UNIVERSITY OF SOUTHAMPTON

FACULTY OF HEALTH SCIENCES

Self-management following stroke. Concepts and measurement

by

Emma Joanne Boger

Thesis for the degree of Doctor of Philosophy

January 2014

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

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SELF-MANAGEMENT FOLLOWING STROKE. CONCEPTS AND MEASUREMENT

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Stroke is a major cause of disability world-wide, representing a significant health and social burden (Feigin et al., 2009). Self-management has potential importance for reducing the personal and health service impact of illness, but is yet to be fully understood or measured in stroke (Boger et al., 2013, Jones & Riazi, 2011).This research sought to develop a new patient-reported outcome measure (PROM) of self-management following stroke. A mixed methods paradigm with three distinct phases was adopted. Focus group methodology (n=28) first explored self-management from the perspectives of people following stroke and informed the content of a preliminary PROM. Three key themes identified from the data affect stroke self-management; *Individual capacity*; *Support for self-management* and *Self-management environment*. Following the focus group enquiry, the preliminary PROM item pool consisted of 57 items relating to *Individual Capacity.* Cognitive Interviewing methodology (n=11) was next employed to refine the item pool and explore acceptability of the items. Finally, the revised PROM was subject to psychometric evaluation using responses from a nationally derived sample (n=87). Mokken scale analysis and correlations with additional outcome measures of theoretical importance were used to identify scale structure and investigate reliability and validity. The subsequent PROM, the Stroke Self-Management Questionnaire (SSMQ) forms a unidimensional Mokken scale which measures the construct of self-management competency. The SSMQ possesses excellent internal consistency reliability (Mokken *r* 0.89), test retest reliability (ICC 0.928) and represents a valid tool for the evaluation of stroke self-management interventions.

Table of Contents

Correct to here

List of figures and tables

Figures

Tables

List of Appendices

Declaration of Authorship

I, Emma Joanne Boger, declare that this thesis titled, '*Self-management following stroke: concepts and measurement*' and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. **This work was done wholly or mainly while in candidature for a research degree at this University;**
2. **Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;**
3. **Where I have consulted the published work of others, this is always clearly attributed;**
4. **Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;**
5. **I have acknowledged all main sources of help;**
6. **Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;**
7. **Parts of this work have been published as: BOGER, E., DEMAIN, S. & LATTER, S. 2013. Self-management: A systematic review of outcome measures adopted in self-management interventions for stroke. Disabil Rehabil, 35, 1415-28**

Signed:

Date:

Acknowledgements

This research and the writing of this thesis would not have been possible without the support of several key people and organisations who I would now like to recognise.

Firstly, I would like to express my sincere thanks to my supervisory team, Dr Sara Demain, Professor Sue Latter and Dr Matthew Hankins. Over and above supplying guidance and the sharing of your academic expertise, you have provided inspiration and fostered a thirst for research. Thank you also for your always constructive feedback and support when things felt tough.

My special thanks go to the participants who graciously gave their time and without whom this research would not have been possible. In addition, thanks to the Stroke Association, Different Strokes and community stroke group organisers for your kind assistance with the focus groups. Thank you also to the user group at the South West Stroke Research Network for providing feedback on participant information sheets and for helping with recruitment.

In addition to the psychometric expertise of Dr Matthew Hankins, thanks to Dr Sean Ewings, Southampton Statistical Sciences Research Institute, for providing statistical support.

This research was supported by a full-time Faculty of Health Sciences studentship. I am very grateful for the opportunity to have pursued this programme of research, for the access to resources, for the accompanying research training offered, for funding to attend conferences and for the wider opportunities available in the university community.

Finally, and most important of all to me, thank you to my gorgeous boys, Phil, Ollie, Henry and Fred, who provided light relief and a much needed sense of perspective throughout.

List of Abbreviations

AISP	Automated item selection procedure
BI	Barthel Index
CI	Cognitive Interviewing
CTT	Classical Test Theory
DoH	UK Department of Health
ESD	Early Supported Discharge
FDA	US Department of Health and Human services Food & Drug Association
HCP	Health care professional
FG	Focus group
ICC	Item characteristic curve
ICC	Intraclass correlation coefficient
ISRF	Item step response function
IRF	Item response function
IRT	Item response theory
MHM	Monotone homogeneity model
MSA	Mokken scale analysis
NAO	UK National Audit Office
NHS	UK National Health Service
NICE	UK National Institute for Health and Care Excellence
PROM	Patient-reported outcome measure
RCT	Randomised controlled trial
SD	Standard Deviation
SIS	Stroke Impact Scale
SMI	Self-management Intervention
SPSS	Statistical package for the social sciences
SSEQ	Stroke self-efficacy questionnaire
SSMQ	Stroke self-management questionnaire

1. Chapter One – Introduction

This thesis outlines the process and findings of a programme of research which sought to develop a new patient-reported outcome measure to evaluate self-management following stroke. This introductory chapter describes the development and context of the overarching research question. Chapter two constitutes a critical review of the literature with respect to stroke self-management and provides justification for the programme of research. Chapters three, five and seven concern the methodology, research design, ethical approval, recruitment process, data collection and procedure for data analysis for the three phases of work. Results from the respective phases of research are presented in chapters four, six and eight. Chapter nine discusses the findings of the research and the implications for future measurement of self-management following stroke. Finally the direction and plans for future work are outlined in chapter ten.

1.1 Why study self-management and stroke?

My most recent clinical role as a condition management practitioner was characterised by the promotion of health and well-being for people with long-term health conditions, some of whom had experienced a stroke. The self-management strategies advocated by the service in which I practised were not designed with the specific needs of people following stroke and perhaps consequently were not always appropriate. For example, one of the areas promoted by the service was effective communication with healthcare professionals. For an individual with communication impairment, different challenges are presented which were not adequately addressed by the generic approach of the service. Questions also existed regarding how someone with physical, cognitive or social impairment as a consequence of stroke could be best enabled to pursue *self*-management. I therefore became interested in exploring self-management following stroke further.

In addition to clinical experience, and prior to commencing my doctoral studies, an interest in outcome measurement was driven following completion of a Masters level module in the Faculty of Health Sciences, University of Southampton. The prospect of combining both interests in self-management and measurement was a motivating factor in undertaking this programme of research.

Self-management is part of an ideological shift towards promoting increased patient responsibility for their health and well-being and an important contemporary issue. The direction of United Kingdom (UK) policy endorses both increased support for self-management (DoH, 2005a,b, 2008, 2010a) and the commissioning of services to support self-management (Imison et al., 2011, Richards, 2012). However, there are limitations with regard to how such services and interventions to promote self-management can be evaluated. The literature review chapter identifies an absence of a valid and reliable measure to evaluate stroke self-management. Moreover, determining the effectiveness of interventions which target stroke self-management may be hindered, in part, by a lack of appropriate outcome measures. This research sought to develop an outcome measure that validly and reliably measures stroke self-management, and which could inform clinicians, researchers and other stakeholders regarding the effectiveness of self-management interventions for stroke.

1.2 What to measure?

Chapter two explores the differing theoretical perspectives which support self-management, and reviews how self-management has been measured historically. Much of current evaluation focuses upon the recognition of change to behaviour, which may be attributable to a self-management intervention. The *Theory of planned behaviour* (Ajzen, 1985) proposes that peoples' attitudes subsequently modify their behaviour (Ajzen & Fishbein, 2005, Hardeman et al., 2002). Some evidence exists with regard to this perspective and self-management. Attitudes towards illness are thought to influence self-management in diabetes (Shigaki et al., 2010) and have been demonstrated as amenable to change via self-management interventions in asthma (Kaptein et al., 2010). Within stroke, interventions that modify attitudes may subsequently affect self-management behaviours, such as goal-setting and adopting relaxation strategies (Hirsche et al., 2011). It follows that, potentially, capturing attitudes towards self-management in a credible measure may extend the knowledge regarding self-management and stroke. Measuring self-management behaviours may help provide information relevant to symptom reduction and prevention strategies (Nour et al., 2006) as well as assisting the evaluation of interventions. Research was required to identify the relevant attitudes and behaviours which concern self-management following stroke.

The following sections outline the burden of stroke and the justification for studying self-management measurement in stroke.

1.3 The Problem of stroke

Stroke represents the third most prevalent cause of death in the UK, accounting for 53,000 deaths annually (Stroke Association, 2009). Approximately 110,000 people per year in the UK survive a stroke (National Audit Office, 2010). Stroke is a major cause of death and disability world-wide (Feigin et al., 2009). In the UK, 300,000 people live with a moderate to severe disability as a result of stroke (National Audit Office, 2010). National Health Service (NHS) annual expenditure on stroke-related direct care is approximately £3 billion, approximately 8% of health-service resources (National Audit Office, 2010). In addition to this cost, a further £8 billion is estimated lost due to disrupted productivity and informal-care costs (National Audit Office, 2010). Stroke therefore represents a significant health and socioeconomic burden.

The experience of stroke for those affected and for their family members, arguably represents the greatest impact of stroke. People recovering from stroke and their informal carers, often family members, are more likely to experience mood disturbances and depression (Skaner et al., 2007, Vickery et al., 2009, Whyte et al., 2004). Stroke may severely reduce health-related quality of life (Gargano & Reeves, 2007, Secrest & Zeller, 2007), for example, individuals following stroke report limitations in social participation (Pang et al., 2007, Rochette et al., 2007). In a large survey of North American people at increased risk of stroke (n=1261), approximately 45% reported preferring death to experiencing a major stroke (Samsa et al., 1998), suggestive of a perception that stroke devastates lives.

In the UK, mortality attributed to stroke has fallen over the last 25 years (Goldacre et al., 2008) largely due to effective prevention strategies. While improved survival rates represent important progress, increased emphasis is placed on the successful rehabilitation of those who survive. Some commentators predict that by 2020 stroke, together with coronary-artery disease, will be the leading cause of lost healthy life-years globally (Mukherjee & Patil, 2011). For the personal and socioeconomic costs of stroke to diminish, stroke rehabilitation and support for people recovering from stroke must deliver positive outcomes and be cost-efficient, not least in view of the current economic uncertainty.

1.3.1 What is a stroke?

'Stroke' is a result of damage to, or death of, brains cells deprived of oxygen as a result of interruption to the brain blood supply. A stroke occurs either due to ischaemia, caused by blood clots in the brain, or due to haemorrhage caused by bleeding into, or of, the brain circulation.

Stroke incidence increases with advancing age, with 75% of strokes affecting those over 65 years of age and is more prevalent in males (Bhatnagar et al., 2010). Hypertension is acknowledged as a significant risk factor for stroke. In patients with hypertension, a linear relationship between elevation of blood pressure and stroke risk is observed (Asayama et al., 2005). Other risk factors for stroke include atrial fibrillation (Medi et al., 2010), tobacco smoking (Myint et al., 2006), diabetes (Junga et al., 2006), increased body mass index (Rundek & Sacco, 2008) and lower socioeconomic status (Hajat et al., 2001).

1.3.2 Symptoms of stroke

Symptoms depend on the severity and location of the stroke. A recent NHS campaign to raise public stroke awareness identified facial weakness, arm weakness and slurred speech as being indicative of possible stroke (NHS Choices, 2010). Other possible symptoms of stroke include deterioration in sensory function, continence, gross and fine motor skills, and cognition (Wiebers et al., 2006). Injury to the brain as a result of stroke may be restricted by early diagnosis and treatment, which focuses upon restoring the interrupted circulation (Intercollegiate Stroke Working Party, 2012a).

1.3.3 Long-term effects of stroke

The extent and range of impairment as a result of stroke are dependent upon the degree and area of injury to the brain. People recovering from stroke may experience impairments to many facets, including vision (Rowe et al., 2009), cognitive function (Kim et al., 2009), continence (Wilson et al., 2008), muscle function (Mirbagheri et al., 2008), mood (Whyte et al., 2004), communication (Darrigrand et al., 2010), swallowing (Martino et al., 2005) and pain (Appelros, 2006). The extent and degree of symptoms experienced following stroke is variable and may fluctuate. The most significant improvements in recovery are often observed in the initial stages following stroke, with therapy being most intensive within this time frame, after which recovery is often considered to ‘plateau’ (Duncan et al., 2003a, Kalra & Langhorne, 2007). However, some evidence suggests that inadequate measurement of recovery, limitations within healthcare systems, practitioner beliefs and individual patient differences, rather than an *absence* of late recovery contribute to the concept of plateau (Demain et al., 2006, Horgan et al., 2009). Robust measurement which allows for these considerations is of paramount importance if rehabilitation and therapy is to be targeted and effective.

1.3.4 Policy context

Several UK policies and initiatives are relevant to the context of this research. The white paper *Saving Lives: Our healthier nation* highlighted the challenge of managing long-term conditions, estimating that a third of people in the UK live with a long-term health condition (DoH, 1999). The *NHS Improvement Plan* outlined a notion for the NHS as a resource, for people to look after themselves (DoH, 2004), indicative of a shifting emphasis towards increased patient responsibility. Recognition of the need to develop services appropriate for individuals with long-term health conditions, including stroke was outlined in *Supporting people with long-term conditions* (DoH, 2005b). More recently, *The Operating Framework for the NHS in England 2012-13*, set out the business and planning arrangements for the NHS (DoH, 2011) against which the newly formed NHS Commissioning Board will be held to account. The importance of providing high quality services is emphasised through five key domains, the second of which is long term conditions. From April 2013, one of three key indicators used to track progress in improving the quality of life for people with long term conditions, is the proportion that feel supported to manage their condition. Within the revised commissioning climate, self-management has become an increased priority (Imison et al., 2011, Richards, 2012).

Chapter three of *The National Stroke Strategy* (DoH, 2007a) recognises the importance of self-management advocating that '*careful planning of the support systems required to enable people with stroke to participate in managing their own care*' (p.39) is required. However, a simultaneous review for the department of health regarding the effectiveness of self-management support, identified only two studies (of almost 400) which pertained specifically to stroke (DoH, 2007b), suggesting that the evidence lags behind the direction of policy. Subsequent White Papers outline a future health policy that intends to make health and social services more responsive to patients' and users' needs, choices and preferences and places emphasis upon patient choice (DoH, 2006, 2010a, b).

The self-management movement has perhaps been compelled by the notion of reducing associated health and social costs (Wanless, 2002) but also in response to demand from patients to become more involved in healthcare (Canter, 2001, Corser & Dontje, 2011). Self-management can be viewed as an approach to managing the increased demand on health and social care resources (Bodenheimer et al., 2002a, DoH, 2005a). As such the direction of policy advocates an increased role for self-management in managing the demands of a 21st century health system. The evidence which supports the drive for self-managment is explored in Chapter Two.

1.4 Researcher Perspective

In order for the reader to understand and critique the foundations of this research, it is necessary to consider the background of the researcher. Before the commencement of a Faculty of Health Sciences post-graduate research studentship in September 2010, I practiced as a registered nurse. My role involved working with adults who were not working due to poor health, to improve their health status and experience of having a long-term condition. This involved promoting health and knowledge to reduce acute episodes, manage symptoms and facilitating integration back to productivity and society. The overwhelming majority of condition and symptom management were undertaken by those living with the health condition, occurring outside the direct involvement of health professionals and could be considered self-management. However, despite recognising the importance of effective self-management and considering myself experienced at promoting it, self-management was difficult to comprehensively define and conceptualise.

Seemingly, ‘self-management’ may appear a relatively simple concept, referring to the management of a health condition by an individual. However, when the different approaches individuals take to living with a health condition are considered, ‘self-management’ becomes much more complicated to define. For example, behaviours, such as smoking, which health professionals would not conventionally consider to be positive self-management, may in fact be a way for the individual to cope with having a long-term condition. Variations in the experience of living with a long-term condition are likely to be influenced by different belief and value systems and different cultures.

The biopsychosocial model was advocated as an underpinning framework in my clinical service, and was used as a framework to remind practitioners how health can be experienced differently, and to guide clinical strategies to help people best support their self-management. The model supposes that biological, psychological and social factors are all contributory to the experience of living with a long-term condition and not separate entities (Engel, 1980). For example, individual experience of post-stroke pain is affected by sensory and cognitive perceptions (Gamble et al., 2000) and may be influenced by how confident the person feels at pursuing a treatment regime (Widar et al., 2004), notwithstanding the influence of care-givers perception of pain (Hung et al., 2007).

Clinical supervision sessions, suggested that my difficulty in defining self-management was shared by colleagues within my service. A lack of consensus existed regarding the processes in our service that affected successful self-management. Some practitioners felt that positive change occurred due to enhanced self-efficacy, or by enhancing mood, others felt it was having individualised support and some felt change was motivated by financial incentives. Uncertainty also existed regarding how best to demonstrate the service's effectiveness through measurement. Outcome measures that had been historically used in other services were adopted. Little attention to the constructs they purported to capture, or how they reflected the theoretical basis of the service was given. My view was that the lack of consensus regarding the theoretical underpinnings and lack of conceptualisation of self-management contributed to these problematic issues.

1.5 Existing stroke provision

Stroke is an acute event, but due to the associated long-term impairments and disabilities, can be viewed as a long-term condition. In the acute phase of stroke, expedient admission and treatment in a specialised stroke unit is advocated, resulting in better mortality rates and recovery outcomes (Intercollegiate Stroke Working Party, 2012a). Stroke units aim to provide organised, specialised care by healthcare professionals with specialised knowledge in stroke and are thought to promote better recovery outcomes than general medical wards (Kalra & Walker, 2009, Seenan et al., 2007). In the recent national stroke sentinel audit, 95% of patients were treated in a designated stroke unit (Royal College of Physicians, 2012).

1.5.1 Stroke Rehabilitation

Rehabilitation can be regarded as the planning towards regaining optimal functioning across the domains of impairment, activity and participation (WHO, 2001). What follows is a brief overview of current stroke rehabilitation provision in England.

Stroke rehabilitation is typically provided by specialised in-patient units or community rehabilitation teams (DoH, 2007a). Stroke units increase the likelihood of independence at one year (Cochrane stroke group, 2005). However, in-patient care has been estimated to account for 70% of all stroke related care costs (Caro et al., 2000), resulting in new approaches to rehabilitation being sought. Early Supported Discharge (ESD) aims to provide specialised rehabilitation and care in the patients' home, once they are medically stable (Langhorne & Widen-Holmqvist, 2007). In comparison to stroke unit care, ESD rehabilitation has been reported as reducing disability after six months (Larsen et al., 2006) and long-term dependency (Anderson et al., 2002; Langhorne et al., 2005) therefore reducing cost.

ESD is thought to be more beneficial for patients. A meta-analysis of randomised controlled trials demonstrated a lower rate of death, greater independence and reduced long-term care needs using an ESD model (Langhorne et al., 2005). However, benefits were predominantly observed in physical functioning measures, with minimal differences found in subjective health status, mood or activities of daily living, suggesting that ESD may not fully address the psychosocial needs of people recovering from stroke and their families, or conversely, that psychosocial issues were not outcome priorities.

1.5.2 Limitations with existing stroke rehabilitation models

Currently, how the optimum type and duration of rehabilitation is determined remains ambiguous. Current clinical stroke guidelines recommend 45 minutes per therapy per day '*at a level that enables them to meet their rehabilitation goals for as long as they are continuing to benefit..and are able to tolerate it'* (Intercollegiate Stroke Working Party, 2012a) (p.56). This suggests that rehabilitation could potentially be unlimited and lacks a clear definition of ‘benefit’ or ‘tolerate’, nor recommends how this goal might be implemented. In practice rehabilitation is limited, with many clinical areas imposing time limits on rehabilitation (NHS Improvement, 2011) suggestive of a conflict between practice and guidance. Moreover, resources across localities vary, creating an inequality of provision, with a significant proportion of primary care trusts (33%) offering generic rehabilitation services as opposed to designated specialised stroke services (Care Quality Commission, 2011).

A disconnect regarding the aims of stroke rehabilitation also appears to exist. Commentators highlight that rehabilitation should extend beyond a focus on physical and functional recovery, to encompass psychosocial recovery such as reduction in distress, improved life satisfaction and quality of life (Cameron, 2010, Geyh et al., 2007). Stroke represents a sudden disruption of life where survivors may experience the loss of physical function, social networks and activities, independence and self-identity (Ellis-Hill et al., 2008, Sabari et al., 2000). The importance of psychosocial recovery to people recovering from stroke and their families has been highlighted (Carlsson et al., 2009, Greenwood & Mackenzie, 2010, Mukherjee et al., 2006, Salter et al., 2008). However, rehabilitation in the UK appears to focus on the recovery of functional ability (Care Quality Commission, 2011, Kalra & Langhorne, 2007), with psychosocial recovery often regarded as a secondary consequence of restored physical function. That restoration of physical functioning automatically leads to better psychosocial functioning has been disputed (Baseman et al., 2010, Cott et al., 2007). Therefore, rehabilitation adopting a holistic approach, may best serve those recovering from stroke.

The process of rehabilitation may inadvertently be detrimental to recovery and future self-management. Hospital stays, including stroke and rehabilitation units, may foster dependent relationships and social isolation, promote immobility and increase the risk of acquired hospital infection (Brewer & Williams, 2010, Graves et al., 2007). Inpatient units may not encourage people recovering from stroke to regain control. An observation study of five Australian stroke units revealed that patients (n=58) engaged in moderate or high therapeutic activities for 12.8% of the therapeutic day, being alone for 60.4% of the time (Bernhardt et al., 2004). Patients spent more than half their time resting in bed, despite an absence of a clinical reason to do so. In the UK, 12% of stroke units were identified as not mobilising patients prior to them being seen by a physiotherapist (Royal College Physicians, 2012), due to insufficient training of ward staff. How this apparent disregard for patient independence adequately prepares people to effectively manage their condition upon discharge is unclear. Hospital environments may also disempower patients. The patient role ascribes powerlessness, helplessness and reduced decision making, where free choice over basic daily activities of living is limited (Ogden, 2007). Early Supported Discharge (ESD) services are thought, in part, to assist individuals recovering from stroke by providing therapy in a familiar environment and enabling them to make more relevant rehabilitation goals (Ivey & Mew, 2010). However, limitations exist with the ESD model.

ESD is not available to all, being primarily aimed at those who experience mild-moderate stroke (Langhorne et al., 2005). In addition, ESD is limited by geographical location, accessible to 66% of NHS trusts in 2012 (Royal College Physicians, 2012). A review of the ESD model suggested that the impact upon family members needs further understanding (Brewer & Williams, 2010). An Australian study of stroke patients randomised to either ESD or conventional care (n=86) suggested that ESD was associated with increased carer burden (Anderson et al., 2000). Conversely, a RCT of stroke ESD versus conventional care (n=114) conducted in the USA, revealed no difference in carer burden (Teng et al., 2003). However, the study by Teng and colleagues excluded those who required assistance with walking or had cognition problems, suggesting a relatively high-functioning cohort, perhaps unrepresentative of a typical stroke population.

ESD has been associated with negative carer experience in models for chronic respiratory patients (Clarke et al., 2010). ESD was perceived by carers as a method of unburdening hospitals and healthcare professionals rather than a way of improving care. Similar studies which explore the carer experience of stroke ESD models have yet to be conducted. Patients are required to be medically stable prior to being considered for ESD, often indicative of those with better long-term recovery prospects, or with less disabling effects from stroke (Hackett et al., 2002). ESD is therefore unsuitable for all stroke patients, raising ethical issues about the division and use of resources and potential creation of health inequalities. The effect of hospital stays, ESD or rehabilitation on patient autonomy may be crucial in influencing how patients manage once discharged from services.

1.6 Chapter summary

This chapter has outlined my interest and rationale for examining self-management measurement in stroke. Self-management is a contemporary issue and is a focus within the direction of health policy. My clinical experience identified questions regarding how self-management is carried out by individuals who have experienced a stroke and how self-management is measured to evaluate a service. Current rehabilitation provision varies across the UK and may not be optimal at promoting effective recovery and self-management in individuals. How self-management is currently promoted and operates in stroke care requires further examination. Chapter two presents a critical review of the literature to assemble the current state of evidence relating to self-management and stroke and support for the research purpose.

2. Chapter Two - Critical review of the self-management literature

2.1 Introduction

This chapter explores the concept of self-management and examines the evidence in support of its role following stroke, including how self-management following stroke is currently measured. Sections 2.2 to 2.5 provide an overview of self-management theory and the evidence base with regard to long-term conditions. Section 2.6 provides an overview of the approach to searching the literature with regard to stroke self-management, before presenting the evidence in support of stroke self-management in section 2.7. Section 2.8 introduces measurement theory and identifies how self-management is currently measured, both in relation to generic conditions and stroke. The chapter presents how the salient issues were identified, interpreted and contributed to the rationale in support of the research purpose.

2.2 Self-management

The terms *self-management* and *self-care* are often used synonymously in the literature. What follows is a brief overview of how the terms may differ in order to provide clarity for the reader and state my position.

2.2.1 Self-Care

The notion of self-care was perhaps first considered by Dorothea Orem, a prominent nursing theorist. She described self-care as a natural activity that could be '*modified by health state, environmental conditions, the effects of medical care and other factors'* (Orem, 1995 p.19). Orem's *Self-Care Deficit Theory* is based upon the assumption that all patients wish to care for themselves and that recovery will be quicker and more holistic, if they are allowed to perform self-care to the best of their ability (Orem, 2001). Orem viewed the role of the nurse as providing a self-care support strategy, where patients are unable to perform self-care. The theory is highly relevant to rehabilitation settings (Burks, 1999), however some critics question the emphasis on task performance within the theory, as opposed to autonomous decision-making (Glasson et al., 2006, Timmins & Horan, 2007).

Other interpretations of self-care have been presented in the literature. Sidani (2003) described self-care, as the '*practice of individuals to promote, maintain, or enhance health, prevent illness, detect and manage symptoms, and restore functioning'* (Sidani, 2003 p.67). More recently, self-care has been described as the '*activities that individuals, families, and communities undertake with the intention of protecting and enhancing health and preventing disease'* (Jonsdottir, 2013 p.622), indicating that the term may be used synonomously with self-management.

2.2.2 Self-management

Self-management appears to be embedded within the notion of self-care, and has been conceptualised as a component of self-care (Wilkinson & Whitehead, 2009). Self-management can refer to health promotion activities, as well as acute conditions, but is most often referred to in the literature with regard to managing long-term conditions. In contrast, *self-care* appears to be located within the experience of all, whereas *self-management* pertains to those with health conditions (Rijken et al., 2008).

Self-management is viewed as a philosophy which minimises the impact of a long-term health condition by '*managing the condition, its treatment and consequences'* (Jonsdottir, 2013 p.622). Similarly the developers of the Condition Management Program (section 2.6.1), view self-management as encompassing the '*active management by individuals of their treatment, symptoms, lifestyle, physical and psychological consequences inherent with living with a chronic condition*' (Lorig & Holman, 2003 p.2). In the UK 'self-management' is often applied to programmes that aim to teach people the skills required to follow treatment or management regimes and/or guide behaviour change, and/or provide emotional support for patients to control their health condition and live purposeful lives (De Silva, 2011). Self-management may involve monitoring and symptom management, but is more expansive encompassing the physical, emotional, psychosocial and functional consequences of living with a long-term condition (Richard & Shea, 2011).

Both *self-care* and *self-management* are viewed as less distinct entities within UK policy. The UK government views self-care as encompassing self-management (DoH, 2008). In publications relating to the strategy for the management of long-term conditions, the term self-care is adopted and refers to both self-care and self-management (DoH, 2006; 2008).

Arguably guidance for the meanings of the concepts of *self-care/self-management* should be sought from those actually affected by a health condition. An interview study investigating perceptions of self-management (n=27) concluded that those with the most effective self-management skills, as measured using the Patient Activation Measure (section 2.8.2.3) viewed self-management in terms of control and pro-activism. Those with the least effective self-management skills viewed it in terms of compliance (Dixon et al., 2009). Caution must therefore be applied before adopting the term *self-management* without acknowledging that its' meaning is dependent on individual context and situation.

I identify most with the term *self-management* since it relates more to the empowerment of patients. Since the terms are often used interchangeably in the literature, and may be context specific, both *self-care* and *self-management* have been included in relevant literature searches.

2.3 The social context of self-management

The notion of self-management appears to have, in part, become more prominent in response to a shift towards encouraging people to become more responsible for their health, and as a strategy for managing growing healthcare costs (DoH, 2005a, Wanless, 2002). The notion that 'good' health, is up to individuals alone can be evidenced in the literature:

'If you choose to be a positive self-manager and undergo all the best treatments that HCPs have to offer along with being proactive in your day-to-day management, this will lead you to live a healthy life'. (Lorig et al., 2006a p.1)

The direction of UK policy places emphasis on people to actively participate in managing their health for their benefit. Self-management may therefore be viewed as a matter of social responsibility. The core principles of self-care, point to '*individuals taking responsibility for their own health and well-being'* implying that individuals are obligated to engage in effective self-management (DoH, 2008) (p.7). However, some commentators argue that policy direction does not adequately acknowledge the experience of living with a long-term condition(s) (Taylor & Bury, 2007, Vassilev et al., 2011). An assumption by policy and other decision-makers that many people do not self-manage effectively perhaps exists. The extent and operation of existing self-management, in the absence of formalised self-management support, in many long-term conditions, including stroke remains uncertain.

An alternative argument exists which acknowledges the impact of the environment and wider society upon self-management. Some are critical that an emphaisis on people taking responsibility for their health ignores the social, cultural, economic and political influences on personal lives (Kendall & Rogers, 2007, Wilkinson & Whitehead, 2009). The ideal self-manager can be viewed as an active, autonomous, informed and rational health decision maker (Lorig et al., 2006a, McDonald et al., 2007). Inherent in this view is the assumption that the necessary environmental and social support exists. It does not acknowledge the marginalisation in society of vulnerable groups, such as those with mental health difficulties (King et al., 2007), poor health literacy (Protheroe et al., 2008) or those from economically disadvantaged groups or affected by disability (Davey Smith et al., 2002), where appropriate support and skills for self-management, along with fewer health chances and choices, may be limited. In such circumstances there is a risk that people are often blamed for their health problems (Bury & Pink, 2005).

Arguably, the state has a role to play in supporting self-management by influencing the operation and function of society and engagement of potentially marginalised groups through adequate policy directives. Partnership between the individual and the state could potentially augment successful self-management practices providing all stakeholders assume responsibility and implement their respective roles. One problem is that there is uncertainty with regard to what those roles and responsibilities may be. One issue relates to those individuals with a long-term health condition determined to 'live well' and who may resent being labelled or treated as disabled or chronically ill. From their perspectives, the self-management movement may represent nothing new, with the associated risk of new policy initiatives patronising or alienating those who have 'managed' with a long-term condition implicitly in the context of their lives. The term self-management may therefore be an anathema to such individuals. Furthermore, encouraging people to take responsibility for their health whilst ignoring the societal and environmental circumstances that contribute to health conditions may be considered immoral (Redman, 2007, Tones, 1997).

The sociological aspects of living with a long-term health condition have been well documented in the literature. The disguising or disclosing of symptoms, associated stigma and social exclusion and the overall impact of illness on relationships and life chances have been discussed (Bury 2001, Charmaz 2000, Kelly & Field, 1996). The influence of social environment on self-management in particular has also been debated in the literature. Successful self-management may be positively associated with social support and a positive social environment (Gallant, 2003) and appears to be negatively related to limited personal resources (Bayliss et al., 2007, Greenhalgh, 2009). The ability to adopt and maintain a health-orientated lifestyle, to self-monitor, and develop individual autonomy is seemingly more evident amongst people from higher socioeconomic groups, than lower socioeconomic groups (Guadagnoli et al., 1995, Lindsay, 2008, 2009, Protheroe et al., 2012).

Of particular relevance to stroke, increased risk of cardiovascular event has been associated with individuals from lower socioeconomic groups who appear more reluctant or less able to access care (Pincus et al., 1998) and possess lower health literacy than those with higher socioeconomic statuses (Hafsteinsdottir et al., 2010). The effect of social status may be further understood by considering how humans construct health and illness, according to the differing social and cultural norms of respective societies.

Medical sociologists suggest that health lifestyles involve a ‘habitus’ which varies according to social group (Cockerham, 2007). ‘Habitus’ refers to deeply rooted sets of dispositions (thought, behaviour, and preference) acquired through a social structure (Bourdieu, 1984). According to the Sociologist and Philosopher Pierre Bourdieu, possessing the character that allows for the natural expression of a particular lifestyle is a cultural resource (Bourdieu, 1984). Thus people and communities express their social class background (and other forms of social background) through their lifestyle and behaviour. The degree to which this is expressed is affected by an individuals’ ‘distance from necessity’ and may in part explain an apparent variation in self-management behaviour attributed to variation in socioeconomic status. Since stroke is more prevalent in individuals from disadvantaged socioeconomic groups (Hajat et al., 2001), this may be of particular relevance to how they engage in self-management.

2.4 Potential theoretical premises of self-management

The processes influencing successful self-management are potentially multifaceted. Meta-analyses of self-management interventions for adults with chronic disease, conclude that the mechanism(s) involved in generating the reported benefits remains uncertain (Chodosh et al., 2005, Weingarten et al., 2002), whilst a Cochrane review concluded similarly (Coster & Norman, 2009).

Despite the emerging social context of self-management, most interventions utilise psychological theories, focusing upon the individual (Greenhalgh, 2009). What follows is a brief overview of the prominent theories that may underpin successful self-management, with a focus upon the dominant theory of *self-efficacy*.

2.4.1 The Chronic care model

The Chronic Care Model (CCM) (Wagner, 1998; 1999) represents a theoretical framework developed in the United States that builds on the inter-relationships between six elements thought to lead to improved clinical quality; community, the health system, self-management support, delivery system design, decision support and clinical information systems. A systematic review of diabetes studies including a self-management component (n=20) concluded that the model improved an outcome or process of care (Bodenheimer et al., 2002b), although it is not clear from the review what these outcomes or processes were.

2.4.2 Perceived Control

Perceived control has been defined as '*the belief that one can determine one's own internal states and behaviour, influence one's environment, and/or bring about desired outcomes'* (Wallston et al., 1987 p.5). The work linking perceived control and health evolved from Rotter's construct of *locus of control,* from his adaptation of social learning theory (Rotter, 1966). Positive control cognitions have been found to predict physical recovery in a longitudinal cohort study (n=71), 6 months following stroke (Johnston et al., 1999). A more recent study (n=203) investigating control cognitions with regard to activity limitations following stroke, reported that perceived control correlated significantly with measures of self-efficacy (r =.74, p=<0.001) and locus of control (r=.37 p=<0.001) (Bonetti & Johnston, 2008). Linear regression modelling concluded that perceived control was the most effective predictor of individual-specific disability and recovery. Results should be viewed in light of the fact that details regarding validity and reliability of the measures utilised in the study are absent from the paper. Whilst perceived control may be important to maintaining physical activity and mobility following stroke, it is yet to be further explored with regard to stroke self-management.

2.4.3 Locus of Control

Locus (Latin for "place") was dichotomised by Rotter into *internal* and *external* (Rotter, 1966). A person with an internal locus of control is described as someone who believes that valued reinforcements (or outcomes) occur as a direct consequence of personal actions. An internal locus of control is equated with perceived personal control (Gross, 2010). An external locus of control signifies a belief that reinforcements or outcomes are the result of other people's behaviours or, are influenced by fate, luck, or chance. An external locus of control is typically thought to signify a lack of perceived personal control.

Whilst relinquishing control to health professionals may be viewed negatively within the move to promote self-management, this may not necessarily be indicative of someone with an external locus of control. Wallston (1987) posits that many patients believe that transferring control to a benevolent, competent health care provider is, in fact, a means of gaining control over health. A workbook intervention based on *Locus of Control Theory* (Rotter, 1966) and designed to enhance perceptions of control in patients (n=39) discharged from hospital following stroke adopted a measure of *Perceived Health Competence* (Frank et al., 2000). A negative association with functional limitations and perceptions of control was reported across both the control and intervention groups (r =-.41, p=<0.05); the authors concluded that improved control perceptions were associated with better physical recovery outcomes. It is unclear if the findings can be attributed to a greater sense of control, due to improved functional ability or that a greater sense of control promoted functional independence.

Some limitations exist in utilising locus of control theory to understand health behaviours. Measurement tools that capture control cognitions provide an indication of a persons' perceived control, but not of how that perception might be applied to facilitate a desired outcome (Wallston, 1989). For example, a person may believe that smoking influences their health, but unless they also believe they are capable of changing their behaviour, they may not perceive to have control over smoking or their health. Feeling responsible for an outcome is different to feeling in control of that outcome. Similarly, individuals who blame themselves for poor health, but who do not feel responsible for their good health, could score highly on a measure of internal health locus of control without feeling in control of their health. Using this theory to evaluate self-management behaviour and interventions is therefore potentially problematic.

2.4.4 The Transtheoretical model of change

The Transtheoretical Model (TTM) of behaviour change has been used to classify the different stages of motivational readiness to change (Prochaska et al., 1992). Using the TTM, individuals are classified into a series of five stages: precontemplation (PC), contemplation (C), preparation (PR), action (A), and maintenance (M). People progress through these stages at varying rates, often moving back and forth a number of times before attaining the goal of maintenance. As people progress, stage-specific strategies, decision-making, and self-efficacy are used to mediate behaviour change. The TTM stems from the work around addiction, but has been applied to numerous behaviours relevant to self-management such as increasing physical activity, weight control and diet (Sarkin et al., 2001), and medication adherence in long-term health conditions (Willey et al., 2000). More recently, the TTM has been used in diabetes (Vallis et al., 2003) and the measurement of arthritis self-management (Arthur et al., 2009).

