening	□ other purposeful sensing
Basic Learning	<ul><li>□ copying</li><li>□ learning to read</li><li>□ learning to calculate</li></ul>	<ul><li>□ rehearsing</li><li>□ learning to write</li><li>□ acquiring skills</li></ul>
Applying Knowledge	<ul><li>□ focusing attention</li><li>□ thinking</li><li>□ reading</li><li>□ writing</li></ul>	<ul><li>□ calculating</li><li>□ solving problems</li><li>□ making decisions</li></ul>
General Tasks and Demand		
□ undertaking a single task □ carrying out daily routine	□ undertaking multiple tasks □ handling stress and other p	sychological demands
Communication		
<ul><li>□ receiving (verbal, nonverbal</li><li>□ producing (verbal, nonverba</li><li>□ conversation and use of cor</li></ul>	ıl, written, formal sign languag	e)
Mobility		
<ul> <li>changing and maintaining body position</li> </ul>	□ carrying, moving and hand	
□ walking and moving	□ moving around using trans	portation
Self-Care		
<ul><li>□ washing oneself</li><li>□ caring for body parts</li></ul>	<ul><li>□ toileting</li><li>□ dressing</li></ul>	<ul><li>□ eating</li><li>□ drinking</li></ul>
Looking after one's health	<ul><li>ensuring oneself physical comfort</li><li>managing diet and fitness</li></ul>	□ maintaining one's health

Domestic Life		
Acquisition of Necessities	□ acquiring a place to live	□ acquisition of goods and services
Household Tasks	<ul><li>□ preparing meals</li><li>□ caring for household</li><li>objects and assisting others</li></ul>	□ doing housework
Interpersonal Interactions a	nd Relationships	
General	<ul> <li>general interpersonal interactions (basic and complex)</li> </ul>	
Particular Interpersonal Relationships	<ul><li>□ informal social realtionships</li><li>□ formal relationships</li></ul>	<ul><li>□ relating with strangers</li><li>□ family relatonships</li><li>□ intimate relationships</li></ul>
Major Life Areas		
Education	□ informal □ preschool □ school	
Work and Employment	<ul> <li>□ apprenticeship</li> <li>□ acquiring, keeping and term</li> <li>□ renumerative employment</li> <li>□ non-renumerative employment</li> </ul>	
Economic Life	<ul> <li>□ basic economic transaction</li> <li>□ complex economic transaction</li> <li>□ economic self-sufficiency</li> </ul>	
Community, Social and Civi	c I ife	
Community	□ community life	
Recreation and Leisure	□ play □ sports □ arts and culture	□ crafts □ hobbies □ soicalizing
Civic	□ religion and spirituality □ human rights	□ political life and citizenship
Environmental Factors		
Products and Technology		
<ul> <li>□ communication</li> <li>□ culture, recreation and sport</li> <li>□ design, construction, and buildings for public use</li> <li>□ religion and spirituality</li> </ul>	<ul> <li>education</li> <li>products or substances for personal consumption</li> <li>design, construction, and buildings for private use</li> <li>land development</li> </ul>	<ul> <li>employment</li> <li>products and technology for personal use in daily living</li> <li>for personal indoor and outdoor mobility and transportation</li> <li>assets</li> </ul>

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Natural Environment and Hu	uman-Made Changes to Env	vironment
<ul><li>□ physical geography</li><li>□ flora and fauna</li><li>□ natural events</li><li>□ light</li></ul>	<ul><li>□ sound</li><li>□ air quality</li><li>□ population</li><li>□ climate</li></ul>	<ul><li>□ human events</li><li>□ time-related changes</li><li>□ vibration</li></ul>
Support and Relationships		
<ul> <li>immediate family</li> <li>health professionals</li> <li>people in positions of authority</li> <li>acquaintances, peers, colleagues, neighbors and community members</li> </ul>	<ul> <li>□ extended family</li> <li>□ other professionals</li> <li>□ people in subordinate positions</li> <li>□ domesticated animals</li> </ul>	<ul> <li>□ friends</li> <li>□ strangers</li> <li>□ personal care providers and personal assistants</li> </ul>
Attitudes		
<ul> <li>of immediate family</li> <li>of strangers</li> <li>of people in positions of authority</li> <li>of acquaintances, peers, colleagues, neighbors and community members</li> </ul>	<ul> <li>□ of extended family</li> <li>□ of health professionals</li> <li>□ of people in subordinate positions</li> <li>□ societal attitudes</li> </ul>	<ul> <li>of friends</li> <li>of health-related professionals</li> <li>of personal care providers and personal assistants</li> <li>social norms, practices and idealogies</li> </ul>
Services, Systems and Poli	cies	
<ul> <li>production of consumer goods</li> <li>open space planning</li> <li>utilities</li> <li>transportation</li> <li>legal</li> <li>media</li> </ul>	<ul> <li>□ architecture and construction</li> <li>□ social security</li> <li>□ health</li> <li>□ labour and employment</li> <li>□ housing</li> <li>□ communication</li> </ul>	<ul> <li>□ associations and organizations</li> <li>□ civil protection</li> <li>□ economic</li> <li>□ general social support</li> <li>□ education and training</li> <li>□ political</li> </ul>
c. Does this measure assess  □ Single □ Multiple	a single attribute or multiple a	attributes?
d. Check purposes that apply	and indicate (*) primary purpo	ose of the measure
□ To describe or discriminate	□ To predict	□ To evaluative
Comments:		
		<del></del>

e.	Perspective - Indicate possible respondents:  □ Client □ Other professional  □ Caregiver/parent □ Other  □ Service provider
f.	Population measure designed for:  Age: Please specify all applicable ages if stated in the manual  □ Infant (birth - < 1 year) □ Adult (> 18 years - <65 years)  □ Child (1 year - < 13 years) □ Senior (> 65 years )  □ Adolescent (13 - < 18 years) □ Age not specified
	Diagnosis: List the diagnostic group(s) for which this measure is designed to be used:
g.	Evaluation context - Indicate suggested/possible environments for this assessment  Home
	. CLINICAL UTILITY
a.	Clarity of Instructions: (check one of the ratings)  Excellent: clear, comprehensive, concise, and available  Adequate: clear, concise, but lacks some information  Poor: not clear and concise or not available  Comments:
b.	Format (check applicable items)  Interview Questionnaire: Self completed Task performance Interview administered Naturalistic observation Caregiver completed
	Physically invasive:
C.	Time to complete assessment: minutes  Administration: □ Easy □ More complex (Consider time, Scoring: □ Easy □ More complex amount of training Interpretation: □ Easy □ More complex and ease)

d. Examiner Qualifications: Is formal training required for administ interpreting?	-
□ Required □ Recommended □ Not required □ N	lot addressed
e. Cost (Cdn. Funds) manual: \$ score sheets: \$ forSheets Indicate year of cost information: Source of cost information:	S -
3. SCALE CONSTRUCTION	
a. Item Selection (check one of the ratings)  □ Excellent: included all relevant characteristics of attrib comprehensive literature review and survey	
□ Adequate: included most relevant characteristics of att	ribute
□ Poor: convenient sample of characteristics of attri	bute
Comments:	
	· · · · · · · · · · · · · · · · · · ·
b. Weighting  Are the items weighted in the calculation of total score? □ Yes  If yes, are the items weighted: □ Implicitly □ Expl	
c. Level of Measurement   Nominal  Ordinal Interval	□ Ratio
Scaling method (Likert, Guttman, etc.):	
Number of items:	····
Indicate if subscale scores are obtained: □ Yes □ No	
	istered: □Yes □ No reted: □ Yes □ No
List subscales:	Number of Items:

. Manual (check o	ne of the ratings)		
□ Excellent:			outlines specific procedures for and interpretation; evidence of reliability
□ Adequate:	lacking or unc	lear regard	enerally complete but some information is ding administration; scoring and of reliability and validity
□ Poor:	no manual ava	ailable or r	manual with unclear administration; n; no evidence of reliability and validity
Norms available	(N/A for instrume	ent whose	purpose is <u>only</u> evaluative)
	□ Yes	□ No	□ N/A
Age: Please spe	cify all applicable	ages for v	which norms are available
□ Infant (birth - < □ Child (1 year - □ Adolescent (13	< 13 years)		□ Adult (> 18 years - <65 years) □ Senior (> 65 years )
Populations for v			
r opalationo loi l	which it is normed	d:	
	which it is normed	<i>d</i> :	
Size of sample:		<b>:</b>	
Size of sample:	n =	d:	
Size of sample: 1	n =		y (check one of the ratings)
Size of sample: 1	n = dization studies fo	or reliability	ed reliability studies completed with
Size of sample: 1  5. RELIABILITY  Rigor of standard	n = dization studies for more than 2 w adequate to e	or reliability vell-design xcellent re signed relia	ed reliability studies completed with liability values ability studies completed with adequate to
Size of sample: 1  5. RELIABILITY  Rigor of standard  Excellent:	dization studies for more than 2 w adequate to e 1 to 2 well-des excellent relia	or reliability vell-design xcellent re signed relia bility value ies poorly	ed reliability studies completed with liability values ability studies completed with adequate to
Size of sample: 1  5. RELIABILITY  Rigor of standard  Excellent:  Adequate:	dization studies for more than 2 w adequate to excellent relia reliability studingoor levels of	or reliability vell-design xcellent re signed relia bility value ies poorly	ed reliability studies completed with liability values ability studies completed with adequate to es

b.	Reliability	Information

Type of Reliability	Statistic Used	Value	Rating (excellent, adequate or poor)

<sup>\*</sup> guidelines for levels of reliability coefficient (see instructions) Excellent: >.80 Adequate: .60 - .79 Poor: <.60

□ Excellent: validity □ Adequate:	ndardization studies for validity (check one of the ratings) more than 2 well-designed validity studies supporting the measure's  1 to 2 well-designed validity studies supporting the measure's validity studies poorly completed or did not support the measure's validity ce available
Comments:	
<ul><li>□ Excellent: measure is Method:</li><li>□ Adequate:</li></ul>	dity (check one of the ratings) judgmental or statistical method (e.g. factor analysis) was used and the s comprehensive and includes items suited to the measurement purpose  ightharpoonup judgmental in statistical has content validity but no specific method was used rument is not comprehensive ce available
<ul><li>Excellent:</li><li>prior theor</li><li>Adequate:</li></ul>	alidity (check one of the ratings) more than 2 well-designed studies have shown that the instrument conforms to etical relationships among characteristics or individuals 1 to 2 studies demonstrate confirmation of theoretical formulations struct validation poorly completed, or did not support measure's construct validice available
Strength of	Association:

10

	concurrent   Predictive			
□ Excellent:	more than 2 well-designed studies have shown adequate agreement with a criterion or gold standard			
□ Adequate:	1 to 2 studies demonstrate adequate agreement with a criterion or gold standard measure			
□ Poor:	criterion validation poorly completed or did not support measure's criterion validity			
□ No evidence a	ıvailable			
Criterion Measure(s)used:				
Strength of Associa	ation:			
e. Responsiveness	(check one of the ratings)			
□ Excellent:	more that 2 well-designed studies showing strong hypothesized relationships between changes on the measure and other measures of change on the same attribute.			
□ Adequate:	1 - 2 studies of responsiveness			
□ Poor:	studies of responsiveness poorly completed or did not support the measure's responsiveness			
□ N/A □ No evidence available				
Comments:				
7. OVERALL U	ITILITY (based on an overall assessment of the quality of this measure)			
□ Excellent:	adequate to excellent clinical utility, easily available, excellent reliability and validity			
□ Adequate:	adequate to excellent clinical utility, easily available, adequate to excellent reliability and adequate to excellent validity			
□ Poor:	poor clinical utility, not easily available, poor reliability and validity			
Comments/Notes/	Explanations:			
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#### MATERIALS USED FOR REVIEW/RATING

Please indicate the sources of information used for this review/rating:  Manual  Journal articles: (attach or indicate location)  by author of measure  by other authors
List sources:
□ Books - provide reference
□ Correspondence with author – attach
□ Other sources:

#### Appendix E. Supporting Documents for Rasch Analysis and Hypothesis Testing

#### **Studies**

#### Ethics clearance from Eastern Health.



6 September 2011

Professor Nicholas Taylor Professor of Physiotherapy Level 2 5 Arnold Street Box Hill Vic 3128

Dear Professor Taylor

5 Arnold Street, Box Hill Victoria 3128 Australia PO Box 94, Box Hill 3128 Tel (03) 9895 3259 Fax (03) 9895 3176 info@easternhealth.org.au

www.easternhealth.org.au

Eastern Health Research and Ethics Committee Ph: 03 9895 3398 Fax: 03 9895 3575 Email: ethics@easternhealth.org.au Website: www.easternhealth.org.au/ethics

**E58/0910** Do additional allied health services for rehabilitation reduce length of stay without compromising patient outcomes?