2.4.5 Self-efficacy

Self-efficacy originates from the psychologist Albert Bandura's '*Social Cognitive Theory'* (Bandura (1989) and is defined as the individual belief to succeed in specific situations. Social Cognitive Theory holds the premise that people learn through two ways; direct experience and social modelling. Bandura believed social modelling to be most influential for human learning, since direct experience opportunities are in comparison limited. Bandura views people as contributors to their life circumstances, or '*agents of change*' and not just products of their circumstances (Bandura, 2011 p.34). In addition to being agents of change, individuals reflect on their own functioning, which is thought to be regulated by evaluative perceptions of costs and benefits, social approval and disapproval and positive and negative reactions (Bandura, 2011). Within self-efficacy theory, capacity for change may therefore be viewed as dependent upon the individual.

The recognition of self-efficacy theory as a potential mediator of behaviour change relevant to self-management is observed in clinical guidelines (NICE, 2007). In the USA, self-efficacy has been identified as one of twelve principles to support self-management in primary care settings (Battersby et al., 2010b). Self-efficacy is the theoretical premise to the Chronic Disease Self-Management Program (CDSMP) in the USA and the Expert Patients Programme (EPP) in the UK. An overview of these initiatives is provided in section 2.6.

Early studies of self-management interventions suggested a theoretical model, where the primary causal mechanism was a change in self-efficacy cognitions which led to secondary changes in self-care behaviour (Lenker et al., 1984, Lorig et al., 1985, 1989). This finding was contrary to an assumption that change in health-related behaviours would result in change to health status. Instead the authors found that changes to reported health status arose from a perception of being in control, despite health-related behaviours remaining largely unchanged. This in turn influenced healthcare utilisation, and reduced the use of resources. Self-efficacy thus became the main theoretical driver of the self-management movement.

Self-efficacy affects individual cognitive, motivational, emotional and decisional processes and shapes individual levels of optimism, pessimism, and vulnerability to stress and depression (Bandura, 2011). Bandura identified four modifiable aspects of self-efficacy, as follows:

1. physiological and affective states
2. verbal persuasion
3. vicarious experience
4. mastery experience

Bandura identified mastery experience as being the most powerful source of self-efficacy. With regard to stroke self-management, this may entail having the opportunity for an individual to ‘test’ themselves in action and is most commonly achieved through goal-setting and review of progress (Jones, 2006) and is often enhanced by breaking goals into smaller, less daunting tasks (van de Laar & van der Bijl, 2001). Vicarious experience may be facilitated through the use of lay-leaders as role-models, for example as in stroke support groups. Physiological and affective states, denotes the appraisal an individual gives to symptoms or feelings they experience to inform their efficacy beliefs. Verbal persuasion can be achieved through the appraisal made by others assuming it is directed in such a way as to enable the individual to interpret the experience of performing the skills as a success, and that goals are meaningful to the individual *not* the appraiser. In the context of self-management interventions these concepts are often appraised or facilitated by healthcare professionals, but might also include others who have experienced stroke and the input of informal carers and family members.

Goal-setting is a vital part of enhancing self-efficacy and by association self-management. Healthcare professionals are key to this process determining (often implicitly) goals that they believe to be in the interest of patients, or goals which are in the best interests of their service. However, critics point out that this runs the risk of disregarding people's experiences of living with health problems (Kielmann et al., 2010, Paterson et al., 2001). Goals which are not *truly* patient-focused run the risk of imposing specific conceptions of how people should live their lives, which may exclude or alienate some people (Lawn et al., 2011).

Further limitations may exist regarding the use of self-efficacy theory in self-management interventions. Self-efficacy theory locates the responsibility for change with the individual (Bandura, 2011). This directly contrasts with the perspective that societal influences are fundamental to successful self-management (Bury & Pink, 2005, Vassilev et al., 2011). Individuals that do not succeed at self-management may be view as somehow deficient if they lack the ability to appropriately function and achieve goals (Kendall & Rogers, 2007). Lower reported levels of self-efficacy, have been associated with those experiencing poorer outcomes following self-management interventions (Lorig et al., 2001), perhaps without sufficient explanation (Bury & Pink, 2005).

A review by Taylor and Bury (2007) concluded that lay-led interventions may have little, or no unique capacity, to promote increased self-efficacy and enhanced chronic illness self-management. Despite these misgivings, along with those highlighted in this section and coupled with the lack of consideration to societal influences upon self-management, the prominent model of chronic disease self-management continues to be based on self-efficacy theory.

The next section explores the evidence in support of self-management of long-term conditions.

2.5 Self-management of long-term conditions

The majority of existing knowledge regarding self-management interventions in chronic disease has been generated by the Stanford University Patient Research Center, led by Professor Kate Lorig. Through their work, Lorig and colleagues developed and implemented the Chronic Disease Self-Management Program (CDSMP), a generic lay-led program of eight week duration, aimed at people with long-term conditions (Lorig et al., 1999). The Expert Patients Programme (EPP) is an anglicised version of the CDSMP accessible to anyone with a long-term condition through self-referral, or referral by healthcare practitioner (DoH, 2001). Due to the prevalence and reported impact of both the CDSMP and the EPP, they are next further examined.

2.5.1 The Chronic Disease Self-Management Program

The CDSMP is an eight-week, peer-led, community based group self-management intervention which aims to help participants gain the skills necessary to manage fatigue, sleep and pain management, communication with others, decision-making, problem-solving, medication and dealing with emotion and fear (Lorig et al., 2013). The principal tenets of the CDSMP are, that through the remodelling of symptom interpretation, skills mastery and social persuasion, participants' self-efficacy increases.

Following a randomised trial (n=952), the CDSMP claimed success in reducing hospitalisations and length of stay for admissions at six months (Lorig et al., 1999) and improvements in self-efficacy, communication with physicians and cognitive symptom management at 12 months (n=489) (Lorig et al., 2001). Improvements at 12 months were also reported in fatigue, pain, role function, depression, and health distress and fewer visits to the emergency department. Improvements in the same outcomes observed in the early studies of the CDSMP have been reported following an online version of the CDSMP (n=958) (Lorig et al., 2006b).

The CDSMP has been licenced worldwide by Stanford University as a cost-effective self-management programme (http://patienteducation.stanford.edu/organ/cdsites accessed 25th June 2013). A recent quantitative synthesis of 23 CDSMP studies found that cognitive symptom management, and communication with physician improved significantly at 4-6 months; cognitive symptom management remained significantly improved at 9-12 months (Brady et al., 2013). The authors propose that although different measures of psychological health were utilised, improvements were demonstrated at 4-6 months and 9-12 months. Energy, fatigue, and self-rated health showed small but significant improvements at 4-6 months but not at 9-12 months. A reduction in the number of in-patient days at 4-6 months was the only change in resource utilisation demonstrated.

However, several limitations exist with the CDSMP studies. Cost-effectiveness of the CDSMP relies upon the accurate establishment of healthcare resource utilisation by participants, which is subject to differing interpretations of 'appropriate' consultations. Quantifying health resource utilisation fails to consider people's existing relationships and experiences of health services and how these affect current and future patterns of service use. For example, differences in the perceptions of patients and GPs about the necessity of a consultation have been highlighted (Michie et al., 2003). Furthermore, that family (general) practitioners and treatment (practice) nurses offers a comprehensive representation of available healthcare resources is questionable. Other resources exist for patients to assist with the management of long-term conditions, for example condition specialists, community matrons, pharmacists and third sector organisations, such as the Stroke Association (www.stroke.org.uk). Changes in the levels of utilisation provide little information about the purported mechanisms and processes within the CDSMP. Referral to the CDSMP is subject to medical confirmation of disease diagnosis, arguably undermining patient autonomy and the spirit of 'self-management'. An estimated 25% of GP consultations are unrelated to chronic disease (Lakhani et al., 2007) therefore, this approach excludes a significant number of people who experience ill-health, or who have conditions associated with medically unexplained symptoms, such as Fibromyalgia or Irritable Bowel syndrome, that could potentially benefit from self-management interventions.

The intended model of operation of the CDSMP is for the intervention to be delivered by trained lay volunteers. However, the CDSMP model is based on a study where 23% of the leaders were healthcare professionals and 15% were students without a health condition, arguably unrepresentative of *lay* leaders (Lorig, 1993). Furthermore, a review of self-management in long-term conditions including 145 articles concluded that the dominant mode of intervention delivery is via health professionals (Barlow et al., 2002b). It is feasible that differences in facilitator background impacts upon the style and intervention fidelity and the bearing of any vicarious modelling.

The substantial benefits of the CDSMP in US cohorts have not been replicated in the UK. A pre-test post-test design study investigating the CDSMP with English patients (Wright et al., 2003) (n=185) demonstrated small to moderate effects (Huck and Cormer, 1996 p.196). In terms of increased self-efficacy (effect size [ES]=0.43), communication with physician (ES=0.33) and decreased fatigue (ES=0.27). No significant effect was observed in visits to GPs or specialists, hospitalisations, pain, anxiety and depression and overall impact of condition. However the time to follow-up was relatively short (four months), and potentially meaningful differences might be observed over a longer period. Moreover, these results may be indicative of differences in the population, culture and society between the UK and USA, particularly the role attributed to individual responsibility for managing health.

Alternatively, the results may highlight deficiencies in the evaluation procedures used. The study used 0-10 visual analogue scales (VAS) for pain, fatigue and shortness of breath which are imprecise measures of complex attributes (Bowling, 2007). These outcome measures were adopted in Wright and colleagues' study based on those used in the US CDSMP studies, in order for results to be comparable. However if these measures were not adequate, questions exist regarding the meaningfulness of results from the original CDSMP studies. This is further explored in section 2.8.

2.5.2 The Expert Patients Programme

The implementation and impact of the EPP has been evaluated across 28 strategic health authorities in England. Using a RCT design (n=629), self-efficacy, healthcare utilisation and health-related quality of life were assessed six months post-participation in the EPP compared with usual treatment (waiting list control) (Kennedy et al., 2007). The study succeeded in gaining follow-up data at six months from 521 participants. No statistically significant differences in utilisation of resources was found between groups, however the EPP group reported higher levels of self-efficacy (p=<0.001, moderate effect size 0.44) and energy (p=0.004) although the effect size was small (0.18) (Huck and Cormer, 1996 p.196). The authors calculated a 70% probability that the EPP was cost-effective, with an estimated saving of £27/patient.

Self-efficacy was measured using the mean score of four unspecified self-report measures of self-efficacy. Since self-efficacy is specific to a situation, using mean scores to generate a global self-efficacy score may be misleading. Moreover, since the measures of self-efficacy adopted are not specified, it is not possible to determine if they were valid or reliable in the study population. Assuming the measurement properties of the measures were adequate, this study suggests the observed effects were mediated most strongly by self-efficacy. However, a secondary analysis of the data, six and twelve months post-participation in the EPP concluded that the effects of the intervention on those with multiple health conditions *and* depression were unlikely to be as a result of self-efficacy (Harrison et al., 2010, 2011). The authors attributed the changes in self-efficacy from the original RCT, (six-month follow-up) to successful group dynamics and the use of goal-setting by participants. The role of self-efficacy as a factor that mediates the EPP therefore appears uncertain.

2.5.3 Limitations of the CDSMP and EPP models

Critics of the EPP and CDSMP point to the predominance of white, middleclass, female participants who arguably already possess the skills, such as assertiveness, health literacy and proficiency in navigating healthcare resources, required to be a successful self-manager (Newbould et al., 2006, Rogers et al., 2008, Thoolen et al., 2007). There is a risk that existing health and social inequalities become exaggerated as these groups become ‘expert’ self-managers. The impact of the CDSMP and EPP models in socially disadvantaged groups appears unclear. This is of particular relevance to self-management in the UK stroke population, being predominantly male (Ronning & Stavem, 2010) and more likely to come from economically disadvantaged backgrounds (Bhatnagar et al., 2010).

Self-management interventions may not appeal to everyone. However, some argue there is currently a lack of explanation regarding participant withdrawal from self-management interventions (Bury & Pink, 2005, Paterson & Hopwood, 2010) which could help to make future interventions more appealing and improve attrition rates. Moreover, greater engagement by patients in managing their health may actually lead to an increased demand for resources, as opposed to reducing demand, as patients become more informed and aware of treatment options (Greenhalgh, 2009).

Currently the long-term effects of the EPP and the CDSMP remain unclear. The mechanisms affecting change appear to remain elusive and some practitioners argue that policy for group interventions to encourage self-management has raced ahead of the evidence (Greaves & Campbell, 2007). A disjoint exists between policies promoting self-management and the results at grassroots. Both the CDSMP and the EPP continue to operate, despite flaws identified in the assimilation of evidence to support them.

2.5.4 Disease specific self-management interventions

Many disease specific self-management interventions now exist, including for asthma (Janson et al., 2009); cancer (Gao and Yuan, 2011); diabetes (Lin et al., 2008b); hypertension (Rudd et al., 2004) mental illness (Lorig et al., 2013) and rheumatoid arthritis (Hammond & Freeman, 2001). The growth of disease specific versions designed and often implemented by healthcare professionals has partly occurred according to patient preference over generic versions (Cadilhac et al., 2011, Huijbregts et al., 2008, Paterson et al., 2002) and the requirements of different treatment and disease processes.

The evidence is inconclusive regarding the superiority of generic or specific self-management interventions. Trials comparing disease specific and generic interventions suggest that disease specific versions may be more effective in asthma (Janson et al., 2009; Schermer et al., 2002) although statistically non-significant differences in predicted outcomes were reported following interventions targeted at chronic obstructive respiratory disease (Coultas et al., 2005); osteoarthritis (Lorig et al., 2005) and stroke (Cadilhac et al., 2011) suggesting that further evidence is required.

2.6 Search Strategy

The literature search sought to identify articles relating to stroke self-management and interventions that focused upon stroke self-management. Introductory reading commenced with UK government policy documents and clinical guidelines to gain an overview of the current context of self-management. Relevant areas were further focused in preparation for a structured literature search using the PICO framework (Patient population, Intervention, Comparison Intervention/control, Outcome) (Centre for Evidence-Based Medicine, 2010).

Stroke and self-management were applied to the PICO framework as follows:

Patient Population Stroke, adult (≥18 years), Community dwelling.

Intervention Self-management intervention(s), or intervention(s) targeting self-care skills.

Comparison intervention/control No control applies in this search. Comparisons can be made with interventions for generic long-term conditions.

Outcome Benefits or effects of self-management intervention(s) in stroke.

Table 2.1 illustrates the search terminology adopted. The following electronic databases were searched: CINAHL (Cumulated Index of Nursing and Allied Health Literature), selected for a comprehensive cover of journals relating to health Professionals; EMBASE, selected for a comprehensive cover of biomedical journals; MEDLINE, selected for a comprehensive cover of medical and health journals and PSYCHinfo, selected for coverage of psychological, behavioural and health sciences literature.

Population	Key terms	Intervention	Outcome
People following stroke (≥18 years) Community dwelling	Self-management Self-care Self-help Adherence Concordance	Self-management intervention(s)/promotion Self-care skill(s) interventions/promotion Program Rehabilitation	Change to self-management/self-care skills Education Outcome Change to utilisation of health care resources Health status changes

Table 2.1 Search terms using the PICO framework.

Search terms were chosen to represent concepts linked to self-management (education, rehabilitation), however articles were excluded unless they specifically stated their purpose was to enhance self-management.

The purpose of the literature search was to identify, summarise and critique the existing literature with regard to stroke self-management. Peer reviewed articles, dissertation and conference abstracts were included in the search, editorial and opinion articles were discounted. An initial review of abstracts determined if articles were of relevance, prior to full retrieval and critical appraisal. All types of study design were included, to ensure the search was as comprehensive as possible. Review and critiquing of research articles was facilitated, where possible, by the use of an appropriate CASP tool (Critical Appraisal Skills Programme, 2010). Reference lists from articles were also reviewed to identify additional articles of potential relevance. Abstracts were reviewed to eliminate articles that were not relevant, based on the following inclusion criteria: (1) the articles were published in English; (2) the article was published between January 1990 and April 2013, unless related to seminal work; (3) the article addressed self-management specific to stroke. Only articles focusing upon stroke self-management in adults aged 18 years or above, were included in the review. No restrictions were placed with regard to the duration post-stroke or rehabilitation setting.

In addition to searching electronic databases, the UK Department of Health website was searched to identify relevant policy documents and links to clinical guidelines (accessed February 10th 2011 www.dh.gov.uk/). Finally, literature searches were conducted again once the research purpose was clear, to check for developments since the initial searches.

2.7 Self-management and stroke

A key principle of stroke self-management interventions is that as people develop the coping skills to adjust to and manage their life post-stroke, their sense of control and quality of life improves (Catalano et al., 2003). However, currently no gold standard definition of the concept of stroke self-management, nor what constitutes a stroke self-management intervention, exists (Lennon et al., 2013). Nonetheless, self-management following stroke appears to be a key research priority for patients, families and health professionals in the UK. A recent consensus study sought to identify the ten top priorities for research, three of which, coping with the long-term consequences of stroke, the management of fatigue and confidence following stroke resonate with self-management (Pollock et al., 2012). These priorities may become of heightened importance as therapy and professional input diminishes, and emphasis shifts towards people self-managing following stroke. The optimal ways to enable people to manage their health and well-being following stroke remain uncertain (Jones et al., 2013, Lennon et al., 2013). Exploring the existing evidence base for stroke specific self-management interventions is therefore of paramount importance, to identify the areas that warrant further research.

Recently, the first systematic review of self-management intervention studies has been published (Lennon et al., 2013). This review, which concerned literature between January 2000-October 2012, included fifteen stroke self-management studies pertaining to 1233 participants. The review rated studies in terms of their quality, according to guidance by Butler (2008), concluding that more high quality studies are required before such interventions can be embedded into practice. Systematic reviews based on such evidence hierarchies often focus upon efficacy and effectiveness. This may be problematic in areas of emerging research, such as stroke self-management, where other types of evidence, such as qualitative studies, may answer questions not easily evaluated by experimental studies (Goldsmith et al., 2007). Therefore, a literature search pertaining to all evidence relating to stroke self-management was conducted.

Stroke self-management literature was systematically searched on the following electronic databases: Medline, PsychInfo, Science Direct, Web of Science and CINAHL. The following terms were used in conjunction with "stroke" to identify self-management studies:

self-management
self-care
intervention(s)
program (s) programme (s)

rehabilitation
outcome(s)
education (educational)

Search terms were chosen to represent concepts linked to self-management (education, rehabilitation), however studies were excluded unless they specifically stated their purpose was to address self-management. Article reference lists, websites of UK government health department, generic internet search engines, and stroke-specific organisations were also searched. Dissertations and conference abstracts were excluded, however searches for publications by dissertation or conference abstract authors were conducted. Selected articles described either 1) a self-management intervention development and/or implementation or 2) presented findings from stroke self-management interventions. Identified studies were extracted and summarised (appendix one).

Each abstract was assessed to eliminate articles that were not relevant, based on the following criteria: (1) the study was published in English; (2) the article addressed self-management specific to stroke; and (3) was published between January 1990 and June 2012, to examine the current and most relevant evidence for practice. Judgements were not made on the quality of the studies; all relevant studies were screened and examined. A search of the literature identified 18 studies relating to stroke self-management (figure 2.1). Four studies were identified that were not included in the review by Lennon and colleagues (2013). Two concerned pilot studies; one related to a telehealth intervention for stroke self-management (Mawson & Mountain, 2011), the other a client-centred self-care intervention (Guidetti & Yterrberg, 2011). One study concerned an occupational therapy intervention to promote self-care for people following stroke (Sackley et al., 2006). A further study explored the experiences of attending the CDSMP for people with stroke (Hirsche et al., 2011). What follows is a synthesis of those findings.

2.7.1 Feasibility of stroke self-management interventions

Some studies examined the feasibility of stroke specific self-management interventions versus generic versions. Participants favoured stroke specific self-management interventions (SMIs) finding them to be more applicable to their situation (Allen et al., 2004; Catalano et al., 2003; Marsden et al., 2010). However satisfaction and attrition ratings between intervention and control groups, where measured, did not reach statistical significance (Cadilhac et al., 2011, Johnston et al., 2007). Some limitations exist in using satisfaction and attrition rates to assess feasibility. Satisfaction is an inherently difficult concept to define and measure being context dependent. Measures of satisfaction may mirror participants' gratefulness or appreciation for care as opposed to satisfaction with the intervention per se (Bowling, 2007, Häggström et al., 1994). Attrition rates need to be considered alongside participant feedback to provide comprehensive judgments on feasibility. For example, participants withdrew from the studies for a variety of reasons, such as study sites being full, the program not meeting their needs (Marsden et al., 2010) or participants requiring hospitalisation (Sit et al., 2007).

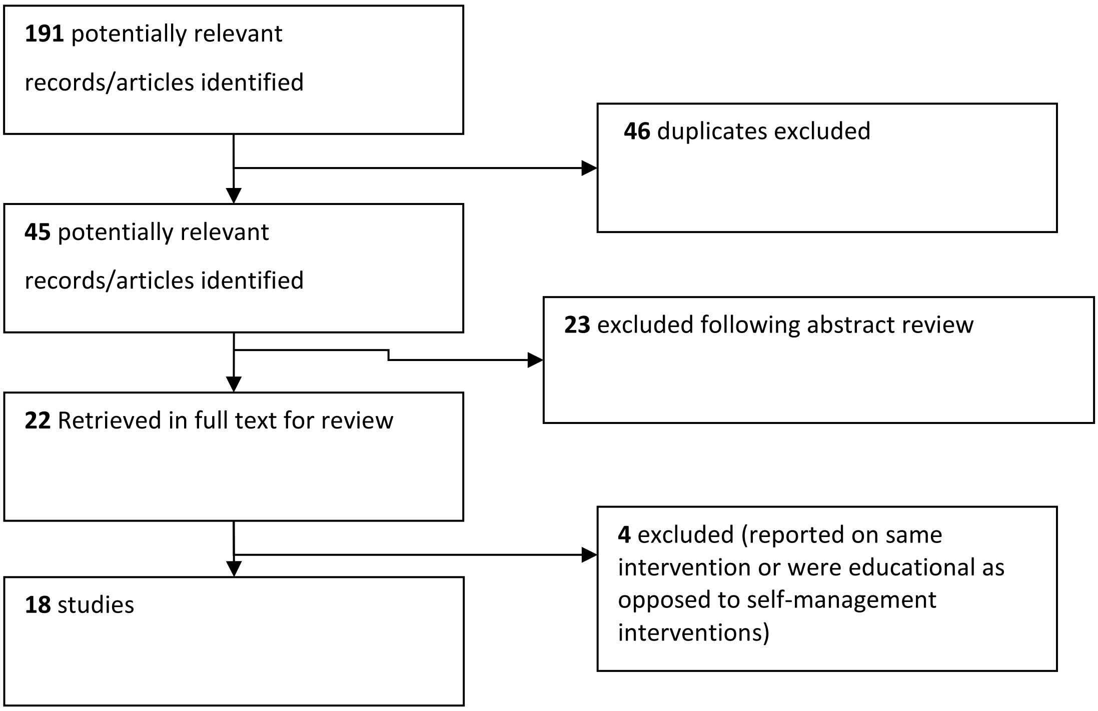


Fig 2.1 Flow chart of search results for stroke self-management interventions

2.7.2 Theoretical premises of stroke self-management interventions

The theoretical premises supporting interventions can offer insights into how change following an intervention occurs. Conceptualising the theoretical premises prior to implementation of an intervention has been advocated as a critical stage in the development of complex interventions (Medical Research Council, 2000). Theory can provide a framework to help refine the hypotheses, and maintain the fidelity and quality of interventions (Michie et al., 2008). Evaluation of interventions is often based on the assumption that the theoretical basis of the intervention has been implemented properly (Webb & Sheeran, 2006). An exploration of the theories cited in the development of stroke self-management interventions is therefore necessary.

Ten (of 18) studies (55%) identified in this review explicitly stated a theoretical premise for the study in question (appendix one). Similar to the paper by Lennon and colleagues, the most commonly cited, was *Social Cognition Theory,* specifically *Self-efficacy* (six studies). Other theories utilised by studies included the Chronic Care Model; Locus of control; Cognitive Behavioural Therapy and Orem's self-care theory. Eight studies did not explicitly state a theory on which the intervention or study was based. One study was an exploratory study of the experience of self-management interventions, and therefore the stating of a theoretical premise was not implicit (Hirsche et al., 2011). Of the remaining studies, no theoretical premise was explicitly stated. An absence of theoretical premises supporting an intervention may contribute to evaluation difficulties, since the intervention nor expected outcomes may not be fully defined or developed (Campbell et al., 2007).

Where a theoretical premise was stated, study authors sought to utilitise outcome measures purporting to reflect changes, or outcomes, related to that theory. An overview of the purported outcomes follows.

2.7.3 Self-efficacy and Locus of Control

A six week modified version of the CDSMP, delivered by telephone reported improvements to communication with physician self-efficacy at six months post-intervention (*p*=<0.02) (Damush et al., 2011). Self-efficacy was measured using Lorig's self-efficacy scales (Lorig, 1996). Questions exist regarding the measures' validity and reliability for use with stroke populations, since they were neither developed nor tested with this population. The additional aspects of self-efficacy measured in the study were not reported in the results, suggesting no changes were found in them. Jones et al. demonstrated significant (*p*=<0.05) improvements in self-efficacy, using a specific self-efficacy measure developed and tested with a stroke population, following a self-management workbook (Jones et al., 2009). Frank et al. also adopted a workbook model in a RCT study design. Functional performance improved in both intervention and waiting-list control groups, suggesting that the workbook had a limited effect (n=39) (Frank et al., 2000). Studies of a Canadian stroke self-management programme based on self-efficacy revealed inconclusive results in both face to face delivery (Huijbregts et al., 2008), (n=30) or delivery through video-conferencing (Huijbregts et al., 2009) (n=15). Significant improvements were demonstrated to balance only (*p*=>0.05) (Huijbregts et al., 2009). Both studies were limited by small sample sizes therefore the possibility for type II errors exists.

Measures of self-efficacy were not adopted in the Frank and colleagues, nor the Huijbregts and colleagues, studies despite the interventions being based on self-efficacy theory. Therefore that change to self-efficacy occurred is difficult to determine. Improvements in self-efficacy were not observed following a self-management program adapted for stroke (Kendall et al., 2007). A measure of self-efficacy was adopted, however it's validity for use with stroke populations is questioned, since it was neither developed nor tested with this population (Lorig, 1996).

Self-efficacy has been suggested as a possible mediator of self-management in stroke in a recent systematic review (Jones & Riazi, 2011). However, currently there appears to be limitations in the evidence to support this view.

Further research is required to examine what and how factors, including self-efficacy contribute to change following self-management interventions.

2.7.4 Self-Care Deficit Theory

A Swedish study of a multi-disciplinary collaborative rehabilitation approach aiming to improve self-management (Ljungberg et al., 2001) based itself on Orem's *Self-Care Deficit Theory* (Orem, 2001). The intervention group (n=32) were more satisfied, more active at making rehabilitation decisions (p=<0.05) and seeking appropriate information from staff, than the control group (n=9) (p=<0.05). Details of the sample are absent making translation to practice difficult. The authors designed outcome measures of self-care and self-management for the purposes of the study to measure these concepts. The reliability and validity of these measures are unknown. Interpreting the results is therefore problematic with robust conclusions about the intervention difficult to draw.

2.7.5 The Chronic Care Model

The *Chronic Care Model* (CCM) (section 2.5.1) was stated as a theoretical framework in Allen and colleagues pilot RCT (2004). The study reported that healthcare utilisation, physical functioning and quality of Life were significantly improved in the intervention group (p=<0.03) (n=96). The study adopted measures of self-management, stroke knowledge and patient, carer and physician satisfaction that were designed by the authors and were not tested for reliability or validity. Consequently, data regarding the robustness of these measures are absent, so full interpretation of study findings is impeded. Details regarding the composition of the sample are absent, further limiting application of results.

2.7.6 Cognitive Behavioural Therapy

The *Cognitive Behavioural Therapy Model* (CBT) model hypothesises that as emotional problems could be driven by negative thinking, emotional problems could be alleviated by altering thinking processes (Beck et al., 1979, Williams & Garland, 2002). A RCT evaluating the effectiveness of a workbook-based CBT intervention, designed to change cognitions about control over recovery, demonstrated significant improvements in recovery from disability (*p*=0.019) (n=103) (Johnston et al., 2007), providing some support for the role of behavioural interventions in stroke recovery. No change was observed in either anxiety or depression levels (*p*=0.40), although the sample were not classified as 'depressed' in either group. In view of the fact that CBT for post-stroke depression, has been previously thought as ineffective (Lincoln & Flannaghan, 2003), the findings add to the debate that participant characteristics, irrespective of emotional state, play a role in the effectiveness of CBT-based interventions. Low mood has been cited as a potential barrier to effective self-management (Jerant et al., 2005). CBT based therapies may have a role in augmenting effective self-management in those with low mood (Broomfield et al., 2011), although the effect on other mood states appears to require further examination.

2.7.7 Effectiveness of stroke self-management

Judgements regarding the effectiveness of stroke SMIs rely upon the collection of appropriate theoretical outcomes. The purported outcomes of the stroke SMIs therefore warrant further examination. The effect on *Self-efficacy* and *Locus of control*, within the stroke SMI literature has already been addressed. What follows is a critical review of the effect on the supposed outcomes of these interventions.

2.7.7.1 Physical Functioning

Physical Function (PF) was most often used as an indicator of effective self-management. This is potentially suggestive of an assumption that effective self-management improves PF, or that improved PF is a desired outcome. 12 of 17 studies (70%) adopted measures of Physical Functioning (PF). Four studies reported a statistically significant improvement in PF (Allen et al., 2004, Huijbregts et al., 2009, Johnston et al., 2007, Sackley et al., 2006). Improvements were also observed in other interventions however statistical significance was not reached (Mawson & Mountain, 2011, Marsden et al., 2010). Five studies reported no change in PF. Change to PF was identified as the primary outcome, of an occupational therapy intervention with residents of care homes (Sackley et. al, 2006). However, the same therapist delivered the intervention and assessed outcomes, raising questions regarding possible observer bias. The effects were not observed at six months, raising questions about the longevity of the intervention and therefore clinical utility.

Questions exist regarding the relationship of PF and self-management. PF remains the dominant focus within stroke rehabilitation. In part, this may reflect that many health service interventions are short-term and focus on regaining physical function, as an indicator of recovery. However, evidence from studies exploring the experience of stroke, identifying that functional measures are often of little relevance to patients (Dowswell et al., 2000, Hirsche et al., 2011, Robinson-Smith, 2002). This raises questions regarding differing rehabilitation priorities between healthcare professionals and those affected (Cott et al., 2007). Effective self-management appears to extend beyond the ability to perform certain physical tasks, encompassing decision making and choices regarding health and behaviour (Kralik et al., 2004). For example, the measurement of PF is of limited value in studies that target speech disorder, mood, social participation or cognitive function (Quinn et al., 2011), debatably all factors in effective stroke self-management. However, how PF aligns with the patient experience of stroke self-management remains unknown. The role of PF in stroke self-management requires further clarification before it can be adopted as a robust indicator of effective self-management.

2.7.7.2 Risk Factor Reduction

One study focused upon risk factor reduction as an outcome (Sit et al., 2007). Improvements were reported in medication compliance, knowledge of warning signs and blood pressure monitoring. However, the outcome measures utilised were adapted by the authors without establishing validity and reliability of the adaptions, creating doubts regarding any inferences elicited from the data. The authors assumed that effective self-management would correspond to changes in health behaviour. Arguably, risk-factor reduction as a sole outcome measure of SMIs does not acknowledge the psychosocial, cultural and environmental experience of self-management, nor addresses the potential barriers to self-management. The withdrawal of 30 participants (n=107) from the study is suggestive of low intervention acceptability, potentially because risk factor reduction offers a narrow view of self-management from a participants' perspective.

2.7.7.3 Self-management behaviours

Three studies reported on changes in self-management behaviours. Qualitative enquiry identified that following a modified CDSMP, participants gained increased motivation to make health changes (Catalano, et al., 2003). No significant changes were seen in exercise, social and recreation activities and cognitive relations as recorded by the Self-Management Behavior Frequency scale (Lorig et al., 1996) in telephone delivery of the CDSMP (Damush et al., 2011). Self-reported information on diet, exercise, smoking and alcohol consumption was recorded in a community based intervention to prevent stroke recurrence (Sit et al., 2007). Given the notion that improved self-management may lead to desirable behaviour change (Barlow et al., 2002b, Lorig & Holman 2003), it is perhaps surprising that few studies focused upon this as an outcome. The self-management behaviours recorded focus upon those most akin to health promotion and those most likely to reduce the risk of further long-term conditions, or recurrence. Which self-management behaviours would be most beneficial in the case of stroke requires further exploration.

2.7.7.4 Healthcare resource utilisation

In light of the drive for efficiencies within finite resources, reduction in the use of healthcare resources is an important potential outcome of SMIs. Three studies reported upon healthcare utilisation, one of which reported a significant reduction in resource use (Allen et al., 2004). The effects past six months were not reported upon; the longer-term effects remain unknown. Recording healthcare use is complicated, requiring the research team to access multiple levels and types of information. For example, self-reported data (collected using diary methods), was eventually omitted in one study, because records were considered too inconsistent and unreliable (Cadilhac et al., 2011). Difficulties also exist in comparing across different healthcare settings due to differences in resource availability and use. Issues of potential greater importance to patients, for example a change in confidence or increased awareness about how to manage fatigue (Pollock et al., 2012), may not be captured in measures focused upon resource utilisation.

Resource utilisation is an important component in calculating the cost-effectiveness of interventions. To date, cost-effectiveness analyses have not been disseminated in relation to stroke self-management, highlighting an important direction for future research.

2.7.7.5 Knowledge of condition

Improvement in *Knowledge* was cited as an outcome by two studies (Sit et al., 2007, Marsden et al., 2010), both of which reported statistically non-significant changes to knowledge. Catalano and colleagues study also identified that knowledge of stroke increased following a modified CDSMP (Catalano et al., 2003). As with all hypothesised outcomes, the selection of ‘knowledge’ as an outcome indicates some assumptions by researchers. Firstly, that SMIs improve participant knowledge of their healthcare condition and secondly that knowledge increase is important to effective self-management. The basis for these assumptions remains speculative since the stroke self-management perspectives of clinicians, researchers or people recovering from stroke are yet to be elaborated. Conceptualisation, through qualitative inquiry, would arguably develop the theoretical basis to stroke SMIs and inform the selection of appropriate outcomes. This represents an important flaw in the current knowledge base.

2.7.7.6 Mood and social isolation

Mood was reported as an outcome in nine studies. *Mood* is thought to be a significant factor in recovery following stroke (White et al., 2008) and low mood has been identified as a barrier to self-management in long-term conditions (Bayliss et al., 2003, 2007). One study reported statistically significant improvements in mood (Allen et al., 2004). However, a measure with unknown psychometric properties was used to capture mood, creating doubts regarding the results. The remaining eight studies reported no significant changes. Possible explanations include the use of small sample sizes increasing the likelihood of Type II errors (Huijbregts et al., 2008; 2009 Jones et al., 2009) and/or the use of outcome measures with questionable validity in stroke populations (Cadilhac et al., 2011; Damush et al., 2011; Harwood et al., 2012; Huijbregts et al., 2008, 2009; Johnston et al., 2007; Jones et al., 2009). The limitations of adopting generic depression screening tools in stroke have been outlined elsewhere (Bennett & Lincoln, 2006, Berg et al., 2009).

In addition to mood, social isolation is common following stroke (Mukherjee et al., 2006, Salter et al., 2008, Secrest & Zeller, 2007). Normal re-integration into society is an important aim of stroke rehabilitation and SMIs. Measures of social participation are therefore relevant to stroke SMI evaluation. The lack of significant results in changes to participation, by all studies adopting this as an outcome, may again in part be explained by type II errors (Huijbregts et al., 2008; 2009, Jones et al., 2009) and the use of measures un-validated for use in stroke populations (Cadilhac et al., 2011; Huijbregts et al., 2008, 2009; Jones et al., 2009).

2.7.7.7 Quality of life

Seven studies recorded quality of life as an outcome. One study used a measure with unknown validity in stroke populations and reported no change to quality of life (Cadilhac et al., 2011). Six studies, utilising a stroke-specific measure of quality of life, reported significant changes. No significant changes were found using the Stroke adapted sickness impact profile (van Straten et al., 1997) following a telehealth (video-conferencing) delivery of a stroke self-management program (Huijbregts et al., 2009) (n=15). One study reported Stroke specific quality of life as a primary outcome (Damush et al., 2011). Improvements were reported at three months post-intervention in the social role domain of stroke specific quality of life (p=<0.05), however these were not sustained at six months. Overall stroke specific quality of life was found to improve following a specialist nursing intervention (p=<0.03) (Allen et al., 2004) and in the self-care domain of stroke specific quality of life following a modified CDSMP (p=<0.05) (Kendall et al., 2007). Marsden and colleagues (2010) used the Stroke Impact Scale (SIS) as a primary measure of health-related quality of life in a pilot randomised community stroke SMI study. Non-statistically significant improvements were reported in all domains, although the study was not powered to establish significance (n=32). Similarly, Guidetti and Yterrberg (2011), utilised the SIS in a client-centred self-management intervention, reporting no statistically significant changes (n=40).