Principal Investigators: Professor Nick Taylor

Eastern Health Site: The Angliss Hospital and Peter James Centre

Thank you for the submission for the project above.

The following documents have been reviewed and **APPROVED** by the Sub-Committee at its meeting on 5 September 2011:

- Request for Approval of Amendment Form dated 22 August 2011
  - Protocol Version 2 dated 18 August 2011 clean and tracked
  - Change of Research Personnel Forms dated 22 August 2011, adding Christine Imms, Marilyn Di Stefano and Susan Darzins
  - Confidentiality agreements dated 22 August 2011, for Christine Imms, Marilyn Di Stefano and Susan Darzins
  - o CVs for Christine Imms, Marilyn Di Stefano and Susan Darzins

Yours sincerely

Dr Andrea Johannessen Acting Ethics Officer

manne ssen

Eastern Health Office of Research and Ethics

N:\02-03&current\Ethics - Eastern Health\All Correspondence\0910 studies\E58-0910 Amendments 6Sept11.doc
Page 1 of 1

Members of Eastern Health

Angliss Hospital

Box Hill Hospital Heal

Tel (03) 9895 3333

Healesville & District Hospital Tel (03) 5962 4300

Maroondah Hospital Tel (03) 9871 3333

Peter James Centre Tel (03) 9881 1888 Wantirna Health Tel (03) 9955 1200

Tel (03) 9091 8888

Yarra Valley
Community Health Service

#### Ethics clearance from La Trobe University.

## La Trobe University Faculty of Health Sciences MEMORANDUM

TO: Prof Nick Taylor

School of Physiotherapy

Natasha Brusco, Jenny Watt, Nora Shields, Natalie Sullivan, Genevieve Kennedy, Kwong Teo, Allison Farley, Kylee Lockwood, Clarissa Koukounas, Renita Yap, S. Darzins, C. Imms, M. DiStefano

SUBJECT:

Reference:

FHEC10/14

Student or

Other Investigator:

Camilla Radia-George, Casey Peiris

Title:

Do additional allied health services for rehabilitation reduce length of stay without comprising patient

outcomes?

DATE:

23 September, 2011

The Faculty Human Ethics Committee's (FHEC) reviewers have considered and approved the modification to the above project - secondary analysis of data and additional researchers (S.Darzins, C.Imms, M.DiStefano) as per Eastern Health HREC approval. You may now proceed.

Please note that the Informed Consent forms need to be retained for a minimum of 5 years. Please ensure that each participant retains a copy of the Informed Consent form. Researchers are also required to retain a copy of all Informed Consent forms separately from the data. The data must be retained for a period of 5 years.

Please note that any modification to the project must be submitted in writing to FHEC for approval. You are required to provide an annual report (where applicable) and/or a final report on completion of the project. A copy of the progress/final report can be downloaded from the following website: http://www.latrobe.edu.au/research-services/ethics/HEC-application.htm

Please return the completed form to The Secretary, FHEC, Faculty of Health Sciences Office, La Trobe University, Victoria 3086.

If you have a student/s involved in this project, a copy of this memorandum is enclosed for you to forward to the student(s) concerned.

Dr Ellie Fossey

Chair

Faculty Human Ethics Committee Faculty of Health Sciences

#### **Appendix F. Supporting Documents for the Clinical Utility Study**

#### Clinical utility Questionnaire





# Questionnaire Clinical Utility of the PC-PART

#### Introduction

Thank you for agreeing to take part in this research, which is investigating the clinical utility of the PC-PART in an in-patient rehabilitation setting. The aim of this questionnaire is to explore your opinions and views about the usefulness of the PC-PART in this setting. It is important for you to know that there are no 'right' or 'wrong' answers to the questions. We are seeking your individual views. You will not be identified by your responses on this questionnaire, nor in any published summary of the study findings. You might find it helpful to look at a PC-PART worksheet when you complete this questionnaire, to help you remember things you would like to mention. It will probably take about 20-30 minutes to answer the questions.

#### From the researchers, thank you for taking the time to complete this questionnaire:

Ms. Susan Darzins, PhD Candidate, Australian Catholic University

Professor Christine Imms, School of Allied and Public Health, Australian Catholic University

Dr. Marilyn Di Stefano, Senior Lecturer, School of Allied Health, La Trobe University

Ms. Camilla Radia-George, OT Manager, Eastern Health

### How do I return this questionnaire when I have completed it?

**Once you have completed the questionnaire**, place it in one of the envelopes provided with the questionnaire, seal the envelope, and send it to us by mail.

**If you do not have a return-addressed envelope**, please place the questionnaire into a fresh envelope, seal it, and send it to:

PC-PART study, c/– Prof. Christine Imms, School of Allied and Pubic Health, Australian Catholic University, Locked Bag 4115 Fitzroy, VIC, 3065

#### Section A: Background

Please answer the following.....

Q1.	Did you use the PC-PART during the Eastern Health weekend therapy Randomised Controlled Trial (RCT) during 2010 and/or 2011?  Yes  (Please answer all questions)  No  (Do not continue, thanks!)	Q2.	What tertiary qualifications have you completed, or are you currently completing? (include your OT qualification)  1  2  3
Q3.	How many years have you been practising as an OT?  years	Q4.	How long have you worked as an OT in an in-patient rehabilitation setting?  years  months
Q5.	How often do, or have you used standardised assessments, other than the PC-PART, as part of usual clinical information gathering in in-patient rehabilitation settings? (eg FIM, Barthel, MMSE, AMPS etc)  Never Seldom Often Almost always Which assessments? Assessments	Q6.	Excluding the PC-PART, how often do you use, or have used standardised assessments (eg FIM, Barthel, MMSE, AMPS etc) as part of usual clinical information gathering in other clinical settings?  Never Seldom Often Almost always Name the assessments and which settings?  Assessments Settings
Q7.	How many PC-PART assessments did you complete during the weekend therapy RCT? (approx. if you are not sure)	Q8.	On average, how long did it take you to gather the necessary information and complete the PC-PART assessment?  minutes
Q9.	What is your age?  Years	Q10	How important is it to use standardised assessments in your clinical practice?  Not important  Somewhat important  Moderately important  Very important

## Section B: Clinical utility of the PC-PART in an in-patient rehabilitation setting

We would like you to evaluate how the PC-PART performs according to defined criteria that are important to the clinical utility of any assessment.

Clinical utility refers to how easy an assessment is to use, the acceptability to client and therapist, and the tool's ability to provide information that assists the therapists' decision-making (Barbara & Whiteford, 2005).

Please rate the influence of each of the following aspects of clinical utility on the clinical usefulness of the PC-PART.....

(Circle <u>one</u> response to each question, and then write your comments in the spaces. Continue on the back of the page if you need more space!)

Q11. The <u>time</u> it takes to complete the PC-PART:	Influence on clinical utility (circle one)					
(i.e. The time it takes to gather relevant information and complete the assessment)	Large negative influence	Small negative influence	No influence on clinical utility	Small positive influence	Large positive influence	
Please comment:						
Q12. The effort needed by you to	Influence on clinical utility (circle one)					
complete the PC-PART: (i.e. the workload, physical and cognitive effort required of you)	Large negative influence	Small negative influence	No influence on clinical utility	Small positive influence	Large positive influence	
Please comment:						

Q13. The type of information gathered by the PC-PART:						
(i.e. the relevance of the information gathered by the items for assessment of a person's problems in managing essential personal and instrumental activities of daily living)	Large negative influence	Small negative influence	No influence on clinical utility	Small positive influence	Large positive influence	
Please comment:						
Q14. The completeness of		Influence or	n clinical utility	(circle one)		
information gathered by the PC-PART:  (i.e. the extent to which the items cover all relevant areas for assessment of a person's problems in managing essential personal and instrumental activities of daily living)	Large negative influence	Small negative influence	No influence on clinical utility	Small positive influence	Large positive influence	
Please comment:						
Q15. The phrasing of the questions in the PC-PART:	Influence on clinical utility (circle one)					
(i.e. the wording, and how the questions are put to the patient and key informant)	Large negative influence	Small negative influence	No influence on clinical utility	Small positive influence	Large positive influence	
Please comment:						

Q16. The <u>rating options</u> in the PC-PART:	Influence on clinical utility (circle one)					
(i.e. the rating of each column as 'self', 'with help', 'no' or 'NA', and then rating final column as 'OK by self', 'OK with help', or 'Not OK')	Large negative influence	Small negative influence	No influence on clinical utility	Small positive influence	Large positive influence	
Please comment:						
Q17. The layout of the PC-PART		Influence or	n clinical utility	(circle one)		
worksheet:		I I I I I I I I I I I I I I I I I I I	Tommour damey	(611-616-6116)		
(i.e. the separate columns for each informant, the observation and	Large	Small	No influence	Small	Large	
standardised task; the spaces for writing; the booklet format; the coloured sections	negative influence	negative influence	on clinical utility	positive influence	positive influence	
etc)	iiiideiide	iiiideiide	J,	iiiideiide	miliacinoc	
Please comment:						
0.00 Til. 1. 1. 11. To						
Q18. The <u>order of items</u> in the PC-PART worksheet:	Influence on clinical utility (circle one)					
(i.e. the sequence of the questions in relation to your information needs and	Large	Small	No influence	Small	Large	
clinical reasoning)	negative influence	negative influence	on clinical utility	positive influence	positive influence	
Discourse	iiiidence	iiiidenee	aunty	iiiidenee	imidence	
Please comment:						

Q19. The <u>involvement of key</u> informants as part of the PC-PART	Influence on clinical utility (circle one)					
information gathering process:	Large	Small	No	Small	Large	
(i.e. the inclusion of carers, family members, other health clinicians during	negative	negative	influence on clinical	positive	positive	
data gathering)	influence	influence	utility	influence	influence	
Please comment:						
Q20. The options provided for		Influence or	n clinical utility	(circle one)		
'patient observation' in the PC- PART assessment:	Large	Small	No	Small	Large	
(ie. the suggested things to observe to aid your decision making when rating individual	negative	negative	influence on clinical	positive	positive	
items)	influence	influence	utility	influence	influence	
Please comment:						
Q21. The options provided as 'standard tasks' in the PC-PART		Influence or	n clinical utility	(circle one)		
assessment:	Large	Small	No	Small	Large	
(ie. the suggested things to observe the patient doing (with the usual help) to aid	negative	negative	influence on clinical	positive	positive	
your decision making when rating individual items)	influence	influence	utility	influence	influence	
Please comment:			I			

Q22. The requirement to purchase	Influence on clinical utility (circle one)					
the PC-PART in order to use it: (ie. the fact that the PC-PART is not a freely available assessment)	Large negative influence	Small negative influence	No influence on clinical utility	Small positive influence	Large positive influence	
Please comment:						

#### Section C: Acceptability of the PC-PART to clients and key informants

Q23. Based on your experience, indicate the <u>level of acceptability</u> of the following aspects of the PC-PART, to <u>clients</u>, and then separately, to <u>key informants</u>:

	ACCEPTABILITY							
Tick (✔) a response to each	TO CLIENTS				TO KEY INFORMANTS			
question for <u>clients</u> , and also for <u>key informants</u> .	Low	Med	High	N/A or don't know	Low	Med	High	N/A or don't know
a. The length of the assessment								
b. The types of questions asked								
c. The wording of the questions								
d. The extent to which the assessment covers all the main activities a person needs to do to live at home								
e. Involving others as part of the information gathering process								
f. The extent to which the assessment picks up problems someone might be having with everyday life								
g. Your comments on the accepta	bility of th	e PC-PA	RT to <u>clie</u>	ents:				
h. Your comments on the acceptability of the PC-PART to key informants:								

### Section D: Training to use the PC-PART

Q24.	Currently, there are no set training requirements for therapists who want to use the PC-PART in clinical practice. Do you think this is adequate? (tick (✔) one)  ☐ Yes ☐ No  Comments:	Q25.	A variety of resources are available for self-guided training. Which of the following did you use? (tick (✔) all that apply)  □ reading the users' manual □ viewing two training video presentations □ peer discussion □ peer review □ other, specify
Q26.	Do you think your training was sufficient to enable you to use the PC-PART effectively in clinical practice? (tick (✔) one)  ☐ Yes ☐ No  Comments:	Q27.	If you responded 'No' to Q26, what should be included in training, to help therapists use the PC-PART effectively in clinical practice?  Comments:
Q28.	One training option would be a dedicated workshop. How much time do you think would be needed for this?  (tick () one)  1-2 hrs  Half day (3-4 hours)  Two half days or one full day (6-7 hours)  None, I don't think this is needed.	Q29.	If a more formalised PC-PART training workshop became available, would this influence your views about the PC-PART's clinical utility? (tick (✔) one)  ☐ Yes ☐ No  Comments:

# Section E: Overall clinical utility of the PC-PART

Q30.	Place a mark across the line to indicate your response to the following statement:
	Overall, I think the clinical utility of the PC-PART is:
	Extremely poor I I Excellent
Se	ection F: Use of the PC-PART since the RCT
Q31.	Since completion of PC-PART data collection for the weekend therapy RCT, how frequently have you used the PC-PART? (tick () one)
	☐ Not at all
	☐ Seldom
	☐ Occasionally
	□ Routinely
Q32.	What have been the biggest influences on your decisions about use of the PC-PART following the RCT?
	Comments:
Q33.	Do you have any further comments about the clinical utility of the PC-PART?
	Comments:

You have reached the end of questionnaire!

Thank you for taking the time to provide us with your responses.

#### What do I do with my completed questionnaire?

☑ Please put the questionnaire into a return-addressed envelope (if you have one for this study), OR into a separate envelope and address it:

PC-PART study, c/- Prof. Christine Imms,

School of Allied and Pubic Health,

Australian Catholic University,

Locked Bag 4115 Fitzroy, VIC, 3065

Put it in the mail!

#### What happens next?

We will collate the responses to the questionnaire from all participants and from this, we will develop topics for the focus group discussion. The focus group discussion will be used to explore and clarify the responses in more depth. Susan Darzins will contact you soon, to arrange a suitable time for your focus group participation.

#### **Focus Group Schedule**

#### Focus Group Schedule - Clinical Utility of the PC-PART

Prepared by: Susan Darzins

Focus group moderator: Karen Roberts

Focus group assistant moderator: Priscilla Ennals

Contact for Camilla Radia-George during focus group: mob 0429 95 562

Contact for Susan Darzins during focus group: 0427 595 675

#### A. Pre-discussion: 5 mins

1. Check everyone is assembled, comfortable, and can see one another.

- 2. Check each participant has a **PC-PART worksheet** and a **summary of the questionnaire feedback** to look at during the discussion.
- 3. Thank everyone for coming along to help with this research on the PC-PART.
- 4. Check everyone has a name-tag
- 5. **Introductions** around the room. Introduce your own roles:

Moderator – to be a facilitator of the group discussion

Assistant moderator – to help the moderator do their job, take some notes.

- 6. Ensure audio-recorder is working.
- 7. Go through confidentiality issues affecting the group:

#### Main concepts:

- Discussions in the group need to be kept confidential and therefore not discussed outside of the group.
- Participants' opinions will be treated in confidence among the researchers for the purpose of the research, and in dissemination of this research.
- The group discussion will be audio-recorded.
- Participants do not have to use their name in the group
- Names that are mentioned in the group will not be transcribed
- Make participants aware that Susan will need to listen to the audio recording as part of the analysis process. No other researcher will be listening to the recording.
- Karen to ask if she has permission to use participants' names in the group
- Check if there are any participants who do not want their name to be used on the recording. If there are, Karen to indicate that she will try not to use the person's name.
- 8. Encourage participants to talk to each other and ask each other questions about what comes up in the discussion, so that they can explore different points of view about the PC-PART's clinical utility
- 9. Remind the group that once the discussion has commenced it will not be possible to withdraw data from the study at a later time.
- 10. Check there are no objections to use of the audio-recorder, then switch it on. (Participants who object will need to withdraw from the study before it is turned on).

#### B. Discussion goals: 5 mins

Get the group to remember back to using the PC-PART for the additional weekend therapy RCT, and acknowledge it may have been a year since they used the assessment. Encourage them to refer to the worksheet during the discussion to help them to remember details about it.

Indicate there are three main goals for the focus group, now that everyone in the group has completed the questionnaire, .......

- a. to talk in more depth about the positive aspects of the PC-PART that promote its usefulness,
- b. to talk about the PC-PART's negative aspects which are barriers to its routine use,

and

c. to explore if aspects of the PC-PART need to be changed in order to improve its clinical utility and if so, how it needs to change to improve its utility.

Indicate there are several aspects to clinical utility of an assessment and these were covered in the questionnaire.

There are no right or wrong opinions about this. We want you to feel comfortable saying what you really think and how you really feel about the PC-PART.

#### C. Main discussion prompts: 65 mins

#### **General opening prompts:**

Refer participants to the PC-PART worksheet and the summary of responses.

Ask participants to take a few minutes to reacquaint themselves with the PC-PART worksheet as well as the feedback from the questionnaire.

#### Part 1. Positive aspects of the tool (confirm and extend)

(The most positively rated aspects of the PC-PART were the type of information it gathers, the completeness of information it gathers, the rating options, as well as the layout and ordering of the assessment, the involvement of key informants, the observations and standard task options)

#### Example prompts:

- What do you see as the PC-PART's **real strengths**, **or positive aspects** for use in an **in-patient rehabilitation setting**?
- What do you see as the PC-PART's valuable aspects in this setting?
- What are the **more clinically useful aspects** of the tool in this setting?
- What makes it a worthwhile assessment in an in-patient rehabilitation setting?
- Why do you think that?

#### Part 2. Negative aspects of the tool (confirm and extend)

(The most negatively rated aspects of the PC-PART were the time and effort taken to gather the information, the phrasing of questions and the need to purchase the assessment).

#### Example prompts:

- What do you see as the PC-PART's **real weaknesses**, or **negative aspects** in an **in-patient rehabilitation setting**?
- What do you see as the PC-PART's **not-so-valuable aspects** in an in-patient rehabilitation setting?
- What are the **least clinically useful aspects of the tool** in this setting?
- What makes it NOT a worthwhile assessment in an in-patient rehabilitation setting?
- Why do you think that?

#### Specific prompts on each aspect of clinical utility:

These more specific questions get to more detail on specific aspects of clinical utility......

#### a. Time and effort (challenge and extend)

#### Example prompts:

- -To what degree does the PC-PART present an **efficient and effective way** to gather relevant clinical information about personal and instrumental ADL participation restrictions in an inpatient rehabilitation setting? Can you expand on your responses?
- -What would you say about the **time it takes** to administer the PC-PART in relation to the usefulness of the information you gather from it, in an in-patient rehabilitation setting?
- -What would you say about the **degree of effort needed by you**, to administer the PC-PART, to ensure you gather the necessary information you need about personal and instrumental ADL in an in-patient rehabilitation setting?
- -The average time used to gather PC-PART information has been measured at about 20-25 minutes
- how does this rate in terms of the assessment's efficiency?

If time and effort are viewed problematic issues:

How could this be improved?

How could this be managed?

#### b. Phrasing of the items (confirm/challenge and extend)

#### Example prompts:

Take a couple of minutes to look at the worksheet again – at how the questions are written, how they are phrased.

Was the phrasing of questions an issue for you?

If yes, can you expand on how the phrasing was an issue?

Were there particular questions where phrasing seemed to be an issue?

Which questions stand out most to you in this way?

Do you have suggestions on how the phrasing could be improved?

#### c. Rating options (confirm and extend)

#### Example prompts:

What do you think of the rating options/categories?

What do you think about the way they are written?

What do you think about how they are named?

How easy or hard was it to understand what they mean?

For the moderator's information:

**OK by Self** = The person can manage the activity alone (includes use of adaptive equipment, i.e. no other personal assistance is needed to help get the activity done)

**OK with Help** = The person needs assistance to manage the activity and this assistance is available **Not OK** = The person needs assistance to manage the activity and this assistance is not available

If the group confirms the rating options were confusing, go on to ask:

How do you think the meaning of these rating options could/should be made clearer?

#### d. The cost of the assessment (challenge and extend)

For the moderator's information:

Each PC-PART worksheet costs Eastern Health \$1.50.

Example prompts:

What do you think about the requirement to purchase the PC-PART in order to use it? Why do you think that?

What is at the heart of your views?

#### e. Type and completeness of information (confirm and extend)

For the moderator's information:

The purpose of the PC-PART is to cover only those areas of ADL that are essential, ie, that need to be managed in order to keep people in the community. In other words, if the ADL activity was not managed, the person would need supported care or hospital admission.

#### Example prompts:

In your view, to what extent does the PC-PART cover all of the essential aspects of ADL that are necessary for community living.

Is there anything missing that is essential?

Is there anything in the assessment that should be removed?

# **f. Options for patient observation and standardised tasks** (challenge and extend) For your information:

The PC-PART does not target any specific diagnostic, or clinical group, other than community dwelling adults, and it is used in a range of clinical settings. Some of the patient observation and standardised tasks in the worksheet clearly need to be done in the home setting which is not possible in the hospital setting.

#### Example prompts:

What was it like having the observations and standardised tasks columns on the PC-PART worksheet?

Does this affect the PC-PART's clinical usefulness, or utility in an in-patient rehabilitation setting? If it impacts negatively.....

How could this be managed?

#### g. Training to use the PC-PART (challenge and extend)

Example prompts:

Can you tell us about the training you had prior to using the PC-PART?

How confident did you feel about using and scoring the PC-PART accurately, after the training?

Do you think that formal training would be useful to you?

What do you think should be the main aim of any training?

Why?

What should be covered in the training?

#### Part 3. Changes to the PC-PART/ Summary question

Example prompts:

If you were in a position to be able to change anything about the PC-PART to make it better to use, what is the single most important thing you would change?

AND

For you to use the PC-PART routinely, what would need to change/happen?

#### Clarify these points if they come up in the conversation.....

#### **Purpose of the PC-PART**

The PC-PART gathers different information to the FIM $^{\rm TM}$  in that the FIM $^{\rm TM}$  tells us what a person is able to do for themselves, but the PC-PART tells us what is going to get done and takes into account the use of available help, as part of the scoring.

#### Temporal aspect of the instrument

The purpose of the PC-PART is to gather information about how the person would get their daily activities managed 'if they were at home today'. This is the case for both admission and discharge assessments/

#### D. Finishing up 15 mins

If it flows, use the responses from section C, Part 3 to summarise.

" It sounds like the group think that......"

Give the group a chance to correct anything you have summarised

"Would you say that this is an accurate representation of the discussion? Is there anything that needs to be corrected?"

Give the group a chance to make any further comments by saying:

"I have no further questions to ask, but is there anything else you would like to bring up, or ask about, before we finish this session?"

Thank the group for their time and communicate to them that the discussion has been most valuable.

Inform the participants that Susan will follow-up by email after the focus group to confirm those participants who want to read the transcript to check accuracy of the account of the conversation. It

may be possible that some participants change their mind about this, and that is OK. So, Susan will check first.

Inform the group that they are welcome to stay to have something to eat and drink.

#### E. Debrief following the Focus group 30 mins

Immediately after the group, the moderator and observer make their own notes about the session, how they felt about it, if there were any problems, particular observations etc. Then, they meet to summarise and compare their thoughts about the issues that were raised during the discussion, as well as identify dominant speakers, quiet members and other dynamics that may influence content analysis of the data.

This discussion should be audio-recorded.

#### **Ethics approval- Eastern Health**



5 Arnold Street, Box Hill Victoria 3128 Australia PO Box 94, Box Hill 3128 Tel (03) 9895 3281 Fax (03) 9895 4896 info@easternhealth.org.au

www.easternhealth.org.au

#### **Human Research Ethics Committee - Scientific and Ethical Review**

#### **Ethical Approval - Granted**

Commencement of Research at Eastern Health has been authorised

06 September 2012

Mrs Camilla Radia-George Angliss Hospital Albert Street Upper Ferntree Gully VIC 3156

Dear Mrs Radia-George

Eastern Health Research and Ethics Committee Ph: 03 9895 3398 Fax: 03 9094 9610 Email: ethics@easternhealth.org.au Website: www.easternhealth.org.au/ethics

LR15/1213 Clinical utility of the Personal Care Participation Assessment and Resource Tool (PC-PART) within an in-patient rehabilitation setting: a mixed methods study.

<u>Principal Investigators:</u> Mrs Camilla Radia-George (Eastern Health contact person), Prof Christine Imms & Dr Marilyn Di Stefano

Student Investigator: Ms Susan Darzins

Eastern Health Sites: Angliss Hospital & Peter James Centre

Approval Period: On-going - subject to a satisfactory progress report being submitted annually

Thank you for the submission of the above project for review. Project has been reviewed by the Eastern Health Research and Ethics Committee. The project is considered of negligible risk in accordance with definitions given in the National Statement (2007). All issues have now been addressed and the project is accordingly **APPROVED**.