The variety of self-management interventions and types of outcome measures used makes it difficult to compare them. The systematic review by Lennon and colleagues similarly highlighted that the range of outcome measures utilised means comparison across intervention studies is limited. SMIs are evaluated for their efficacy partly in terms of measurable outcomes. Within this approach, there are two main assumptions; firstly that individuals develop into effective self-managers as a result of an intervention, and secondly that this development is measurable. Many of the outcomes utilised in the studies seek to measure concepts that are latent, meaning that the evaluation of stroke SMIs is reliant on well conceptualised, valid and reliable outcome measures. The following sections focus upon important issues to consider in the measurement of self-management.

2.8 Measurement of self-management

Measurement aids the quantification of phenomena and is of paramount importance to evidence based health care, in demonstrating effectiveness and, if patient derived measures are used, in identifying the needs of patients (Laver-Fawcet, 2007). Measurement can assess progress or change, but also extends to observing and acquiring knowledge about people, objects, events and processes (DeVellis, 2003). Measurement is subject to individual philosophical stances. Some theorists argue that measurement techniques drive scientific development (Laver-Fawcet, 2007, Streiner & Norman, 2008) whilst others place more emphasis on understanding meaning (Paley, 2010, Pope & Mays, 1995). My position is that attempts to develop or refine theories are critically dependent upon careful measurement, but that measurement should incorporate significant endeavours to capture meaning.

Capturing meaning is of particular relevance when considering the measurement of patient experience. Patient-reported outcome measures (PROMs) are utilised to measure how patients function or feel in relation to their health condition, and are recognised as fundamental health outcomes in their own right (Devlin & Appleby, 2010a). PROMs are particularly useful in measuring latent concepts, such as quality of life or mood, which have an important bearing on the experience of health. The following sections provide an overview of differing measurement theories before outlining the qualities required of PROMs.

2.8.1 Measurement theories

Measurement theories aim to explain how items in a measure represent the construct being measured (Edwards & Bagozzi, 2000) and describe the statistical relationship between the items, used to capture information, and the entity, termed construct, that is measured. Two main measurement theories are used to explain the relationship between the items and construct; Classical Test Theory and Item Response Theory. A brief overview of both will now be provided, with consideration to the underlying assumptions of each model.

2.8.2 Classical Test Theory

Classical Test Theory (CTT) ascended at the beginning of the twentieth century due to the work of psychologists such as Spearman and Cronbach (de Vet et al., 2011). CTT operates on the basis that items within a measure are manifestations of the construct being measured. Therefore information about a construct that is not directly observable (e.g. fatigue, quality of life) is measured through the items. The score or value obtained by an individual's response to an item is theorised as being comprised of two components: an underlying 'true' score, and error caused by imprecision in measurement (Streiner & Norman, 2008, Wilson, 2005). For this to hold true, CTT operates with several assumptions. Firstly, that the error score is uncorrelated with the true score and secondly that the average error score for all the items equals zero. Importantly for PROMs, each item is thought to accurately reflect the construct to be measured to the same degree.

In practice, the assumptions of CTT are problematic. ‘Error’ in measurement is affected by the differing attributes of the responding population. Some items may be considered more problematic for people to answer than others. Therefore, the ‘error’ score is likely to be correlated to the ‘true’ score. CTT also does not allow for determination for which items reflect the construct most effectively, or most easily. In CTT, a summed total score of items provides a representation of the level of the construct the individual possesses. However, this means treatment of the data as interval level data, whereby the distance between response options is the same; the distance between ‘strongly disagree’ and ‘disagree’ is considered the same for ‘agree’ and ‘strongly disagree’ and the same for each item. Therefore the totalling of respondents’ scores to give an overall ‘level’ of the construct is misleading. Measurement theorists argue that data from PROMs are more likely in fact to be ordinal level data (Streiner & Norman, 2008).

2.8.3 Item Response Theory

Item Response Theory (IRT) was developed in the 1950s by psychologists. IRT is based on the premises of Guttman scaling (chapter five) whereby, a list of hierarchical items ranging from easiest to most difficult describe a single construct. The premise being that someone who endorses the more ‘difficult’ items, will also endorse less difficult items. IRT describes the association between the respondent’s underlying level of ability relating to the construct and the probability of a particular response to the item.

IRT is based on the assumption that the items reflect the construct to be measured and that there is only one construct within the scale (unidimensionality). IRT also assumes that items can be ordered according to difficulty according to the characteristics of the respondents (de Vet et al., 2011).

2.8.4 Measurement properties

Accurate inferences drawn from PROM data are reliant upon the use of robust measurement techniques and measurement properties. A measure judged to be appropriate and effective for the measurement task to which it is applied will have adequate measurement, or psychometric, properties and be developed using suitable methodology. Differing criteria have been adopted to evaluate psychometric properties, subject to different interpretations of measurement properties (Andresen, 2000, Greenhalgh et al., 1998). This lack of clear guidance is further compounded by suggestions that the quality of reviews of measure properties is weak (Mokkink et al., 2009). Chiefly several key measurement properties should be considered when assessing an outcome measure, which are outlined next.

2.8.5 Reliability

Reliability of a measure refers to its' ability to detect the true score, rather than any measurement error. Reliability provides a quantitative estimate of how well a measure performs in *a given population*, based on the assumption that human attributes are stable in the short-term (Nunnally & Bernstein, 1994). Cronbach's alpha (denoted α) calculations are commonly used to estimate *Internal-consistency*, the extent to which items on a measure co-vary and refer to the same underlying construct (McDowell & Newell, 1996). Scores range from 0.0-1.0 with scores closer to 1.0 indicating higher internal consistency. Conventionally, outcome measures should have values between α 0.5-0.8 to be judged as possessing acceptable internal consistency (Kline, 2000). Within IRT, the calculation for reliability depends on the specifics of the model used, which is dependent on the nature and format of the scale (Streiner & Norman, 2008).

In relation to PROMs, a further important form of reliability is *test-retest reliability.* This refers to how well the PROM produces consistent estimates of the construct over multiple time points, assuming no change to the construct has occurred. Clinical judgement is required when considering test-retest reliability, in relation to how the construct in question may change in a given time period. When estimating this form of reliability, the time point should be large enough for the responses to be unaffected by recall of the items, but not so large that the construct will have changed (Kline, 2000).

2.8.6 Determining Validity

Exploring the validity of a measure is a process of assembling evidence to support its' meaningfulness. Validity is described as the extent to which an instrument measures what it is intended to measure (Laver-Fawcet, 2007).Three types of validity are most often cited as being central to a PROMs' validity: *content, criterion* and *construct*.

Content Validity concerns the extent to which items in an outcome measure accurately reflect the breadth of the construct. Content validity demonstrates that a representative set of items are chosen to accurately reflect a construct (Streiner & Norman, 2008). Establishing content validity is a prerequisite to determining additional assessments of validity and is best informed through qualitative inquiry (Brod et al., 2009, Lasch et al., 2010).

Criterion Validity concerns the extent to which the measure correlates with another 'gold standard' measure of the construct under examination. Criterion validity can be further defined in terms of *concurrent* (when the criterion and new measure are assessed simultaneously) and *predictive* validity (when the new measure is used first, to predict the score on the established criterion).

Construct Validity is an estimation of how well the measure reflects an underlying construct and the extent to which a theoretical relationship(s) with other variables that are consistent with any supporting theory can be established (Deellis, 2003).

2.8.7 Sensitivity and responsiveness

Sensitivity refers to the ability of the measure to record any change (Nunnally & Bernstein, 1994). This may include change unrelated to the construct in question e.g. as a result of response error, change in a different construct or change due to time. *Responsiveness* is the ability of the measure to detect change over time in the construct measured (Mokkink et al., 2010b), an important consideration for measures intended to detect health status change (Beaton et al., 2001). Responsiveness can be viewed as being directly related to the validity of the scale, since a valid measure will detect change over time, and not distinguished as a separate entity (de Vet et al., 2011, Streiner & Norman, 2008).

2.8.8 User-derived Measures

A user-derived measure is one which has been developed with the involvement of the population it is intended to measure. Such a measure should reflect the values, perspectives and experiences of the target population (Kabir & Wykes, 2010). User-derived measures facilitate the gaining of information about health, illness and the effects of health care interventions from the perspective of the service user (Fitzpatrick et al., 1998), hence enhancing content validity and clinical utility (Bowling, 1995, Vogt et al., 2004). As well as enabling healthcare professionals to understand patient experience, user-derived measures may facilitate other stakeholders' ability to understand issues related to health (Devlin & Appleby, 2010b). Arguably, PROMs developed without user-involvement have abstract meaning and questionable content validity. Without steps in the development to capture the experience of the population, the PROM remains largely the experience or interpretation of its developers (Switzer et al., 1999, Terwee et al., 2007). A PROM has little clinical or research utility, if its' measurement properties are judged to be unsatisfactory.

2.9 Potential measurement tools for self-management

This section considers the extent to which the measurement properties identified in section 2.8 are found in measures used in the stroke self-management literature.

Few scales exist that purport to measure self-management as an independent concept. Although all studies in this literature review focused upon stroke self-management, none purported to measure stroke self-management as a primary outcome, nor as a discrete concept (Boger et al., 2013). Attempts to measure stroke self-management have included using both generic and stroke specific measures. What follows is an overview of these existing measures. First, an overview of measures used to capture concepts related to self-management in generic health conditions (appendix two) is presented, before examining stroke specific measures purporting to capture self-management.

2.9.1 The Therapeutic Self-Care Scale

The *Therapeutic Self-Care Scale* (TSCS) purports to measure self-care ability. It was developed for use in studies exploring outcomes associated with inpatient nursing interventions (Doran et al., 2002, 2006). The reported reliability co-efficient of the scale is α0.88-0.93, indicating good reliability, although as methodology was absent from both studies it is difficult to critique fully. The authors posited that self-care ability was positively associated with functional ability, nurse autonomy and nurse level of education and negatively associated with patient mood (Doran et al., 2002) and nursing self-care interventions predicted functional status, but not mood or self-care ability (Doran et al., 2006).

Examination of the scale structure of the TSCS in a trauma population 3 months post discharge using principal components analysis, revised the scale to ten items consisting of three factors: taking medications; recognising and managing symptoms and managing changes in health conditions (Chaboyer et al., 2012). The scale's internal reliability was reported as α0.76, indicating acceptable reliability (Streiner & Norman, 2008). In a study exploring factors effecting self-management in people with Multiple Sclerosis, the TSCS did not correlate with a validated, specific measure of self-efficacy as hypothesised (Wollin et al., 2010). Further evidence of the construct validity of the scale is required.

2.9.2 Barriers to self-management questionnaire

A questionnaire to assess barriers to self-management, developed following semi-structured interviews (n=16) with individuals over 65 years with more than one chronic health condition (Bayliss et al., 2003) reported an internal consistency across 11 separate domains of between α 0.38-0.92. According to some authors', scales with alpha values less than 0.5 possess questionable reliability (Kline, 2000). Positive correlations (p=<0.05) with measures of disease burden and health status were reported across the majority of domains (n=156) (Bayliss et al., 2005). The response rate of 28% and incomplete data in 30% of returned items is potentially indicative of problems with scale construction, wording and comprehension for respondents. Further refinement of the measure to improve the tools' reliability is as yet unreported. The tool is aimed for use with populations with multiple long-term conditions; its' reliability and validity in stroke populations is, to date, unknown.

2.9.3 Patient Activation Measure

The *Patient Activation Measure* (PAM), a measure of the degree of '*activation*' or willingness of an individual to engage in care maybe related to self-management ability. The theoretical concept of 'activation' was conceptualised by the authors as part of development of the measure. The construction of the scale involved the in-put of potential users through two focus groups (n=19) and cognitive interviewing (n=20) before the assessment of psychometric properties (Hibbard et al., 2004). A literature review and involvement of 'experts' were also employed to inform scale development although the boundaries of the review, and details of both the experts and 'lay' focus group sample were absent. Items included in the scale were included if judged relevant by both the expert panel and focus group participants, suggesting that some items identified by lay users to be important, may have been dismissed. The total number of items proposed by lay users was not specified.

IRT employed to assess the validity of the scale using responses to telephone administration of a battery of measures in a lay convenience sample (n=100), revealed that activation positively correlated with better health (p<.001), and negatively correlated with healthcare utilisation (p=<.01). Limitations exist with the measures chosen to assess validity. One measure of health behaviour used had unknown psychometric properties. Self-reported healthcare utilisation was not defined by the authors. Furthermore, work would be required to conceptualise 'activation' in relation to self-management in stroke and UK populations.

2.9.4 The Health Education impact Questionnaire (HEiQ)

A review of concepts key to self-management programmes in Australia informed the development of the HEiQ (Osborne et al., 2007), a tool used to evaluate outcomes of self-management programmes. Key stakeholders (number unspecified) were consulted to identify relevant items, although patients were excluded from this process, and were instead asked for their strength of agreement with items. It is plausible that some items deemed relevant by patients were therefore excluded by this process. Confirmatory factor analyses conducted using populations of previous arthritis self-management programme attendees (n=591) and from outpatient apartments (n=598) proposed a measure consisting of eight domains. Responsiveness and sensitivity data is as yet unreported. Further work including people recovering from stroke would be required to assess scale validity in stroke self-management.

The *positive and active engagement in life* domain of the HEiQ was adopted in a RCT comparing specific stroke and generic self-management interventions (Cadilhac et al., 2011). Positive increases were found with both groups, although the between group difference was not statistically significant. Whether this result was due to a limited effect of the intervention or lack of sensitivity in the measures adopted is unclear.

2.9.5 Self-care agency

The *Exercise of Self-care Agency* scale is based on Orem's theory of self-care and was developed using the consensus of 11 nurse experts in the theory (Kearney & Fleischer, 1979). Test-retest reliability was reported as α0.77, in a student sample (n=237). The measure was found to positively correlate with self-confidence, achievement, and intraception (a need to analyse our behaviours) and negatively correlate with abasement (a need to accept blame and confess errors). Later factor analyses with further samples of students, healthy adolescents, university staff, pregnant women and their partners (n=506) reduced the tool to 12 items after eight items were excluded due to poor item correlation (items with a correlation score of 0.40 or below, were excluded). Correlations in the tool for the remaining 12 items ranged from 0.40-0.63. Some factor analysis theorists advocate excluding items with correlations less than 0.60 to maintain validity, meaning only one item would be retained if this guidance had been adopted (Streiner & Norman, 2008).

Caution needs to be applied before adopting the scale with stroke populations, since the study samples were non-clinical and the validity of the scale is unknown in stroke populations.

2.9.6 The Supporting people to promote health scale

The *SUpporting People to Promote Health* (SUPPH) scale was designed to be a measure of self-care self-efficacy, developed with cancer and end stage renal disease populations (Lev & Owen, 1996) and has been used with stroke populations (Robinson-Smith et al., 2000, 2002). Criterion validity was investigated by establishing correlations with responses to the Health Behavior Scale (Owen et al., 1990) (0.61, $p<0.001$) and the Revised Grief Experience inventory (Lev et al., 1993) (-0.38, $p<0.01$) (n=114). Confirmatory factor analyses (n=275) reported a positive correlation across some domains of quality of life ($p=<0.05$), and a negative correlation across some domains of mood and symptom distress ($p=<0.05$). Factor analysis revealed four factors (Coping, enjoying life, stress reduction and making decisions) accounting for 81% of the variance. Reported internal consistency for the SUPPH was α0.95 and test-retest reliability was α0.94, demonstrating high reliability. Sensitivity and responsiveness of the measure were not explored.

Questions exist regarding the methodology adopted in the development of the SUPPH. It is not clear how the measures used to investigate construct validity of relate conceptually to self-care self-efficacy. Additionally, the *Health Behaviour Scale* was an unpublished measure with unknown psychometric properties. Both populations in the study faced uncertainty with regard to their future, with death being a real possibility. This is likely to be reflected in their responses, affecting the measures' potential use with other long-term conditions. The authors propose the SUPPH is consistent with self-efficacy theory however further testing would be required to assess this assumption in other populations.

Robinson-Smith and colleagues adopted the SUPPH in studies with stroke populations (Robinson-Smith et al., 2000; 2002). The SUPPH, as a measure of self-care self-efficacy, was found to positively correlate to quality of life

(p=<0.001), functional independence (p=<0.01) and mood (p=<0.001), one and six months post stroke (Robinson-Smith et al., 2000).

Limitations exist with the methodology adopted. Notwithstanding the questionable properties of the original SUPPH, 23 of 29 items from the measure were adapted by Robinson-Smith et al. to be more relevant to stroke without testing these adaptions, therefore the revised measure had undetermined validity and reliability. Additionally, as the SUPPH had not been previously tested for sensitivity and responsiveness, it is not possible to comment if changes observed in the measure reflect change occurring due to on-going recovery post-stroke, or otherwise. Both studies' findings are flawed by the use of an untested measure, meaning any inferences drawn from the data may be unsubstantiated.

2.9.7 The Cognitive Appraisal of Health scale

The *Cognitive Appraisal of Health* scale (CAHS) a measure of health appraisal, based on the theory of stress, appraisal and coping (Lazarus & Folkman, 1984) aims to explain why some individuals with severe impairments adapt well, whereas others with little impairment are severely disabled. Content validity in stroke populations, was explored following expert opinion consensus (n=6) and unstructured telephone interviews with people recovering from stroke (n=4) (Johnson et al., 2008). Details on how the expert and lay participant opinions contributed to the development of the measure are absent. Reliability and construct validity of the CAHS was not explored. In addition the small sample size adopted limits the applicability of this measure. Whilst further work is in progress to further develop the measure, the findings are currently unpublished.

2.9.8 Self-management self-efficacy

Self-efficacy to perform self-management behaviours may be a concept relevant to stroke self-management. One stroke self-management RCT study utilised a measure of this concept, reporting no significant change in either the intervention or control groups (Kendall et al., 2007). The *Self-efficacy to perform self-management behaviours* scale (Lorig, 1996) was developed by the authors of the Stanford CDSMP, following conceptualisation of the concept as incorporating four distinct forms of self-efficacy:

1. to exercise regularly
2. gain information about disease
3. obtain help from community, family and friends
4. communication with physician

Each item within the measure adopts a 10 point Likert response format (chapter five), and scores are summed to provide a total score. The summing of items within the scale to create an overall score may lead to inaccuracies in interpretation. For example, an individual may have high self-efficacy beliefs in relation to gaining information about their condition, but low in relation to exercising, resulting in a total mid-level score.

The scale was informed by focus groups conducted with people with long-term conditions, with the aim of gaining opinion regarding the future composition of the CDSMP. Questions exist regarding the relevance of these findings for a UK population, and how the focus group method informed the scale development, since the aim of the focus group was not to seek understanding of self-management from the participants' perspective, but to gain feedback on the CDSMP. Reported internal consistency of the four sub-scales ranged between α0.77-0.90 (n=292-478) indicating acceptable reliability (Kline, 2000). Test-retest reliability measured using intraclass coefficients was acceptable, ranging from 0.72-0.88 (n=51). Correlations for the items on the scale with unspecified additional measures perceived to have theoretical importance varied between r-0.1 – 0.41 (n=140-478), implying weak evidence of construct validity (Cohen, 1997).

As the characteristics of the study sample were unreported, how the scale relates to other populations is unknown. As the role of self-efficacy is not fully understood in stroke (Jones & Riazi, 2011, Jones et al., 2013), nor in self-management generally (Chodosh et al., 2005; Harrison et al., 2010), further evidence is required before utilising such a measure to evaluate stroke self-management.

A recent review of generic self-management interventions showed that over 70 different outcomes had been assessed (Nolte et al., 2012). The diversity of indicators of successful self-management is arguably indicative of the conceptual complexity of self-management. However, given that clear outcome expectations aid the design and evaluation of complex interventions (Campbell et al., 2007) the absence of certainty regarding the most appropriate outcomes represents a critical limitation. Without consensus of these outcomes, there is potential for irrelevant outcomes to be targeted and evaluated.

2.9.9 Potential measurement of stroke self-management

Outcome measures are vital for informing researchers and clinicians about the changes associated with self-management interventions (SMIs). Robust psychometric properties of outcome measures are important to ensure that legitimate information is used to evaluate self-management. Despite the recognised value of reliable and valid outcome measures and the increasing importance of identifying effective self-management interventions in stroke, no evidence for a systematic evaluation for the quality of outcome measures used in stroke self-management was identified. Therefore, a systematic review was conducted to determine the quality of the outcome measures used in stroke SMIs.

The literature was systematically searched, appraised and systematically scored, using the COSMIN (COnsensus-based Standards for the selection of health status Measurement Instruments) checklist (Mokkink et al., 2010b). COSMIN was developed following an international Delphi study of 57 psychometric experts (63% response rate). COSMIN has good inter-rater agreement and reliability (Mokkink et al., 2010a) and represents the first critical appraisal tool that is based on the consensus of experts in psychometric theory. Further information on COSMIN can be accessed via www.cosmin.nl. The results of the systematic review have been published (Boger et al., 2013) (appendix A).

The stroke self-management studies identified in the literature adopted a range of outcome measures. This suggests a current lack of consensus regarding the conceptualisation of stroke self-management, its' potential outcomes and the most appropriate outcome measures to utilise. The relationship to self-management of any of the measures utilised in the studies was not explicitly stated. Further clarification is thus required to determine the extent to which those outcome measures used reflect the concept of self-management. This view is also corroborated in the recent systematic review by Lennon and colleagues (2013).

Two studies adopted measures of self-management designed by the investigators which had unknown psychometric properties (Allen et al., 2004; Ljungberg et al., 2001). The existence and use of untested measures should be viewed with caution, as arguably inferences drawn from them are unreliable. Five studies identified primary outcomes; quality of Life (Damush et al., 2011, Marsden et al., 2010); self-efficacy (Jones et al., 2009); physical functioning (Sackley et al., 2006) and feasibility (Cadilhac et al., 2011). The range of concepts measured by studies is summarised in Figure 2.2. Feasibility, self-efficacy and physical function as key outcomes have been detailed in sections 2.7.1, 2.7.3 and 2.7.7 respectively. The primary outcome of quality of life is next considered.

2.9.10 Health-related Quality of Life

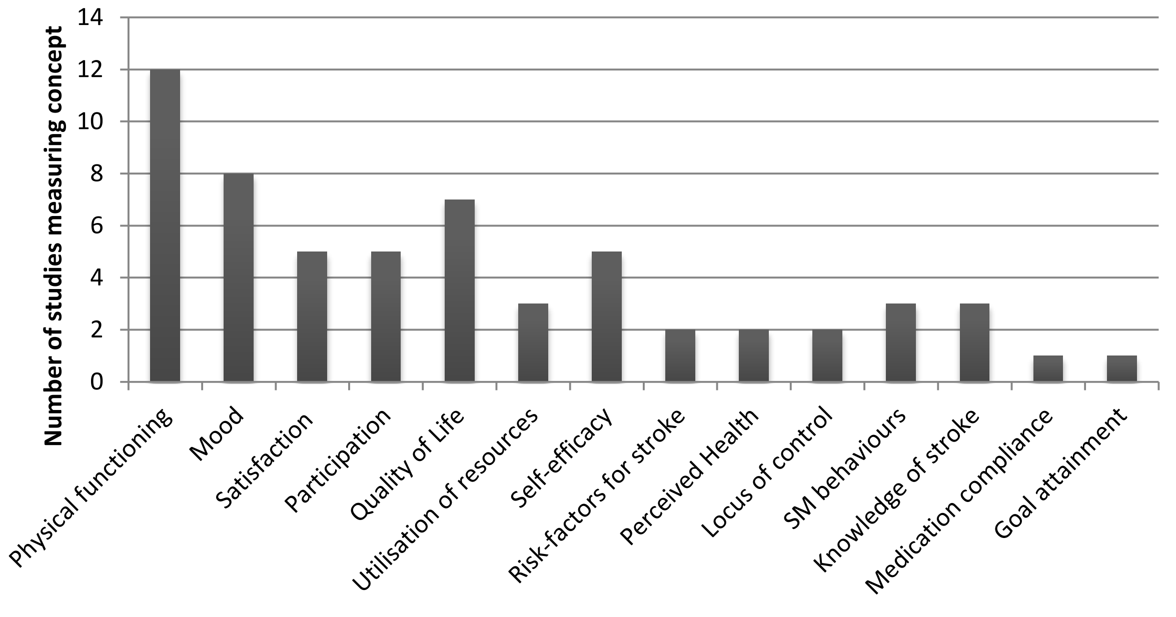
Health-related Quality of life (HRQoL) has been conceptualised as the physical, psychological and social aspects of life that may be affected by changes in health status (Guyatt et al., 1993). Implicit within the self-management literature is that effective self-management leads to a better quality of life and improved well-being (Battersby et al., 2010a, Lorig & Holman, 2003). Moreover, a systematic review of the outcomes of interventions for diabetes concluded that self-management training was most likely to impact upon HRQoL (Steed et al., 2003).

HRQoL was measured by seven studies constituting the third most commonly evaluated concept by stroke SMIs (figure 2.2). None of the studies that measured HRQoL explicitly stated a reason for doing so, nor a hypothesis relating to quality of life. Improvements were reported in HRQoL as measured by three studies utilising the Stroke Specific Quality of Life tool (SSQoL) (Williams et al, 1999). Marsden and colleagues (2010) used the Stroke Impact Scale (SIS, see section 7.7.2) as an indicator of HRQoL. However, the SIS may not explicitly measure HRQoL, Cadilhac and colleagues (2011) adopted the Assessment of QoL (AQoL) instrument (Hawthorne et al., 1999) to demonstrate non-statistically significant improvements in quality of life following a stroke specific SMI versus a generic self-management intervention. However, the AQoL has unknown reliability and validity in stroke populations.

The SIS was the primary outcome measure in a seven-week group programme intervention combining physical activity, education and self-management principles (Marsden et al., 2010). Non-statistically significant improvements were observed in the intervention group in all domains, except memory, where no change was observed 12 weeks following the programme. No significant differences in the SIS between intervention and control groups was also reported following a client-centred self-care intervention (Guidetti & Yterrberg 2011), although both groups showed significant improvement at 12 months (p=<0.001).

HRQoL is conceptualised differently by the stroke specific measures of quality of life used in the SMI studies (Geyh et al., 2007). The Stroke Impact Scale (SIS) (Duncan et al., 1999) consists of eight domains (memory, communication, emotion, hand function, mobility, ADLs, social role and strength) while the Stroke Specific Quality of Life questionnaire (SSQoL) (Williams et al., 1999) consists of 12 domains identified as important to quality of life by people following stroke (fine motor tasks, energy, language, vision, mobility, mood, personality, thinking, work productivity, social roles, family roles and self-care). The SSQoL was developed following individual interviews with 32 people who were 1-6 months following stroke and asked specifically about quality of life. Developers of the SIS conducted 30 interviews with people less than six months following stroke, regarding impairment (Duncan et al., 2001). Quality of life appears to play a role in stroke self-management however its conceptual relationship to self-management remains unclear.

Fig. 2.2 Summary of concepts measured by studies (n=18)



2.10 Summary of literature Review

Stroke represents an important health burden for the UK. As the focus of healthcare shifts from treatment and cure to prevention and rehabilitation, self-management has gained increasing recognition as an approach to alleviating the burden of stroke for the individual and society.

Several stroke specific self-management interventions have been developed and reported upon, however the evidence in support of their effectiveness remains inconclusive, not least because of a lack of conceptual clarity, theoretical premises and credible outcome measures. Whilst potential theoretical bases for the self-management of long-term conditions, such as self-efficacy, have gained increasing acknowledgement, the role in stroke self-management remains unclear. This is in part due to a lack of robust outcome measures and, in addition, a lack of clarity regarding the purported theoretical foundations of stroke self-management. The lack of reported significant changes to outcomes following the stroke self-management studies may, in part, be indicative of the selection of inappropriate outcome measures, and/or lack of sensitivity and validity in stroke populations.

The literature reveals a paucity of knowledge with regard to the measurement of self-management in stroke. Further work is required to determine how the outcome measures identified in this review, align with the concept of self-management.

The range of concepts measured suggests a current lack of consensus regarding the appropriate outcome measures to assist the evaluation of stroke self-management. Alternatively, the use of heterogeneous outcome measures may be reflective of recognition by researchers that self-management embraces a range of differing concepts. The lack of specific measures of self-management may reflect the difficulty in the operation of the concept, a view also expressed elsewhere (Battersby et al., 2010a, Blakeman et al., 2010). In addition, most SMIs have been developed for generic audiences, which may partly explain the lack of specific measures developed for stroke self-management and the absence of measures with evidence of reliability and validity for use with stroke SMIs.
The concept of self-management in stroke has yet to be defined. Questions exist concerning how people recovering from stroke are enabled to self-manage, if their level of impairment is such that care or support is required from others. The evidence regarding SMIs for impaired individuals is imprecise owing to the exclusion of individuals with moderate-severe impairment particularly those with cognitive limitations (Frank et al., 2000; Huijbregts et al., 2008; Jones et al., 2009; Sit et al., 2007) without detailed reasoning. Given the high proportion of individuals experiencing limitations following stroke (Horgan et al., 2009) this remains an important unresolved matter for the evidence base.

An argument exists for research to investigate the conceptual properties of stroke self-management, to examine which measurement concepts currently being used, if any, are appropriate. Identifying the underpinning concepts of stroke self-management would also facilitate the development of a new outcome measure. The current lack of credible measures of stroke self-management limits the ability to report upon the impact of interventions and identify need for self-management support for patients. Work to conceptualise stroke self-management is required to help identify which outcomes are most appropriate for evaluating interventions, to further inform the theoretical basis for SMIs and to assist the development of interventions and appropriate outcome measures (Cano and Hobart, 2011).

A robust outcome measure is therefore required to adequately inform practitioners, researchers, decision makers and other stakeholders regarding the effectiveness of self-management interventions. This research is therefore relevant and opportune.

2.11 Research Aim

This literature review has informed the development of an over-arching research goal *'The development of a new patient-reported outcome measure for self-management following stroke.'*

Chapter three provides a detailed overview of the study design and methodology adopted.

3. Chapter Three – Methodology and Method- Phase I

3.1 Introduction

The preceding chapter demonstrated the paucity of knowledge with regard to measuring self-management following stroke. This thesis relates to a programme of research, the aim of which is to develop a patient-reported outcome measure (PROM) that has well conceptualised constructs. The research operated in three distinct phases. This chapter outlines the methodology and methods adopted in the first phase. Chapters five and seven respectively address the methodology for the second and third phases. Firstly, the theoretical assumptions underpinning the study are outlined and justifications are made for the chosen methodology. The research design and procedure is described and defended. Finally the method of analysis chosen to understand the findings is outlined and explained.

Theoretical assumptions about how the world frame the questions that are considered important and legitimate to ask (Green & Thorogood, 2009). Such assumptions should be set out at the inception of the research, since they inform the research questions and guide the selection of the appropriate methodology (Creswell & Plano Clark, 2011). Indeed, where theoretical assumptions are not explicitly set out, questions may exist about the quality of the study, and thus the rigour of the reported findings (Gerrish & Lacey, 2010, Morse et al., 2002, Reeves et al., 2008). To provide the reader with an understanding of the chosen methodology for this programme of research, and in addition, the ability to critique the methods employed, consideration of my theoretical assumptions are next presented.

3.2 Ontological and epistemological assumptions

"*We must be systematic, but we should keep our systems open.*"
Alfred North Whitehead, Mathematician and Philosopher

Ontology, within the context of research, refers to the study of categories of things that exist or may exist. Epistemology refers to the assumptions that humans make about what it is possible to know and how we gain that knowledge. Ontological and epistemological perspectives can be viewed as a continuum, polarised with Positivism at one end and Constructivism at the other.

A positivist ontological view holds that we can only measure what is directly measurable or observable, thus discovering what is 'real' and 'true'. Within this paradigm, truth is considered to be objective, independent of human insight. Within a positivist approach, the goal is to evaluate phenomena within the context of a value-free framework (Bruce et al., 2008). Epistemologically, the researcher and phenomena under investigation are considered to be independent entities; the researcher aims to conduct enquiries, analyse data and draw conclusions in a manner that eliminates researcher bias. Therefore, the researcher is capable of studying the phenomenon without influencing it or being influenced by it. Positivism is well-aligned with quantitative enquiry (Broom & Willis, 2007, Bowling, 2009). Positivistic paradigms systematise the knowledge generation process with the help of quantification. Several principles hold within this paradigm (Singh, 2007). Firstly, events are caused by other circumstances and understanding the casual links are necessary for prediction. Secondly, collection of verifiable empirical evidence supports theories or hypotheses. Thirdly, the findings of phenomena are replicable and can be generalised to other situations. The goal is to integrate findings into a meaningful theory, which is regarded as tentative and not the ultimate truth. The theory is then subject to revision or modification as new evidence is found.

In contrast to positivism, constructivism rejects the notion of a single 'true' reality, posing that what we know is constructed inter-subjectively (Gerrish & Lacey, 2010; Green & Thorogood, 2009). Instead, meaning and understanding of phenomena are viewed as developing socially and experientially. Reality is considered to be socially constructed, and therefore constantly changing. Constructivists consider there to be multiple realities and truths based on an individuals' ideological position (Sale et al., 2002). Therefore, knowledge is personally experienced rather than acquired from or imposed externally. Since human beings have a value-system, they are considered to think and reflect upon scientific inquiry (Mason, 2002). This impacts upon what is considered directly observable or measurable. In contrast to positivism, the researchers' own worldview influences the research process and the interpretation of data. Reflexivity is the recognition that the researcher's perspectives influence the research they are conducting. Within this paradigm, and arguably to some degree in positivist paradigms also, no researcher can claim to be completely objective (Mays & Pope, 2000). The ontological assumption of constructivism is Realism (Guba & Lincoln, 1994) and the worldview is aligned with qualitative enquiry.

It has been argued that researchers should move away from the polarised extremes of positivism and constructivism (Foss & Ellesfens, 2002). To indiscriminately apply one approach to all research may be misleading (Morgan, 2007). Researchers should be reflexive to the research question, since qualitative and quantitative methods are part of a continuum of research, with specific techniques selected based on the research objective (Casebeer & Verhoef, 1997). A perhaps light-hearted view from two well-respected theorists is that researchers should not be preoccupied with the quantitative-qualitative debate, because epistemological purity does not get research done (Miles & Huberman, 1984)! Nonetheless, there are several reasons why qualitative and quantitative approaches can be combined which are worthy of consideration. Both seek to disseminate knowledge for practical use, and share a commitment for rigor, conscientiousness, and critique in the research process (Teddlie &Tashakkori, 2008). In both approaches, researchers need to remain aware of the possible impact their perspectives and theories have on interpretation of the data, and any conclusions drawn. Finally, both approaches share the goal of understanding the world in which we live and a commitment to understanding and improving the human condition (Sale et al., 2002).

A philosophical position that I identify with, and which is drawn from the extreme positions of Positivism and Constructivism is Critical Realism. Critical realism is a form of post-positivism (Benton & Craib, 2001). Within positivism, the primary purpose of research inquiry can be viewed as gaining knowledge about underlying causal mechanisms. However the critical realist view of causation differs primarily from a positivist stance, which views causation as resting on the constant conjunction of events connected in time and space (Brante, 2001). In contrast to this perspective, critical realism holds that all measurement is fallible. Critical realists believe that that all observations are theory-laden and researchers are inherently biased by their cultural experiences and worldviews. As such, positivist observations are fallible, as they are shaped by the conceptual frameworks within which positivist researchers operate (McEvoy & Richards, 2003).

Critical realists maintain that the world functions as a multi-dimensional system and that generative mechanisms may remain latent until they are activated in specific circumstances (Benton & Craib, 2001). Similar to constructivism, critical realism contends that reality and ‘truth’ can only be known from the researchers’ perspective of it. However, critical realism contends that it is possible to evaluate the extent to which objectivity or truth is attained (Pawson & Tilley, 1997).

Critical realism poses that we cannot separate ourselves from what we know, however objectivity is an ideal and can be enhanced through careful sampling and specific techniques (Angus & Clark, 2012). For critical realists, deductive and inductive methods of enquiry are necessary but insufficient for theory development without retroductive reasoning. Retroduction is a form of reasoning that occurs retrospectively as mechanisms are postulated to account for observed phenomena via analogy, metaphor and model building (Meyer & Lunnay, 2013). Retroduction involves making observations and devising a theory to explain them (McEvoy & Richards, 2003). Within critical realism the importance of multiple measures and observations, each of which possess different types of error, is emphasised. Critical realists argue that researchers can be pragmatic and use methods most appropriate for particular circumstances. Critical realism is thus well aligned with a mixed methods approach (Lipscomb, 2008) and the paradigm adopted for this programme of research.

3.3 Overarching research aims

The paucity of knowledge with regard to stroke and the concept and evaluation of self-management has been outlined following chapter two. No study specifically explored self-management from the perspectives of those recovering from stroke. No credible outcome measure was identified that could be employed to evaluate stroke self-management. Little is known about the experience of self-management in stroke, what this might involve for the individual and the problems or successes encountered in pursuing self-management.

The aim of the programme of research was to develop a PROM suitable for measuring stroke self-management. This first phase of the research had two primary aims. Firstly, to explore the concept of self-management from the perspectives of people recovering from stroke, and secondly, to inform the development of items of a new PROM.