Documents submitted for review:

- Module 1 Revised section 1.8
- Protocol version 2 dated 03 September 2012
- Email advertisement 'Invitation to participate' version 1 dated 02 August 2012
- Poster advertisement 'Invitation to participate' version 1 dated 02 August 2012
- Reminder advertisement 'Reminder: Invitation to participate' version 1 dated 02 August 2012
- Participant Information and Consent Form version 1 dated 02 August 2012
- Certificate of Participation version 1 dated 30 July 2012
- Participant Questionnaire version 30 July 2012
- Draft Focus Group Schedule version 1 dated 05 July 2012

N:\02-03&current\Ethics - Eastern Health\All Correspondence\LOW\_NEGLIGIBLE RISK PROJECTS\Jul12 - Jun13\LR15-1213\LR15-1213 Correspondence from EH\LR15-1213 Final Approval 06Sep12.doc
Page 1 of 2



5 Arnold Street, Box Hill Victoria 3128 Australia PO Box 94, Box Hill 3128 (03) 9895 3281 (03) 9895 4896 Fax info@easternhealth.org.au ABN 68 223 819 017

www.easternhealth.org.au

- Eastern Health Confidentiality Agreement to be signed by Pacific Transcription personnel
- Confidentiality Agreements Christine Imms, Marilyn Distefano, Susan Darzins & Karen Roberts
- Curriculum Vitaes Christine Imms, Marilyn Di Stefano, Susan Darzins & Karen Roberts
- Email response to ethics queries from Ms Susan Darzins dated 05 September 2012

**IMPORTANT**: A final progress report should be submitted on project completion. If the project continues beyond 12 months an annual progress report should be submitted in September 2013. Continuing approval is subject to the submission of satisfactory progress reports. Progress report template can be downloaded from our web-page:

http://www.easternhealth.org.au/research/ethics/progressreports.aspx

Please quote our reference number *LR15/1213* in all future correspondence.

Yours sincerely

Ms Virginia Ma

Research Governance Officer

Eastern Health Office of Research and Ethics

(Signed on behalf of the Eastern Health Research and Ethics Committee)

#### **Confidentiality, Privacy & Research**

Research data stored on personal computers, USBs and other portable electronic devices must not be identifiable. No patients' names or UR numbers must be stored on these devices.

Electronic storage devices must be password protected or encrypted.

The conduct of research must be compliant with the conditions of ethics approval and Eastern Health policies.

#### **Publications**

Whilst the Eastern Health Research and Ethics Committee is an independent committee, the committee and Eastern Health management encourage the publication of the results of research in a discipline appropriate manner. Publications provide evidence of the contribution that participants, researchers and funding sources make.

It is very important that the role of Eastern Health is acknowledged in publications.

 $N: \ 02-03 \& current \ | Ethics - Eastern \ Health \ | All \ Correspondence \ | LOW_NEGLIGIBLE \ RISK \ PROJECTS \ | Jul 12 - Jun 13 \ | LR 15-1213 \ | LR$ Correspondence from EH\LR15-1213 Final Approval 06Sep12.doc - Members of Eastern Health

**Angliss Hospital** Tel (03) 9764 6111

**Box Hill Hospital** Tel (03) 9895 3333 Healesville & District Hospital Tel (03) 5962 4300

Maroondah Hospital Tel (03) 9871 3333

Peter James Centre Tel (03) 9881 1888

Wantirna Health Tel (03) 9955 1200 Yarra Ranges Health Tel (03) 9091 8888

Yarra Valley Tel 1300 130 381

#### **Ethics approval- Australian Catholic University**

#### Registration of External Ethics Approval 2012 243V

# Gabrielle Ryan <Gabrielle.Ryan@acu.edu.au> on behalf of Res Ethics <Res.Ethics@acu.edu.au>

Mon 17/09/2012 10:43 AM

Inbox

To:Christine Imms <Christine.Imms@acu.edu.au>; Susan Darzins <ssdarz001@myacu.edu.au>;

Dear Christine and Susan,

Principal Investigator: Christine Imms Student Researcher: Susan Darzins Ethics Register Number: 2012 243V

Project Title: Clinical utility of the Personal Care PArticipation Assessment and Resource Tool (PC-PART) within an in-

patient rehabilitation setting: a mixed methods study.

Risk Level: Multi Site Date Approved: 17/09/2012

Ethics Clearance End Date: 30/06/2013

The ACU HREC has considered your application for ethics approval 2012 243V Clinical utility of the Personal Care PArticipation Assessment and Resource Tool (PC-PART) within an in-patient rehabilitation setting: a mixed methods study..

As this application already has ethics approval from Eastern Health HREC, ACU HREC accepts the approval with no additional requirements, save that ACU HREC is informed of any modifications of the research proposal and that copies of all progress reports and any other documents be forwarded to it. Any complaints involving ACU staff must also be notified to ACU HREC (National Statement 5.3.3)

We wish you well in this research project.

Regards,

Gabrielle Ryan
Ethics Officer | Research Services
Office of the Deputy Vice Chancellor (Research) res.ethics@acu.edu.au

#### **Participant Information and Consent Forms**





#### PARTICIPANT INFORMATION STATEMENT

#### **Eastern Health Occupational Therapy Department**

Full Project Title: Clinical utility of the Personal Care Participation Assessment and Resource Tool (PC-PART) within an in-patient rehabilitation setting: a mixed methods study.

**Principal Researchers**: Dr Christine Imms, Professor of Occupational Therapy and Head, School of Allied & Public Health, Australian Catholic University, ph 03 99533404.

Ms. Camilla Radia-George, Manager of Occupational Therapy, Angliss Hospital, Healesville and Yarra Ranges, Eastern Health, ph 03 9764 6432.

**Student Researcher:** Ms Susan Darzins, PhD Candidate, School of Allied & Public Health, Australian Catholic University, ph 03 99533404 (supervised by Dr Christine Imms and Dr Marilyn Di Stefano)

**Associate Researcher:** Dr Marilyn Di Stefano, Senior Lecturer, School of Allied Health, La Trobe University, ph 03 9479 5650

#### 1. Introduction

This study aims to investigate the usefulness and relevance of the PC-PART in an in-patient rehabilitation setting. We will ask occupational therapists who have used the PC-PART for their views and opinions about this assessment tool via a questionnaire and through focus group discussion on this topic.

If you are an occupational therapist who used the PC-PART during the recent Randomised Controlled Trial (RCT) investigating the effectiveness of additional allied health services at the Peter James Centre or the Angliss Hospital between July 2010 and January 2012, we invite you to participate in this study.

This Participant Information Statement and the adjoining consent form tells you about the research project. It explains what is involved to help you decide if you want to take part.

Please read this information carefully. Ask questions about anything that you do not understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with others.

Participation in this research is voluntary. If you do not wish to take part, you do not have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you: understand what you have read; consent to take part in the research project; and

consent to be involved in the procedures described;

You may keep this Participant Information Statement and you will be given a signed copy of your consent form to keep.

#### 2. What is the purpose of this research project?

Reliable and valid standardised clinical assessments are useful for measuring the effect of our clinical interventions on client outcomes and for gathering evidence about our health care services. However, it is also important to establish whether these assessments provide clinically useful information and are acceptable to therapists and patients.

This study explores the usefulness of the PC-PART as a clinical assessment in an in-patient rehabilitation setting. Eligible participants are <u>occupational therapists</u> who used the PC-PART during the recent Eastern Health additional allied health RCT at Peter James Centre and Angliss Hospital between July 2010 and January 2012. This represents between 35 and 40 therapists. All volunteer participants will be invited to complete one questionnaire and participate in one focus group discussion to gather this information.

This study is separate to the RCT, and therefore your decision about participation in this study will not influence the findings of the RCT. You do not have to participate if you do not want to.

Collaborators in this study involve researchers and therapists from The Australian Catholic University, La Trobe University and Eastern Health. This is one of three main studies that will be used by Susan Darzins' to obtain her PhD degree.

Funding for this research comes from a Faculty Research Student Support Scheme (FRSS) grant from the Australian Catholic University. Susan Darzins also holds an Australian Post Graduate Award scholarship to support her doctoral research.

#### 3. What does participation in this research project involve?

#### **Procedures**

If you decide to take part in this study you will be asked to:

- (a) Sign the consent form and return it to Susan Darzins in one of the enclosed returnaddressed envelopes, indicating your consent to all or some of (b), (c) and (d), below:
- (b) Complete one hard-copy questionnaire (see enclosed/attached). This will take about 20 minutes to complete. We would like you to complete and return the questionnaire within 3 weeks of receipt. We do not want you to provide your name on the questionnaire. The questionnaire will not contain any personally identifiable information to the researchers. If you want to participate, the enclosed questionnaire should be completed and returned to the address supplied on the questionnaire in (a) one of the envelopes supplied if you received a package OR (b) a separate envelope if you are reading this via e-mail.
- (c) Participate in one focus-group discussion. This will run for about 90 minutes during your working hours. Dates and times for the focus groups will be arranged with the aim of accommodating Eastern Health Occupational Therapy Departmental commitments and the preferences of participants. Focus groups will occur at the Peter James Centre and the Angliss Hospital. Focus groups will be conducted by an independent and experienced focus group moderator who is not employed by Eastern Health (Ms Karen Roberts). An observer/note-taker will be present and this will be either Dr. Christine Imms or Dr. Marilyn Di Stefano. The focus group discussion will be audio-recorded and transcribed. You will not be required to say your name on the recording. The discussion will focus only on your views about the clinical utility of the PC-PART. The researchers will analyse the content of the transcripts to summarise participants' views about the clinical utility of the PC-PART in an inpatient rehabilitation setting.
- **(d) Review a transcript of the focus group discussion** to ensure the transcript accurately reflects the discussion.

#### Will personal information about me be collected?

Personal information about you will *not* be collected as part of this research.

You are, however, asked for your preferred contact details on the consent form. This information will be used only for the purposes of enabling communication with you to coordinate a suitable focus group date and time.

This research does seek voluntary expression of your views, beliefs and opinions about various aspects of the PC-PART's usefulness in an in-patient rehabilitation setting, but will not require information of a personally sensitive nature and will not require access to any of your personal records.

#### Reimbursement

You will not be paid for your participation in this research, however, with the support of the Occupational Therapy Department, the focus groups will be held during your working hours. Your participation in this research may be used to gather Australian Health Practitioner Regulation Agency (AHPRA) based Continuing Professional Development (CPD) hours. To facilitate this, documentation of your participation will be provided to you, following your involvement in the focus group discussion.

#### **Declaration of Interest and managing potential for biased outcomes**

It is important that you know Susan Darzins is a Director of Darzins Consulting Pty Ltd., which operates using the business name The PART Group, which distributes the PC-PART assessment. The author of the PC-PART is Susan Darzins' spouse. Because of this conflict of interest, it is important we manage the potential for her interests in the PC-PART to bias the study findings and so that you do not feel pressured to provide positive opinions about the PC-PART. Therefore, we do not want you to put your name on your completed questionnaire and your completed questionnaire will be sent to Dr Christine Imms in a reply-paid envelope. This will ensure you cannot be identified from your questionnaire.

Susan will not be present or involved in any focus group discussions. She will only be present to set up the room and will leave prior to commencement of the focus group discussion. Any names that may be recorded on the audio recording of the focus group will be removed during transcription of the discussion and will be replaced by a number (ie participant 1). Therefore, none of the researchers will be able to identify any participant from the transcripts.

Susan Darzins will listen to the audio-recording of the focus group discussion. It is important that you know that you do not have to use your name during the focus group discussion if you do not want to be identified on the audio-recording by Susan Darzins.

Four researchers will analyse all data arising from the study. This will manage Susan Darzins' potential to bias the research outcomes.

#### **Unequal relationship**

An OT Manager (Camilla Radia-George), who is one of the researchers, will only see collated, group responses to each item in the questionnaire. Your individual answers to questions will not be viewed by anyone at Eastern Health. Therefore you will not be identified by your responses to questions to the questionnaire.

It is also important for you to know that Camilla Radia-George will not be present or involved in any of the focus group discussions. She will not listen to the audio recording of the discussion, but she may view the transcript of the discussion, which will have all names removed (mentioned above).

It is also important for you to know that your decision to take part, not take part, or to take part and then withdraw in this research, will in no way have negative consequences for you personally or professionally in your employment at Eastern Health.

#### 4. What are the possible benefits?

There are no specific benefits to you if you participate in this study. However, you may benefit from the opportunity to discuss the usefulness of the PC-PART in an inpatient rehabilitation setting with your colleagues, as this may be useful to future decisions about clinical assessment practices in this setting. It is possible you may enjoy the experience of participating in, and contributing to this research.

#### 5. What are the possible risks?

It is possible you may feel slight inconvenience about participating in this research. As the questionnaire is self-administered, completion of this can be done when it suits you. We aim to schedule the focus groups at a time that suits you to attend one of them. However, it is possible that you may feel some inconvenience if none of the dates or times of the focus groups match your schedule and involves rearranging some other activities to enable participation.

We do not foresee that you will feel discomfort as a result of participating in this research. The focus group discussion will be about the PC-PART instrument and it's strengths and limitations as a clinical assessment. As such, the substance of the discussion will not be of a sensitive or personal nature.

Although we consider the likelihood to be extremely low, it is feasible that a quote (un-identified) in a published peer-reviewed journal article or conference presentation, may be recognised by you as your own, or as that of another participant. The researchers will make every effort to avoid publishing comments that by their nature, may enable identification of a particular participant. However, full elimination of this possibility cannot be guaranteed.

If you do become upset or distressed as a result of your participation in the research, the researchers will arrange for counselling or other appropriate support. Any counselling or support will be provided by staff who are not members of the research team.

#### 6. Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to, and you do not have to provide reasons for your decision. If you decide to take part and later change your mind, please notify the researchers. If you do consent to participate and later change your mind, there are two points in the study at which you will be able withdraw. This has to do with the inability to withdraw your unidentifiable data after it has been collected.

- (a) you may withdraw from the study prior to submitting the questionnaire. After this time, it will not be possible to withdraw your questionnaire data (as it will be unidentifiable).
- (b) you may withdraw from the study prior to commencement of the focus group discussion, and you will be provided the opportunity to do so just prior to the discussion. If you decide to withdraw at this stage, you must be aware that your previously gathered questionnaire data will still be included in the study.

Your decision to take part, not take part, or to take part and then withdraw in this research, will in no way have negative consequences for you personally or professionally in your employment at Eastern Health, nor in your relations with the researchers, nor with Australian Catholic University.

#### 7. How will I be informed of the final results of this research project?

When this research is completed, towards the end of 2013, a summary of the results will be provided to the occupational therapy department at Eastern Health. You can elect to have a copy of this sent to you by indicating your wishes on the consent form. A summary of the results will be disseminated within the Eastern Health occupational therapy department, and posted on the School of Occupational Therapy's website at Australian Catholic University.

#### 8. What will happen to information about me?

Data collected as part of this research will be non-identifiable. You will not be required to provide your name or any identifying information on the questionnaire or say your name on the audio-recording of the focus group. In any publication and/or presentation, information you provide will therefore be presented in a non-identifiable manner.

Completed questionnaires will be kept in a locked filing cabinet in the School of Allied and Public Health at Australian Catholic University. Electronic data will be kept in a password protected computer file that only the researchers of this study will have access to. Questionnaire data will be shredded and the electronic data will be deleted after 7 years.

There is no intention to use data from this study for future research, and therefore you are being asked only for your consent to participate in this study. This research does not involve the establishment of a databank.

#### 9. Can I access research information kept about me?

In accordance with regulatory guidelines, the information collected in this research project will be kept for at least 7 years. You must be aware that it will not be possible to identify your own information once you have submitted the questionnaire and also once you have participated in a focus group. Access to your own information after these events will not be possible.

#### 10. Is this research project approved?

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of Eastern Health and Australian Catholic University.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)* produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.





#### PARTICIPANT CONSENT FORM

#### Eastern Health Occupational Therapy Department

Full Project Title: Clinical utility of the Personal Care Participation Assessment and Resource Tool (PC-PART) within an in-patient rehabilitation setting: a mixed methods study.

**Principal Researchers**: Dr Christine Imms, Professor of Occupational Therapy and Head, School of Allied & Public Health, Australian Catholic University, ph 03 99533404.

Ms. Camilla Radia-George, Manager of Occupational Therapy, Angliss Hospital, Healesville and Yarra Ranges, Eastern Health, ph 03 9764 6432.

**Student Researcher:** Ms Susan Darzins, PhD Candidate, School of Allied & Public Health, Australian Catholic University, ph 03 99533404 (supervised by Dr Christine Imms and Dr Marilyn Di Stefano)

**Associate Researcher:** Dr Marilyn Di Stefano, Senior Lecturer, School of Allied Health, La Trobe University, ph 03 9479 5650

#### **Consent Statement**

I am an occupational therapist who used the PC-PART during the additional allied health Randomised Controlled Trial at the Peter James Centre or Angliss Hospital between July 2010 and January 2012.

I have read the Participant Information Statement about this research. I understand the purposes, procedures and risks of this research project as described within it. I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I agree to participate in this research, realising that I may physically withdraw from the study prior to submission of a completed questionnaire OR just prior to commencement of the focus group discussion (knowing that questionnaire data that I may have provided will continue to be used in the study).

I agree that research data provided by me or with my permission during the project may be included in a thesis, presented at conferences and published in journals on the condition that neither my name nor any identifying information is used (as described in the Participant Information Statement).

Please respond to the following statements (please mark your responses with an X'):

(a) I consent to completion of the 'Clinical utility of the PC-PART' <u>questionnaire</u> (enclosed/attached)	Yes □	No □			
If you ticked 'yes' please complete the questionnaire and return it to the address supplied on the questionnaire in (a) one of the envelopes supplied if you received a package OR (b) a separate envelope if you are reading this via e-mail					
If you ticked 'no' you may still consent to participation in	n a focus group (be	elow),			
(b) I consent to participation in a focus group discussion with OT colleagues about the clinical utility of the PC-PART in an in-patient rehabilitation setting, facilitated by an independent moderator and with the presence of an independent observer and note-taker.	Yes □	No □			
If you ticked ' <b>yes'</b> , please provide your preferred e-mail and telephone number which will only be used to communicate with you to arrange a suitable date and time for the focus group discussion and to provide you with documentation (only if chosen by you in (d) and (e), below).					
Preferred e-mail:					
Preferred phone number:					
(c). I consent to audio-recording of the focus group discussion.	Yes □	No □			
(d) I am interested in reading a transcript of the focus group discussion, once this is available, in order to verify the accuracy of the discussion (this will be delivered in hard copy, with arrangements made using your contact details, above).	Yes □	No □			
(e) I would like to receive an overall summary of the study findings once the study is completed, sent to my preferred e-mail address (stated above)	Yes □	No □			
I understand that I will be given a signed copy of this document to keep.					
Participant's name (Block letters)					
Signature Date					
Researcher's name (printed) SUSAN DARZINS					
Signature Student supervisor's name: DR CHRISTINE IMMS		Date			

Please return this signed consent form in one of the return-addressed envelopes provided in this package.

#### 12. Who can I contact?

The person you may need to contact will depend on the nature of your query. Therefore, please note the following:

#### For further information or appointments:

If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project (for example, feelings of distress), you can contact the Student Researcher - Susan Darzins, or Principal Researcher - Dr Christine Imms, on ph 03 99533404; or any of the following Researchers: Dr Marilyn Di Stefano (03 9479 5650); Ms Camilla Radia-George (03 9764 6432).

#### For complaints:

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Name: Professor Bridie Kent,

Position: Chairperson Eastern Health Human Research and Ethics Committee

Telephone: 03 9895 3398

Email: ethics@easternhealth.org.au

OR

The Chair, Human Research Ethics Committee C/- Research Services
Australian Catholic University
Melbourne Campus
Locked Bag 4115
Fitzroy VIC 3065

Tel: 03 9953 3158 Fax: 03 9953 3315

#### Advertisement





#### Invitation to participate

Did you use the PC-PART during the additional allied health RCT at Peter James Centre or Angliss Hospital between July 2010 and January 2012?

Yes? Then we would like to hear your views about the PC-PART.

You can participate during work hours and earn CPD hours!



#### About the study....

Researchers from Australian Catholic University, La Trobe University and Eastern Health are conducting a study to better understand the strengths and limitations of the Personal Care Participation Assessment and Resource Tool (PC-PART) as a clinical assessment in a rehabilitation setting. This will form part of Susan Darzins' doctoral research.

#### Who can participate?

Occupational therapists who used the PC-PART with rehabilitation patients as part of the additional allied health RCT at the Peter James Centre and Angliss Hospital, between July 2010 and January 2012, are invited to participate in this study. Even if you only completed a small number of PC-PART assessments, you can still take part.

#### Know anyone else who could participate?

If you know of other occupational therapists who might be eligible to participate and might not see this e-mail, it would help us if you would forward this invitation to them.

We will invite you to: 1. complete an anonymous questionnaire (about 20 mins) 2. take part in one focus group discussion with other participants (about 90 minutes).

Discussions will be facilitated by an independent moderator, who is not a member of the research team, nor employed by Eastern Health. These will be held at the Peter James Centre and the Angliss Hospital.

#### Why might you want to participate?

- Your department has given permission for you to do this during working hours
- Your department believes this study is worthwhile and will make a valuable contribution.
- · You will be provided with evidence to support 2 hours of CPD activity.
- The discussion may help you with future decisions about use of clinical assessments.

• It can be interesting to participate in research with your colleagues.

#### Who do I contact to get more information?

If you want to find out more about the study before deciding if you want to participate, please contact Susan Darzins (contact details below).

Remember, you can also read the Participant Information and Consent Forms and the questionnaire attached to this e-mail to find out more.

#### What if I already know that I want to participate in this research?

If you have already read the Participant Information and Consent Forms and know you want to participate in the study, please do the following:

- 1. Print the consent form and fill it in,
- 2. Send the consent form back to **Susan Darzins** by mail (in a separate envelope to the questionnaire).
- 3. Print the guestionnaire attached to this email and complete it.
- 4. Place the questionnaire in a separate envelope to your consent form and return it to **Dr Christine Imms** at the address below:

Mail address: Susan Darzins and Christine Imms, School of Allied and Public Health,

Australian Catholic University, Locked Bag 4115, Fitzroy, 3065

e-mail: Susan Darzins: S00131883@myacu.edu.au

mobile: Susan Darzins: 0427595675

phone: Susan Darzins and Christine Imms: 03 9953 3404

#### Who are the researchers, specifically?

Ms Susan Darzins, PhD Candidate, Australian Catholic University

Prof Christine Imms, Professor of Occupational Therapy, Head of Allied & Public Health, Australian Catholic University

Dr Marilyn Di Stefano, Senior Lecturer, Department of Occupational Therapy, School of Allied Health, La Trobe University

Ms Camilla Radia-George, Manager of Occupational Therapy, Angliss Hospital, Healesville and Yarra Ranges, Eastern Health.

#### Appendix G. Self Care and Domestic Life Scale Items and Conversion Table

Table G.1 Self Care and Domestic Life Scale items.

No.		Self Care scale items	No.		Domestic Life scale items
1	D1	Mobility (indoors)	1	D5	Outside mobility & safety
2	D4	Steps or Stairs	2	C4	Meal Preparation
3	В7	Bathing	3	A5	Laundry
4	A2	Dressing: Bottom (lower body)	4	D7	Transport
5	A3	Dressing: Footwear	5	C5	Groceries
6	D3	Falls	6	F4	Shopping for personal needs, household items etc.
7	B1	Toileting	7	C7	Stove
8	В8	Bath Transfers	8	E1	Medication use
9	D2	Bed	9	C3	Meal Planning
10	A1	Dressing: Top (upper body)	10	F1	Money Management
11	A4	(Clothing) selection appropriate for environment	11	E4	Emergency Help
12	B5	Grooming: Teeth	12	F3	Basic Personal Information
13	E3	Illness/crisis management	13	E2	Alcohol and other substance abuse
14	C6	Food-Restrictions	14	F2	Home security
15	C8	Spoiled Food			
16	F5	Temperature			

Table G.2. Conversion table for the *Self Care* and *Domestic Life* scale, derived from Rasch location scores for each scale.

Self Care so	cale	Domestic Life scale		
Raw score	0-100 scale score	Raw score	0-100 scale score	
0	0	0	0	
1	11	1	15	
2	19	2	26	
3	25	3	33	
4	30	4	38	
5	34	5	43	
6	38	6	48	
7	43	7	54	
8	48	8	59	
9	53	9	64	
10	59	10	69	
11	65	11	75	
12	71	12	82	
13	77	13	90	
14	83	14	100	
15	91			
16	100			

#### Appendix H. Research Portfolio

#### Actual or potential publications and corresponding statements of contribution

**Paper 1**. As co-authors of the paper "Darzins, S., Imms, C., Di Stefano, M. (2013). Measurement properties of the Personal Care Participation Assessment and Resource Tool (PC-PART): a systematic review, *Disability & Rehabilitation*, 35(4):265-281" we confirm that each of the authors made the following contributions:

#### Susan Darzins (80%):

- Study design, literature searches, development of inclusion/exclusion criteria, study selection, COSMIN study quality ratings, critical appraisal;
- Collation of data and synthesis of results;
- Planning, writing, preparation and submission of the manuscript for publication;
- Corresponding author for communication.