3.3.1 A Mixed methods approach

Combining research methods is useful in health research because the complexity of phenomena requires data from a large number of perspectives (Creswell, 2011). There has been some debate regarding the approaches that constitute the term ‘mixed-methods’. Often research is categorised by being either qualitative or quantitative in nature. However, the terms quantitative and qualitative may not be useful descriptors since they represent a distinction between approaches which may not hold in health practice (Tashakkori & Creswell, 2007). For example, counting often involves making qualitative judgments (e.g. dividing a bag of sweets ‘fairly’), and numbers often relate to a given context (e.g. ‘it was ten times worse’) (Sandelowski et al., 2009). In health research, the term ‘multi-method’ archetypally refers to studies in which both qualitative and quantitative data are gathered (Stange et al., 2006). Some researchers propose that mixed methods refers to collecting either multiple sources of qualitative *or* quantitative sources of data, but not both (Vogt, 2008).

The most widely acknowledged interpretation of mixed methods research is one that includes both qualitative and quantitative approaches to facilitate a more comprehensive understanding of the research question (Creswell & Plano Clark, 2011, Johnson et al., 2007, Teddlie & Tashakkori, 2008). This interpretation of mixed methods has informed this programme of research.

The overall research design adopted an exploratory sequential mixed methods approach (Creswell & Plano Clark, 2011), consisting of three phases. The first phase was an exploratory phase, which sought to understand stroke self-management from the perspectives of people recovering from stroke. The second phase combines the concepts identified following the first phase of research, to refine the preliminary item content for a new PROM of stroke self-management. Items were explored for acceptability to people recovering from stroke and content validity, using cognitive interviewing methodology. The final phase aimed to strengthen the concepts generated in the qualitative phases through the psychometric evaluation of the PROM. Figure 3.1 provides a visual representation of the study design.

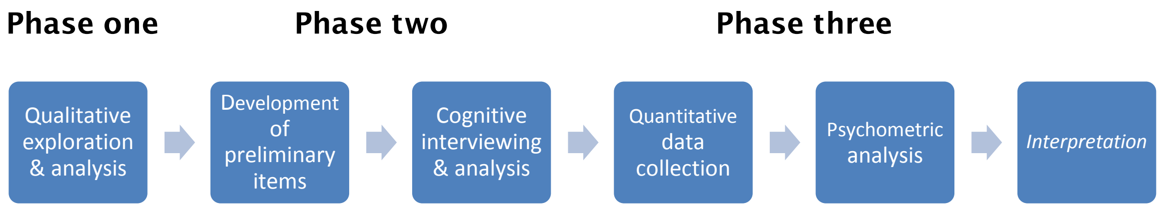


Figure 3.1. Overview of the chosen exploratory sequential study design, adapted from (Creswell & Plano Clark, 2011)

3.3.2 Justification for a mixed methods methodology

A common argument is that mixed methods research is unfeasible since qualitative and quantitative methodology originate from separate paradigms and different epistemological assumptions (Bryman, 2004). However, counter arguments suggest that research methods do not possess a completely fixed epistemological and ontological assumption (Creswell & Plano Clark, 2011, Greene, 2007), and that it is unnecessary to fix a research approach from a dichotomy of options (Broom & Willis, 2007, Foss & Ellesfens, 2002). That qualitative and quantitative approaches are incommensurate does not mean that multiple methods cannot be combined if done so for complementary purposes (Sale et al., 2002), such as the development of a PROM.

‘Mixed methods’ constitutes a research design and methodology, not merely a summary of different methods (Tashakkori & Creswell, 2007). Within a mixed methods paradigm, neither quantitative nor qualitative methods are viewed as being superior, each having a particular role according to the research purpose (Broom & Willis, 2007). The overall aim of this research was to develop a new PROM. In the context of PROMs, measurement is reliant upon the quantifying of latent variables (or constructs) that are supposed to exist, because of our knowledge and understanding of the world, but which are not directly observable. The evidence in support of a construct determines the content of a PROM and originates from qualitative enquiry (Magasi et al., 2011); subsequent quantitative testing examines these assumptions (Laver-Fawcet, 2007). It follows that development of a credible PROM must integrate distinctive qualitative and quantitative phases, and is thus well suited to mixed methods methodology.

Within mixed methods methodology, there are several research designs. The design adopted in this programme of research used an exploratory sequential design (figure 3.1). Development of an outcome measure is advocated through specific sequential steps (DeVellis, 2003), well aligned to a mixed methods approach. The involvement of potential users of the PROM to conceptualise the construct(s) to be measured and develop content validity is vital (Meadows, 2011, Scholtes et al., 2011). This step ensures that the concepts relevant to patients are captured in the PROM (Marshall et al., 2006) and hence patient perspectives are appropriately captured in assessment (Sloan et al., 2007). Without this step, the PROM is at risk of being irrelevant to the patient, and thus possessing questionable validity (Lasch et al., 2010). Further development phases involve psychometric evaluation of the preliminary PROM (employing quantitative methods) to further investigate the findings in the exploratory phases (Creswell & Plano Clark, 2011; Streiner & Norman, 2008). In the context of this research, this encompasses the investigation of reliability and validity of the preliminary PROM (chapters seven and eight).

An exploratory phase using inductive enquiry was thus first required. The next sections outline the methodology employed in the first phase of the research.

3.4 Research Question

The research question for phase one was influenced by my research interests and philosophical assumptions which guided the appropriate chosen methodology and research design. The research question is stated below:

What is the experience of self-management for people living in the community following a stroke?

3.5 Research Design

There is increasing recognition that emphasis on the quantitative testing of outcome measures leads to measures with often poorly defined theoretical constructs (Hobart, 2007). Qualitative investigation, along with assimilation of existing knowledge through the literature, provides the theoretical underpinnings of a PROM and is therefore an essential first step in PROM development (Lasch et al., 2010). A strong inductive phase was consequently required to try and comprehend the experience of stroke self-management and identify possible concepts to be represented in the new PROM. What follows in as overview and justification of the elected research design of focus groups.

Following consideration of other forms of qualitative enquiry, focus group methodology was selected. Documentary analysis was inappropriate, since an appropriate source from which to elicit the meaning of stroke self-management was not identifiable. Pursuing an observational line of enquiry through an ethnographic approach was considered problematic since it would involve observation, without a clear understanding of what self-management might encompass to those being observed. Interviews were considered to be an appropriate method, and are now considered in further depth, before presenting the rationale for selection of focus group interviews.

3.5.1 Interviews

In-depth interviews aim to capture the complexities of a situation and discover participants' meanings and understandings (Green & Thorogood, 2009, Wimpenny & Gass, 2000). Through prompting, an interviewer encourages the interviewee to give an account of their situation in their own words (King, 2010). Interviews loosely fall into several categories; narrative, unstructured and semi-structured. Interviews are primarily conducted on a one to one basis (i.e. researcher and interviewee).

In narrative interview, the aim is to encourage the interviewee to tell their story, using their own words with minimal influence from the interviewer (Morse, 1994). Unstructured interviews, in theory allow the interviewee to have most freedom to respond in the way they wish and with minimal direction from the researcher. However, even in the context of unstructured interviewing there may be a tendency to suppress stories (Holstein & Gubrium, 2003). Since the discourse of an interview is jointly constructed by the interviewer and the interviewee, the notion that an unstructured interview can ever be truly unstructured is questionable. Even with the best intentions to allow the interview to progress in a free manner, the researcher will invariably have an agenda, at the least in relation to answering the research question. Semi-structured interviews by contrast usually adhere to an interview schedule or topic guide, and often include prescribed questions, prompts and responses for the interviewer (Bowling, 2009, Tod, 2010).

Individual interviews aim to capture the views of individuals. Group interviews aim to elicit the differing or collective views of a defined group of people (e.g. school leavers, people receiving housing benefit or particular ethnic groups). Focus groups are a form of group interview. They are distinct from other interpretations of group interviews which involve interviewing a number of people at the same time, the emphasis being on questions and responses between the researcher and participants. Focus groups in contrast rely upon interaction within the group based on topics supplied by the researcher.

The interaction between participants makes focus groups distinct to other forms of interviewing (Morgan, 1997; Barbour, 2007). Focus groups draw upon participants' attitudes, feelings, beliefs, experiences and reactions in a way that is difficult using other methods. Compared to individual interviews, focus groups elicit a multiplicity of views and emotional processes within a group context. Focus groups can produce information in a way which allows researchers to find out why an issue is salient, as well as what is salient about it (Morgan, 1997). Both are relevant when identifying potential concepts of importance for inclusion in a new PROM.

An interview guide for the focus groups was considered necessary to ensure that areas which appeared relevant to self-management from the literature were covered. It was also important that participant responses were not constrained, to enable the full perspectives of participants to be captured in the data. The aim was to conduct interviews that allowed participants to lead the discussion following prompts and questions that were framed on an interview guide informed by a research question. My position was therefore to conduct semi-structured, focus group interviews.

3.5.2 Rationale for the use of Focus Groups

Focus groups should be interactive and facilitate discussion, debate and possibly disagreement between participants (Kreuger & Casey, 2009). Some believe this interaction is the central tenet of focus group research:

"*Any group discussion may be called a focus group as long as the researcher is actively encouraging of, and attentive to, the group interaction*" (Kitzinger & Barbour, 1999 p.20).

The group dynamics that focus groups afford potentially facilitate discussion and provide a forum for participants to explore their ideas, beliefs and values about self-management (Kitzinger, 1996, Rabiee, 2004, Warr, 2005). The aim of focus groups is to enable participants to listen to the discussion, reflect on what is said, make their own contributions and potentially reconsider their viewpoint, or provide further arguments in favour of their viewpoint. The reflective and reflexive nature of focus groups means they are particularly appropriate to research involving the exploration of complex, poorly understood or un-researched areas, such as stroke self-management (Barbour, 2007, Powell & Single, 1996).

Focus groups have been used to explore the experience and concept of self-management in other long-term conditions such as diabetes (Lin et al., 2008b), HIV; multiple sclerosis (Thorne et al., 2003); cancer (Gao & Yuan, 2011) and renal disease (Sakraida & Robinson, 2009). Focus groups may provide insight into how knowledge relating to self-management is produced and reproduced. In addition, focus groups have been used, and advocated, in the preliminary stages of the development of new outcome measures (Hibbard et al., 2004, Lutz et al., 2009, Wacherbarth et al., 2002, Willgerodt, 2003). The use of focus group methodology in these studies provides evidence of a precedent in similar areas of research.

According to Morgan (1997) there are three basic ways that focus groups enhance the development of outcome measures. The first is by identifying the relevant concepts that need to be measured. Thus, rather than formulating the measure on the researcher's own assumptions about what is relevant, focus groups ensure that the researcher accesses what participants' consider salient. Secondly, focus groups can be efficient in conceptualising the dimensions of any construct. A relatively small number of groups can generate a large number of ideas about the items required to represent each aspect of a construct. Finally, focus groups can provide insights into appropriate item wording.

3.6 Research Process

The use of focus groups has been justified for phase one of this research. The following sections outline the procedures used to collect and analyse the data.

3.6.1 Setting

This study was conducted at five different localities across the South of England. This constituted a feasible sphere of operation for the researcher within the confines of time and resources, whilst still representing an extensive area of the South of England. Three localities were situated within large urban conurbations; two localities were situated within medium sized urban conurbations.

3.6.2 Sampling Frame

The study took a pragmatic approach to sampling within the confines of resources and time. A decision was taken to recruit from community sources near the locality of Southampton University (maximum distance 50 miles). Community sources were selected because the experience of individuals managing their condition following a stroke, and following discharge from formal healthcare settings is crucial to understanding how people manage their health in their own environment. In addition, it was unlikely that any participant would be known to the researcher, meaning the context of the research would be that of researcher and participant. People who have recently experienced stroke may feasibly be continuing to adapt to new life circumstances, or require more intensive support from health and social services. To understand how individuals manage their health and well-being following the acute phase of stroke, and potential discharge from formal services, a decision to exclude people who had experienced stroke less than three months previously was taken. Therefore, recruitment was sought from community sources with the aim of recruiting individuals at different time points following stroke.

Group dynamics and relationships between participants are thought to be fundamental to participation in focus groups (Farnsworth & Boon, 2010). Since the success of focus groups relies in part on the interaction between participants, questions exist regarding the extent to which the conversation could be ‘natural’ if participants were not known to each other. Focus groups are considered by some to be more ‘natural’ and more akin to everyday conversation than individual interviews (Finch & Lewis, 2003). Within natural groups, participants are thought more likely to respond freely and spontaneously to discussion, within the confines imposed by any questions and group dynamics. The advantages of using pre-existing groups include participants drawing upon group support and more likely to disclose views potentially considered abnormal by those outside of the group (Bloor et al., 2001, Farquhar & Das, 1999). Moreover, researchers recommend aiming for homogeneity within each group in order to capitalise on people's shared experiences (Kitzinger, 1996).

Following consideration of these views, I opted to use pre-existing groups since self-management following stroke is potentially a sensitive topic, whereby shared experiences may facilitate support and discussion. Stroke group members shared a commonality; that of having had a stroke, but their experiences of self-management were likely to differ sufficiently to allow exploration through discussion.

3.6.3 Participants and Sampling

The approach to sampling was purposive. Purposive sampling involves recruiting people with a range of features considered potentially important to the research topic (Curtis et al., 2000, Miles & Huberman, 1994). In order to gain an understanding of the experience of stroke self-management, the inclusion criteria were kept broad to recruit as wide a range of participants as possible. Socio-demographic variations were likely to exist within each group, particularly in terms of the length of duration since stroke, gender, age, ethnicity and level of impairment. This was desirable to reflect a broad range of experience since having a stroke. Participants were invited to take part in the study providing they attended a stroke support group in one of the five localities identified in the sampling frame, and met the following inclusion criteria:

- Community dwelling individuals who reported having had a stroke requiring hospital admission and treatment and who were discharged home, but not to nursing or supported accommodation.
- Individuals who were able and willing to travel to focus group sessions.

In addition to the inclusion criteria, the following exclusion criteria were identified:

- Individuals less than 18 years of age.
- Stroke less than three months previously
- Individuals who had other existing long-term conditions that impaired their ability to manage their stroke e.g. Alzheimer's disease, Motor-neurone disease (this was assessed on an individual basis prior to inclusion into the study).
- Individuals who did not speak English sufficiently to participate in a group discussion.
- Individuals who were cognitively impaired to the extent their communication and ability to participate in an interview was affected, or was a barrier to their free participation.

Cognitive impairment is further explored in the next section.

3.6.4 Ethical Approval

Ethical approval was sought from the University of Southampton, Faculty of Health Sciences ethics committee prior to the commencement of the study. Conditional approval was given in May 2011, and following amendments full approval was granted in June 2011 (appendix three). What follows is an overview of some of the key ethical and governance considerations.

Cognitive impairment to the extent that free and voluntary participation could not take place constituted an exclusion criterion. Approximately 30-40% of people recovering from stroke may experience cognitive impairment (Patel et al., 2002, del Ser et al., 2005). This may involve memory problems, confusion and limitations in the ability to analyse, interpret, plan, organise, and execute information. Communication skills may also be affected. Cognitive impairment however, does not equate to an inability to provide informed consent or free participation (Rose & Kasner, 2011). My stance was that participants should not be excluded provided they could give informed, voluntary consent and have decisional capacity. The participant had to demonstrate the ability for the following through discussion with the researcher at recruitment: understand the study information; appreciate the situation and its likely consequences; manipulate information rationally and evidence a choice. The prospective participant's objection or resistance to participation in any way, at any time, was understood as a refusal or withdrawal and honoured immediately.

Confidentiality and anonymity are important ethical considerations for participants in research, with the principles upheld by researchers unless there are issues of risk or harm. However, the nature of focus group discussion means that researchers are unable to guarantee that other participants in the group will also maintain confidentiality. Both the information sheet and consent form highlighted this to participants. In addition, I requested that confidentiality was maintained at the beginning of each focus group as part of the 'ground rules'. Pseudonyms were also adopted for participants and for any other identifiable feature (e.g. a hospital setting) in the transcription and analysis of data. Focus group data was transcribed by the researcher only and kept electronically, accessible by an encrypted password. All hard copies of personal data were kept in a secure, locked filing cabinet.

Fatigue is another common experience for people recovering from stroke. The focus group sessions aimed to keep to around 45-60 minutes in duration to help minimise fatigue. Participants were encouraged to stand and/or change position as necessary during the focus group session to minimise discomfort.

3.6.5 Research Governance

For all phases of this programme of research, the University of Southampton was the research sponsor and ensured that the protocol had been peer reviewed, that appropriate funding was in place, that I had appropriate and adequate skills and supervision, that a risk assessment was conducted, that the relevant ethical approvals were in place and provided indemnity insurance (appendix three).

3.6.6 Recruitment

The literature suggests different numbers of participants should be recruited for focus group research. Rabiee (2004) advocates between six and ten participants per group. Barbour (2007) suggests an optimal maximum of eight participants. Focus groups conducted with stroke participants suggest that smaller numbers may be more conducive to discussion (Barrett & Kirk, 2000, O'Connell et al., 2001, Salter et al., 2008). Some researchers recommend continuing with focus groups until a clear pattern emerges and subsequent groups produce only repetitious information (theoretical saturation) (Ritchie & Lewis, 2003, Kreuger & Casey, 2009). However, other researchers propose that for simple research questions the number of focus groups necessary may only be three or four (Burrows & Kendall, 1997). This raises questions regarding what can be considered a *simple* research question. In view of the discussion in the literature a decision to conduct a minimum of five focus groups, consisting of no more than ten participants per group was taken.

Access to participants was sought through permission from two stroke organisations. Permission was gained from the Stroke Association (a UK wide charity concerned with combating stroke www.stroke.org.uk) and Different Strokes (a UK wide charity aimed at younger stroke survivors www.differentstrokes.co.uk) to contact community stroke support groups. Both charities run affiliated stroke support groups within the geographical area of the study. In addition, contact was been made with leaders of local stroke clubs to gain permission to advertise the study to their members (appendix four).

In total, eight groups were contacted with agreement to approach members gained from five stroke groups. Once permission was gained from the stroke group leader, the researcher attended one of the group meetings to meet members and as an opportunity to introduce the study and distribute participant information sheets. For participants who found large amounts of text difficult to manage, a pictorial version of the information sheet and consent form was available to aid understanding (appendix five). These were used by potential participants either together with, or independent of, the text version to facilitate understanding. No assumptions about the cognitive abilities of potential participants were made to avoid offence and therefore all participants were offered both versions.

Potential participants were asked to contact the researcher if they required more information about the study or wished to participate. In practice, the participants indicated an interest in participating at the first meeting at each stroke group. On reflection, visualising the researcher and having the study explained verbally contributed to participants' willingness to take part. Potential participants were able to have any queries answered immediately and were able to gauge me, as a person and as a researcher.

As access to groups was largely controlled by the group leaders, this represented my first methodological dilemma. I immediately found that group leaders were often very protective of their members, to the extent that they would on occasion comment on which members would, or would not be suitable to take part in the study, or who was 'interesting' and who was not. I had to ensure that all members in the stroke group were invited, regardless of a leaders' recommendation or opinion. I had to take care that potential participants did not feel that the study was sanctioned (or not) by the group leaders and that people understood that they could freely participate or decline to do so. These were delicate situations, as I did not at the same time wish to undermine the authority of the group leader.

Following contact with one group, the leader was initially receptive and invited me to attend one of their meetings to discuss the study with members. Several of the members were keen to participate, but unfortunately the leader ultimately decided she did not want me conducting the research, due to the group schedule and also due to a perception that the members weren't capable of taking part (despite the interest already shown by individuals). It was difficult to know if the leader was actually acting as an advocate for the group, who perhaps indeed did not wish to take part, or from a personal agenda. I kept a reflective log throughout the duration of the study to help me make sense of the data, but also made a point of reflecting on my contact with group leaders, as it became apparent how crucial this relationship was. In this incident, the people I spoke to appeared genuinely interested in speaking with me and taking part in the study, to the extent that they began recalling some of their experiences and wished to *'sign up'* at the initial meeting. The leader had run the group for 20 years, and had commented previously that they had contact with a researcher before and '*never heard hide nor hair'* following initial contact. Perhaps this poor experience was influencing the leader's decision to engage with additional researchers. In addition, the prior research contact with the group appeared to involve individual interviews with members in their own homes. The leader was very keen that I use this approach as opposed to a group discussion. Unfortunately, ultimately I could not undermine the group leader, nor indeed hold a focus group without their consent. As a courtesy, I wrote to those participants who had indicated an interest to apologise that the study could not take part due to the group schedule.

Each group leader suggested a convenient date, where I could return and conduct the focus group. These dates fell on the same day and time as the usual stroke group meetings. Each venue had a separate area where the discussion could be held, so that for those who did not wish to participate, the meeting could proceed as usual. Following recruitment, a confirmation letter was sent to each participant with a reminder of the date for the focus group and a copy of the consent form, so that participants could familiarise themselves with what they were being asked to consent to.

Socio-demographic information

Once a participant indicated an interest in participating, they suggested a convenient time for me to contact them to collect some additional information. Some participants wished to do so by telephone or through face to face contact with the researcher. Others, particularly those with speech limitations, opted to use email communication.

In order to describe the sample, the participants' level of functional independence was recorded using the Barthel Index (BI) (Mahoney & Barthel, 1965) (appendix six). The BI is advocated as a measure of functional independence and physical functioning by the Intercollegiate Stroke Working Party (2012a) and had been used widely in stroke research (van Hartingsveld et al., 2006, Quinn et al., 2011). The BI comprises ten items about activities of daily living and has a maximum score of 100, indicating optimum independence and function. Physical functioning remains a dominant concept within stroke rehabilitation, despite increasing evidence of the role of psychosocial factors in recovery (Chau et al., 2009). Effective stroke self-management is likely to extend beyond the ability to perform certain tasks, encompassing decision making and choices regarding health and behaviour. Nonetheless, in order for the study to have maximum transferability, BI scores were collected to enable description of the range and average functional abilities of the sample.

Sociodemographic information was also collected to enable description of the sample (table 3.1). Some details provided information which supported potential lines of questioning in the focus groups. For example, if a participant required home care to carry out activities of daily living, or was a widow, this was something that I could be sensitive too during the focus group. On reflection, this also enabled the development of rapport and empathy between the researcher and the participant which helped to foster trust.

Characteristic	Rationale
Age	Describe sample
Gender	Describe sample
Length of time since first stroke	Describe sample
Social circumstances (where residing, with whom)	Describe sample
Marital Status	Describe sample
Current occupation	Describe sample
Other Health Conditions	Enables researcher to establish if stroke is the main heath problem for the participant, or assess the extent that other conditions impact upon ability to self-manage.
Occupation prior to stroke	Provides supporting information regarding the impact stroke has had on participant
Details of any care	Provides researcher with information to assist focus group discussion and supporting information on participant self-management ability
Stroke history (treatment and rehabilitation)	Provides researcher with information to assist focus group discussion. Enables development of rapport and building of empathy.

Table 3.1 Summary of socio-demographic characteristics collected at recruitment.

3.7 Interview schedule

A semi-structured interview schedule was developed to enable the discussion to flow and to allow probing with regard to areas identified as potentially relevant to stroke self-management from the literature (appendix seven). The aim was not to constrict the discussion to the topic guide, since the intention was to understand the experience of participants, but to use the guide as a way of ensuring the discussion remained focused upon the research question. In line with standard practice, the discussion commenced with a neutral question to ease participants into the discussion (Barbour, 2007; Kreuger & Casey, 2009).

3.8 Conducting the Focus groups

3.8.1 Pilot Group

Planning and running a focus group is a skilled endeavour (Barbour, 2007). Individuals used to group work and meetings may have useful skills transferable to conducting focus groups (Puchta & Potter, 2004). Although I had previous experience of running groups from clinical practice, I had not conducted a focus group before. Therefore, a pilot focus group was first organised to enable me to become familiar with the different skills required in running a successful focus group and to enable the procedures and interview schedule to be tested and revised. The group was arranged with a local stroke group. A colleague of mine who had previously run focus groups acted as an observer, both for additional support and to provide constructive feedback. The group was not told that the discussion was a pilot, since at this point it was uncertain what procedures, if any might be changed as a result of the pilot and I did not want to unduly influence any data that could consequently be used.

I was able to share and discuss my interview schedule with the observer prior to the pilot, which enabled me to enhance my style as a moderator. The observer made a plan of where the focus group participants sat, assisted with ensuring the participants were comfortable, had refreshments and contributed in making everyone feel at ease. The observer also made a record of any non-verbal communication that occurred during the discussion. Overall, the feedback from the observer was very positive. I was encouraged to intervene in situations that deviated from the topic guide earlier. In addition we discussed the quality of data that could be obtained if future groups were conducted with the relatively large number (n=9) of participants. I was also able to discuss the pilot proceedings in depth with my supervisory team. Following this discussion, it was clear that the pilot procedures and topic guide were acceptable to address the research question and study aims and was therefore the procedure adopted in the remaining focus groups. The data from the pilot group was therefore justifiably included in the analysis.

3.8.2 Procedure

Focus group sessions were held in stroke group venues at times familiar to participants to minimise disruption to participants. Prior to the groups commencing, the researcher checked and set up the venue and recording equipment, organising the seating in a circular arrangement, around a small table so that refreshments and the audio-recording equipment were easily accessible. Participants were asked to arrive around thirty minutes before the actual planned start of the focus group discussion. As participants arrived the researcher or observer greeted them. The researcher completed any travel reimbursement requests and checked through the consent process. The consent form was available in both text and pictorial versions, as with the participant information sheet. Participants were advised to sign (where able) the version of the consent form that made most sense to them. Where a participant was unable to sign, a signature by proxy was required and was sought by their carer. The consent form was documented to indicate the reasons for consent by proxy.

Participants often wished to attend with a carer; often this was a relative but on some occasions was a formal carer. My stance was that unless the participant had communication difficulties, and required somebody to accompany them to facilitate their communication, carers could not attend the focus group. Carers were invited to join the stroke group meeting that ran concurrently, or wait outside until the discussion finished. This decision was made to ensure equity to all members of the focus group, and to allow the discussion to focus upon the perspectives of the person recovering from stroke. This decision appeared to be acceptable to participants.

Following consent, participants were invited to sit where they felt comfortable, offered refreshments and asked to wear a name badge to enable me to remember names. This was particularly relevant in the pilot group (nine participants) however in subsequent focus groups, which were smaller this was less of an issue and not required. Once all consent forms were completed and checked, the focus group discussion commenced as per the interview schedule.

Focus group discussions were recorded using a professional quality digital recorder and transcription kit (Olympus WS300M & AS4000). Prior to the discussion commencing, participants were first asked to state their name and favourite food to enable recognition of voices and ease of transcription. This also served as an ice-breaker and as a way of relaxing participants (Bloor et al., 2001). I introduced myself as a researcher interested in stroke. I also chose to introduce myself as a nurse. I felt participants would potentially be more willing to discuss issues relating to health if they felt I had some understanding and empathy regarding their situation. However, I was aware that this may prevent participants from discussing potentially negative experiences of care. Therefore, I was careful to point out that I was not currently practicing as a nurse and would not disclose anything they chose to discuss with anyone, unless it was clear that somebody was at risk of harm. The five focus groups lasted between 45 and 80 minutes. At the end of each discussion, the recording equipment was switched off and participants were thanked for their time.

Immediately following the discussion and clearing away, I took the opportunity to reflect on the proceedings, recording any immediate impressions and areas of interest in my reflective log. I also reflected on what had gone well, or not as well as expected so I could make plans and revisions for the next focus group session. These field notes, in addition to the notes made by the observers were used to assist analysis of the data.

Additionally a more detailed reflection occurred as soon as possible following focus groups sessions, in private, based on a pro forma used in previous clinical practice (figure 3.2).

Fig 3.2. Pro forma used to guide focus group reflection
Significant external factors? (current affairs, transport, weather, etc.)
Was venue and access to venue acceptable? (seating, temperature, facilities, parking etc.)
Was there sufficient time prior to commencing? (consent procedures, participants to settle, etc.)
Initial impressions of Group Dynamics:
What went well & why?
What could have gone better & why?
What could be improved upon for the next session?
Initial significant impressions of data:
Other comments:

3.9 Approach to analysis

Before formal transcription of the data, the focus group recordings were listened to several times along with the written field notes, to familiarise with the content and context of the data. I transcribed the data, to allow myself to become familiar with the data, identify early areas of interest and further reflect on the focus group proceedings (Bloor et al., 2001). As well as verbatim transcription of the data, changes in tone, pauses in speech and non-verbal utterances such as sighs and laughter were recorded. Interruptions or where more than one person spoke at the same time were indicated using ‘…..’ to indicate where there was an overlap in speech.

The main speaker for each section of the transcript was identified. Pseudonyms were used throughout. Where, I as the facilitator spoke, this was indicated in bold type. Speech was designated in italic text. Non-verbal utterances, body language and where an explanation of context was required were indicated in square brackets e.g. [laughs]. Where a section of a quote was taken, this was indicated using ‘….’. Figure 3.3 illustrates an example of transcription style.

Tim: [laughs] *I said that er* [pause] *it's like a* [pause] *well the expert patient programme are coming down to talk to us* [the stroke group] *in October* [interrupted] (FG II)

Alex: ….*and just that* [pause] *gives you, you know, self-help. This* [indicates group] is *self-management* (FG V)

Fig 3.3. Example of transcription style

According to Rabiee (2004), qualitative data analysis follows a process which aims to bring meaning to a situation rather than the search for an absolute truth. Critics have pointed to the lack of clear analysis procedures in focus group research (Webb & Kevern, 2001). Inevitably there is an extent of subjective selection and interpretation of the data by the researcher. As Mays and Pope cite '*All research is selective--there is no way that the researcher can capture the literal truth of events'* (Mays & Pope, 1995 p.110). However, it is important to draw attention to the potential for subjectivity, regardless of the type of research paradigm. Therefore to promote the rigour of focus group findings researchers must state a clear, systematic, sequential, verifiable, and continuous data analysis process (Kreuger & Casey, 2009).

Analysis focused on bringing understanding to the substantive issues from the focus group data, to inform a conceptual model of stroke self-management and identify potential content for a new PROM. It was vital to maintain a focus on the goal of the focus groups, in order to drive the purpose of the analysis process and avoid being distracted by interesting issues that did not relate to the purpose of the study (Miles & Huberman, 1994; Kreuger & Casey, 2009). This study had a clear purpose, and therefore it would have been disingenuous to adopt a data-driven grounded theory approach, since there was a distinct desired end product; the generation of items for a new PROM.

Some researchers advocate clearly stating the approach to analysis prior to commencement so that it could be reproducible, thus enhancing rigour

(Green & Thorogood, 2009; Rabiee, 2004). Other researchers argue that stating a clear procedure for data analysis is hindered by the reflexive nature of analysis as researchers make choices during analysis about the interpretation of data and which extracts to present as evidence (Mauthner & Doucet, 2003). To ensure the analysis process is understood and to inhibit selective perception, the approach to data analysis prior to commencing the analysis process is next asserted. The influence of my epistemological, cultural and ontological positions upon analysis are considered in chapter four.

The approach adopted, given these considerations was Thematic Analysis to help identify the salient issues in the focus group transcripts. Analytic Induction was used to help synthesise these themes and move towards a conceptual model of stroke self-management. Thematic analysis is not attached to a specific theory or epistemological background (Braun & Clarke, 2006). Therefore it has the advantage of not possessing any constraints and can be applied in a wide range of scenarios. The data analysis process followed is stated below:

1. Focus group recordings were transcribed by the researcher and integrated with the additional field notes of the observer and reflective log, to allow development of familiarity with the data.
2. Transcripts were re-read in conjunction with the recording. Transcripts were amended accordingly if items were missed or transcribed incorrectly. This allowed further reflection on the focus group proceedings.
3. An overview of the group, including items of interest, initial impressions, thoughts and reflections were noted.
4. Transcripts were read and codes were generated to describe the content of the data in a literal sense (Mason, 2002).
5. Transcripts were re-read to identify relationships between the initial descriptive codes, sufficient to constitute a similar category (Gibbs, 2007) (e.g. requesting a referral and sourcing aids become ‘resources’)
6. Categories were then considered in light of the context of the focus group (drawing on reflections made after each group) and emerging themes were identified (Green & Thorogood, 2009). Data were managed by organising

sections from the transcripts that referred to the relevant theme, using Microsoft Word™.

7. Each focus group was transcribed and reviewed, before the next group was conducted to enable me to gain a sense of the salient issues and adapt my questioning style accordingly.

The bulk of the analysis was conducted using visual representations and Microsoft Word™. The volume of data generated made computer software packages an attractive possibility, to help manage the analysis process. Therefore NVivo was initially used after the transcription and manual coding of all the Focus group interviews was complete (NVIVO, 2010). However this required treating the data in such a manner that the underlying context and meaning of the data became distorted. The concern that using a qualitative software package potentially seduces the researcher away from a reflective engagement with the data has been commented upon elsewhere (Green & Thorogood, 2009). Additionally, some researchers argue that the use of a software package may distract a novice researcher from developing a robust coding scheme (Gibbs, 2007; Kidd & Parshall, 2000).

Making sense of relationships between sub-themes and themes

A process of Analytic Induction was adopted to help synthesise findings from the focus groups. Analytic induction is a method of data analysis described by the Sociologist Znaniecki, who named the method and organised many of the associated ideas (Znaniecki, 1934). Analytic Induction holds similar tenets to Grounded Theory. Inductive reasoning is involved, allowing for modification of concepts and relationships between concepts, with the goal of most accurately representing the reality of the situation. Glaser and Strauss make the distinction between the theories arguing that Analytic Induction involves '*generating theory as well as testing theory*', in contrast to Grounded Theory which emphasises the '*generation of theory without testing*' (Glaser & Strauss, 1967 pp 103-105). All available data is used to test hypotheses, in contrast with the constant comparison approach (used in Grounded Theory) which requires that data is collected until all categories become saturated.

Frankland and Bloor (Frankland & Bloor, 1999) have since revised Znaniecki's method of Analytical Induction, as follows:

1. Initial theoretical statements are constructed to explain the data
2. Statements are modified following comparison with emerging themes and concepts
3. Theoretical statements are continually revised until they reflect the data as accurately as possible and anomalies can be justified.

An example of how Analytic induction guided analysis is set out in table 3.2 with regard to the sub-theme of *Determination* (over-arching theme *Individual capacity).*

- An initial statement to explain the data was constructed, as follows: 'Motivation is required for people to carry out self-management activities'.
- Motivation appeared to be affected by additional factors (e.g. responses of health professionals, access to resources to enact self-management).
- 'Motivation' was revised to 'determination', the term used by participants.
- The initial statement was thus revised to 'People require determination to navigate the self-management resources' 'People's determination to self-manage may depend on the responses of professionals'.
- This process continued until the facets of determination exhibited in the data were described adequately by the theoretical statements.

Table 3.2 Example of Analytic induction process (Determination, from theme of 'Individual capacity').

From the transcripts, motivation to return to a 'normal' life appeared to be central to participants' experiences. An initial statement was constructed to explain the data. The data suggested that motivation might be dependent upon additional factors as illustrated in table 3.2. 'Motivation' was subsequently revised to determination, since this term was most often used by participants and 'motivation' may be associated with value judgements about desirable behaviours. The initial statement was thus revised to account for other findings in the data. This process continued until the facets of determination exhibited in the data were described adequately by

the theoretical statements. To provide clarity for the reader, a summary is provided of the key concepts relating to self-management within the literature that informed thinking during analysis (table 3.3).

Concept	**Associated literature**
Goal setting, motivation (are these separate issues)	(Dixon et al., 2007; (Karner et al., 2005)
Social support- Emotional, Practical, Financial, Informational, Motivational	(Audulv, 2011; Dixon et al., 2007, Robison et al., 2009; Kendall & Rogers, 2007)
Support from healthcare professionals	(Audulv et al., 2010; Dowswell et al., 2000; Rogers et al., 2009 ; Wilson et al., 2006)
Decision Making	(Thorne et al., 2003)(Battersby et al., 2010b)
Self-regulation, monitoring	(Clark et al., 2001; Kralik et al., 2004)
Social role	(Townsend et al., 2006)
Adapting to living with a long-term condition	(Robison et al., 2009; Dixon et al., 2007; Doyle et al., 2004)
Barriers to self-management	(Audulv et al., 2009; 2011; Bayliss et al., 2003; 2007; Jerant et al., 2005; Kennedy et al., 2007)
Self-efficacy	(Audulv et al., 2009; Dixon et al., 2007; Dowswell et al., 2000; Kralik et al., 2004 ; Jones & Riazi, 2011 ; Jones et al., 2006, 2009 ; Marks et al., 2005 ; Robinson-Smith and Pizzi, 2003 ; van de Laar & van der Bijl)

Table 3.3 Summary of concepts used to inform focus group analysis

Limitations with this approach

Whilst transcription of focus group proceedings can be viewed as a necessary step in managing and analysing data generated, this approach is not without its pitfalls. Kvale (1996) highlights that researchers should be mindful of transcripts, since the change in medium introduces issues of accuracy, fidelity and interpretation. It is difficult to replicate key aspects of the focus group such as tone, body language and the context of the spoken word within a transcript. Arguably in this sense transcripts can never be completely accurate and coding may remove fragments of the text from its context, resulting in some loss of meaning. It was therefore essential to re-read sections of transcripts with the original recording playing simultaneously during analysis, to draw upon the essence of the group that could not be captured in a textual representation.

Questions exist regarding the extent to which maintaining complete objectivity in analysis is achievable, since researchers are intuitive beings with their own life-world. A researcher inevitably brings their own experiences and frames of reference to the interpretation of meaning (Kidd & Parshall, 2000, Silverman, 2001). This viewpoint is countered as far as possible by openly stating the processes adopted in analysis (Tong et al., 2007).