Signed: Starzus Date: 21/09/2015

#### Christine Imms (12.5%):

- Supervision related to study design, development of inclusion/exclusion criteria, study selection, COSMIN quality ratings, collation and synthesis of results and planning of manuscript;
- Independent COSMIN quality ratings, critical appraisal;
- Review and editing of draft manuscript.

Signed: Date: 22/09/2015

#### Marilyn Di Stefano (7.5%):

- Supervision related to study design, development of inclusion/exclusion criteria, study selection, collation and synthesis of results and planning of manuscript;
- Independent study selection;
- Review and editing of draft manuscript.

**Paper 2.** As co-authors of the paper "Darzins, S., Imms, C., Di Stefano, M. (submitted, under review). Measurement of activity limitations and participation restrictions: examination of ICF-linked content and scale properties of the PC-PART and FIM<sup>TM</sup> instruments, *Disability & Rehabilitation*." we confirm that each of the authors made the following contributions:

#### Susan Darzins (80%):

- Concept and design of the research and study methods;
- Literature searches and comparisons of ICF-linked FIM studies;
- Linking PC-PART items to ICF; collation, analysis and interpretation of data;
- Collation of data and synthesis of results;
- Planning, writing, preparation and submission of the manuscript for publication;
- Corresponding author for communication.

Signed: Date: 21/09/2015

#### Christine Imms (12.5%):

- Supervision related to concept and design of the research and study methods;
- Independent linking of PC-PART items to the ICF;
- Review and editing of draft manuscript.

Signed: Date: 22/09/2015

#### Marilyn Di Stefano (7.5%):

- Supervision related to concept and design of the research and study methods;
- Independent review of ICF-linked FIM items;
- Review and editing of draft manuscript.

**Paper 3.** As co-authors of the paper "Darzins, S., Imms, C., Di Stefano, M., Radia-George, C. (submitted, under review). Personal Care Participation Assessment and Resource Tool: Clinical utility for inpatient rehabilitation. *Canadian Journal of Occupational Therapy*", we confirm that each of the authors made the following contributions:

#### Susan Darzins (75%):

- Concept and design of the research and study methods;
- Design of data collection instruments, recruitment of participants and coordination of data collection;
- Data analysis and interpretation of the findings;
- Planning, writing, preparation and submission of the manuscript for publication;
- Corresponding author for communication.

Signed: Date: 21/09/2015

#### Christine Imms (12.5%):

- Supervision related to concept and design of the research and study methods, design of data collection instruments, recruitment of participants, data collection and analysis;
- Independent review of abstraction of qualitative data codes;
- Review and editing of draft manuscript.

Signed: Date: 22/09/2015

#### Marilyn Di Stefano (7.5%):

- Supervision related to concept and design of the research and study methods, design of data collection instruments, recruitment of participants, data collection and analysis;
- Independent review of coded qualitative data;
- Review and editing of draft manuscript.

#### Camilla Radia-George (5%)

- Independent review of coded qualitative data;
- Review and editing of draft manuscript.

Signed: Date: 22/09/2015

**Paper 4.** As co-authors of the paper "Darzins, S., Imms, C., Di Stefano, M., Taylor, N.F., Pallant, J.F. (2014). Evaluation of the internal construct validity of the Personal Care Participation Assessment and Resource Tool (PC-PART) using Rasch analysis, *BMC Health Services Research*, 14:543", we confirm that each of the authors made the following contributions:

#### Susan Darzins (80%):

- Concept and design of the research and study methods;
- Entry of data into database and all data analysis;
- Interpretation of the findings;
- Planning, writing, preparation and submission of the manuscript for publication;
- Corresponding author for communication.

Signed: Date: 21/09/2015

#### Christine Imms (7.5%):

- Supervision related to concept and design of the research and study methods, data analysis and interpretation of findings;
- Review and editing of draft manuscript.

Signed: Date: 22/09/2015

#### Marilyn Di Stefano (2.5%):

- Supervision related to concept and design of the research and study methods, data analysis and interpretation of findings;
- Review and editing of draft manuscript.

#### Nicholas Taylor (2.5%):

- Provided the study data;
- Assisted in study design;
- Review and editing of draft manuscript.

Signed:

1/8

Date: 28/9/2015

#### Julie Pallant (7.5%)

- Methodological training and advice on Rasch analysis;
- Review and editing of methods and results section of the manuscript.

Signed:

d: Jules Pallant

Date:

25/9/2015

Paper 5. As co-authors of the paper "Darzins, S., Imms, C., Shields, N. Taylor, N.F. (2015). Responsiveness, construct and criterion validity of the Personal Care-Participation Assessment and Resource Tool (PC-PART), Health and Quality of Life Outcomes, 13(1):125" we confirm that each of the authors made the following contributions:

#### Susan Darzins (80%):

- Concept and design of the research and study methods;
- Entry of data into database and all data analysis
- Interpretation of the findings;
- Planning, writing, preparation and submission of the manuscript for publication;
- Corresponding author for communication.

Signed:

8 Darzus

Date: 21/09/2015

#### Christine Imms (10%):

- Supervision related to concept and design of the research and study methods,
   data analysis and interpretation of findings;
- Review and editing of draft manuscript.

Signed:

b/6

Date: 22/09/2015

#### Nora Shields (5%):

- Assisted with research design and methods, advice on data analysis and interpretation of findings;
- Advice on data analysis
- Review and editing of draft manuscript.

Signed: Nun Shulds

Date: 23 9 15

#### Nicholas Taylor (5%):

- Provided the study data
- Assisted in study design and methods
- Advice on data analysis
- Review and editing of draft manuscript.

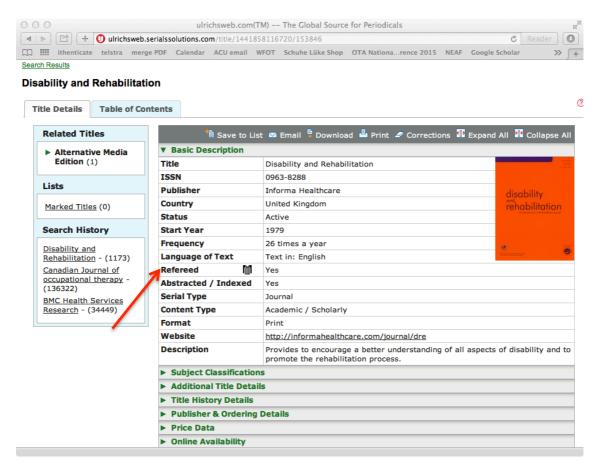
Signed:

Date: 28/9/2015

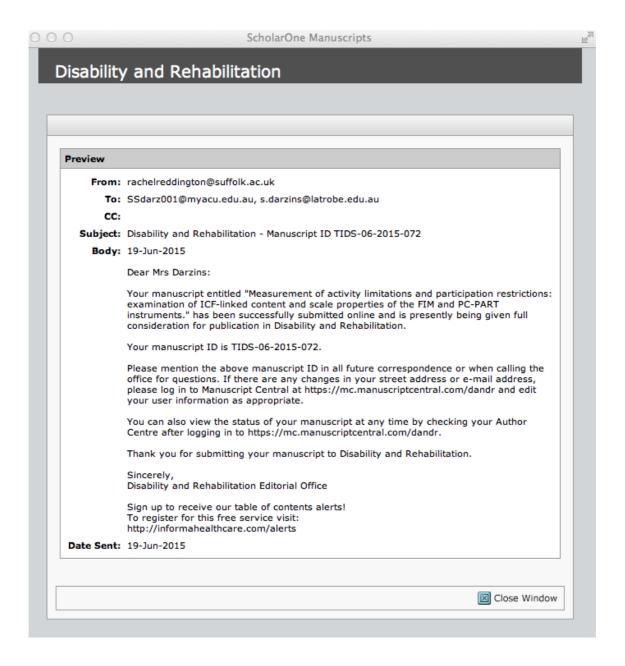
#### Evidence of manuscript submission and peer review.

Evidence of manuscript submission is provided by way of communication from each of the relevant journal editors for Papers 2 and 3. No evidence of submission is provided for published manuscripts (Papers 1, 4 and 5). Evidence of peer-review for each mansucript was obtained through the Ulrichsweb website (<a href="www.ulrichsweb.serialssolutions.com">www.ulrichsweb.serialssolutions.com</a>), which is an internationally known and authoritative repository of detailed information about periodicals. This website was accessed through a portal from the Australian Catholic University library.

#### Evidence of peer review of Papers 1 and 2



#### Evidence of submission of Paper 2.



#### Evidence of submission of paper 3.

From: onbehalfof+cjotassistant+caot.ca@manuscriptcentral.com on behalf of cjotassistant@caot.ca

To: Susan Darzins

Subject: Canadian Journal of Occupational Therapy / La Revue canadienne d'ergothérapie - Manuscript ID / Code

d'identification du manuscrit

**Date:** Saturday, 25 July 2015 3:11:35 PM

25-Jul-2015

Dear Ms Darzins

Your manuscript titled "PERSONAL CARE PARTICIPATION ASSESSMENT AND RESOURCE TOOL: CLINICAL UTILITY FOR INPATIENT REHABILITATION" has been successfully submitted online and is presently being given full consideration for publication in Canadian Journal of Occupational Therapy.

Your manuscript ID is CJOT-15-0068.

Please mention the above manuscript ID in all future correspondence or when calling the office for questions. If there are any changes in your street address or e-mail address, please log in to ScholarOne Manuscripts at <a href="https://mc.manuscriptcentral.com/cjot">https://mc.manuscriptcentral.com/cjot</a> and edit your user information as appropriate.

You can also view the status of your manuscript at any time by checking your Author Centre after logging in to <a href="https://mc.manuscriptcentral.com/cjot">https://mc.manuscriptcentral.com/cjot</a>.

Thank you for submitting your manuscript to Canadian Journal of Occupational Therapy.

Sincerely,

Canadian Journal of Occupational Therapy Editorial Office

\*\*\*\*\*\*\*\*\*\*\*\*\*\*

Madame/Monsieur,

Votre manuscrit intitulé << PERSONAL CARE PARTICIPATION ASSESSMENT AND RESOURCE TOOL: CLINICAL UTILITY FOR INPATIENT REHABILITATION >> a été soumis en ligne avec succès et il est actuellement évalué en vue d'une éventuelle publication dans la Revue canadienne d'ergothérapie.

Le code d'identification de votre manuscrit est CJOT-15-0068.

Veuillez inscrire le code d'identification de votre manuscrit ci-dessus dans toute correspondance future ou veuillez mentionner le code lorsque vous appelez au bureau pour poser des questions. Pour apporter des changements à votre adresse postale ou à votre adresse de courriel, veuillez vous connecter à ScholarOne Manuscripts, au <a href="https://mc.manuscriptcentral.com/cjot">https://mc.manuscriptcentral.com/cjot</a> et modifier vos coordonnées personnelles, selon le cas.

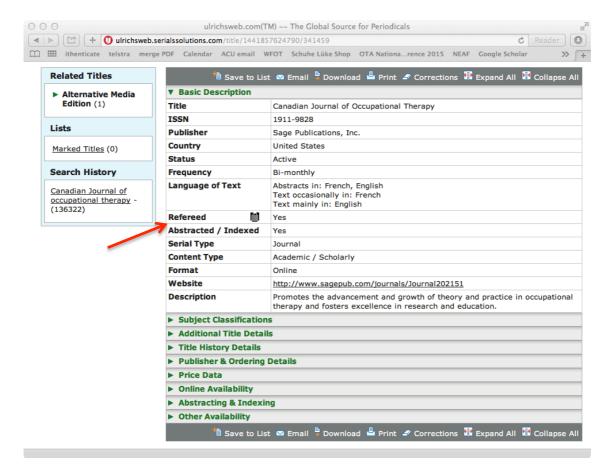
Vous pouvez également connaître l'état d'avancement de votre manuscrit en tout temps, en vérifiant votre 'Author Centre', en vous connectant au <a href="https://mc.manuscriptcentral.com/cjot">https://mc.manuscriptcentral.com/cjot</a>.

Nous vous remercions d'avoir soumis votre manuscrit à la Revue canadienne d'ergothérapie.

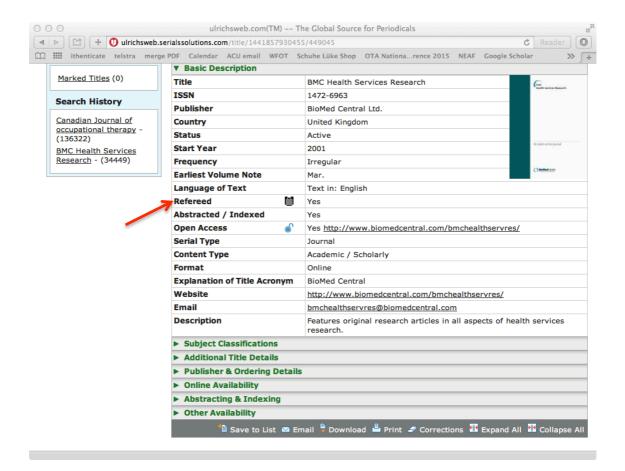
Cordialement,

Bureau de la rédaction de la Revue canadienne d'ergothérapie

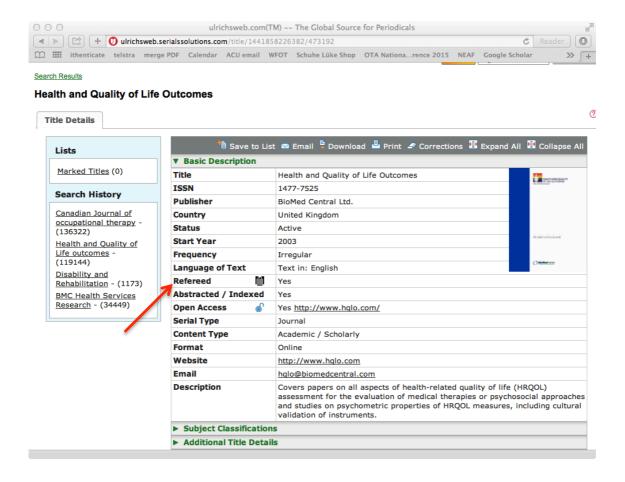
#### Evidence of peer review of Paper 3.



#### Evidence of peer review of Paper 4.



#### Evidence of peer review of Paper 5.



#### **Appendix I. Additional Permission to Use Published Works**

#### Permission to include Paper 1 in this thesis

Reply Reply All Forward

# RE: Permission to include paper in PhD thesis and to receive a clean version for the thesis

#### Hunter, Dawn [Dawn.Hunter@informa.com]

To: Susan Darzins [ssdarz001@myacu.edu.au]

Cc: Avey, Neshla [Neshla.Avey@informa.com]; davemuller@suffolk.ac.uk

Thursday, 17 April 2014 9:51 PM

Dear Susan

We grant you permission to publish your paper as part of your thesis.

Neshla, please could you send Susan a clean PDF copy of the article?

Kind regards

Dawn

----Original Message----

From: Susan Darzins [mailto:ssdarz001@myacu.edu.au]

Sent: 17 April 2014 06:42

To: Dave Muller; Neshla.Avey@informa.com

Cc: Susan Darzins

Subject: Permission to include paper in PhD thesis and to receive a clean version for the thesis

Dear Professor Muller and Neshla Avey,

I am preparing my doctoral thesis by publication and seek permission to insert my published paper from 'Disability & Rehabilitation' into the thesis.

If possible, I would be very pleased to receive a clean PDF of the paper without the watermark on the first page, solely for this purpose. This paper will form one of my thesis chapters and I would like the examiner to read a clean first page.

The paper is as follows:

Darzins, S; Imms, C; Di Stefano, M. (2013). Measurement properties of the Personal Care Participation Assessment and Resource Tool: a systematic review, Disability & Rehabilitation, 35(4):265-281.

I look forward to hearing from you.

Kind Regards Susan

Susan Darzins PhD Candidate School of Allied Health

.

#### Appendix J. Additional Publication Relevant to This Doctoral Research.

Prodinger, B., **Darzins, S**, Magasi, S., Baptiste, S (in press). The International Classification of Functioning, Disability and Health (ICF): Opportunities and challenges to the use of ICF for occupational therapy, *World Federation of Occupational Therapists Bulletin*.

#### Research paper

# The International Classification of Functioning, Disability and Health (ICF): Opportunities and Challenges to the Use of ICF for Occupational Therapy

#### Birgit Prodinger<sup>1,2,3</sup>, Susan Darzins<sup>4</sup>, Susan Magasi<sup>5</sup>, Sue Baptiste<sup>6</sup>

<sup>1</sup>Swiss Paraplegic Research, Switzerland, <sup>2</sup>Department of Health Sciences and Health Policy, University of Lucerne, Switzerland, <sup>3</sup>ICF Research Branch, a cooperation partner within the WHO Collaborating Centre for the Family of International Classifications in Germany (at DIMDI), Germany, <sup>4</sup>School of Allied Health, Australian Catholic University, Melbourne, Australia, <sup>5</sup>Department of Occupational Therapy, University of Illinois at Chicago, USA, <sup>6</sup>School of Rehabilitation Sciences, McMaster University, Canada

The occupational therapy community has been receptive to the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) published in 2001. Building upon results of a survey (2008–2009) and subsequent workshop (2010) conducted by the World Federation of Occupational Therapists on the use and utility of the ICF for occupational therapists, this paper addresses some of the opportunities and challenges to strengthening the use of the ICF in occupational therapy practice. Attaining further clarity on the relationship of occupational therapy concepts and the ICF and developing crosswalk tables to exemplify linkages between occupational therapy terminology and the ICF will strengthen utility of the ICF for occupational therapy. Enhanced clarity about the concepts within occupational therapy that correspond to the ICF will ultimately assist other professions and disciplines in their understanding about occupational therapy and occupational therapists' roles in health and related systems.

 $\textbf{Keywords:} \ \textbf{ICF,} \ \textbf{Occupational therapy,} \ \textbf{Standardisation,} \ \textbf{Health care terminology,} \ \textbf{Rehabilitation,} \ \textbf{Semantic interoperability} \ \textbf{Standardisation,} \ \textbf{Semantic interoperability} \ \textbf{Sema$ 

#### Introduction

In 2001, the World Health Organisation (WHO) released the International Classification of Functioning, Disability and Health (ICF) as a unified taxonomy providing a standard language for describing people's states of health (WHO, 2001). Complementary to the WHO's 1948 aspirational definition of health as complete physical, mental and social well-being, the ICF provides an operational definition of health as functioning (Salomon et al., 2003). Functioning, as defined in the ICF, is an umbrella term referring to the interaction of aspects related to functions and related structures of the body, what a person does in daily life, and its interaction with a health condition and contextual factors. The interrelation between ICF components is central to embracing an understanding of health

and disability within the context of a health condition. Disability, as defined in the ICF, is an umbrella term for the interaction of impairments occurring at the level of body functions and structures, limitations in activities, and restrictions in participation or involvement in life situations (WHO, 2001). The ICF addresses 'an individual's body, the things that a person does, and the person's functioning in society' (Badley, 2008, p. 2336). Hence, disability becomes an interactive and multidimensional process rather than linear and unidirectional caused by a particular health condition (Stucki, 2005). Through the ICF, the WHO introduced a paradigm shift in how disability is conceptualised, and at the same time, released a classification based upon this understanding to describe relevant aspects of health and its determinants and be used for standardised reporting of information about health and disability in clinical practice and research.

Correspondence to: Birgit Prodinger, Swiss Paraplegic Research Nottwil, Switzerland. Email: birgit.prodinger@paraplegie.ch

Classifications that reflect the complexity and multidimensionality of health, such as the ICF, are particularly valuable, as Hollenweger (2013) states:

classifications and their application organise thinking and action (...) by providing structure and definitions for entities and clarifying the relationship between them, classifications allow us to make our knowledge explicit, breaking it down into well-organised pieces of information that can be encoded, recorded, and shared with others (Hollenweger, 2013, p. 1087).

The ICF may serve as a coordinating tool, bridging disparate information across time, place and persons, toward more efficient and transparent healthcare (Üstün, Chatterji, & Kostanjsek, 2004). The value of standardised language and classification systems is the possibility to integrate and aggregate information linked to the same ICF categories and to compare this information across individuals, settings and countries. As information about people's functioning becomes available in administrative databases within the health and its related systems, a comprehensive picture of people's health states may be available for planning and allocation of services and interventions, including occupational therapy services.

Principles underlying the ICF and its integrative model are well aligned with basic assumptions and perspectives of the occupational therapy profession. The World Federation of Occupational Therapists (WFOT) refers to occupational therapy as a clientcentred profession that is concerned about the promotion of health and well-being through occupation (WFOT, 2010c). The primary goal of occupational therapy is to enable individuals to participate in activities of their everyday lives which they want, need, or are expected to do given their social and cultural context (WFOT, 2010a). The profession of occupational therapy is committed to contributing to an inclusive society in which all individuals are able to benefit from equitable opportunities to participate in daily life and citizenship (WFOT, 2010b). The ICF moves beyond being a classification of health conditions, to include important domains of concern for occupational therapy, including activities, participation and environmental factors (Stamm, 2009). Variants of these domains are central to many occupational therapy practice models. The terminology incorporates occupational therapy language because the occupational therapy community was involved throughout the development of the ICF.

An international survey conducted in 2008–2009 by the WFOT to examine the use and utility of the ICF in occupational therapy practice, education and research concluded that the majority of OTs are not using the ICF (70% of occupational therapists in clinical practice, 86% in research, 95% in management and administration, as well as in education). Those using the ICF indicated that they mainly used the biopsychosocial model of health and disability which formed the basis of the ICF rather than the ICF classification itself. Similar to the findings of the survey and the workshop, the current body of literature examining the ICF and occupational therapy points to a positive position of occupational therapists toward the ICF and yet also some caution about its use (Haglund, 2008; Hemmingsson & Jonsson, 2005; Pettersson, Pettersson, & Frisk, 2011).

A review of interdisciplinary research and practice identifies similarly mixed findings. On one hand, the promises of the ICF for strengthening interdisciplinary and multi-sectorial practice, service provision, and research are emphasised (Stucki, 2005). Wiegand, Belting, Fekete, Gutenbrunner, and Reinhardt (2012) argued, based on a systematic review and semantic network analysis, that the conceptual model informing the ICF has been widely accepted by health professionals and taken up conceptually while its actual implementation as standard for describing functioning remains idiosyncratic. Such discussions reflect the strengths of the ICF, namely that it builds upon an integrative model and provides a universal classification to describe health, while also highlighting the need for greater guidance on how to implement the ICF and operationalise its concepts effectively in practice.

This paper aims to identify opportunities and challenges to strengthening implementation of the ICF in occupational therapy practice. We refer to some examples of strategies identified in the workshop in 2010, and implemented, to demonstrate the progress made since then. We also point to remaining challenges in implementing the ICF as a conceptual model and classification into occupational therapy and some opportunities that arise from these challenges.

# Opportunity 1: Integrating the ICF into the education of the next generations' of occupational therapists

The WFOT added the ICF to the Minimum Standards for Educational Programs in Occupational Therapy (MSEOT) at its council meeting in 2014 based on a recommendation specified by occupational therapists at the WFOT Congress in 2010 in Chile to foster the use of the ICF (Stewart *et al.*, 2013). This action indicates a clear commitment by WFOT to strengthen the implementation of the ICF in occupational therapy education, and ultimately practice and research. This calls for greater attention to development of guidance on how to efficiently implement the ICF in occupational therapy practice and how to embed this guidance into occupational therapy education.

# Opportunity 2: Ensuring publicly available teaching materials on the ICF

The WFOT survey and subsequent workshop identified occupational therapists' lack of awareness of the ICF. This was grounded also in a lack of existing publicly available teaching materials. It was proposed in the WFOT workshop in 2010 that such materials would ideally include information about the ICF and case studies to better convey the use of the ICF. The WHO has developed an ICF eLearning tool (WHO, 2015) with basic and advanced modules to learn about the ICF and its use in practice. Furthermore, Swiss Paraplegic Research has developed in collaboration with partners, such as WHO, the International Society of Physical and Rehabilitation Medicine (ISPRM), the International Spinal Cord Society (ISCOS), the World Confederation of Physical Therapy (WCPT), and WFOT a series of case studies to demonstrate the use of ICF-based tools to guide the rehabilitation management process (Swiss Paraplegic Research, 2015). All these materials are freely available.