3.10 Summary

This chapter has justified focus groups as an appropriate method for exploring the experience of self-management for those recovering from stroke and has outlined and justified the procedures adopted for collection and analysis of data. Chapter four discusses the findings from the focus groups.

4. Chapter Four- Focus group results

4.1 Introduction

This chapter presents the findings from the focus group study. First, an overview of the participant socio-demographic characteristics is provided. Next, consideration is given to the effects of the researchers' professional and cultural positions on the collection, analysis and interpretation of the data. To further illustrate this, an exploration of critical incidents is used. Thereafter, each of the themes that developed from the data, are discussed in detail, drawing on quotations from participants to evidence the interpretations made. Reflections are next made concerning the issues around interpreting data from differing groups, and of the role of group dynamics. Finally, a proposed conceptual model of stroke self-management, informed by the data analysis is presented.

4.2 Focus group participants

Eight community stroke groups were contacted to take part in the study; five groups subsequently agreed to participate. A total of 31 people expressed an interest in taking part in the study; 28 of whom actually participated. Two people withdrew due to prior appointments that clashed with the focus group discussion, and one person was excluded because of advanced dementia. A summary of the participant socio-demographic characteristics is presented in table 4.1.

Two focus groups (FG II and V), representing 32% of the total sample, were conducted with younger participants recovering from stroke, (<65 years old) recruited via Different Strokes, a charity aimed at supporting younger stroke survivors. Table 4.1 indicates that the sample was broadly representative of a typical stroke population, and that the groups were similar to each other. The following sections highlight socio-demographic details of particular note.

4.2.1 Participants with communication limitations

Eight participants (28%) experienced dysphasia and limitations to their communication as a result of their stroke. Five participants with dysphasia opted to bring a relative to help support their communication in the focus group discussion. Three of these participants had almost no vocal speech. Relatives were asked to present only the perspective of the person with stroke. However, it is impossible to guage the extent to which this was the case. To minimise the possibility of eliciting carer perspectives, the researcher sought to direct questions to the person affected by stroke, and verified the accounts of carers using verbal prompts, such as ‘*Is that what you feel*, *X*?’ or ‘*Does that sound right, X*?’. The field notes of the observer were crucial to the interpretation of the data, as notes on body-language and facial expressions became vital to understanding the perspective of those with communication impairment and verifying the accounts of relatives.

	FG I	**FG II**	**FG III**	**FG IV**	**FG V**	**Summary for all groups**
No. of participants	9	4	4	6	5	28
Age range (years) Mean [SD]	(66-92) 80.44 [8.09]	(38-58) 47.5 [8.22]	(73-85) 76.75 [5.56]	(56-75) 64.33 [7.68]	(41-60) 46.6 [7.98]	(41-92) 65.67 Mode 74
Male: Female gender	4:5	2:2	1:3	2:4	2:3	11:17
No. with dysphasia	4	2	1	1	0	8
Mean duration since stroke (months) [SD]	83 [95.7]	23.5 [10.21]	43 [15.87]	76 [31.96]	50 [37.93]	57.89 [60.80]
Marital status						
Married	3	3	3	3	2	14
Single	1	0	0	0	0	1
Widowed	4	0	1	1	1	7
Living with partner	0	1	0	0	2	3
Divorced/separated	1	0	0	2	0	2
Mean length of formal education [SD]	13.4 [4.77]	10.5 [0.57]	10.5 [0.57]	11 [2.68]	13.4 [3.57]	11.89 [3.62]
Ethnicity						
White UK	7	3	4	6	4	24
Non-EU	1	1	0	0	0	2
Other EU	1	0	0	0	0	1
Other UK	0	0	0	0	1	1
Mean Barthel Index [SD]	76.1 [25.34]	76.25 [7.5]	75 [28.28]	80 [18.70]	87 [29.06]	78.70 [22.34]

Table 4.1. Socio-demographic characteristics of focus group participants

Of those participants with communication impairment, and who did not bring a relative to support communication, one person had almost no speech. In this case, the participant opted to use a personal communication book to facilitate participation. During the focus groups, the researcher ensured that I sat next to, or opposite participants with communication difficulties to be more attuned to non-verbal communication, and maintain eye-contact.

It is testament to the supportive nature of the stroke groups that people with communication impairment participated. The environment was welcoming, and fellow participants were people with whom they were familiar and who were accustomed to pausing and allowing people time to express themselves. Therefore, conducting the focus groups with pre-existing groups arguably aided the inclusion of people with communication impairment. This was important, to ensure the study was inclusive and because people with communication impairments are often under-represented in stroke research.

4.2.2 Barthel Index Scores

The Barthel Index (BI) a measure of functional independence (score range 0-100, higher scores indicate greater independence), was scored at recruitment by the researcher with participants. The lowest BI score was 35 (FG III), the highest 100 (FG I, V). BI scores were not statistically different between the five groups (p=0.27), providing evidence of the homogeneity of the sample. The mean BI score across groups was 78.7, indicating a limitation in the ability to perform activities of daily living. It is difficult to describe the typical limitations of a person with this score. There is a lack of consensus regarding the categorisation of scores to indicate what constitutes a moderate or minor limitation (Roberts & Counsell, 1998). The BI is limited by a lack of comprehensiveness in assessing independence (Duncan et al., 2000). In this study several participants scored a maximum of 100 indicating no limitations, yet could not read, write and had problems with memory, arguably affecting their ability to be independent. Despite the limitations of the BI, it remains the preferred outcome measure of choice for assessing function following stroke (Intercollegiate Stroke Working Party, 2012a) and therefore it's inclusion in this study assists transferability of findings.

4.2.3 Duration since stroke

The mean duration since stroke for the five groups was 60 months. Large variations in duration since stroke were observed across the sample. The shortest duration since stroke was three months (FG V) and the longest was 27 years (FG I). This was advantageous to the study since the sample most likely had a wide range of perspectives and experiences of self-management that could be drawn upon.

4.2.4 Social circumstances

Whether or not a person affected by stroke is living alone may affect their ability to perform self-management. 61% of the sample were married or living with a partner (mean BI score 75, SD 21.28). The remaining 39% lived alone (mean BI score 85, SD 18.03).

4.3 Data Analysis- the researcher perspective

Qualitative researchers, in this case as a focus group facilitator, are part of the generation of data and are therefore unable to completely avoid personal bias. The consolidated guidelines for reporting qualitative research (CO-REQ) advocate standards that researchers should adopt in reporting study findings (Tong et al., 2007), one of which concerns specifying the researchers '*identity, credentials, occupation, gender, experience and training'* (p.351). This increases the credibility of study findings by allowing readers to assess how these factors may have influenced the researchers' observations and interpretations (Mays & Pope, 2000, Morse et al., 2002). Accordingly, the researcher's background is next stipulated to enable the reader to consider the extent this may affect interpretation of the data.

I am a registered nurse undertaking further learning in pursuit of a PhD. Both affiliation with the University of Southampton and status as a registered nurse, could have been perceived by participants as positions of authority possibly with ‘expert’ knowledge. During one group meeting I attended to introduce this study, the first question asked was ‘*Am I going to have another stroke?*’ This was a disconcerting question. The introduction as a researcher, perhaps lead the audience to think I was attending to provide general information about stroke. Another person commented about how someone she knew was different because ‘*he’s had a stroke, actually in his brain’*. Both incidents were valuable lessons in the importance of choosing language carefully by not assuming that what researchers, or clinicians, hold as ‘obvious’, may not be the case with other people. The revealing of my profession was done so in order to help engender trust with participants. Some participants were, however, wary of this profession due to prior poor experiences with nurses. Conversely, some participants were very keen to emphasise how wonderful nurses were, perhaps indicative of an attempt on their part to build a relationship with me.

My appearance was that of a white caucasian, professionally dressed female in her mid-thirties, without any obvious impairment. I speak without any obvious regional accent. Many of the participants had an obvious physical impairment, and some had limitations in speaking. It is reasonable to say therefore that my appearance did not resemble the majority of focus group participants. I took particular care with my appearance on the day of the focus group discussions. This was particularly important when visiting groups with older participants. A conscious effort to dress more conservatively was made in line with a perception that this appearance would be considered appropriate by this age group.

Some of the concerns appeared more indicative of my anxieties in conducting the study and wishing to make a good impression. One group leader appeared to scrutinise me more than any other. The group was run by several retired physiotherapists, as clearly expressed by them on my first contact with the group. It is interesting to consider why this was revealed. Perhaps it was because of a perceived professional courtesy, so we could therefore engage in an open professional dialogue. However, the leader was keen to know if I was ‘*used to patients and how difficult they could be*?’

perhaps more indicative of a desire to protect 'her' group or to gauge my credentials. The leader indicated that the group was the '*only source of support'* for people with stroke, also giving the impression that she found this unacceptable.

Arrangements with this group were approached cautiously. A conscious effort was made to ensure the leaders felt involved in the study as far as possible, without actually revealing details of the focus group discussion. It was challenging to defer those concerns before commencing the focus group. Interestingly this group was the most smoothly run focus group, in terms of organisation, refreshments and timing, largely due to the efforts of the leaders. Therefore it is reasonable to suppose that I was in fact accepted by the leaders.

4.4 Qualifying the term 'self-management'

As part of the focus group enquiry it was first necessary to clarify participants understanding of the term self-management. An element common to all groups was that the term 'self-management' was unfamiliar, and was not used by participants in their usual discourse. This is perhaps unsurprising considering that the term has evolved from the spheres of policy and professional practice, and as yet has not been clearly conceptualised in the literature. When the meaning of self-management was explored, participant interpretations suggested that self-management was a way of maintaining independence (Box A).

Box A
What do you think it [self-management] ***might mean?***
Felicity: *helping yourself, yeah*
Joy: *getting on and doing it yourself*
(FG, IV)

It's having the ability to look after yourself in the sense that you are able do things for yourself.." (Nathan, FG II)

The term 'self-management' appeared to encompass coping, promoting recovery, and maintaining independence (Box B). The range of perceptions is

partly reflective of unfamiliarity with the term self-management prior to the focus group. Despite being unfamiliar with the term, participants gave a broad range of activities that they considered to relate to managing their health post-stroke and appeared to be familiar with the operation of the concept (Box B). Participants clearly articulated a range of physical, psychological and social actions they took as part of managing their health post-stroke.

Box B

'I assume it's [self-management] *trying to help people with strokes, or problems, to utilise whatever they can get their hands on to try and get them back into society and into erm communities..'* (Male, FG V)

'*Coping with stuff like your finances and getting your own care*..' (Female, FG IV)

'*It's like a day to day routine. How to help yourself and maybe improve your condition…'* (Male FG II)

'It's about taking your pills ….' (Male FG I)

Conversely, some participants expressed that self-management appeared to be a pointless term to them, in part shaped by previous experience (Box C).

Box C

Well, er [pause] *it's just that it* [Self-management] *could be a load of rubbish* [laughs] *No disrespect, but.*
A load of old Rubbish
Yeah, I mean, a lot of the things in the old thingy-bob, in the old er OT [occupational therapy] *I mean it's just obvious stuff really.*
Ok, so it might be telling you stuff that you already know?
Yeah, just silly stuff, you know what I mean? Borders on being really patronising.

(Male, FG II)

Participants acknowledged that self-management is something people following stroke 'do' anyway and therefore may not require a separate focus, since it is an implicit part of life after stroke. That self-management is not optional for most people with a long-term condition, has been highlighted in the literature (Kendall & Rogers, 2007). Self-management was often discussed in terms suggestive of an on-going struggle and of the need to self-manage to maintain independence and autonomy (Box D).

Box D

So you know, I've always tried to be a bit of a fighter [laughs, pause] *so when I did get up I was trying to walk round the ward, because you know I was paralysed on the right side because I'm left-handed, I can still write* [pause] *Well I think you have to, you have to put yourself through it....*

(Male, FG III)

Well it's survival, isn't it? At the end of the day, you've got to get on yourself and do the best you can.... I think you just try and be independent. Be it physically or mentally...'

(Female, FG IV)

The term 'self-management' appeared to encompass a range of elements, such as coping, promoting recovery, and maintaining independence plus being acknowledged as an implicit part of life after stroke. The range of perceptions is partly reflective of unfamiliarity with the term self-management prior to the focus group. The following sections discuss the key themes which describe the experience of self-management following stroke.

4.5 Development of themes

Analysis was an evolving process that took place over a period of approximately ten months, including further reflection upon analysis to present the data for the final thesis and preparation for publication. The principal focus of analysis was to identify possible areas of stroke self-management which may be conducive to measurement, and thus inform potential items for a new PROM. However, a consequence of analysis also revealed the reality of stroke self-management from the perspectives of the focus group participants. This is of importance to understanding the overall experience of self-management following stroke.

Not everything described by participants about their self-management experiences, had relevance to a PROM which seeks to measure stroke self-management behaviours and attitudes. For example, participants reported dissatisfaction with hospital inpatient stays which left many feeling disempowered. This may require organisational or cultural changes on the hospitals and staffs' parts to rectify, arguably outside the remit of a self-

management intervention focused on the individual. A self-management intervention targeted at the individual may focus on improving coping skills for future situations. Coping skills may be amenable to measurement in a PROM, however the original dissatisfaction with the hospital stay is unlikely to change, but still represents an important aspect of the individuals self-management experience.

Analysis of participants' experiences of self-management revealed three over-arching themes that affect self-management following stroke; *Individual Capacity*, *Support for self-management* and *Self-management environment* (Fig. 4.1). The theme *Individual Capacity* is thought most likely to reflect facets indicative of an individual's attitudes or behaviours that relate to self-management and that potentially may change following an appropriate intervention. What follows is an exploration of these themes and the contributing sub-themes. Consideration is given with regard to the extent that the findings are favourable to measurement.

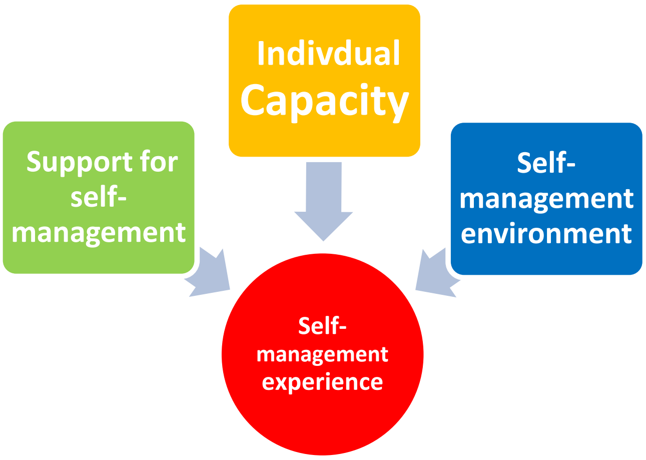


Figure 4.1. Themes contributing to stroke self-management experience.

4.5.1 Theme One – Individual Capacity

The data suggests that a persons' effectiveness at self-management is an important influence upon the stroke self-management experience of that individual. 'Capacity' in this context refers to an individuals' ability or readiness to respond to the demands of self-management following stroke. Individual capacity includes both the presence of skills which facilitate self-management and the absence of barriers. The accounts of participants

suggested that individual capacity was a key component of self-management. Several concepts, represented as sub-themes (figure 4.2) appeared to be significant to an individuals' capacity for self-management. What follows is a description of these concepts and the relationship to the theme of *Individual Capacity*.

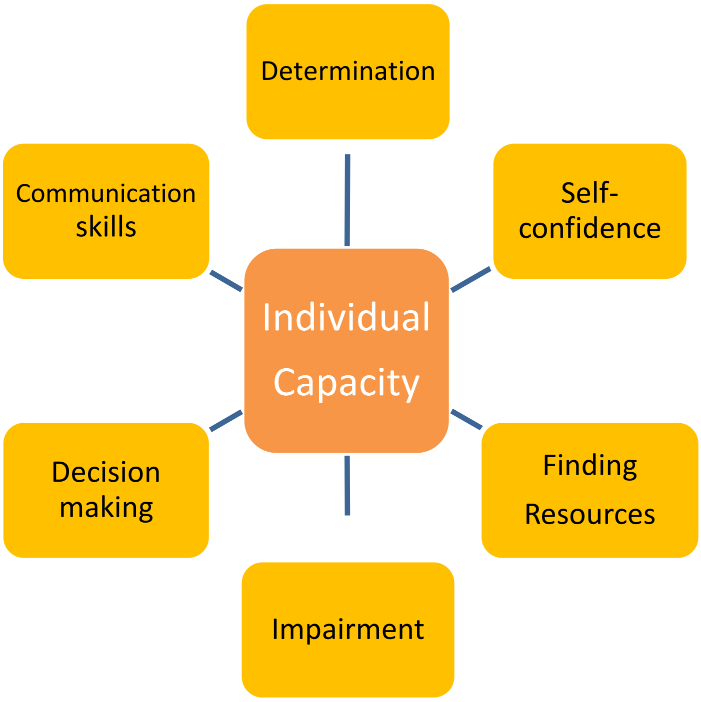


Figure 4.2. Sub-themes contributing to the theme of 'Individual capacity'

4.5.2 Self-confidence

The data suggested that confidence was important to an individuals' capacity for stroke self-management. The extract in box one illustrates how confidence was important to maintaining capacity and progress and can be facilitated by other people. Participants' accounts suggested that capacity to self-manage is often difficult to maintain without external support (Box one).

Box one

. *....somewhere where you can get together and just chat about your condition, and if you felt, or they would say to you 'you're better than you were 2 weeks ago'. Someone to give you* (pause) *confidence, that sort of thing, to keep you going....*

(Male, FG I)

Participants talked about the role of self-confidence in maintaining progress after stroke. Health professionals appear to have a role in maintaining confidence after stroke (box two).

Box two

But I think, self-help can only kick in, once you've had that initial support. If you then, if you start of by not getting that initial support, how do you find the way to self-help?

(Female, FG V)

You feel good when he [stroke physician] *says how well I am doing* (Male, FG II)

Differing levels of confidence appeared to exist in relation to different aspects of capacity for self-management. For example, a person with memory impairment may have less self-confidence impacting on capacity to take medication than to exercise.

Participants recognised that stroke groups constituted a self-management strategy in their own right, often serving as a forum for exchanging ideas and support on how best to self-manage. This exchanging of ideas and strategies may also serve to increase confidence (box three). Recognition of self-improvements and achievements appeared to be a vital source of encouragement and a way of enhancing confidence.

Box three

This is why it's [the stroke group] *so important because otherwise you can be so isolated..and don't know what you're doing* (Male, FG IV)

Improving confidence may be a feature targetable in self-management interventions. As well as stroke groups, professionals have a role in promoting confidence; this role is discussed in section 4.5.9. Confidence appears to be an important aspect of individual capacity to self-manage following stroke and is potentially amenable to measurement in a PROM.

4.5.3 Decision Making

Participant accounts suggested making decisions is an essential requirement of self-management (box four). The notion of being an active decision maker,

not a passive recipient, appears important to individual capacity following stroke.

Box four
Ron: *well, that's the thing, is it's having the mind to be able* [emphasis] *to control what you want to do and how you want to do it..*
mmm
Gwen: *mmm*
Ron: *…if you, if you know become a vegetable, you can't make up your mind on anything* [emphasis], *you know, then you really do want some help, don't you? You know*
[FG III]

Participants discussed how making decisions about treatment and therapies was aided by appropriate information, and felt that making decisions on such issues was their right and central to self-management. Decision-making within self-management was reported as a complex process, frequently undertaken by individuals as they appraise and evaluate the cost or benefit of different treatment and therapies. Often, it was apparent that the factors that enhance the ability to make decisions, such as adequate information and communication skills were not ideal (box five). Decisions taken appear to have the potential to have long-lasting consequences on an individuals' capacity to self-manage.

Box five
I know that when I was in hospital, they (physiotherapists) *said 'you can either work on your leg or your arm. We can't, we can't do them both'...No, so I thought, 'what do you want?' well I thought 'I'd rather be able to walk'.....because I had two young daughters at home, I'd rather be able to walk, but not use my arm. Because I thought, you know I've still got one arm and I can faff about at home on me own, but there was walking I really wanted, because they said your brain can't cope at the time with trying to get your arm going and your leg at the same time. They said we've only got this much time, so we concentrated on my leg. And that's why the arm is left like this* [indicates arm which rests on the table], *because they just didn't do any physio on it. You know we concentrated on my leg all the time..*
[Teresa, FG IV]

Decision-making following stroke appears to be important to maintaining control and autonomy in recovery. Decision-making and the factors that enhance the ability to make decisions, such as adequate information and communication skills are potentially amenable to measurement and represents an important aspect to include in a new PROM.

4.5.4 Determination

Stroke represents an unexpected and dramatic event in an individuals' life. Participants talked about how determination played an important part in their capacity for stroke self-management. Determination was important to individual capacity to self-manage and the continuation of progress in spite of adversity, frustration and impairment (box six).

Box six

So it might be that things like pain, and other things too, stop you from doing what you really want to do?

Rihanna: *'No.. I will do it I erm erm* [pause] *I will do it with the pain. And my leg is* [emphasis] *painful, and I, I erm* [pause] *will do it erm* [smiles]

What makes you carry on [with therapy exercises]?

PAUSE

Rihanna: *erm,* [pause] *hope* [laughs]

Frances: *Determination*

Rihanna: *Hope* [speaks at same time as Frances]

Nathan: *Desire and bloody mindedness* [all laugh]

Rihanna: *yes ,yes*

Nathan: *Yes, it's hard to describe really, isn't it?*

Rihanna: *Yes*

Frances: *Yeh, I think you really* [interrupted]

Nathan: *I think you're kinda stuck between expectation and hope*

(FG II)

Determination appeared to be an attribute valued by participants. Participants discussed needing determination to adapt to life after stroke and the maintenance of well-being (box seven).

Box seven

Teresa: *you've got to adapt the way you do things at home and maybe you have different you know gadgets to help you and that, or whatever it may be, you know. People say 'it must be hard that you've had a stroke' and I say 'it is hard, but..'*

Joy: *you have to fight it*

Teresa: *yes, but it's like everybody else whatever they may have, you know every day is a challenge, but you've got to get through that day*

(FG IV)

Determination may be enhanced and maintained through targeting in appropriate interventions. Items which measure determination may also be possible to include in a PROM.

4.5.5 Communication skills

In order to enhance capacity for and enact self-management, participants reported the need to engage others. For example, in expressing needs and concerns in appointments with health professionals. Communication skills are therefore a vital part of individual capacity. As well as health professionals, participants talked about the need to engage family members or friends to help them perform things important to self-management, such as shopping or food preparation to enable a healthy diet, or providing transport to appointments. To obtain the support from others, participants were required to have good communication skills. This appeared to be of particular importance since following stroke people may find their communication skills change. Dave initially lost his speech after his stroke, and felt reliant on family members to communicate his needs. The quote in box eight indicates how difficulty in communicating hindered Dave from expressing choices about self-care.

> Box eight
>
> Sue (wife and carer of Dave): *Dave needed a lot of care, and he's a proud man, and so for other people to come in and bathe him, bed-bath him he found very* [pause] *how can I say?*
> Joy: *intimidating?*
> Sue: *very, well sort of intimidating, so he refused it. So I said to the Sister, 'could we* [wife and daughter] *come in, in the morning, give him his daily wash and stuff, I'm not expecting to stay long and go?' 'If he doesn't want his wash in the morning, that's his choice, he doesn't get it'* [puts on a superior tone to affect response of Nursing Sister]. *That was the attitude!*
> **And what did you think about this?** [to Dave]
> Dave*: I could n't…. say anything….*
> Sue: *He couldn't say anything*
> **Did you try to talk to any of the staff** [to Dave]?
> Dave: *Yes! Because I …a bath and I couldn't get…them to put me in* (the bath). *Me mate put me in* (the bath)*… in the end* [FG IV]

Participants' accounts highlight the importance of developing relationships with others, to foster confidence to negotiate strategies for management of health and well-being. Participants expressed the importance of mutual

understanding with health care professionals and having the opportunity to discuss areas of concern (box nine).

<u>Box nine</u>

Macy: *I've moaned about this eye, since it* [the stroke] *happened. My eye is not right*
Alex: *You should phone them up, get the GP* [family doctor] *to refer you*
Macy: *Yeah?*
Alex: *It's a long* [waiting] *list, as well*
Macy: *Even if there is nothing wrong with it, it's peace of mind. Even if it's 'oh it's time will heal it'*
Clive: *yeah, that's good enough*
Macy: *It's good enough, I've had it checked* [nods]
Clive: *there's your self-help there, like we were saying!* [laughs]
Carrie: *yeah!* **(FG IV)**

Challenges may exist in measuring communication skills; changes in communication behaviour may be viewed by some as unimportant outcomes in themselves in the absence of changes to other outcomes. However, the participant accounts suggest that improved communication can be viewed as something with fundamental value regardless of additional outcomes. Therefore the inclusion of items that reflect communication in the new PROM appears to be of importance.

4.5.6 Impairment

The term 'impairment' has been adopted to refer to the consequences of stroke that contribute to physical, cognitive and participative disability. Many participants experienced impairments as a consequence of stroke, for example impaired limb function, memory or speech. Such impairments not only resulted in the loss or limitation of their previous physical, psychological and social activities, but also on their capacity to perform self-management following stroke.

The data suggested that many participants capacity to self-manage was limited by impairment following stroke. Some participant's impairments were such that they required the input of others to perform essential activities of daily living and to facilitate self-management activities, such as performing

exercises or practicing reading. Impairment may present practical limitations, which affect an individuals' capacity to self-manage and which were often not considered by services. The female in the extract in box ten reported being given lots of information on discharge, however was unable to access it due to impairment.

Box ten

Do you know what I had, as well? I lost my sight. I couldn't even see a phone, let alone phone for help! (Female, FG V)

Impairment also extended beyond physical limitations, to encompass cognitive and psychological limitations. The extract in box 11 illustrates how cognitive impairment created extra work for participants wishing to engage others in self-management strategies.

Box 11

It's difficult to get people sometimes to say what it is that I want to say [pause] *do what I want* [pause] *write what I want* [pause] *very difficult* [long pause] *to me anyway*.

(Male, FG I)

Impairment negatively impacted upon the individuals' capacity to enact self-management. In the face of limitations, participants reported that self-management often became more about developing a partnership with carers to enact self-management rather than being solely carried out by the individual. Such adaptation can arguably be viewed as a self-management strategy and an approach to enhancing capacity to perform self-management. In the proposed PROM, impairment may best be captured in relation to the effect on individual self-management capacity, as opposed to the impairment itself.

4.5.7 Finding Resources

Identifying appropriate support or resources (e.g. from social services, third sector organisations, public and private health services, etc) following stroke may be a complex endeavour. This sub-theme relates to people's skills in searching for and using information; how accessibility and usability of resources is discussed in section 4.5.11.

Participants used terms such as '*Finding out information'* and *'services'*, for example in relation to finding out about stroke specific exercise classes, or identifying which health professionals are most helpful for specific issues. The ability to identify and pursue appropriate resources appears to be important to an individuals' capacity to self-manage. In addition, the resource or knowledge itself once accessed becomes important to self-management capacity. Participants reported that once discharged from formal care, relevant information about progress was difficult to access (Box 12).

Box 12

I think it would be good (pause) *to hear about information that you can* (pause) *er which I know* (pause) *that you can make your hand move much better* (pause) *or your leg move much better* (pause) *but unfortunately they are not available with NHS. If they were available I will grab it! Right there and then. I don't know why they don't (pause) tell you (pause) I suppose it's very expensive to do (pause)* [Male, FG I]

The timing and nature of information may also affect how an individual responds to it (Box 13).

Box 13

When it (stroke) *first happened, you know I was given all these leaflets, and I just dismissed the whole lot. I thought 'I am not* [emphasis] *going out looking like this' and that's just how I felt. But as it's gone on and on, I feel differently, because I know there are other people like me, and I need to meet these people because you do feel alone.*

[Female, FG V]

The notion of *self*-management, suggests that individuals have a pivotal role in managing their health and accessing resources to support that. Capturing how people access resources in a new PROM will be of importance to understanding an individuals' capacity to self-manage.

4.5.8 Theme Two – Support for self-management

The data illustrated that support is crucial to the way in which people are enabled to self-manage. The term *Support for self-management* has been adopted to refer to the collected elements that support self-management. Three sub-themes were identified as aspects of the overarching theme of *Support for self-management* (fig 4.3). Support may not be appropriate to

target in an intervention aimed at the individual level. However, support appeared to be crucial to participants in how self-management was enacted, and is therefore worthy of discussion.

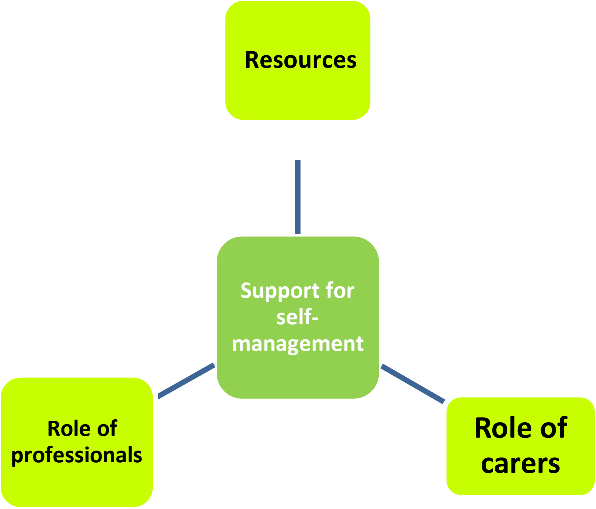


Figure 4.3. Sub-themes contributing to the theme of ‘Support for self-management’

4.5.9 Role of Professionals

Participants referred to the imperative role of professionals in supporting people following stroke to self-manage. Participants felt that support from professionals was a requirement of continued progress after stroke (box 14). Evidence from the data suggests that healthcare professionals can enhance the way people engage in self-management strategies, through the way information is provided, or in how therapy goals are set.

Box 14

I can go on myself all I like, it’s kick-starting others that I find a problem with. You know, I just feel like I’ve got to a dead-end, and not through any fault of my own (Female, FG III)

The quote in box 15 suggests that it was not sufficient for professionals to tell people what to do; people also wanted to know the justifications underpinning advice.

<u>Box 15</u>
You know how important it is to keep doing things, coz they [physiotherapists] *just tell you to do it, but they* [physiotherapists] *don't tell you why. I think that's one of the most important things to change for people coming out* [qualifying as a health professional]. *You know how important, but they don't tell you why.* (Female, FG IV)

Many participants felt that support from healthcare professionals was significant to ensuring engagement in the 'right' self-management practices and doing so correctly. Often participants questioned the point of continuing rehabilitation exercises if they weren't performed correctly. This appears to have a bearing on confidence to perform self-management. For example, some felt there was the potential for harm, or deterioration, without professional guidance (box 16).

<u>Box 16</u>
She does all this stuff herself, but often it will really hurt. You know perhaps a physio [physiotherapist] *could say 'strap this up and do it like this' or whatever, but instead she doesn't know how far to go and she ends up over-doing it and having tendonitis or some associated thing when really you need the guidance. She could be laid off for a few weeks and go backwards.* [Carer of aphasic participant, FG II]

I think everybody could really do with more physiotherapy and for as long as possible. Because you just start getting there and it stops. And then you have to do it yourself, and you're not sure doing it the right way or wrong way. Because I couldn't walk 'til the end, so I just had 2 sessions to walk up and down the pole. Then I was sent home, so I've had to sort of learn myself, and you don't know if you are doing it right or wrong.
[Female, FG IV]

Participants needed to feel confident in the skills of the health professionals providing care. Some participants suggested that professionals lacked the skills necessary to support self-management (box 17). Some participants reported that professionals were not always empathetic to their situation, or that they provided ineffective help. In the example in box 17, the participant describes frustration at not having his needs met following a community review from a stroke nurse.

Box 17

I think a lot of the problem is, that a lot of the nurses and that that come out to you, they're sort of like programmed that a stroke is a stroke, but everybody's [stroke] *is so different to one another, there's individual reasons. But they don't seem to have the time, or the ability. I had the stroke nurse came out to me once* [emphasis, pause] *and she looked at me and said 'oh you're back at work then' I said 'yeah' and that was it. Never came back again. I was going through such like psychological problems.*

[Male, FG V]

The exemplar quotes in this section suggest that it was not sufficient for health professionals to tell people what to do; those with stroke also wanted to know why they should do it. This suggests that self-management is more than passive adherence to recommendations but is an active process requiring understanding of the rationales behind treatment recommendations and a concordance between professionals and patients. The role of professionals appears to have been key to supporting and promoting patients to self-manage, and contributed to the overall support available through health services.

4.5.10 Role of carers

In the context of this theme, 'carers' refer to those individuals who provide formal (provided by social or third sector organisations) or informal (usually family members or friends and often unpaid) care to the person affected by stroke. The role of carers was applauded throughout all of the focus groups and appears to be crucial to supporting self-management. Carers were often involved in providing personal care, emotional support, plus practical support to enable a person to practice vital self-management strategies, e.g. by providing transport, or practicing therapy. Carers are often therefore crucial to self-management following stroke. Alternatively, carers could hinder people from performing self-management activities themselves, by performing elements of self-management on the behalf of the individual, unwittingly limiting their opportunities to practice, and potentially improve or gain confidence relating to self-management (box 18).

Box 18

Well not so much the self (pause) *But erm you can't* (sighs) *no I can't, I don't do* (pause) *meds* [sorting out medication] (pause) *my wife has to do that* (pause) *well, she doesn't have to* (pause) *but she does it.* (Male, FG I)

The examples in Box 19 illustrates how this can be an intricate interplay that reflects the tensions faced by people following stroke in deciding whether to continually push themselves or to sometimes make life easier.

Box 19

Would you like to be doing more yourself?

John: *I do agree, I can do some of it* [washing and dressing] *myself. But it's quicker, and I like to be on time, regardless of where I've got to be*

Beth: *It's nice to have somebody do it for you. It's nice to have sometimes though, isn't it?*

(FG IV)

Everytime they (carers) *come in I have to tell 'em what to do* (laughs from others) *So I give up!* (more laughs) *however* (Shrugs) (Female, FG I)

That carers can potentially facilitate or hinder self-management, highlights the complex nature of stroke-related impairment and the impact of stroke upon family structures. Family members who provide care and support for their relatives, may do so in response to a perception that there is no alternative. The carer in the extract in box 20, talks about his experience when his wife was discharged.

Box 20

...urm, for the first month nobody [health professionals] *bothered. I took to writing everything down on a piece of paper to make sure I hadn't overdosed* [administering medication].

mmm

when I phoned up.. errh [heavy sigh] *the Rapid Response.. 'oh! Does Lizzy* [wife] *need help? '* [refers to their response, appears exasperated] *That was the comment I got…but apart from that... now there's a new matron in the rapid response who's going to come out every so often, but apart from that the only help I get, is that when Lizzy develops on a chest* [chest infection]*, because obviously she can't swallow, I phone up the local surgery and they come. But apart from that... I've had no, really no help, who's conversant with the stroke care. I've had to do it all myself.*

[Carer of aphasic participant, FG III]

Self-management following stroke appeared to extend beyond the individual, requiring support from others to enact, particularly where impairment and subsequent disability were present. In the example in box 20, the family member is supporting self-management but without the adequate skills or knowledge (e.g. on drug administration) to do so. He demonstrates resilience and determination in engaging professional support, however the burden appears significant.

The role of carers may be difficult to capture directly in a PROM. Instead measurement should focus upon how individuals manage relationships with carers that help them to facilitate self-management.

4.5.11 Resources

In order for people to engage in self-management, the data suggests that health service resources have a key role in creating support. Resources in the context of this theme are viewed as the provision of services, equipment or information that support self-management. The data raised questions regarding the adequacy and quality of existing resources to facilitate self-management following stroke. All participants reported a desire to actively engage in self-management. However, many reported that the support they anticipated was not available, be it a lack of therapy, lack of equipment or difficulty in arranging appointments with appropriate health care professionals. Attempts to engage support entailed substantial work for the person affected by stroke or carer, which lead to feelings of uncertainty and frustration (Box 21).

Box 21

If it's going to help, I'll try my best', you know? Well, I waited and waited a couple of weeks to hear back from XXX [therapist] *or the xxx* [rehabilitation centre] *and not a word, so I phoned the receptionist, and she says 'oh, XXX's* [therapist] *is leaving' so I says 'well, what do I do now?' and she says 'well, you'll have to get to yer GP and get a new referral to whoever is taking over'. So, I did that, waited three weeks, to get to see my GP and not a thing. I don't even know where this piece of equipment is supposed to be coming from. Is it the XXX* [rehabilitation centre] *or the hospital?* (Female, FG **II)**

Many participants felt that they had been abandoned by the health service following the end of therapy or rehabilitation services. The extract in box 22, is typical of the feelings displayed by all of the groups, whereby the intermittent provision or limiting of services without adequate explanation was unsettling and frustrating to participants. In response to dissatisfaction felt with their experiences, participant accounts reveal how they sought to find their own resources. This is arguably a self-management strategy, although may be associated with additional burden for both the person and care givers.