The development of teaching materials and relevant ICF-based tools to enhance the awareness and practicability of the ICF should be an international and interdisciplinary approach. Various national international professional bodies, such as the American Speech Language Hearing Association (Threats, 2002) and the American Physical Therapy Association, have endorsed the conceptual underpinnings of the ICF into their practice frameworks. The American Psychology Association is developing a 'Procedural Manual and Guide for a Standardized Application of the ICF' (Reed et al., 2005), and the ISPRM has a special sub-committee entitled Implementation of ICF within its ISPRM-WHO Liaison Committee. Therefore, there is the great opportunity to share materials and experiences, and learn from and with each other about the ICF, its implementation and utility as an international and interdisciplinary classification, and how this may be applied to occupational therapy practice contexts.

# Opportunity 3: Having minimum standards on systematic documentation based on the ICF The potential benefits of a standard classification system may be realised if users across diverse contexts adopt its concepts and terminology (Halamka et al., 2005). While standards foster universality, and in particular information standards enhance comparability, they rely on real-time use and localised processes, as well as existing institutional infrastructures that shape their use (Timmermans & Almeling, 2009). The numerous categories contained in the ICF assure that the complexity of different states of health can be classified, but may also be a barrier to widespread

implementation of the ICF, when used in this way. To assist the practical application of the ICF in practice and research, rigorously developed ICF Core Sets have been created for specific health conditions, condition groups, or health care contexts. ICF Core Sets are tailored sets of ICF categories that reflect the spectrum (comprehensive) or essence (brief) of people's experience of functioning given a particular health condition and were developed using a systematic, multi-stage process, integrating empirical and expert knowledge and obtaining international expert consensus (Selb *et al.*, 2014). These core sets can be customised for any given purpose by inserting additional categories from the ICF.

As ICF Core Sets are condition-specific, a minimum generic set of seven ICF categories, the ICF Generic Set, has been statistically derived. This Generic Set describes functioning across a general population and persons with various health conditions (Cieza, Oberhauser, Bickenbach, Chatterji, & Stucki, 2014). An extended version, the ICF Rehabilitation Set, complements the ICF Generic Set with 23 ICF categories. This provides a more detailed description of functioning, and is specifically suited to clinical populations from acute, early post-acute to long-term and community-based care (Prodinger, Bickenbach, Stucki, & Cieza, 2014). Defining a set of essential categories on which health data are collected at all levels, along with options for adding categories at each level to meet local needs, allows for flexibility within an information system and yet facilitates the implementation of minimum standards (Jacucci, Shaw, & Braa, 2006). Categories from the brief or comprehensive ICF Core Sets and from the full ICF may be added to the ICF Generic and Rehabilitation Sets to meet local needs. Such layering of information gathering within health information systems may assist in meeting local needs and requirements and may ultimately strengthen quality and comprehensiveness of health information more widely (Halamka et al., 2005). The ICF Generic and Rehabilitation Sets can also be seen as a response to the minimum standards called for by occupational therapists in 2010 on systematic documentation using the ICF to facilitate standardized reporting and recording in the administration and management of services.

Sets of ICF categories may be integrated into a documentation template to gain a profile of an individual's functioning, as a starting point for interdisciplinary team discussions to monitor the rehabilitation process, including assessment, goal setting, intervention and evaluation (Bickenbach, Cieza, Rauch, & Stucki, 2012; Rauch *et al.*, 2010). As these sets are limited to specifying relevant aspects for consideration in the interdisciplinary rehabilitation process, it is important to link profession-specific knowledge and

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expertise about appropriate and accurate assessment of these pre-defined aspects. For example, the ICF Rehabilitation Set contains the ICF categories d230 Carrying out daily routine, d660 Assisting others, and d920 Recreation and leisure. Occupational therapists have accumulated extensive knowledge on how to assess these aspects.

# Challenge 1: Using the ICF to make the scope and orientation of occupational therapy practice transparent

In spite of the potential benefits of the ICF, it can be a challenge to find a balance between sustaining profession-specific knowledge while accommodating this standardised language and classification system for information about people's health and disability. Clarifying occupational therapy's unique perspective and contribution, based on an interdisciplinary, commonly understood language, can facilitate communication with other disciplines and will ultimately assist other professions and disciplines in their understanding of occupational therapy and the occupational therapist's role in interdisciplinary teams. Integrating the ICF in occupational therapy documentation and reporting has the potential to make transparent the orientation of occupational therapy practice toward body functions and structures, activities and participation, and its interaction with contextual factors. For instance, in the context of child and youth rehabilitation, Cramm, Aiken, and Stewart (2012) indicated that the ICF's emphasis on 'areas such as leisure assessment and intervention become locatable within a global framework and serve to shore up occupational therapists' interest in enabling it' (p. 398). In the context of disability evaluation, Conti-Becker et al. (2007) used the ICF to analyse the Canadian Disability Tax Credit (DTC) system. They concluded that 'the DTC certification process neglects certain concepts critical for disability assessment. Occupational therapists are well positioned to take a leadership role towards refining and developing disability measures that reflect the ICF's comprehensive concept of disability' (pp. 286-87). These are but a few illustrative examples of how the ICF can facilitate a structured and transparent approach of what is at the core of occupational therapy.

# Challenge 2: Strengthening profession-specific knowledge while accommodating the strengths of the ICF

What is at the core of occupational therapy's professional knowledge base is properly most clearly articulated in occupational therapy practice models. Occupational therapy practice models assist in making transparent decisions about professional actions. More concretely, this means that aspects of

an individual, his or her context, plus professional knowledge are put into a structured framework to guide occupational therapy practice (Turpin & Iwama, 2011). Unlike conceptual models which foster an understanding of central constructs that are important to a profession or field of study, practice models (likely derived from a conceptual model) have a primary purpose of guiding professional assessment and intervention (McColl & Pranger, 1994). However, the ICF cannot replace occupational therapy practice models or frameworks. Therefore, a critical challenge for occupational therapists is to solve how to make best use of these synergies to enable communication of information that is important to occupational therapy practice within an interdisciplinary context.

Occupational therapy profession-specific concepts and domains of practice may go far beyond the ICF. For instance, not all aspects related to participation relevant to occupational therapy theory and practice can be subsumed within the ICF. A systematic literature review on the use of participation in occupational therapy literature by Vessby and Kjellberg (2010) revealed that occupational therapists refer to participation in three distinct ways; first, in the context of client-centeredness and the person-provider relationship; second, with a focus on the interaction of the individual with their physical, cultural, institutional and social environment; and third, with reference to people's involvement in activities they value and perceive meaningful. Only the second area overlaps with the ICF. These findings support the contention that an occupational therapy perspective extends the ICF's concept of participation to include the subjective perspective of people about their perceived involvement in valued life situations holding meaning for them. Similarly, Magasi et al. (2015) highlighted that the dynamic interaction of participation within and across diverse environmental factors are challenging to conceptualise within the ICF. Therefore, occupational therapy professional knowledge may provide a meaningful and complementary contribution to building a full and comprehensive picture of people's participation in life.

#### Challenge 3: Articulating the relationship between occupational therapy terminology and ICF terminology

To identify concepts contained in occupational therapy models and their derived instruments, and to allocate the corresponding index term in the ICF is of great value to occupational therapists. This type of linking may facilitate the co-existence of profession-specific concepts with concepts in other health care professions. However, concerns have been raised about the compatibility of occupational

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therapy models with the ICF (Stewart et al., 2013). Previous researchers have linked occupational therapy models (Stamm, Cieza, Machold, Smolen, & Stucki, 2006) and selected instruments derived from these models to the ICF (Haglund, 2008; Stamm, Cieza, Machold, Smolen, & Stucki, 2004) based on existing linking rules (Cieza et al., 2002, 2005). The results of such studies show both similarities and differences in how researchers linked concepts relevant to occupational therapy to the ICF. When linking meaningful concepts to ICF categories, it may be difficult to identify whether certain concepts highly relevant to occupational therapy are situated, for example, within the body functions or activities and participation component of the ICF. For instance, it has been argued by Stamm et al. (2004) that items from the Assessment of Motor and Process Skills (AMPS) describe underlying functions of an activity and were therefore linked to various body functions. In contrast, Fisher (2006) contended that the process skills detailed in the AMPS are more granular than activity and participation codes in the ICF and may serve as operational definitions for these codes. On a theoretical level, it is clear that functions of the body system, e.g. muscle contractions or joint movement, are body functions, and activities such as grasping a coin or bending to pick up something from the floor, are activities. It remains a challenge though in the linking process to specify whether such items as in the latter examples do assess the body function or the activity. Linking meaningful concepts to ICF categories is a process of abstraction and interpretation. Nevertheless, to enhance the transparency and credibility of the linking process and outcome, it is paramount to make explicit the interpretative frame of reference which includes the conceptual framework as well as the purpose for which an instrument was developed. Engaging in linking of existing models and instruments to the ICF may also assist in disentangling separate concepts within a particular piece of information. Accurate linking requires an in-depth understanding of the models, their entities and relationships and their associated assessment technology, as they stand alone, prior to their linking.

To foster transparency in the linking process, the linking rules (Cieza et al., 2002, 2005) may be complemented with international standards for indexing and cross-walking different terminologies and taxonomies (ISO, 2013). These standards pay attention to the examination of relationships between terms to ensure most accurate representation of any terminology in light of a designated reference classification. For instance, a term, such as occupation, is used in the ICF in the context of employment, whereas occupation in occupational therapy is understood to be more conceptually related to the ICF participation

domains. The term 'self-care' in the Canadian occupational performance pleasure (COPM) includes aspects related to getting ready for the day; it refers to personal care, functional mobility and community management (Law *et al.*, 2014). When linked to the ICF as a reference terminology, it becomes obvious that self-care is more narrowly defined in the ICF. There, it includes aspects of washing oneself, toileting, dressing, eating and drinking, as well as caring for one's body and looking after one's health. Though the same terms are used, their scope and meaning vary.

Another challenge in linking occupational therapy knowledge to the ICF is the understanding of roles in occupational therapy. Inhabiting and acting according to one's role implies 'the incorporation of a socially and/or personally defined status and a related cluster of attitudes and actions' (Kielhofner, 2002, p. 72). There is no agreement amongst occupational therapists on where roles sit in relation to the ICF. Piškur et al. (2013) proposed that participation as defined in the ICF can be described as the societal involvement defined by the engagement in socially defined roles. Others have argued that not all domains listed in the ICF can be assigned to a specific role. There are certain things people do that are not necessarily defined as actions related to a certain role (Coster & Khetani, 2008). Hence, gaining more clarity on the linked relationship of occupational therapy terminology and the ICF will enable occupational therapists to more clearly articulate the complementarities and distinct aspects of the meanings implied within occupational therapy terms in relation to the ICF.

Crosswalk tables could be generated to open up an understanding of pairs of terms that correspond to each other (ISO, 2013) and would illustrate the relationships between concepts contained in occupational therapy models and instruments with the ICF. Furthermore, such a detailed and comprehensive process would demonstrate that the ICF can be utilised by occupational therapists when appropriate and adequate, and at the same time may assure that profession-specific knowledge and terminology will sustain and reflect occupational therapy's distinct perspective and accumulated knowledge (Haglund & Henriksson, 2003). The proposed linking process may also reveal aspects of occupational therapy models and derived instruments that cannot be linked to the ICF but are highly relevant for occupational therapy practice. These tables can serve subsequently as the foundation for a documentation template which specifies the domains of occupational therapy knowledge that are interoperable with the ICF, as well as the domains that are profession-specific and essentially unique elements of an occupational therapy report. Such linking tables and documentation templates would be most valuable for occupational

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therapy educators, practitioners and researchers to strengthen the implementation of the ICF in routine practice by fostering profession-specific knowledge while accommodating the ICF as an international and interdisciplinary agreed-upon language.

#### Conclusion

Using the ICF, as an international standard for describing people's states of health serves a conceptual support to occupational therapy practice and could enhance transparency about the scope and orientation of occupational therapy practice. Much effort is still needed in occupational therapy practice, education and research to enhance the practicability of the ICF. Such efforts are ideally aligned with efforts of other health professions. The challenges and recommendation addressed in this paper provide ways of connecting professional scopes of knowledge and practice to international reference standards aimed at encompassing the essence of health care overall. Engaging in a systematic and transparent process to link occupational therapy knowledge and practice models to the ICF can highlight points of intersection and divergence between the two and make explicit the ways the occupational therapy knowledge extends and complements the ICF framework.

Given the knowledge and expertise that the field of occupational therapy has accumulated in describing the impact of health conditions on people's everyday lives, occupational therapists are well positioned to strengthen the utility of the ICF as a standard for conveying health and disability information.

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