> Box 22
>
> John: *Things could've got better ages ago if they'd carried on with physio, but they just stopped it. Then they started it again with a different one* [physiotherapist], *and after I just got used to it, they stopped it again. Now I've found me own, it's going along all right again.*
>
> Mike: Recession
>
> **That might be an issue for many of you** [when therapy stops]**. What reasons were you given, how was it explained** [to you]?
>
> John: *No I thought I was coming along all right*
>
> **You thought you were still progressing?**
>
> John: *yeah, and they just stopped*
>
> Felicity: *it seemed to be 6 months* [of therapy] *and that was it*
>
> (FG IV)

Resources also appear to play an important part in preparing people to self-manage. The extract in box 23 describes the experience of one family trying to enable a family members' mobility and independence following stroke. Their perception was that enhancing independence was not viewed as a priority by support services.

> Box 23
>
> *We got her home, more or less lift her in the chair to get her indoors. And when we did finally get someone to come out, they said 'you can have a ramp, but we won't know until April whether we've got the money, and then we'll have to get a builder in'. And this was November. So you know she'd've been stuck indoors all that time. So we built ramps ourselves, and all the handrails.* [Carer, FG IV]

Participants' accounts suggest that accessibility of appropriate resources to support self-management are key to their success. Therefore interventions that seek to enhance ability to seek out and access resources may be of benefit to self-management. An individuals' ability to access and identify resources may be measurable in the proposed PROM.

4.5.12 Theme three – Self-management environment

In the context of this theme, *environment* refers to the additional conditions necessary, outside of the individual, family and health service, for self-management to be successful. Participant accounts suggest that to self-manage effectively, a supporting self-management culture is required. Figure 4.4 illustrates the sub-themes that relate to the over-arching theme of *self-management environment*. This theme may not be directly amenable to change in an intervention to promote self-management targeted at individuals. The *self-management environment* appeared to be important to participants self-management, and therefore worthy of discussion and possible inclusion in the new PROM where appropriate. The relationship between the sub-themes and overarching theme will now be described along with extracts from the data.

4.5.13 Others response to impairment

The effects of stroke may mean that individuals experience impairment(s). How impairment may impact upon self-management ability has already been discussed previously in section 4.5.6. Participant accounts suggest that how impairment is received by other people within the community also impacts upon their ability to self-manage. In the extracts in box 24, participants highlight how the negative responses of other people affected confidence to enact self-management strategies.

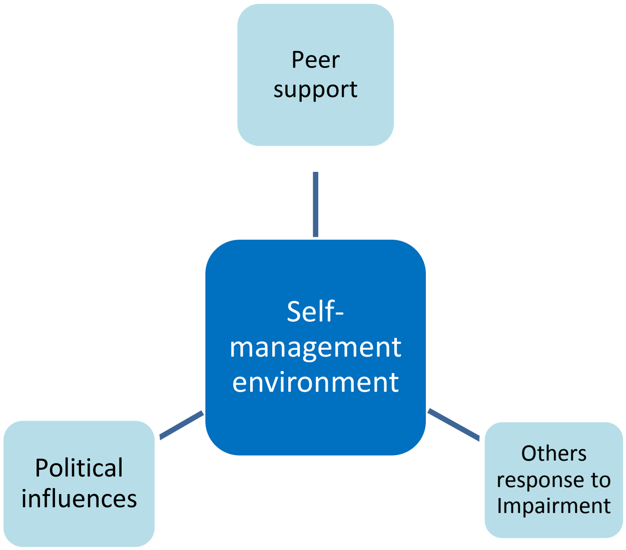


Figure 4.4. Sub-themes contributing to the overarching theme of 'self-management environment'

The response from the wider community appears important to promoting individual confidence to self-manage, and to enable individuals' to feel valued. Individual confidence to participate in the community may be conducive to measurement in the proposed PROM.

Box 24

...One lady in XXX [health centre] *up here, she just thought I was drunk because of the way I walk, that you know was her thing, she didn't think about anything else it could be. It was embarrassing.* [Male, FG II]

Rihanna: *But, sorry* [to researcher] *people stare at me, really really stare at me.. and no, no. And erm, men you know stare at me*
So how do you handle that, then?
Frances: *I don't care if people stare at me*
Rihanna: *well erm,*[pause] *I cry*
Clare [Rihanna's carer]: *In the summer holidays with the school children, she wouldn't go at all* [to the gym] [FG

4.5.14 Political influences

Self-management is a contemporary issue affected by relevant policy and directives. Participants did not explicitly refer to politics or policies (nor were explicitly asked about them). However, participant accounts often made reference to issues are affected by policy guidance. For example, participants often discussed their perception of a lack of access, or rationing of treatment, technology or stroke services (box 25), particularly in light of the current global economic downturn.

Box 25

Sharon: *you have to press* [for referrals], *don't you*?
Clive: *that's right*
Sharon: *that's what's wrong though, you are always having to push* (FG V)

Where there was a perception of limited services/resources, participants reported that emphasis was placed on them to actively develop and engage in their own self-management strategies. The extract in box 26, highlights the potential of some individuals to become activists in promoting engagement in self-management activities to a wider community audience.

Box 26

It's a case of, so this whole self-help self-management thing, I think is a great thought [pause]..*because that's what we're* [people following stroke] *already doing, but I think it's been executed pretty badly because there is nothing* [support for self-management] *out here*. *Which is why we've set up this group* [community stroke club] [Male, FG V]

Participants also discussed explanations to try and rationalise why services were currently not ideal. The extract in box 27, illustrates that participants are conscious of and consider the potential influence of policy on their health.

Box 27

Vera: *And have they* [hospital staff] *got time for explaining it* [medication, treatment, diagnosis]*? I mean they're so rushed...*

Ron: *They are*

Vera: *...and if you say 'can you explain it to me?', they haven't got the time to put it in layman's language*

Gwen: *the trouble is they've got the government saying they've got to do more..*

Ron: *yes, that's right*

Gwen:*...and they haven't got time, all these things, paperwork.. and they can't spend time with the patients* (FG III)

The data extract in boxes 26 and 27 additionally highlights the need for appropriate information for patients as a pre-requisite to effective self-management. Some participants actually reflected more overtly on the political context of self-management, in that self-management can be viewed as a way of encouraging the person affected by stroke to take responsibility for their health and progress (box 28). It was not possible to tell if the participant in this extract was critical of this view or not.

Box 28

Clive: *yeah, I suppose you should've* [emphasis] *done it yourself. The government would say 'help yourself'* (Male, FG V)

Participants may have limited opportunities to directly influence policy, and therefore the impact of policy may not be a useful evaluative component nor be conducive to measurement in a PROM. The data suggested that participants felt frustrated with the current state of support for self-management and therefore this was an important issue worthy of comment in analysis. However the influence of policy will not be directly targeted in the proposed PROM.

4.5.15 Peer support

Peer support appears to be an important aspect of successful self-management. Participant accounts suggest that in order to create a culture that fosters self-management, appropriate support from peers is required. Peer support appears to be drawn from different guises. Participant accounts

recognised that attendance at stroke clubs represents a useful source of peer support. This appeared, in part, to be from being in an environment that acknowledged a unique shared experience (box 29). Members report being encouraged and enabled to try new strategies to help progress, which can be viewed as a component of self-management.

> Box 29
>
> **So what is it** [that is helpful] **about all coming together, what is it about the stroke club?**
> Tim: *I think for me, I go to these NHS things* [EPP], *er they tell you what they're doing, all the good work they're doing, as much as they can do the work, they haven't had a stroke. So they can understand to a degree but not fully. So hopefully you can come here* [the stroke group], *and see people's improvement over time..*
> Frances: *That's right*
> Tim: *...that will hopefully encourage you to do stuff as well, so you know.*
> Nathan: *Well, coz they actually know what they're on about* [someone who's experienced a stroke] (FG II)
>
> *People come along here* [stroke group] *and you know, they can talk about what they do, maybe talk about the fact that once a week they try and get out of their chair, maybe walk along the side wall there using the side rail* [points to large wide corridor outside with hand rails along both walls*], or anything. Some people find different things work for them.*
> (Male, FG V)

Peer support was often provided by third sector organisations, such as charities. Participants often accessed such organisations, which may be viewed as a self-management strategy. However, often this was accompanied by a sense of frustration and associated burden at having to seek such information (box 30).

> Box 30
>
> *Sue: but at least now he's* [husband with aphasia] *having regular exercises of two hours a week….but you know that's having to go outside of the NHS* [looks to ceiling]...*obviously couldn't afford it privately* [looks to ceiling, appears exasperated] *uhmm, but under the XX banner which is a charity..*
> ***Hmm***
> Teresa: *But you had to do that yourself, did you? You had to find all that yourself (*appears surprised)? [FG IV]

The data suggests that people following stroke often feel abandoned by the health service and that the support they anticipate to be provided by the NHS is not available.

The impact of peer support on self-management may be difficult to mediate in an intervention and may not be conducive to measurement in the proposed PROM. However, the data suggests that participants find peer support an important aspect of overall self-management.

4.6 Reflections on analysing across groups

In this study, each group was analysed before conducting the next and a summary of any emerging interpretations of the data or sub-themes was recorded. Arguably summarising emerging sub-themes can inform subsequent interpretations made in analysis of the next group. However, this summary was an advantage in conducting comparisons between groups, particularly as the key aim of the study was to inform possible items for a new outcome measure. At this stage in the development of the PROM, it was necessary to be inclusive to avoid excluding possible relevant items. It felt more natural to question the evidence supporting concordance across participants experiences within a new transcript, with existing evidence from an earlier transcript.

4.7 A conceptual model of stroke self-management

The focus of analysis was to most accurately identify the aspects of stroke self-management that might be amenable to measurement in a PROM. The reality of stroke self-management from the perspectives and experiences of the focus group participants was also derived from analysis and has informed the development of a conceptual model. The conceptual model represents a theoretical representation of the concepts of interest, their interfaces and possible determinants. A conceptual model is an important step in the development of a new PROM since it can assist the selection of target measurable concepts (Tulsky et al., 2011). A preliminary conceptual model of stroke self-management is illustrated in figure 4.5.

The overarching theme of *Individual capacity,* relates to the factors that affect an individuals' ability to enact self-management. As such, since features that affect individuals are central to *self*-management, the theme of Individual Capacity features as the key component of the conceptual model. The model suggests that *Individual capacity* is affected by *Support for self-management*, and more widely the *Self-management environment.* For individual capacity to be most effective, optimal support mechanisms from the health service need to be in place; these in turn, are underpinned by a self-management environment.

The themes and sub-themes identified and described are justified as contributing to the overall experience of stroke self-management. The data provided evidence that the themes, whilst being related, may differ in relation to how conducive to measurement they would be in a PROM of stroke self-management attitudes and behaviours. The elements discussed in the theme of *Individual capacity* and its' related sub-themes can be viewed as theoretically amenable to change, for example as a result of targeting in an intervention. Moreover, the aspects identified in the theme *Individual capacity* directly impact upon, and can be mediated by individuals, to provide insight into the perspectives of patients and are therefore appropriate for a PROM.

Questions exist with regard to the extent the themes of *Support for self-management* and *Self-management environment* and their associated sub-themes, are amenable to change following a self-management intervention and therefore how measurable they would in a PROM of attitudes and behaviours. Relating the aspects identified within these themes in a PROM may be of minimal value. Since the features within these themes may be too abstract from the patients' own experience, instead influencing experience remotely. Patients are unlikely to be able to directly influence on Health Service, or community provision. Instead, it may be possible to mediate an individuals' perception or understanding of such aspects in an intervention to facilitate confidence or minimise frustrations.

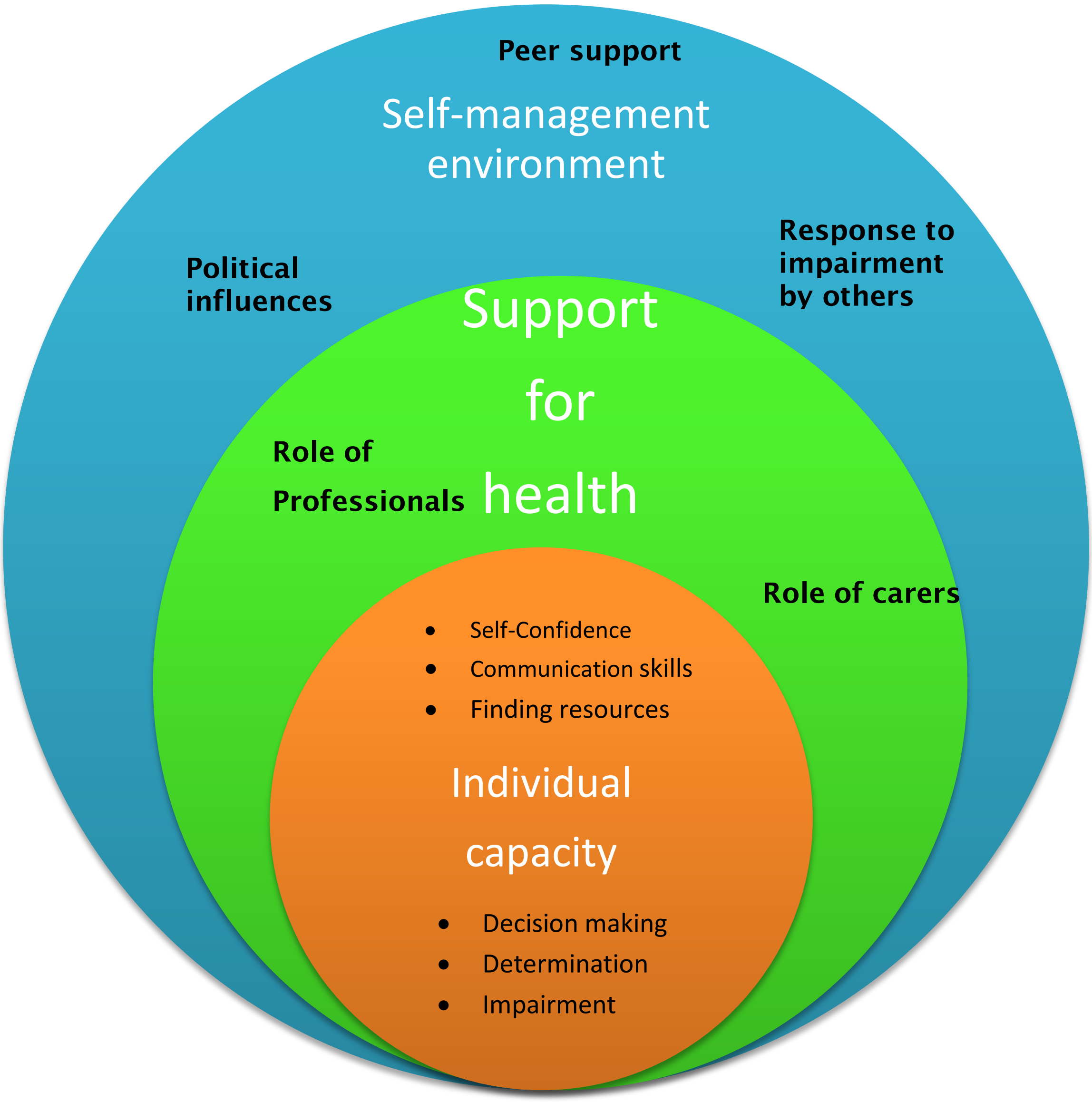


Figure 4.5. A preliminary conceptual model of stroke self-management.

4.8 Limitations with the analysis

The findings represent the evidence from inductive focus group inquiry, based on the experiences of 28 stroke survivors. The findings need to be considered in relation to the sampling strategy adopted. Conceivably, those who agreed to participate may be more effective 'self-managers' through their attendance at stroke support groups, which may evidence a proactive nature towards self-management. Alternatively, it may be that people who do not attend stroke groups are successful self-managers, and therefore do not seek additional support. Nonetheless, participants contributed perceptive

and reasoned comments about their experiences of self-management. People who are less articulate or have communication impairments may have been discouraged from participating in a group discussion. However, this study and the procedures adopted effectively elicited the views of eight participants with impaired communication.

It is important to highlight that the aim of this enquiry was to explore the concept of self-management from the perspectives of people recovering from stroke, without drawing on pre-existing assumptions about the nature of stroke self-management. The analysis then represents the best interpretation of the data given the limitations outlined above. It may be that the preliminary conceptual model may be further aided and developed by individual interviews, given the potentially sensitive and complex nature of stroke self-management.

4.8.1 Transferability of focus group findings

Arguably the rich, detailed, and perceptive nature of the focus group findings make them suitable for extrapolation beyond the specific setting. Of particular relevance to self-management, some qualitative researchers argue that a vital aim of qualitative findings is to influence the opinions of decision-makers (Groleau et al., 2009). The preliminary conceptual model, derived from the participants' experience, may be a useful template for the design of future self-management interventions. Of particular note for decision-makers is the paucity of adequate support for self-management following stroke that these findings suggest. However, it is important to consider that participants in this study may not have expressed their own definitive individual view. Participants spoke within a specific context, that of being in the group, in which it may have been difficult to clearly identify an individual message. Transferability of qualitative or quantitative data may be viewed as something that exists on a continuum, and not an absolute property (Polit & Beck, 2010). It therefore follows, that the focus group data does not, nor cannot, represent every facet of stroke self-management. In accordance with guidance by Polit and Beck, the transferability of the findings may be aided by further work to explore the extent to which the experiences documented in this research are replicated elsewhere.

4.9 Chapter Summary

The analysis of the data was a challenging and lengthy process. Justification of the themes generated from the data has been provided. Evidence in the data suggests three over-arching themes represent the experience of stroke self-management; *Individual capacity*, *Support for self-management* and *Self-management environment*. The use of focus group inquiry as a method to gather evidence of concepts that could potentially be measured in a new PROM has been justified. Chapter nine considers how the focus group findings extend the existing knowledge base regarding self-management following stroke. Chapter five concerns the development of potential items for the proposed PROM.

5. Chapter five – Phase Two Methodology and Method

5.1 Introduction

This chapter outlines the methodology and methods adopted in the second qualitative phase in this programme of research. Firstly the aims of this phase of the research are revisited and justifications are made for the chosen methodology of Cognitive Interviewing. The procedures used in developing and writing potential items for the PROM are outlined. The research design and procedures for the Cognitive Interviews are described and defended. Finally the methods of analysis chosen to understand the findings are outlined and explained.

5.2 Ontological and epistemological assumptions

An overview of the differing Ontological and epistemological positions associated with this research has been provided in section 3.2.

5.3 Aim and objectives of Phase II

The second qualitative phase, to which this chapter refers, had two aims as follows:

1. To employ the findings of the Focus Groups to generate a pool of potential items for the new PROM
2. To develop and refine potential items to produce a preliminary PROM that was acceptable and feasible to people recovering from stroke

The following were key objectives of Phase II:

1. To amend the item pool of the preliminary PROM in light of the results of cognitive interviews with potential users of the PROM
2. To refine the preliminary PROM in terms of clarity of language, face validity, appropriateness of items and response format

The procedures employed to generate items from the focus group study data will first be described and justified. The methodology for the refinement and development of the items will then be outlined and defended.

5.4 Writing potential items

The focus groups provided vivid, thought-provoking data and identified possible concepts relating to self-management which would be potentially measurable in a new PROM. Key recommendations from the literature exist to advocate best practice for the writing of potential items, as follows:

- Language should be simple and appropriate for the target population. Items should be understandable by persons of 12 years (Streiner & Norman, 2008)
- Items should contain only one question (Oppenheim, 2000)
- Negative wording should be avoided (Bradburn et al., 2004)
- Colloquialisms and activities that might not be familiar across different age groups, ethnicities, cultures should be avoided (Foddy, 1993)
- The item should have specific context for the respondent. The context should bear a clear relationship to the concepts identified in any underlying conceptual model (de Vet et al., 2011)

DeVellis (2003) advocates approaching the construction of items in distinct phases as follows:

- Express relevant ideas
- Generate additional statements that relate to the same idea
- Generate approximately 3-4 times the proposed final number of items required
- critically review the items for language, length and response format, omitting/amending as appropriate

DeVellis' approach guided writing the items; the specific procedure used is next outlined.

5.4.1 Item writing procedure

The focus group data informed the content of the items in the PROM. To provide transparency for the reader and evidence that the PROM is grounded in user perspectives, how the data was converted into potential items is now outlined. The items were derived predominantly from the focus group data. However, it may not be prudent to exclude items from other measures of self-management that have been developed and tested and which could be amended for stroke (Streiner & Norman, 2008). Of the 57 final items in the preliminary PROM, two were not directly derived from the focus group data. Therefore, the item pool was based overwhelmingly on the focus group data and perspectives of potential users.

Using the recommendations of DeVellis, the conceptual model, themes and sub-themes generated from the data were reviewed. Loose statements were written to reflect each sub-theme derived from the focus group data. Statements were written based on participants' own words in relation to each sub-theme to reflect the range of their self-management experiences (figure 5.1, provides an example). The statements were then reviewed and re-written into potential items to improve clarity and ease of understanding for respondents. Items were reviewed and discussed with the supervisory team prior to inclusion in the item pool, to check that every facet of the focus group data thought appropriate to include in a PROM was included. This process was repeated for each theme and sub-theme until a preliminary item pool consisting of 57 items was developed for examination in Phase II.

5.4.2 Determining the measurement scale

A measurement scale is a type of measure composed of several items that target the same concept. Determination of a measurement scale involves associating qualitative constructs with quantitative metric units. In a scale, the intensity of the concept under measurement can be determined due to the alignment of the responses on a continuum (de Vet et al., 2011). There are several main scale formats which will be briefly addressed, before attention focuses upon the Mokken scale, selected for this research.

Figure 5.1 Example of process for deriving items from the Focus group data

From sub-theme '*Impairment*', overarching theme '*Individual Capacity*':

Rationale: Stroke-related impairment meant that people often felt unable to manage their condition. Impairment is an important aspect of an individuals' capacity to self-manage.

Examples of initial statements to capture the role of impairment on self-management:

Limitations due to stroke may result in difficulties managing condition

Stroke-related impairment may mean that people cannot perform activities to maintain health/well-being

People following stroke may find ways of adapting to maintain health/well-being (e.g. engaging others for help, prioritising, using equipment)

There may be a perception that carrying out exercises is pointless if disability is perceived as permanent

How people perceive themselves and their disability may affect how they respond on a PROM

Issues in deriving items:

Set context to make item clear- ask the respondent about their experience, not stroke generally, or comparisons to others – e.g. use of 'My', use of 'stroke'.

Different facets of impairment – should and can they be captured collectively? Potential of causing offence through implicit assumptions in items.

Items reflecting impairment in the preliminary item pool:

My communication problems mean that I cannot manage my condition as I would like

My physical limitations mean that I cannot manage my condition as I would like

There is little point in carrying out exercises as my condition will not change

My limitations due to stroke mean that I cannot manage any aspect of my condition, by myself

My limitations due to stroke mean that I cannot manage my condition at all

I am confident in asking family members or friends to help me perform activities important to my recovery

5.4.2.1 Semantic differential scales

Semantic differential scales seek to measure attitude (Osgood et al., 1957). The respondent is asked to choose where their position lies (between numerical anchors), on a scale between two bipolar adjectives (e.g. 'Active-Passive', 'Good-Bad', 'Valuable-Worthless'). The score for each word then suggests a relationship between the word and the respondent. A limitation with this type of scale is the cognitive burden involved in making fine distinctions between the adjectives. This type of response scale is therefore

unsuitable for a PROM aimed at people following stroke who may experience cognitive limitations.

5.4.2.2 Thurstone scales

American psychologist Thurstone developed the first formal method, the paired comparison technique, to estimate measurement of attitudes (Thurstone, 1928). Thurstone scaling involves first asking a sample of people to rank statements, in order of which is the weakest to the strongest indicator of the construct in question. Once the statements are rated, the scores assigned to each statement are examined to determine the median rank of each statement, which becomes the value assigned to the statement. Scale developers then select a number of statements from the original list to span the range of values assigned, and place statements in approximately equal intervals (using the median rank of statements). This becomes the final scale. Respondents are asked to select the statements with which they agree. The respondents' average score is then calculated from the items selected (using the values previously assigned).

A limitation with Thurstone scales is the complex and lengthy process with which they are developed (Streiner & Norman, 2008). It is also difficult to study statements which may not be manifestly related, for example such as the concepts of impairment and determination from the focus group enquiry. Therefore, Thurstone scales are considered to be unsuitable for the new PROM.

5.4.2.3 Guttman scales

Guttman scaling (Guttman et al., 1950) uses a list of items or statements to determine the level of agreement to a specific construct. Guttman scales are written in a hierarchical order of difficulty. The assumption is that respondents who agree with any specific item in the list, agrees with all previous items. For example, on a ten-item cumulative scale, if the respondent scores a four, the inference is that he/she agreed with the first four statements. A limitation with Guttman-type scales is the high levels of error introduced related to the assumptions around ordering of responses (Stochl et al., 2012). Guttman scales are inherently difficult to apply to measures of psychological and social constructs where hierarchies of items that do not allow for error are problematic to apply (van Schuur, 2003) and are therefore unsuitable for the new PROM.

5.4.2.4 Mokken scales

Mokken models advance the premise of Guttman scales, which unrealistically assumes that responses are error-free. Mokken models belong to the class of models called non-parametric item response theory (NIRT) (Mokken, 1971). As with Guttman scales, items within a Mokken scale can be said to form a hierarchy relating to their level of difficulty, or the probability that the item will be endorsed or not. Mokken scales allow the modelling of data in light of the measurement error associated with Guttman scales. Mokken scales allow for item scores to be totalled to represent the level of the construct possessed by the respondent. Section 7.10.1 provides a more in-depth overview of the chosen measurement scale for the new PROM.

5.4.3 Determining the Response Format

Response formats refer to the way responses are collected from people on a PROM. Response formats aim to enhance the ability of the PROM to discriminate differences in the underlying concept under measurement (DeVellis, 2003). There are many different types of response formats. Most response formats generate quantitative data, the exception being open-ended formats which allow for the collection of qualitative data (Bowling, 2007). Selection of the appropriate response format is important since this affects the precision of the data collected and if chosen poorly may result in loss of information (Ogden & Lo, 2011). This section provides a brief overview of the most common types and justification for the inclusion of the formats explored in Phase II.

Response formats, at a minimum have two response options (e.g. ‘Yes’ or ‘No’, ‘Select’ or ‘Do not select’). Dichotomous response formats may be advantageous in allowing respondents to answer more easily and for facilitating the same interpretation of the question between the researcher and the respondent (Laver-Fawcet, 2007). However, a disadvantage may be that they do not sufficiently explore the range of viewpoints the respondent may have.

Multiple choice formats allow the respondent to select from several responses and may be advantageous in identifying the priorities of respondents. Rank ordering allows respondents to state their preferences from a list of items and also provides information regarding the sequence of preference. A disadvantage of both formats may be the forcing of responses, if the viewpoint of the respondent is not represented.

Rating and continuum scales are based on a fixed response format, whereby the extreme of each possible response is represented in the format. Respondents are asked to select one option from either a list of options, for example a Likert response format, or from a continuum, such as a Visual analogue scale (VAS). VASs are simple, minimally intrusive methods that are effective and easy to administer and score. Respondents indicate their responses by marking along the contiunuum; this then corresponds to the level of the concept the respondent possesses. The VAS may be preferred by respondents who perceive their response to fall between two categories, however in comparison to Likert response formats, VAS are sometimes more difficult for people to understand (Brunier & Graydon, 1996).

5.4.3.1 Likert response formats

Likert response formats are so named after the American Psychologist Rensis Likert, who introduced a new way of measuring attitudes. Likert (Likert, 1932) supposed that attitudes towards any object or idea varied along the same positive-negative continuum (figure 5.2). The degree of agreement is then assigned a numerical value, which can be summed to give an indication of the overall level of agreement.

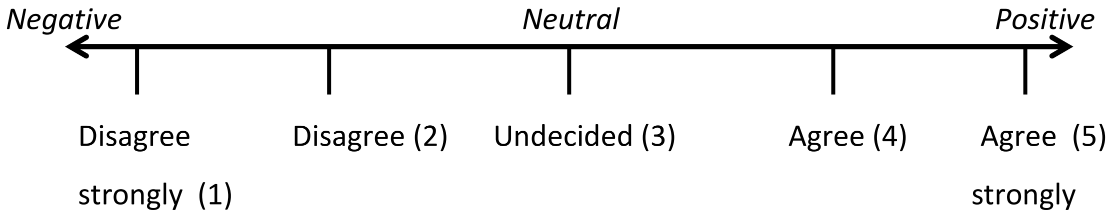


Figure 5.2 Illustration of the assumptions of a Likert scale

Likert designed his early scales with five points (two either side of a neutral point). There is no theoretical reason to use scales with more than five points, however evidence suggests that data from scales with points less than five or more than seven, become appreciably less accurate (Johns, 2010). The assignment of a numerical label to qualitative judgements generates implicit assumptions worthy of comment. For example, using the scale in figure 5.2 as an example, it may be difficult to explain the difference between 'Agree' and 'Strongly agree' in a uniform way. Some researchers have highlighted a possible response bias dependent on the respondents' 'frame of reference' in their approach to Likert formats. For example, people from socially deprived groups may possess a different 'frame of reference' to more affluent groups (Ogden & Lo, 2011). Such limitations point to the importance of good item construction and exploration of their context with the intended respondents.

There are several advantages in using a Likert response format, relevant to the purpose of the proposed PROM. Likert response formats measure multiple facets of, and degrees of opinion relating to the concept of interest. Likert response formats may reduce the potential response burden of participants. They limit forcing participants to state a position on a particular topic and can accommodate neutral feelings (Laver-Fawcet, 2007). They are commonly used, and therefore potentially more familiar and easier to use for participants, minimising response burden (Bowling, 2007). Likert response formats may be considered more reliable, since unlike other scales, such as Thurstone and Guttman scales, respondents should answer all items in the scale, thus providing more complete information about the concept of interest (Kothari, 2004, Devellis, 2003). Following consideration of the literature, a decision to use a Likert response format in the Cognitive Interviewing (CI) phase was taken.

5.4.4 Number of items

Determining the final number of items required was problematic for two reasons. Firstly, no credible measure of self-management in stroke existed to guide this decision (Chapter Two). Secondly, deciding *a priori* the optimum number of items required would generate an assumption incongruent with the inductive aims of the research. However, it was not feasible to generate an infinite number of items for pragmatic reasons; it is unnecessarily burdensome to respondents, particularly in light of potential cognitive impairment associated with stroke, plus not practical in the resource confines of the research. Therefore guidance was sought from similar measures used in other long-term conditions and within stroke.

Measures of self-management developed for use in other conditions have utilised between 6-35 items (Hoffman et al., 2011, Lin et al., 2008a, Schuurmans et al., 2005, Wallston et al., 2007). The systematic review paper related to this research (Boger et al., 2013), identified three measures of concepts related to self-management that possessed excellent content validity in stroke populations. These measures consist of between 10-30 items (Jones et al., 2008b, van Straten et al., 1997, Trigg & Wood, 2000).

Using the guidance by DeVellis (section 5.4) this suggested that the preliminary item pool should consist of a maximum of 90-120 items. The actual number of items derived inductively from the focus group data totalled 57. This represented the data extensively but was felt to be a number that would not overly burden participants. The next sections outline the methodology and procedures utilised in Phase II of the research.

5.5 Research Question

The research question for this phase guided the chosen methodology and research design. The research question is stated below:

How acceptable and feasible are the potential items to a convenience sample of people who have experienced stroke?

5.5.1 Research Design

A key recommendation is that PROMs should be developed with involvement from their target population to identify what is meaningful from their perspective to enhance validity and clinical utility (McDowell & Newell, 1996, de Vet et al., 2011). The focus group study sought to identify the concepts relevant to self-management relevant to people with stroke, from which a preliminary item pool was derived. The second inductive phase was considered important to refine the content of the preliminary item pool, so items had context and relevance for potential respondents. What follows in as overview and justification of the elected research design of Cognitive Interviewing.

5.5.2 Cognitive Interviewing methodology

Cognitive interviewing (CI) has been posited as a technique to ensure items included in PROMs have precision and relevance to potential respondents (Willis, 2005). During CI, participants are probed for their interpretation of item content and response formats to help determine potential problems or concerns associated with each item. Items are then modified in light of the responses of those interviewed, before being re-tested for interpretation. CI seeks to examine the decision processes made during providing a response. This is of importance, since people understand words and interpret meaning in different ways (Tourangeau et al., 2000). In addition, consideration can be given to factors such as social desirability on the response processes of participants. For example, politeness may mean that people may answer questions without really understanding what the question means, or provide answers which they perceive will satisfy, however which may not reflect their true situation (Collins, 2003).

The Cognitive Interviewing process aims to elicit the following (Beatty & Willis, 2007):

1. Understanding of the question (e.g. What the respondent believes the question is asking. What do specific words and phrases in the question mean to the respondent?)

2. The processes used by the respondent to retrieve relevant information from memory (e.g. What does the respondent need to recall to answer the question?)

3. Decision processes, such as motivation and social desirability (e.g. Is the respondent sufficiently motivated to accurately and thoughtfully answer the question? How does social desirability influence answering the question?)

4. Response processes (e.g. Can the respondent match their response to the question's response options? Do the response options need to be altered to facilitate this?).

There are two main CI techniques; think-aloud interviewing and probing. In 'think-aloud' interviewing, information is collected concurrently as the respondent answers the items on the PROM by 'thinking-aloud'. More emphasis is placed on the role of the participant and therefore, arguably this method can place more burden on participants with cognitive impairment (DeMuro et al., 2012). In contrast, 'probing' places more emphasis on the interviewer, who asks specific questions aimed at eliciting how the respondent approaches answering the question. This minimises burden for participants, however, means that the interview is researcher as opposed to participant driven. A decision to use the 'probing' technique was adopted for phase II, since cognitive impairment and communication limitations were significant potential issues for participants.

5.5.3 Rationale for the use of Cognitive Interviewing

Phase II was grounded in developing a PROM that had context and relevance to the individuals it purported to evaluate. CI aims to reduce response error and enhance face and content validity (Beatty & Willis, 2007, Willis, 2005) by examining how the content, response skills, and the instructions are understood as intended by the scale developer. CI aims to ensure the PROM contains concepts that are relevant from the perspectives of patients, thus enhancing face and content validity (Leidy & Vernon, 2008). CI is also thought to increase the likelihood that the PROM will have clinical utility and thus be integrated into practice (Drennan, 2003). Of particular relevance to stroke, CI is an appropriate methodology for evaluating which response formats make most sense, which are less cognitively challenging and thus presenting the least burden on participants (DeMuro et al., 2012). If this stage is overlooked, there is a risk of alienating potential users from engaging with the measure due to irrelevance of, and dissatisfaction with, items (Lasch et al., 2010, Rat et al., 2007).

CI has been used successfully in the development of PROMs for use with other health conditions (Christodoulou et al., 2008, Nicklin et al., 2010, Wu & McSweeney, 2004). Despite the potential for problems associated with cognitive and communication limitations following stroke, there is a paucity of research that specifically address the use of CI in the development of PROMs intended for use with stroke. A report prepared for an NHS stroke survey utilised CI (Howell et al., 2004), although the details regarding the procedures used are scant. One explanation for the lack of stroke PROMs employing CI may be the difficulty associated with conducting CI with groups who have communication or cognitive limitations (DeMuro et al., 2012). The lack of stroke PROMs employing CI in development however, presents a strong argument for conducting a CI phase. Without a CI phase, there is a risk the PROM may not accurately reflect the perspectives of stroke survivors.

Cognitive Interviewing has been justified for the second phase in the development of the PROM. The next sections concern the research process for phase II.

5.6 Research Process

The following sections outline the procedures used to collect and analyse the data.

5.6.1 Ethical Approval

Ethical approval was sought from the University of Southampton, Faculty of Health Sciences Research ethics committee prior to the commencement of the study. Conditional approval was given in January 2012, and following amendments full approval was granted in February 2012. What follows is an overview of some of the key ethical and governance considerations.

The interviews took place in an environment familiar to the participant, in almost all cases in their own home. This minimised the burden of participation, for the participant, in terms of minimising travel and being in a familiar environment.
Conducting interviews in participants' homes, places increased risk on the researcher as a lone-worker. Prior to the study commencing, a risk assessment was carried out to ensure the researcher was familiar with the University's policies and safeguards relating to lone-working. Prior to each interview taking place, the Faculty of Health Sciences research office received a telephone call from the researcher to notify of arrival at the venue, and expected finish time. At the end of each interview, the researcher rang the office to notify staff.

In addition to issues around personal safety, there were issues regarding conducting the interview in an unfamiliar environment. The presence of other people in the home can change the interaction within the interview, and it may be difficult to exclude them from the interview without causing offence. In four interviews, other people were present and on occasion came into the room where the interviews took place. When this occurred the researcher stopped the interview and took part in any conversation that the interviewee started, as appropriate. In all cases this was to offer refreshment, or greetings, but also may possibly have been, in part, to check that the researcher was legitimate.

Pseudonyms were adopted for participants and for other identifiable features (e.g. hospital settings) in the transcription and analysis of data. Data was transcribed by the researcher only and kept electronically, accessible by an encrypted password. All hard copies of personal data were kept in a secure, locked filing cabinet in accordance with University policy on data protection.

Participants were invited to break during the interview at any time to help reduce fatigue. This invitation was often upheld, in contrast to the focus group study, possibly as a result of the interview being very much on the participants 'territory'. This was particularly the case in the earlier interviews where more changes to items were suggested and discussed with participants hence the interviews lasted longer and required more breaks.

As with the focus group study, cognitive impairment to the extent that free and voluntary participation could not take place constituted an exclusion criterion. This has already been discussed in section 3.6.4.

5.6.2 Study Setting

The interviews were conducted at localities within a 50 mile radius of the University of Southampton. This represented a feasible sphere of operation for the researcher whilst still representing an extensive area of the South of England.

5.6.3 Sampling frame

A decision to recruit from the University of Southampton's Faculty of Health Sciences research participant register was taken for phase II. At the time of conducting phase II, the register had around 50 individuals with stroke who had consented to be contacted for research by the Faculty of Health Sciences. The contact details of participants on the register are not freely available to researchers within the Faculty. Participants are therefore contacted by a third party, the register manager, on the behalf of researchers. If participants decide they wish to take part, they contact the researcher concerned for further information.

A pragmatic approach to sampling was taken that acknowledged the confines of resources and time. The number of participants on the register was felt sufficient to allow for a range of socio-demographic characteristics that could be captured through a convenience sampling approach.

5.6.4 Participants and Sampling

The approach to sampling was convenience. Socio-demographic variations of importance to stroke self-management were likely to exist between participants, such as length of time since stroke, gender, age, ethnicity and level of disability or impairment. This was desirable to reflect a broad range of experience since having a stroke.

The inclusion criteria were kept broad to recruit as wide a range of participants as possible. The following inclusion criterion was set and discussed with potential participants prior to recruitment:

- Community dwelling individuals who reported having had a stroke requiring hospital admission and treatment.

In addition to the inclusion criterion, the following exclusion criteria were identified:

- Individuals less than 18 years of age.
- Stroke less than three months previously.
- Individuals who had other existing long-term conditions that took precedence over their ability to manage their stroke e.g. Alzheimer's disease, Motor-neurone disease (assessed on an individual basis prior to inclusion into the study).
- Individuals who did not speak English sufficiently to participate in an interview.
- Individuals living greater than 50 miles from the University of Southampton
- Cognitive impairment - Individuals who were cognitively impaired to the extent their communication and ability to participate in an interview was impeded, or was a barrier to their free participation (section 3.6.4.)

5.6.4.1 Sample size

There are no definitive recommendations on the required sample size for conducting Cognitive Interviewing research (Collins, 2003). Therefore, guidance was sought from studies of published work. Studies using CI in PROM development have reported sample sizes, ranging from 9-30 participants (Carbone et al., 2002, Christodoulou et al., 2008, Nicklin et al., 2010, Wu & McSweeney, 2004). None of these studies involved participants recovering from stroke. A study that developed a measure of quality of life in older people used three focus groups, (3-7 participants) to examine content validity (Hyde et al., 2003). However, questions exist regarding the effectiveness of group interviewing for the generation of in-depth knowledge for this purpose, individual interviews being advocated (Beatty & Willis, 2007, Drennan, 2003). A report prepared for an NHS stroke survey conducted CI with 29 participants who'd had a stroke (Howell et al., 2004). Details on the methods are scant within the report therefore it is difficult to comment on the rigour of the techniques employed. However, this suggests a precedent for the role of CI in developing PROMs for stroke.

Using the literature, a decision to aim for between 3-5 participants per 'round' of CI was taken. This number is sufficient to allow a range of characteristics within the sample, yet represents a realistic number to recruit within the constraints of the study.

5.7 Recruitment

Potential participants were contacted by the manager of the research participant database, who forwarded the participant information sheet (appendix eight) by post to participants meeting the inclusion criteria. For participants who found large amounts of text difficult to manage, a pictorial version of the information sheet and consent form was available to aid understanding. As with the focus group study, these were used by potential participants either together with, or independent of, the text version to facilitate understanding. Similarly, no assumptions about the cognitive abilities of potential participants were made to avoid offence and all participants were sent both versions.

Potential participants were asked to contact the researcher if they required more information about the study or wished to participate. At this contact, the inclusion and exclusion criteria were checked and socio-demographic information was collected.

5.7.1.1 Socio-demographic information

The Barthel Index (BI) was used to describe the participants' level of functional ability. An overview of the BI can be found in section 3.6. A summary of the socio-demographic variables collected from participants is shown in table 5.1. Characteristics were collected to inform sampling, to reflect a range of characteristics in the sample. Socio-demographic information was collected chronologically according to when participants made contact. Participants were recruited if the information was sufficiently varied from the previous recruited participant. Participants were asked to provide a convenient date for a visit at home, or were offered an interview at the Faculty of Health Sciences. A confirmation letter was sent to each participant with a reminder of the date for the interview and a copy of the consent form, to enable participants to familiarise themselves with the consent form.

Variable/Characteristic
Age
Gender
Length of time since Stroke
Marital Status
Other Health Conditions
Ethnicity
Social circumstances (where residing, with whom, level of care)
Current occupation
Functional ability (Barthel Index)

Table 5.1. Summary of socio-demographic characteristics collected to aid sampling.

5.8 Conducting the Interviews

5.8.1 Pilot Interview

Cognitive Interviewing is a skilled technique. Therefore, a pilot interview was first performed to enable familiarisation with the skills required to conduct a successful cognitive interview. This enabled the procedures to be tested and revised. The pilot took place in the participants own home, allowing the safeguarding procedures to also be familiarised. The participant was not told that the interview was a pilot, since at this point it was uncertain what procedures might change and to avoid unduly influencing any data.

The procedure for the interview was first outlined with the participant. The obtaining and checking of informed consent followed. The participant offered refreshment, and we took part in ‘small-talk’ which helped to create a relaxing environment and generate trust (DeMuro et al., 2012). The participant was given the item pool, which appeared as an A4 document, each number being clearly labelled and double spaced. The participant was asked to read the first item and differing response options to themselves. Next they were asked to specify their response in relation to each of the three response formats. Probing was used to elicit why the participant had responded in that way, and to examine their interpretation of specific terms within the item. The participant was asked to specify (where there was) a preference in terms of which of the three response formats was the easiest to understand.

There were some learning points from the pilot. Only one copy of the item pool was taken to the interview, which made note taking unduly complicated. Several copies were then bought to subsequent interviews. The first interview was conducted with a person with communication impairment. Therefore, more time than was anticipated was necessary to conduct the interview to allow for breaks, and to avoid rushing the participant. It also was clear that in some interviews, it would be necessary to read the item pool aloud, to avoid additional burden on participants who found reading and speaking difficult. Following discussion with the supervisory team, the procedure (5.8.2) was felt acceptable to address the research question and therefore was adopted in the remaining interviews. Data from the pilot interview was therefore used in analysis.

5.8.2 Procedure

The cognitive interviews were conducted between March and June 2012. Three possible response formats were presented to participants, as follows:

Option A
Strongly Disagree 1 2 3 4 5 6 Strongly Agree

Option B
YES NO

Option C
Disagree Disagree slightly Neither Agree nor Disagree Agree slightly Agree

The preliminary item pool to be examined in the first round of interviews consisted of 57 items (appendix nine). Three response options were selected to examine the cognitive burden associated with different response formats. A theoretically simpler dichotomous scale (YES/NO), and a numerical version of the Likert response format were included.

Cognitive Interviewing was initially conducted with three participants, and consisted of ‘round one’ of the interviews. Further participants were then recruited for subsequent rounds of interviews, so that changes made to the item pool in light of comments from participants in a previous round could be examined. This process continued for three rounds at which point, minimal changes were suggested by participants and the item pool was justified as being optimal, in terms of item content, language and response format. Each round of interviews was analysed before commencing the next round. Following each round of interviews, the proposed changes to the item pool were discussed with the supervisory team. A flow chart illustrates this process (figure 5.2). Due to confines of resources and time, a decision to limit the process to a maximum of five rounds was made prior to commencing the CI study.

In each interview the participant read to themselves, or where the participant had reading or speaking difficulties, the researcher read each item aloud. Participants were then asked to verbally give an overview of what they thought the item was asking, or what it concerned. Further probes were used guided by their response. Probing particularly sought to understand their perspectives on terminology within each item. An example of the type of probing adopted is shown in figure 5.3. In addition, spontaneous questioning was used throughout the interview to clarify and to understand participant responses (e.g. can you tell me what you mean by that?).

Items were grouped together randomly in clusters of 5-6 in the item pool. This was to allow natural pauses and breaks within the interview to minimise burden on the participant. To avoid potential response patterns, items on similar topics were separated. For example, items relating to impairment appeared in separate groups.

Item 3. I cannot rely on others to help me recover from stroke.

Strongly Disagree 1 2 3 4 5 6 Strongly Agree

1) What did you think about when you answered this question?
2) What do ‘‘rely’’ and ’’recover’’ mean to you?
3) How did you decide to pick that number? (Referring to scale)
4) Do you think other people would answer this question honestly?
5) How could we say this better?

Figure 5.3. Example of Cognitive Interviewing probes

Interviews were recorded using a professional quality digital recorder and transcription kit (Olympus WS300M & AS4000). Hand-written notes were taken during the interviews in relation to key points made by the participant to aid analysis. Interviews lasted between 45 and 120 minutes, including breaks at the suggestion of the participant or by the researcher. At the end of each interview, the recording equipment was switched off and participants

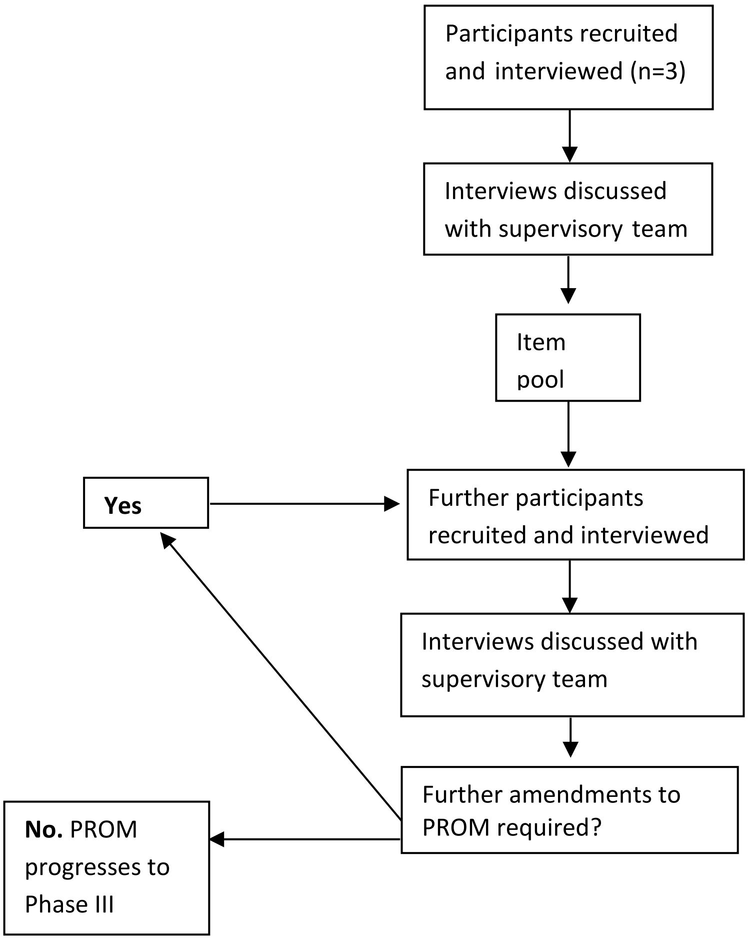


Figure 5.2 Cognitive Interviewing process

were thanked for their time. Future steps in the development of the PROM were explained briefly and they were offered a summary of the research, once completed.

5.9 Approach to analysis of data

In a review of CI procedures, analysis was thought to be '*overtly subjective*' and therefore the '*greatest flaw in an otherwise comprehensive method*' (Drennan, 2003 p.62). In order to avoid this criticism, the procedures adopted in analysis will now be set out to provide transparency for the reader.

Interview transcripts represented the data. Interview recordings were transcribed by the researcher to assist authentication of and familiarity with the data. Analysis followed a procedure advocated by (Willis, 2005) and content analysis (Mason, 2002). The summative form of content analysis focuses upon identifying key words and content in the data to understand their contextual use (Hsieh &Shannon, 2005). Summative content analysis extends beyond the quantification of words or terminology (manifest content analysis) to examining interpretation of content (Latent analysis) (Green & Thorogood, 2009).

Interview recordings and field notes were first reviewed to give an overall impression of the participants' perspective of each item. Responses from each round were then pooled and analysed for commonalities, specifically the frequency of particular terms used. Where possible, the number of participants expressing each comment or view was indicated to provide transparency for the reader (Knafl et al., 2007). Comments and participant interpretations on each item were then summarised for all interviews within each round. The summaries for each item enabled exploration of any latent meaning, and justification for amendments to items.

Following each round of interviews, discussion with the supervisory team helped to challenge the justification presented for the retention, deletion, or rewording of items. As items were reworded or deleted, the item pool was adjusted, so that during subsequent rounds of interviews the most recent and shortest version was used. Following all rounds of interviews, data from the final round were reviewed in light of participant comments from previous rounds. CI rounds continued until theoretical data saturation was reached; no new interpretations were emerging from participants, no further amendments could be made, and that no further exploration of the item pool was required. The exploration of amendments to the item pool following each round with additional participants provides credibility for the interpretation of the data (Hsieh & Shannon, 2005).

5.10 Summary

Cognitive interviewing has been justified as an appropriate methodology to refine and further develop potential PROMs. Chapter six presents the findings of the Cognitive Interviewing phase.

6. Chapter Six – Findings from Cognitive Interviews

6.1 Introduction

This chapter presents the findings from the Cognitive Interviewing (CI) phase. Firstly, an overview of the participants' socio-demographic details is provided. Thereafter, each round of cognitive interviews is discussed, using example items to evidence the interpretations made. Subsequent amendments to the item pool are discussed and justified. Finally, reflections are made concerning the issues around interpreting data from the interviews.

6.2 Participants

Cognitive interviews were conducted between March and June 2012. A total of 18 individuals from the Faculty of Health Sciences participant register were invited to participate. 15 people responded to the invitation; two of which subsequently withdrew interest. One person was in the process of moving areas and the other felt personal commitments would prevent participation in the study. 13 people were interested in taking part, 11 of whom actually participated. Each potential participant provided socio-demographic information and Barthel Index scores to aid sampling; all were considered sufficiently different from one another to warrant inclusion in the study. A summary of the participant characteristics is presented in table 6.1. Following three rounds of CI, no new data emerged and further amendments to the item pool were considered not to be required. Therefore, interviews were not conducted with the remaining two interested participants. The following sections highlight participant characteristics of note.

6.2.1 Barthel Index (BI)

The Barthel Index (BI) (Mahoney & Barthel, 1965), a measure of functional independence (score range 0-100, higher scores indicate greater independence) was scored at recruitment. The lowest BI score was 35 (round II), the highest 100 scored by three participants. Two participants scored <80

(18%) indicating that in the main the sample were able to perform most activities of daily living. However, the BI does not examine communication or cognitive function, the implications of which have been outlined in chapter four, section 4.2.2.

	Round I	Round II	Round III	**Summary for all rounds**
No. of participants	4	3	4	11
Age range (years) **Mean [SD]**	37-69 52.75 [15.63]	49-70 59.66 [10.50]	61-68 64 [3.60]	37-70 58.2 [11.57]
Male gender	2	2	2	6 (55%)
Communication limitation	2	1	0	3 (27%)
Mean duration since stroke (months) [SD]	60.25 [35.18]	35 [14.18]	56.67 [50.20]	53.11 [33.92]
Marital status				
Married	2	2	1	5
Single	1	0	1	2
Widowed	0	1	1	2
Living with partner	1	0	0	1
Divorced/separated	0	0	1	1
Mean length of formal education [SD]	12.50 [3.51]	15.33 [2.08]	14.33 [3.78]	13.90 [3.14]
Ethnicity				
Caucasian UK	3	2	3	8
Non-EU	0	1	1	2
Other UK	1	0	0	1
Mean Barthel Index [SD]	93.75 [7.5]	66.66 [28.43]	96.66 [5.77]	86.5 [19.87]

Table 6.1 Summary of cognitive interviewing participant characteristics

6.2.2 Communication impairment

Three participants were affected by a communication impairment as a result of stroke. The individual nature of the interviews meant that enabling participants to speak and express themselves was more straightforward than the focus group study. All interviews with participants with a communication limitation took place in their home, in an environment familiar to them. Participants had ready access to communication aids and used non-verbal communication effectively to express their needs, for

example, pointing to photographs of relatives when talking about the role of families. Being attuned to non-verbal communication and the maintenance of eye-contact was simpler, without the distractions of managing a group. Inclusion of these participants was of paramount importance to developing a PROM that is understandable and appropriate for people with stroke.

6.2.3 Duration since stroke

The mean duration since stroke was approximately 53 months. Large variations in duration since stroke were observed across the sample. The shortest duration since stroke was six months (round II); the longest was just over nine years (round III). This was advantageous since the sample represented a wide range of perspectives and experiences of stroke self-management to guide refinement of the item pool and development of the PROM.

6.2.4 Ethnicity of sample

Differing cultural backgrounds may influence how self-management is enacted, and how PROMs are interpreted. Therefore, inclusion of people with a range of ethnic backgrounds was desirable in the sample. The majority of the sample came from a white, UK background (73%). Three people from differing backgrounds were recruited, one of whom spoke English as a second language.

6.3 Findings from Cognitive Interviewing

Cognitive interviews were conducted for a total of three rounds (figure 6.1). The term ‘round’ was assigned to a group of interviews which were analysed collectively and which were used to make amendments to the item pool. Subsequent rounds sought to explore the amended item pool and investigate for further potential modifications. This process has been outlined in chapter five.

The approach to analysis has been outlined in chapter five. Each round is now discussed in turn, to include illustrations of amendments made to the item pool and consideration of the rationale informing modifications.

6.3.1 Round one

The preliminary item pool examined in the first round of CI consisted of 57 items (appendix nine) and included four participants (table 6.2). Duration of the interviews ranged from 65-120 minutes.

ID	Gender	Age (years)	Duration since stroke (months)	Living situation	Barthel Index score	Comments
1 (pilot participant)	F	69	65	Spouse	85	Communication impairment
2	M	42	30	Spouse and extended family	100	
3	F	63	108	Partner	90	
4	M	37	38	Alone	100	Communication impairment

Table 6.2 – Summary of participants (Round I of Cognitive Interviewing)

A summary of the findings from the first round of CI, and subsequent amendments to all items in the preliminary item pool are presented in appendix ten. Examples of item refinement, as informed by the findings of the first round of CI, are next illustrated. Each item is first presented as worded in the preliminary item pool used. Words italicised and in inverted commas indicate the verbatim words of participants. Suggested interpretations and amendments to improve the item were discussed with the supervisory team.

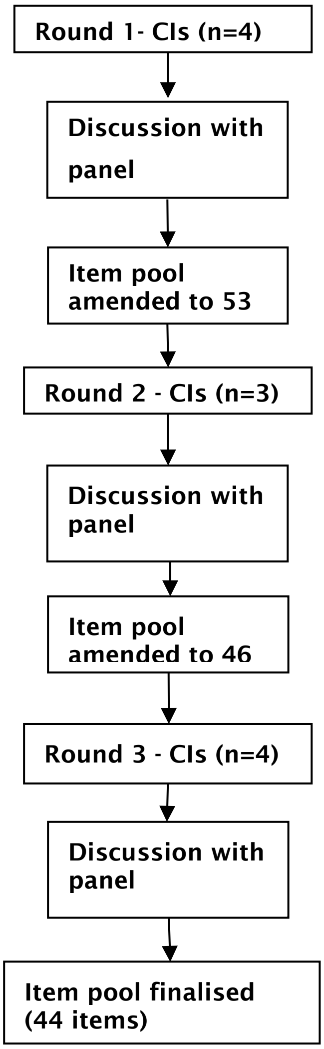


Figure 6.1 Summary of Cognitive Interviewing process

Example 1

No matter how hard I try, managing my stroke doesn't turn out the way I would like

Answering this item was difficult for participants because it meant reviewing a time period that had passed and was not clearly delineated within the item. The approach to the item appeared to be affected by the participants' understanding of their role in managing their health. Participants talked about examples where they felt they had managed well, such as persevering with walking exercise, or trying to reduce blood pressure. However, participant ID4 felt there was '*nothing to manage'*, since the stroke had happened already and could therefore not be changed. ID2 thought that 'no matter how hard I try' was an '*extreme*' phrase, suggesting that the participant was able to consider the extent to which they influenced managing stroke. ID2 reported not revisiting any strategy again unless it worked initially, and reflected that this was not '*trying very hard'*. However, he felt this was a reasonable decision and way of managing due to a '*lack of time'*. The term 'no matter how hard I try' appeared to have social desirability implications, as some participants wished to emphasise that they could not '*try any harder'*. There appears to be the potential for value judgements in relation to 'trying hard'. ID4 felt the term 'my condition' was too vague, covering '*too many variables'*. 'My condition' was felt to be a confusing term by all participants; for example does it mean '*my stroke, or my health or what condition*'?

Implication: Item should be amended to exclude the perceived extreme statement and any connotations of a preferred behaviour (trying hard) and reduce ambiguity over the term 'condition'. Amended item: *Generally speaking, my efforts to manage the consequences of stroke turn out the way I would like*

Example 2

Healthcare professionals should make most of the decisions about my condition

The term 'Healthcare professionals' was understood to mean '*Doctors, Nurses, Physiotherapists, anyone really who provides you with help…Even the blood* [phlebotomist] *lady*'. This highlighted that 'Health professionals' might be interpreted as anyone who provides care. Two participants asserted that shared decision making (described as '*jointly deciding'*) with professionals was preferred. 'My condition' was interpreted as '*my stroke*', however the comments expressed in relation to the term 'my condition' in other items were noted (see example 1). One participant felt strongly that any decisions should be made by the patient (and not by health professionals), and talked about his experience in asserting himself at a GP

appointment. Most participants appeared to find this a straightforward item to answer.
Implication: Item unchanged for round II. In round II, probing was used to clarify what kinds of decisions about stroke, participants perceive the item refers to.

Example 3
I have too much going on in life to pay as much attention to self-care as I should

This item was included to encourage self-appraisal and evaluation of the level of action required by potential respondents to be effective self-managers. However, the item was not interpreted with ease. Three participants felt the item was difficult to answer, due to complicated wording. One participant suggested that '*There would never be too much going on to ignore looking after yourself*' would be easier to understand (ID3). One participant felt she was '*too lazy to change'* (but not too busy), and that self-care was not as high on her priorities as '*it should be'*. ID4 felt the item was a '*pointless statement'* because '*it doesn't mean anything'*.

The term '*as I should'* suggests that an evaluative judgement regarding a desired behaviour is required to answer the item. The optimal level of 'attention to self-care' required, was also considered to be subjective. The item may potentially offend people, perhaps due to an implicit inference that respondents may not pay as much attention to self-care as the 'PROM' or interviewer deemed necessary. If items are considered offensive, or alienate potential respondents, they are unlikely to be answered honestly (Williams, 2003). There is a risk that respondent opinion of the overall PROM might also reduce, making it less likely to be accepted into practice (Magasi et al., 2011).
Implication: Item removed.

Perhaps not unexpectedly, since this was the first opportunity to formally test items with intended potential respondents, the first round of CI generated most amendments. As a result of this round, the preliminary item

pool reduced from 57 to 53 items, with 37 items amended. 57 items appeared to be a burdensome number for two participants (ID 1 and 2). This interpretation arose from the longer duration of these interviews (120 and 110 minutes), notwithstanding additional pauses for breaks during these interviews. Final items would therefore need to be succinct to avoid un-necessary burden on future respondents.

6.3.2 Round two

The item pool examined in the second round of CI consisted of 53 items (appendix 11). The second round of CI included three participants (table 6.3). The duration of interviews ranged from 80-100 minutes.

To provide continuity for the reader, the examples used in section 6.3.1 are revisited to follow development of the items. A new example (3) is given to demonstrate justification for removing an item from the pool.

ID	Gender	Age (years)	Duration since stroke (months)	Living situation	Barthel Index score	Comments
5	M	60	24	Spouse	75	
6	F	49	51	Spouse	35	Communication impairment
7	M	70	30	Spouse	90	

Table 6.3 – Summary of participants (Round II of Cognitive Interviews)

A summary of findings from the second round of CI, and associated amendments to all items reviewed in round two is presented in appendix 12. Words italicised in inverted commas indicate the verbatim words of participants. Suggested amendments to improve each item were discussed with the supervisory team.

Example 1

Generally speaking, my efforts to manage the consequences of stroke turn out the way I would like

(Round 1- No matter how hard I try, managing my stroke doesn't turn out the way I would like)

Participants 5 and 7 approached this item by reflecting on the timeframe of their own improvements in function following stroke and summarising this. ‘Consequences of stroke’ was interpreted as the resulting ‘*disability*’. Disability was interpreted as largely relating to physical problems. ‘*Emotional problems’* were also highlighted as problem, but were not considered a disability. ID7 felt that ‘consequences of stroke’ was ‘*a good way of putting it’* because it avoided defining people through their stroke, which may be offensive. ID6 felt her efforts were ‘*usually thwarted’* due to her ‘*severe disability’* (Barthel Index score 40). ID6 perceived that disability limited the efforts she could make on managing health.

This item attempts to elicit the efforts made by people in managing health after stroke, irrespective of any limitation they may have. Further probing was thought to be required in a further round of CI to check for the interpretation of ‘my efforts’. Overall, the item was well received by participants, though the language was thought overly complicated due to the use of different tenses.
Implication: Amend for clarity - *Generally speaking, my efforts to manage the consequences of stroke turn out how I like*

Example 2
Healthcare professionals should make most of the decisions about my condition
(Unchanged from round one)

ID5 pointed to the distinction between the advice of medical professionals ‘*interested in keeping you alive’* and therapists who are ‘*concerned with recovery’*. Based on this perspective ID5 would agree with medical professionals (GP and consultants) but would question therapy advice more readily. ID5 perceived that therapy advice is more ‘*common sense*’ and therefore did not rely on ‘*specific knowledge*’. ID6 also asserted that she would more readily follow ‘*doctors orders’*. The item seeks to elicit a respondents’ attitude to decision making. The term ‘Healthcare professionals’ may arguably be superfluous in the item, and avoids unnecessary confusion about which professional the item relates to. ID7 felt

that answering the item would depend on what decisions were being made, and also highlighted that this might vary at different times after stroke. The item was amended to omit the term 'healthcare professionals'. Further exploration in round three was sought to clarify interpretation of 'decisions'.
Implication: *I should make most of the decisions about how my stroke is managed*

Example 3
It is important to pay similar attention to my physical and emotional health
(Round 1 - *I pay equal attention to my physical and emotional health*)

Physical health was interpreted as factors related to physical well-being such as '*weight, balance and ability'* (ID5). ID5 found this difficult to answer as he didn't perceive he had any '*emotional issues'*. ID5 could not relate to this item as he stated he had not experienced emotional problems before ('*I am content')*. Interestingly, he then proceeded to talk about regular early-morning waking due to anxiety. This highlighted the term 'emotional health' may be too elusive for potential respondents, or alternatively that respondents have difficulty in endorsing this item due to issues of perceived social desirability (mental health being possibly associated with stigma). ID6 felt that physical problems were more important to address, since '*the rest will follow'.* ID7 felt that emotional health was a problem for him, and that these were more complex than physical health because '*no one can see them'*.

Physical and emotional health are relevant to stroke. However, following two rounds of CI it was unclear how this item related directly to either a self-management attitude or behaviour following stroke. Due to an awareness that potential respondents may feel burdened by unwarranted items, it was felt prudent to remove an item that did not have a clear conceptual relationship to a self-management attitude or behaviour.
Implication: remove item

As a result of the second round, the item pool reduced from 53 to 46 items, with 29 items amended. The number of items presented in round two appeared to be demanding for some of the participants. This may in part relate to the nature of cognitive interviewing and to the length of the interviews. ID7 felt that following 45 minutes of CI his '*concentration was going'*, adding that he could concentrate optimally for 20-25 minutes. However, answering items within a PROM should be quicker and less demanding in practice than during CI.

6.3.3 Round three

The item pool examined in the third round of CI consisted of 46 items (appendix 13). This round of CI included four participants (table 6.4). The duration of the interviews ranged from 60-90 minutes.

ID	Gender	Age (years)	Duration since stroke (months)	Living situation	Barthel Index score
8	M	63	12	Alone	100
9	M	68	47	Alone	90
10	F	61	111	Alone	100
11	F	58	35	Spouse	85

Table 6.4 – Summary of participants (Round III of Cognitive Interviewing)

The examples used in section 6.3.1 and 6.3.2 are revisited to follow development of the items. Two items were removed from the item pool following this round of CI. Example (3) describes the justification for removing one of these items. A summary of findings from the third round of CI, and associated amendments to all items reviewed in this round is presented in appendix 14. As before, words italicised presented in inverted commas indicate the verbatim words of participants.

<u>Example 1</u>
Generally speaking, my efforts to manage the consequences of stroke turn out how I like
(<u>Round 1</u>- *No matter how hard I try, managing my stroke doesn't turn out the way I would like)*

(<u>Round 2</u> - *Generally speaking, my efforts to manage the consequences of stroke turn out the way I would like)*

Participants 8, 9 and 10 endorsed this item readily and, similar to participants in earlier rounds, drew on their experiences since having a stroke to appraise this item. Participant 11 felt this item was difficult to answer as she couldn't describe her efforts to manage stroke, suggesting that some respondents may find this item complex. ID10 used a specific example to illustrate her answer. She described being '*determined*' (following a wish to go swimming she crawled along a poolside and was helped in to the pool by the caretaker) and despite the experience being '*awful*', it was '*liberating*' due to the sense of achievement gained. 'Generally speaking' was interpreted as '*most of the time*' by all participants. The language in this version of the item overall to be easier to understand and encouraged participants to appraise their role in self-management.
Implication: Item remains

<u>Example two</u>
I should make most of the decisions about how my stroke is managed
(<u>Rounds 1&2</u>- *Healthcare professionals should make most of the decisions about my condition)*

Following round two, further investigation of the term 'decisions' was felt necessary. Participant nine did not endorse this item, strongly feeling that professional advice was required relating to '*how best to manage'*. On probing, ID9 reported he would follow anything recommended to him (by healthcare professionals), as it '*would be stupid, not to*'. This success of this strategy may then depend on the quality of the advice given and the extent to which any advice was relevant to the person. For example, ID10 reported having '*the right to say no'* and would consider advice from professionals, but ultimately felt it was necessary to make the final decision. ID8 endorsed the item, but highlighted that in the early stages of stroke ('*hospital part')*, reliance on health professionals to make decisions was implicit. ID11 felt that she should be involved in how decisions are made, but as '*they* [HCPs] *know best'* would defer to any advice they offered.

The wording of this item appeared to be clearer and better able to encourage participants to reflect on their own circumstances. Participants felt the item would be answered honestly by others, but answers might vary according to the period after stroke. None of the participants in this sample were less than three months post stroke; therefore judgements on how the item would be approached in the acute stages of stroke are unobtainable. How the PROM performs in populations less than three months post-stroke, is something to explore in its on-going validation. Implication: Item remains.

Example three

I have made changes to my lifestyle since having a stroke to improve my health (Round 1&2 - *I take more care with my diet to stay healthy since having a stroke)*

Lifestyle changes were interpreted as '*smoking, drinking, exercise'*. ID11 felt that her lifestyle had changed, but perhaps not for the better, as she took less exercise and ate more irregularly. ID10 felt she had made some changes because of stroke, such as '*trying to lose weight*' and '*drinking wine with my meal'*. However, the item did not appear to reflect changes made to lifestyle in pursuit of better health on the part of participants. For example, ID8 felt that he was healthy before having his stroke, so had not made any deliberate lifestyle changes. ID9 talked about the changes made to his diet and alcohol consumption, but pointed that these were not an intentional action for health reasons, but rather a consequence of stroke (decreased appetite and alcohol tolerance).

This item was very similar to another item (35, appendix nine), which participants reported finding easier to understand due to the use of specific examples in the item. Therefore, this item was removed in favour of the other item which still captured self-management behaviours relating to lifestyle.

As a result of the third round, the item pool reduced from 46 to 44 items and eight items were amended. The amendments made as a result of this phase were minor. For example, in the item 'I cannot affect what my healthcare professionals decide to do about my stroke', the term affect was changed to 'alter', the rest of the item being unchanged. 'Alter' appeared to better capture the extent an individual may influence healthcare professionals, whereas 'affect' was considered a much more 'direct' term. Another example was deleting the term 'always' from the item 'I find it difficult to always tell professionals what I want or need' as a response to the comments of participants, who found 'extreme' position statements more difficult to approach.

Following this round of CI and after discussion with the supervisory team, a decision to cease cognitive interviewing was taken. Participant interpretations of the terminology included in items were not sufficiently different to earlier rounds of interviews to warrant further exploration. The wording of items appeared to be as clear and acceptable as pragmatically possible, within the confines of resources. The amendments made to the item pool were therefore viewed as optimal in readiness for exploration in the final phase of the research.

6.3.4 Response format

During CI, participants were asked regarding their preferences for the response format of the new PROM. Two participants preferred the dichotomous response option. The rest of the sample reported this format was either too 'simple' or 'stark'. Participants appeared very familiar with the Likert response formats used in this study. That participants were familiar with the response formats used may have been an advantage in reducing burden for participants. However, two participants considered the Likert response formats used to be too familiar, even '*boring*' and reported that this could potentially deter future participants. Therefore, participants were also asked about alternative anchors to Strongly Agree- Strongly Disagree continuums for the Likert response formats. The preference appeared to be for a scale that was anchored from Always True – Always False. This was the eventual response format utilised in the psychometric evaluation of the PROM.

All participants requested that the eventual PROM be divided into sections to make approaching the PROM easier. Suggestions for presentation in terms of font and colour were also given.

6.3.5 Summary of Item pool

Following the third round of CI, and in order to formulate the preliminary PROM, the remaining items were organised with regard to their original potential relationship to the conceptual model, developed following the focus group enquiry. Briefly, three main themes were identified as follows; *Individual Capacity*; *Support for self-management* and *Self-management environment*.

The concepts of interest to be targeted in the PROM were stroke self-management attitudes and behaviours. To guide organisation and presentation of items in readiness for the preliminary PROM, the items were revisited with regard to the qualitative data (table 6.5). To provide transparency for the reader, the origin of each item and relationship to the focus group data is indicated in parentheses. During the CI phase, participants highlighted how grouping items with similar content together would be preferable for the eventual PROM. Five sections were therefore presented, for inclusion in the preliminary PROM.

Section	Item	Relationship to themes and conceptual model	Attitude or behaviour
Effect of self-management on recovery following stroke (1-13)	I regularly think about how I might change things to better manage the consequences of stroke (1)	Capacity- decision making	A/B
	I cannot rely solely on others to help me manage the consequences of stroke (2)	Capacity – determination	A
	Whatever I do, I will not improve my condition (3)	Capacity- self-confidence	A
	When things do not go well with my stroke, it is hard to stay positive (4)	Capacity – self-confidence, determination	A
	I always follow professional advice about my health, to the letter (5)	Capacity – decision making Support for self-management – role	B

		of professionals	
	General self-care is important to me to stay as healthy as possible (6)	Capacity- decision making	A
	There is little point in trying new ways of managing the consequences of stroke, as it will not change my condition (7)	Capacity -determination	A
	I should make most of the decisions about how my stroke is managed (8)	Capacity- decision making	A
	It is hard to be motivated to seek out solutions to problems relating to stroke (9)	Capacity – determination, finding resources	A/B
	It is difficult to stay motivated to do tasks or strategies important to my recovery (10)	Capacity - determination	A/B
	My condition would improve if I received more professional help (11)	Capacity – Finding resources, self-confidence	A
	It is not up to me to decide what the best ways to manage my stroke are (12)	Capacity – decision making	A
	I cannot alter what my healthcare professionals decide to do about my stroke (13)	Capacity- communication skills, self-confidence	A
Managing Health after stroke (14-21)	Treatment or therapy regimes do not take over my life (14)	Capacity –decision making	A/B
	I apply professional advice so it is relevant to my situation (15)	Capacity – decision making, communication skills	B
	I plan my day so I can get things done without being tired (16)	Capacity – decision making	B
	I talk about any medication I am prescribed with healthcare professionals (17)	Capacity – communication skills	B
	I find answers to problems about stroke without seeking professional advice (18)	Capacity – finding resources, decision making	B
	I try different ways of doing things, until I find out what works for my health (19)	Capacity – determination, finding resources	B
	I know how to get help if I am concerned about my condition (20)	Capacity- finding resources, communication skills	B
	The lifestyle choices that affect my health (for example, smoking, diet,	Capacity – decision making	B

	alcohol, etc) have changed since having a stroke (21)		
Role of professionals (22-29)	I am concerned that the things I do to manage stroke, may cause harm if not guided by health care professionals (22)	Capacity –self-confidence	A/B
	I feel confident at discussing any advice I don't understand with Doctors (23)	Capacity – self-confidence, communication skills	A/B
	I find it difficult to tell health care professionals what I want or need (24)	Capacity – self-confidence, communication skills	B
	I always ask health care professionals to explain why I should follow their advice (25)	Capacity- communication skills	B
	Constant professional advice would help me to manage my stroke (26)	Capacity- self-confidence	A
	I am confident that health care professionals can answer my questions (27)	Capacity- communication skills	A
	Following advice from health care professionals is the only way I will manage stroke (28)	Capacity – self-confidence	A
	I work out ways of managing my health following stroke together with health care professionals (29)	Capacity- communication skills, decision making	B
The impact of stroke on managing health (30-40)	The physical effects of stroke mean that I cannot manage my health as I would like (30)	Capacity - impairment	A/B
	My problems with communication mean that I cannot manage my health as I would like (31)	Capacity - impairment	A/B
	The effects of stroke mean that I cannot control any aspect of my recovery and health (32)	Capacity – impairment, self-confidence	A
	The effects of stroke mean that I cannot manage my recovery and health (33)	Capacity – impairment, self-confidence	A
	I am not sure what signs or symptoms might mean my health is changing (34)	Capacity – self-confidence, finding resources, decision making	A
	I feel confident in getting the information I need from health care professionals (35)	Capacity – communication skills Support for self-management – role of professionals	A

	My efforts to manage the consequences of stroke turn out how I like (36)	Capacity – self-confidence	A
	I am able to control my general health (37)	Capacity – decision making	A
	The efforts I take to manage my health have a positive effect (38)	Capacity -determination	A/B
	I manage things related to stroke as well as other people with stroke (39)	Capacity – self-confidence	A
Role of other people (not HCPs) in enabling self-management (40-44)	I have useful information or advice to give to others regarding managing stroke (40)	Capacity- self-confidence	A
	I am reliant upon others to help me do things important to my health and well-being (this might involve attending appointments, shopping for food, social activities, etc) (41)	Capacity – finding resources, self-confidence Support for self-management- role of carers	A
	I feel comfortable asking friends to help me do things important to my health (42)	Capacity – communication skills Support for self-management – role of carers	A
	I feel confident asking family members to help me do things important to my health (43)	Capacity – communication skills, self-confidence	A
	Ideas and things that work for other people with stroke are helpful to my recovery (44)	Capacity- decision making, self-confidence	A

Table 6.5 Relationship of items to qualitative data

6.4 Reflections on Cognitive Interviewing

These findings provide support for the assumption that people following stroke can make judgements about self-management behaviours and attitudes in a self-report PROM format. Other researchers have used deductive approaches to CI (Rosal et al., 2003). In this study an iterative process to item amendment or exclusion was followed, based on qualitative judgements to reduce burden on participants. The process was invaluable at exploring participants’ interpretation of items and providing continuing evidence of the content validity of the PROM.

6.5 Summary

Cognitive interviewing has been successful at revealing possible pitfalls related to item acceptability and reducing ambiguity of wording for maximum clarity and validity of the PROM. The final stage in the development of the PROM is to examine its' psychometric performance. Chapter seven details the methodology for the final phase.

7. Chapter Seven – Phase Three Methodology and Method

7.1 Introduction

This chapter outlines the methodology and methods adopted in the final quantitative phase, concerning the psychometric evaluation of the preliminary PROM. The ontological and epistemological assumptions associated with research and overarching research design have been outlined and justified in chapter three. The theoretical assumptions underpinning the measurement model are outlined and justifications are made for the chosen methodology. The research design and procedures are described and defended. Finally, the methods of analysis chosen to interpret the findings are outlined and explained.

7.2 Research aims

The overall research design adopted an exploratory sequential mixed methods approach (Creswell & Plano Clark, 2011) consisting of three phases. Figure 7.1 revisits the overall study design. The first two phases were exploratory, seeking to understand stroke self-management from the perspectives of people following stroke and to refine an item pool for a new PROM. The third phase, to which this chapter refers, seeks to strengthen the concepts generated through the psychometric examination of the PROM. The aim is to determine the extent to which the numbers generated by the PROM are meaningful measurements rather than numerals (Streiner & Norman, 2008).

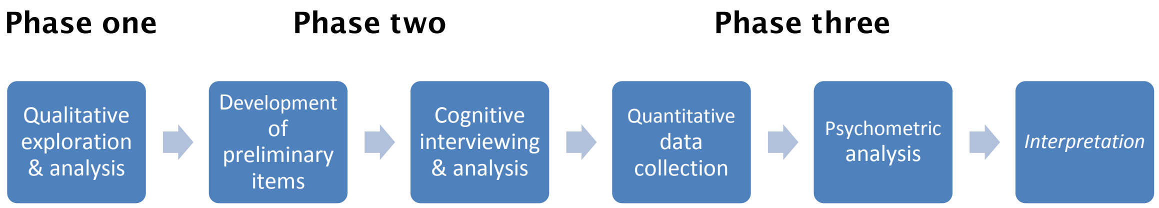


Figure 7.1 Overview of the exploratory sequential study design

7.3 Measurement Model

A measurement model seeks to describe the relationship between the item scores and theoretical construct represented in a PROM (Wilson, 2005). The relationship to the underlying theoretical construct is of importance when considering the measurement model adopted to examine the psychometric properties of the PROM (de Vet et al., 2011). The inductive work suggested that some items within the PROM, may be considered to define the construct of self-management, and some items may be causal indicators of self-management (table 6.5). To provide clarity for the reader, the differing models which inform measurement are now discussed.

In seminal work, two measurement models known as causal and effect indicator models were outlined by Bollen and Lennox (Bollen & Lennox, 1991). Classical test theory (CTT) assumes that the variation in scores on measures of a construct is a function of the true score, plus any error. Thus, CTT assumes that the latent construct causes the observed variation in the item scores (Nunnally & Bernstein, 1994). In such cases, items can be described as effect indicators (Bollen & Lennox, 1991) also known as reflective indicators (de Vet et al., 2011). This assumed direction of causality, from the latent variable to the items, may be conceptually appropriate in some examples in the proposed PROM. For example, the item response for *'I plan my day so I can get things done without being tired'* (item 16) may vary according to an individuals' skill at goal-setting. However, in the item *'I am reliant upon others to help me do things important to my health and well-being'* (41), the direction of causality instead conceptually flows from the item to the latent variable. In this case, the model can be said to be causal (Bollen & Lennox, 1991) or formative (de Vet et al., 2011).

Figure 7.2 demonstrates the differences between these two measurement models using path diagrams to illustrate the direction of causation. In diagram one, variable= latent or observed variable, Y=the item score, e= measurement error and R=the coefficient giving the expected effect of the variable on Y. In this case the dependent variables (Y) are observed, meaning that the item scores will change in relation to a change in the latent variable. In diagram two, X= the item score, the dependent variable is latent and the independent variables are observed. In practice, the distinction between the two models is sometimes ambiguous, particularly with regard to more complex latent variables, such as quality of life, which may contain both causal and reflective elements (de Vet et al., 2011).

Section 7.9 further discusses the analysis process in relation to the measurement model.

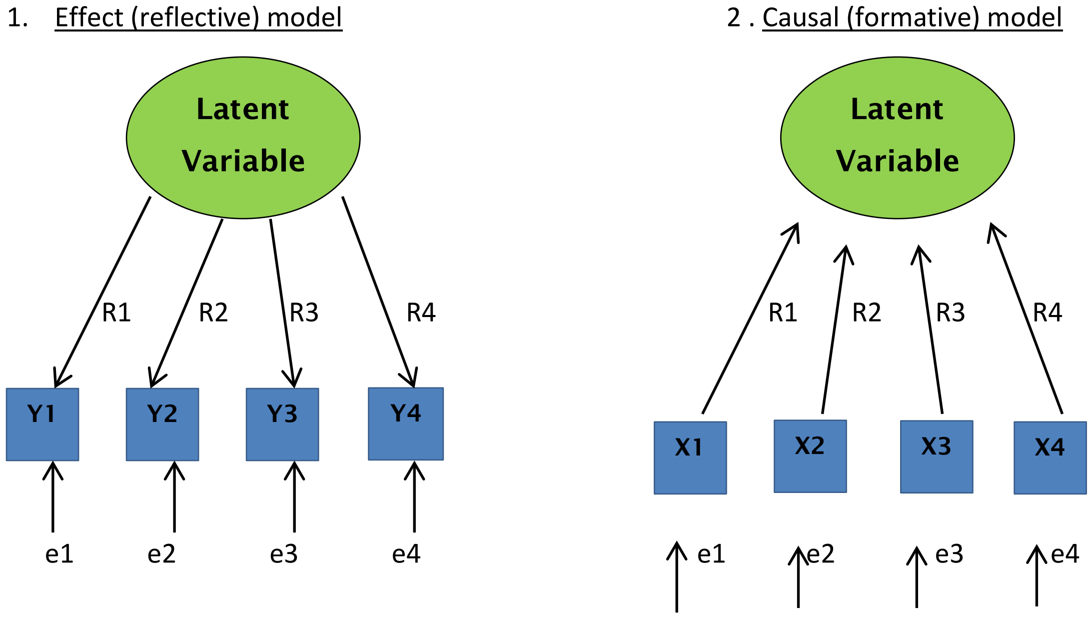


Figure 7.2. Path diagrams of Effect (1) and Causal (2) indicator measurement models (Bollen & Lennox, 1991).

7.4 Research Question

This final phase sought to examine the evidence for the psychometric properties of the PROM. The preliminary PROM was labelled the Stroke Self-Management Questionnaire (SSMQ) and consisted of 44 items, seeking to quantify respondents' self-management attitudes and behaviours. The research question for this final phase is stated below:

What is the evidence for preliminary reliability and validity of the Stroke Self-Management Questionnaire (SSMQ)?

7.4.1 Aim and objectives of Phase III

Phase III had two aims, as follows:

- To provide an empirical estimate of the theoretical construct of stroke self-management, specifically attitudes, skills or behaviours pertaining to self-management.
- To determine the scale structure of the SSMQ.
- To provide evidence of potential reliability and validity of the SSMQ.

The key objectives of phase III were:

- To investigate the following psychometric properties of the Stroke Self-Management questionnaire (SSMQ); Measurement error (internal consistency reliability and test- retest reliability) construct validity and further quantitative evidence of content validity.
- Assessment of the response burden of the SSMQ for participants

Exploration of construct validity involves a continuous process which seeks to find evidence that the PROM measures what it purports to measure. Stroke self-management is a newly developed construct where the theory supporting it is emerging. In such situations where the theory may be uncertain, the process of validation seeks to explore and strengthen the theoretical construct (Nunnally & Bernstein, 1994, de Vet et al., 2011, Wilson, 2005). Construct validity may be described as the degree to which the item scores are consistent with the hypotheses (Mokkink et al., 2010b) which emerge from the theory in support of the construct.

Preliminary assessment of construct validity was explored using the following hypotheses drawn from the literature:

1. *Stroke self-management behaviour, attitudes are positively associated with functional ability*
2. *Stroke self-management behaviour, attitudes are positively associated with mood*
3. *Stroke self-management behaviour, attitudes are positively associated with communication ability*

4. *Stroke self-management behaviour, attitudes are positively associated with memory*
5. *Stroke self-management behaviour, attitudes are positively associated with participation*
6. *Stroke self-management behaviour, attitudes are positively associated with self- efficacy*

For examination of internal consistency and test-retest reliability the following hypotheses were used:

1. *Stroke self-management behaviour is positively associated with stroke self-management attitudes*
2. *Stroke self-management behaviour and attitudes scores are stable over time*

7.5 Research Design

This section provides an overview and justification of the elected research design. The aim of this phase was to explore the psychometric properties of the SSMQ. To achieve this aim, examination of the performance of the SSMQ was required by analysing responses to the SSMQ and supplementary questionnaires from individuals who had experienced stroke. The research design elected to meet the research question, aims and objectives of the study was *remote administration* of the SSMQ and supplementary questionnaires.

Remote administration was selected for the following reasons. Firstly, the SSMQ is a self-report measure and, if used in future practice, is likely to be used independently by patients. It was therefore imperative to examine whether the SSMQ could feasibly be completed by people without researcher or clinician input, especially since interviewer administration of PROMs may unduly bias responses (Unruh et al., 2003, Bowling, 2005). Secondly, remote administration enables the recruitment of larger numbers of participants within the confines of time and resources for this research, then for example, interviewer administration. Finally, there is a precedent of stroke specific outcome measures being developed using this method (Dorman et al., 1998, Duncan et al., 1999, Lincoln et al., 2003).

7.6 Research Process

The following sections outline the procedures used to collect and analyse the data.

7.6.1 Ethical Approval and Research Governance

Ethical approval was sought from the University of Southampton, Faculty of Health Sciences Research ethics committee. Following amendments, full approval was granted in August 2012 (reference no. 2982). What follows is an overview of some of the key ethical and governance considerations.

Maintenance of confidentiality and anonymity for participants was protected as far as possible by limiting the amount of personal identifiable information on the study documents. Participants were assigned codes for use on the questionnaires and were given the option of providing either their name, or being addressed as ‘research participant’ in any communication. Participants taking part in the test-retest element of the study provided either a return address, or email address. Data were kept electronically where possible, accessible by an encrypted password and protected with anti-virus software. Hard copies of data were transferred to an electronic source, before storage in a secure locked filing cabinet.

Participants were not approached directly by the researcher; participants identified via the Faculty participant register and via the stroke support groups were contacted by a third party who forwarded the study information sheets. Individuals who wished to participate or required additional information contacted the researcher directly.

Participants were conceivably susceptible to fatigue which may have been exacerbated by completing questionnaires. To minimise burden, participants were encouraged to complete the questionnaires at a time and place convenient to them. In addition, following feedback from participants in the cognitive interviewing phase, the SSMQ was divided into sections to aid completion. Appreciation and gratitude for participation was expressed in the study information sheets and on completion of the questionnaire pack (both postal and on-line versions). In line with good practice guidance (ESCR, 2011), participants were given the option of receiving a summary of the research findings.

7.6.2 Research Governance

The University of Southampton was the research sponsor, ensuring the protocol was peer reviewed, that appropriate funding was in place, that I had appropriate and adequate skills and supervision, that a risk assessment was conducted, that the relevant ethical approvals were in place and provided indemnity insurance.

7.6.3 Sampling Frame

In contrast to other quantitative studies, the intention of this study was not to generalise findings to a wider population. Nonetheless, a diverse sample was required to fully examine the performance of items within the PROM and to support interpretation of data in different groups (Streiner & Norman, 2008). The sampling frame consisted of people who met the inclusion criteria residing throughout the UK, drawn from the following five sources:

1. Selected community stroke support groups
2. The Faculty of Health Sciences, University of Southampton, participant register
3. The South West Stroke Research Network (SWSRN) newsletter
4. The Stroke Association website and newsletter
5. Different Strokes website and newsletter

This enabled access to participants with a potentially varied range of experiences of stroke self-management and diversity of socio-demographic characteristics. Further information about the sampling sources is provided in section 7.7.

7.6.4 Participants and Sampling

The approach to sampling was convenience sampling. The following inclusion and exclusion criteria were applied for this study:

Inclusion criteria

- Community dwelling individuals who had had at least one stroke not less than 3 months previously AND
- were discharged from acute medical management

Exclusion criteria

- Individuals less than 18 years of age.
- Individuals who do not read English sufficiently to complete a questionnaire written in English

For the test-retest element only, individuals who had participated in a self-management intervention within the preceding six weeks were excluded. This was to avoid any potentially confounding effects of such an intervention on responses.

7.6.5 Sample size

Differing estimates exist for the sample size required to establish validity in the development of a PROM. Some authors suggest a minimum sample size of 50-100 is required (Terwee et al., 2007, Mokkink et al., 2010b), whereas DeVellis advocates a minimum of 300 (DeVellis, 2003). One of the aims of this PhD was to enable the researcher to develop expertise within the field of psychometrics. As such, the sample sizes required to meet this aim were less stringent at this stage of the SSMQ development. Nonetheless, the aim was to provide robust preliminary evidence of the psychometric properties of the SSMQ. Therefore, a pragmatic approach to sampling was adopted, given the resource constraints of the PhD, with an aim to recruit a sample size of 100 people to the study.

7.7 Recruitment

Recruitment occurred via several routes. Two charities, Different Strokes and The Stroke Association were contacted and agreed to advertise and promote the study on their websites and in their regular newsletters (appendix 15). Permission was granted to approach individual stroke groups affiliated to them. There are over 500 clubs and groups supporting people affected by stroke across the UK (Stroke association, 2012). Due to the constraints of the study it was not feasible to approach every group. The Stroke Association organises these groups in terms of the regions in which they are based (South West, South central, South East, Midlands, Wales, North East, North West Scotland and Northern Ireland). This information, including contact details, is accessible on their respective websites, and was used to contact group leaders with regard to the study. Two groups from each region, where possible, one urban and one rural, were contacted and the leader approached regarding the study.

Leaders of stroke groups were initially contacted via telephone and email. Following subsequent interest, leaders were provided with detailed information about the study in the form of participant information sheets and invited to pass the information to group members.

The South West Stroke Research Network based in Exeter is a NHS collaborative group which holds a register of potentially interested participants and carers affected by stroke. Permission was granted to advertise the study in its quarterly patient involvement newsletter.

The Faculty of Health Sciences participant register is a database of people who have volunteered to be contacted for research. Individuals belonging to the register specify the kind of research that interests them. Their personal details are accessible only by the register manager. Researchers then identify possible participants by searching the database for key characteristics. The register manager contacted participants on behalf of the researcher, and forwarded relevant information sheets to interested participants.

7.7.1 Additional measures

The following socio-demographic information was collected to enable description of the sample; Age, Gender, Length of time since most recent stroke, living situation and Ethnicity.

7.7.2 Data collection tools – questionnaire pack

The SSMQ signified the new PROM undergoing psychometric evaluation. Following findings from the preceding inductive phases, the SSMQ consisted of 44 items thought appropriate for measuring stroke self-management attitudes and behaviours. In completing the SSMQ, respondents are asked to indicate the extent to which item statements are ‘true’ or ‘false’ on a 6 point Likert response format, each point given an ordinal numerical value (1. Always True; 2.Mostly True; 3. Somewhat True; 4. Somewhat false; 5. Mostly false; 6. Always false). This response format option represented the preference of the cognitive interviewing sample. The assumption was that higher scores equated to greater strength of agreement and more desirable self-management attitudes, skills or behaviours. To avoid a response pattern bias (Streiner & Norman, 2008), some items applied reverse scoring. In these cases, a higher score equated to less desirable attitude, skill or behaviour.

In addition to the SSMQ, two additional PROMs were administered to enable description of the sample. The additional measures were also selected to investigate construct validity, through exploration of the associations between scores on these measures and the SSMQ.

The *Stroke Impact Scale version 3.0* (SIS) (Duncan et al., 2003b) is a stroke specific measure purported to measure health status and health-related quality of life following stroke. The SIS consists of 59 items, entailing eight domains as follows: Strength, Hand function, ADL/IADL, Mobility, Communication, Emotion, Memory and thinking and Participation/Role function (appendix 16). Each item prompts responders to rate their level of difficulty experienced on a 5-point Likert response format. Raw scores from each SIS domain are then transformed so that each domain score is comparable up to a maximum of 100. The following equation is used:

Transformed score = $[(mean - 1) \div (5 - 1)] \times 100$

In the preliminary psychometric evaluation study, 91 people completed a 64-itemed version of the SIS at one, three and six months following stroke; reported internal consistency reliability in stroke populations ranged from α 0.83-0.90 (Duncan et al., 1999). Subsequent Rasch analysis (n=696) with people between one and three months post-stroke reduced the SIS to 59 items (version 3.0), removing five items which did not meet the criteria of the Rasch model (Duncan et al., 2003b). The SIS has been used to evaluate a pilot stroke self-management intervention study (Marsden et al., 2010) and a client centred self-care intervention (Guidetti & Yterrberg, 2011) as an indicator of health-related quality of life.

There are some limitations with the SIS. It may be limited in the extent to which it equally measures the individual domains. Evidence following a Rasch analysis of the SIS (n=696) suggested that the communication, memory and emotion domains contain ‘easy’ items, which only capture limitations in the most impaired individuals (Duncan et al., 2003b). The SIS was developed following interviews and focus groups with patients, caregivers, and health care professionals (Duncan et al., 2001). The purpose of the qualitative enquiry was to ‘*generate an index of stroke-related impairment, disabilities and handicap*’ (p.24). Quality of life is likely to extend beyond the presence or absence and impact of impairment. It is therefore difficult to determine the extent to which the findings align with quality of life following stroke. Questions exist about the validity of the SIS as a measure of health-related quality of life following stroke, as opposed to it being a measure of impairment. According to a systematic review of health-related quality of life measures for stroke, the SIS is considered to be a comprehensive measure of the level of impairment following stroke, to include psychosocial aspects of impairment in addition to physical impairments (Geyh et al., 2007).

The focus group findings presented in this thesis suggested that impairment was an important issue for stroke self-management (section 4.5.6). The SIS was selected to enable description of the range of limitations the study sample have as a result of stroke. In addition, data from the SIS enabled comparisons using statistical analysis with items on the SSMQ and provided information regarding how people with differing limitations respond to the SSMQ. The SIS takes approximately 15-20 minutes to complete. No permissions are required to use the SIS in non-profit clinical or research practice.

The *Stroke Self-Efficacy Questionnaire* (SSEQ) (Jones et al., 2008b) was selected because of the increasing evidence of the role of self-efficacy in self-management (section 2.5.5, 2.7.3). How self-efficacy mediates self-management is not clear (Jones & Riazi, 2001). Conceivably, individuals who possess greater confidence in their ability to enact self-management may be more likely to exhibit desirable self-management attitudes, behaviours or skills. Alternatively, being an effective self-manager may increase self-efficacy levels through gaining proficiency in self-management (mastery experience, 2.5.5). The SSEQ was developed following in-depth interviews with people recovering from stroke (n=unspecified), consultations with experts and a literature review (Jones et al., 2008b). The initial 29-itemed SSEQ was further refined to 19 items following consensus from experts in self-efficacy (n=3), stroke rehabilitation (n=10) and people recovering from stroke (n=15). Principal component analysis, using responses from inpatients at an acute hospital or community rehabilitation unit (n=40), further refined the scale to 13 items (appendix 16). Internal consistency reliability of the SSEQ was judged to be excellent at α0.90 (Streiner & Norman, 2008).

Several limitations regarding the SSEQ exist. The SSEQ maximum score is 130, indicating high self-efficacy. It is possible that participants had inherently higher levels of self-efficacy than those refusing participation. Whilst this does not affect the psychometric testing and properties of the measure, it may illustrate why no participant scored less than 20 on the measure (low self-efficacy). This could relate to higher levels of optimism experienced by participants engaging in the early phases of rehabilitation. The CDSMP studies have also reported a trend for data to be skewed towards higher self-efficacy both pre and post intervention (Lorig, 1996).

The SSEQ enabled comparisons with item scores from the SSMQ and provided information regarding the responses to the SSMQ of people with varying self-efficacy levels. The SSEQ measures self-efficacy judgements, specific to stroke and was developed with a stroke population. The SSEQ consists of 13 items and is scored from 0-130, with 130 indicating highest self-efficacy. Respondents are asked to rate their levels of confidence in response to items related to stroke recovery, on a 0-10 visual analogue scale (VAS). Reported internal consistency is reported as α0.90. T for completion was 5-10 minutes and no permissions are required to use the SSEQ in non-profit clinical or research practice.

Although the SSEQ has not been tested with populations more than four weeks post-stroke, the SSEQ remains the only stroke specific PROM of self-efficacy. In addition, contact with the SSEQ authors has revealed that subsequent analyses using item response theory, at time of writing as yet unpublished, have further developed the SSEQ providing further potential evidence of validity with differing stroke populations.

7.8 Data collection procedure

Data collection took place through the completion of a questionnaire pack, which consisted of the 44-itemed preliminary SSMQ, the SSEQ and the SIS plus questions to obtain socio-demographic information. Participants were given the option to complete either a paper or online version of the pack. Participants completing the paper version received the three separate questionnaires, a socio-demographic information form, a postage paid return envelope and a covering letter via a postal mailing.

The online questionnaire pack was designed using software from www.smart-survey.co.uk. This software is developed for professionals and academics interested in survey and outcome measurement development. The software provided a function for respondents to save and return to completion, progress bars and ‘thank you’ pages to minimise participant burden (appendix 17). Permission was sought from the authors of both the SSEQ and SIS to convert them to an online format. Participants choosing this mode of completion opted to do so by following a link directing them to the pack. The link was accessed via study information sheets and advertisements on charity websites (appendix 17). The link was also presented in paper versions of the participant information sheets, so participants could choose to complete the pack on-line, if preferred.

7.8.1 Pilot

To test that completion of the questionnaire pack in both formats was feasible and acceptable to people with stroke, and to identify any practical issues with the methods of participation, a pilot study preceded the main study.

The pilot study sample consisted of five participants, who provided evidence of the feasibility of both methods. Participants for the pilot study were recruited from the Faculty of Health Sciences, University of Southampton, participant register. The inclusion and exclusion criteria for the pilot were synonymous with those of the main sample (section 7.6.4).

Participants in the pilot were asked to complete the questionnaire pack both by post and on-line, plus provide feedback on both processes. Feedback was obtained through a short telephone interview. Specifically, the following information was required from the pilot participants:

- Length of time to complete the questionnaires (individually and collectively)
- Comments on the readability of both versions (font, colour, etc)
- Comments on the ease of instructions and navigation through the packs
- Preferences for paper or on-line versions

Following the pilot, the design (colour and font size) was altered for the on-line version. Typographical errors were also identified and amended. The pilot study procedure was appropriate to the research question and was, therefore, the procedure adopted, for the main study sample (bar requesting feedback). Data from the pilot (n=5) were included in the final analysis.

7.8.2 Test –retest reliability

Investigating test-retest reliability is important to assessing another facet of reliability, by establishing the degree to which responses are consistent and stable following a specified time point. Determining the second time point to collect further data relies upon selecting an appropriate time period. The elapsed time must be sufficient to prevent response recall by participants, but not to the extent that any underlying change in the construct has occurred (Streiner & Norman, 2008). Estimates for the appropriate time period to establish test-retest reliability range from two hours to 14 days (Streiner & Norman, 2008), and are dependent upon the outcome measure and context.

The inductive work, bringing together the experience of people at a range of time points following stroke, suggests that in the absence of any intervention, self-management attitudes and behaviours are relatively stable concepts. Guidance for the appropriate time elapse was sought from test-retest reliability investigations in other stroke specific PROMS that measure similarly stable concepts. In developing the SIS, a period of one week was adopted (Duncan et al., 1999); in the Subjective Index of Physical and Social Outcome (SIPSO) a period of two weeks was adopted (Trigg & Wood, 2003). Test-retest reliability data for the SSEQ has not to date been published. A period of two weeks following return of the first response was selected before the second mailing was sent. Participants were given two weeks from receipt of the second mailing to respond; no reminders were issued to participants.

Following completion of the questionnaire packs, participants were asked to indicate if they would like to take part in the test-retest part of the study. Interested participants were randomly selected to take part using block randomisation (Campbell & Machin, 1993). Those wishing to take part in the test-retest stage were grouped consecutively into a ‘block’ of five participants and randomised as follows:

Block 1 – YYNNY   Block 2 – YNYNY   Block 3- NNYYY
(Where, 'Y' received second mailing, 'N' did not receive second mailing)

Following the first 15 positive responders, the block allocation resumed at block 1, and repeated until close of recruitment. Participants wishing to participate in test-retest reliability on-line were asked to leave their email details on completion of the on-line version. A link to a further online version of the SSMQ was emailed to the participant 10-14 days later. First and second responses of the SSMQ were linked by an anonymous identification code. The aim was to investigate how well the SSMQ performs over time; repeat completion of the additional questionnaires was therefore not required.

7.9 Approach to data analysis

Section 7.3 highlighted the potential for items with both cause and effect indicators to coexist in the preliminary SSMQ. This has implications when considering the approach to analysis. Within CTT, the direction of causality is thought to flow from the construct to the item scores (Bollen & Lennox, 1991). Therefore, CTT may not be an appropriate theory for establishing reliability and validity in measures where the direction of causality is posited to flow from the item scores to the constructs. In CTT, internal consistency reliability assumes that items which positively correlate with the construct also positively correlate with each other. However, in causal indicator models this may not be the case. Item scores may provide different information about the latent construct, such as which items are harder or easier for respondents to endorse. In CTT, items are included on the basis of correlations and which items group together. Thus the order of 'difficulty' of items is disregarded, with the potential that important theoretical interpretations regarding the relationship between items and constructs are commonly overlooked (van Schuur, 2003).

A further limitation of CTT is the potential for acceptable items to be omitted due to low item correlations. This potential was highlighted in early work by Bollen (1984). Bollen argued that, using "item-total" correlations as a basis for selecting retainable items in a measure, plus the process of factor-analysing items to determine which items "sit together" is invalid if causal-indicators are present. Techniques employing Item Response Theory (IRT) to investigate the properties of outcome measures use different assumptions to CTT that may be more appropriate to mixed measurement models (de Vet et al, 2011). An overview and justification for the chosen IRT method of Mokken scale analysis is next provided.

7.9.1 Mokken scale analysis

Mokken scale analysis (MSA) was selected to examine the questionnaire responses. MSA is a non-parametric item response theory developed by Robert Mokken (Mokken, 1971). MSA evolved from the principles of Guttman scaling where items are presented in a cumulative scale representing a hierarchical order of difficulty (to endorse) (see section 5.4.2). Guttman scaling is a deterministic measurement model, whereby the relationship between item scores and the latent construct is viewed as being absolutely discriminative between the presence (or absence) of the latent construct based on the endorsement (or lack of) items. In contrast to Guttman scaling, MSA adopts a probabilistic model which allows for the possibility that respondents will endorse a more difficult item, without endorsing a less difficult item (also known as a Guttman error).

Within parametric Item Response Theory (IRT) models measurement scales are conceptualised like a ruler, whereby items are viewed as graduations of the scale. IRT supposes that items are located along the measurement scale according to their difficulty (the likelihood the item will be endorsed by a respondent). Parametric IRT models supposes that respondents can also be ordered along the measurement scale. The probability of a respondent endorsing an item is viewed as being related to the difficulty of the test. This premise is applicable to tests which generate parametric data such as mobility. For example, a person who can walk 100metres unaided, is almost certainly able to walk 50metres, and can probably transfer from bed to chair. However, in the measurement of psychological concepts the application of parametric IRT models becomes more cumbersome (Drenth &Sijtsma, 1990). For example, a person with anxiety who finds it difficult to attend a social gathering, may or not be able to attend a place of work, and may or may not be able to use public transport. The qualitative work suggested that many psychosocial factors influence a persons' capacity to perform self-management, and their attitudes and behaviours towards self-management. The SSMQ adopts an ordinal response format, and proposes to measure attitudes and behaviours relating to self-management. Therefore, data generated from the SSMQ can be considered to be non-parametric. A non-parametric IRT method, such as MSA is thus appropriate to analyse the SSMQ.

Within MSA, development of a scale that meets the Monotone Homogeneity model (MHM) is considered the primary benchmark of a Mokken scale (van Schuur, 2003). The MHM, which will be used to investigate the SSMQ, has several assumptions which are next outlined:

The scale is unidimensional. MSA seeks to form a unidimensional scale consisting of a set of items that measure one construct. Feasibly, PROMs may contain sets of items which individually form unidimensional scales. For example, Mokken scale analysis of the well-known SF-36 (Ware et al., 1993) which measures health-related quality of life, indicates that it consists of six unidimensional scales (Mishra et al., 2011). With regard to the preliminary SSMQ, different scales may exist in the item pool (e.g. self-management attitudes or behaviours). The first step within MSA was to establish what, if any, unidimensional scales exist within the preliminary SSMQ.

Montonicity. The Monotone Homogeneity model (MHM) refers to the increasing probability of the item score increasing as the level of the latent construct increases. This is described as a monotonic relationship. In this study, this would imply that the likelihood of endorsing an item theoretically increases with greater self-management capacity. Monotonicity is determined by examining either Item Characteristic Curves (ICCs) for scales with dichotomous response options or item step response functions (ISRFs) in the case of polytomous responses, such as the SSMQ. If the item meets the MHM, the corresponding ISRF should be non-decreasing.

The primary advantage of MSA over parametric IRT models, is the relaxation of the assumptions about the non-linear behaviour of response probabilities

(Sijtsma and Molenaar, 2002). In a parametric IRT approach, the item characteristic curve is usually expected to follow a smooth and symmetric S-shaped function (figure 7.3). Items that do not meet this smooth shape are consequently rejected from the measure. Arguably, this means that potentially useful items are rejected; subsequently the measure's validity may be compromised (Bollen, 1984, Stochl et al., 2012).

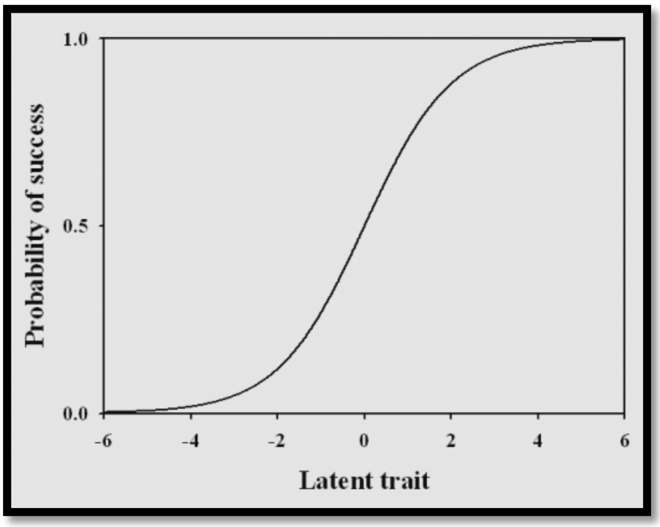


Figure 7.3. Examples of expected S-shaped curves for parametric IRT models (Bond & Fox, 2001). Reprint permission granted from Elseveir Ltd. (License number 3161270091630).

Within MSA ICCs, or in the case of polytomous responses ISRFs, are relaxed to allow a more general increasing form, without the degree of regularity characteristic of the sigmoid-shapes (figure 7.4). This approach enables items to be retained with consistently increasing, but less regular curve shapes for the item step response functions to be included (van Schuur, 2011).

Stochastic independence of items. This implies that an individual's response to an item depends on the level of the latent construct being measured. A response to one item will not be influenced by responses to another item (Nunnally & Bernstein, 1994).

This section has introduced the principles in support of Mokken Scale Analysis for the development of the SSMQ. The Mokken analysis procedures taken to analyse the results are set out in further detail in chapter eight.

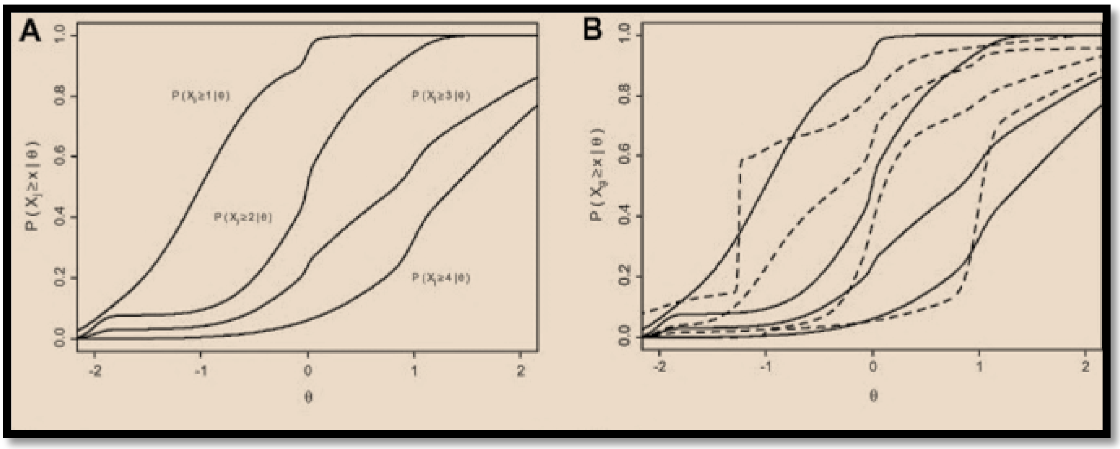


Figure 7.4. Examples of ISRFs using MSA (Sijtsma et al., 2011). **A** 4 ISRFs of an item with 5 ordered item scores; **B** 2 sets of 4 ISRFs each, each set for an item with five ordered scores. Reprint permission granted from Elseveir Ltd. (License number 3161270091630).

7.9.2 Statistical approaches

The sample is described using descriptive statistics of frequencies (nominal data) median, range and interquartile range (ordinal data). Differing statistical tests will be adopted to evaluate measurement properties, and whether the preliminary SSMQ meets the monotone homogeneity model, as follows:

- **The scale structure and monotonicity of the SSMQ will be determined using ISRFs and Loevinger's coefficient *H* (higher *H* values indicate fewer Guttman errors).**
- **Test-retest reliability will be investigated using Intraclass correlation coefficients (ICCs).**
- **Homogeneity of the items will be calculated using scalability Loevinger's coefficient *H*.**
- **Reliability of the resulting scales of the SSMQ will be investigated using Mokken reliability coefficients and alpha.**

Construct validity of the SSMQ and any subscales is estimated by investigation of the relationships between scores from the SSMQ, the SSEQ and the SIS, according to the *a priori* hypotheses outlined (section 7.4.1).

7.10 Summary

This chapter has outlined and justified remote administration of questionnaires as an appropriate method for the research purpose. The procedures adopted for collection and analysis of data have been justified and outlined. Chapter eight discusses the analyses and results of the psychometric analysis.

8. Chapter Eight- Psychometric analyses

8.1 Introduction

This chapter concerns the psychometric analyses and refinement of the preliminary 44-itemed SSMQ. First, an overview of the sample is provided using descriptive statistics. Each step of the Mokken Scale analysis procedure is next outlined, with corresponding results presented. Justification is made for the refinement and analysis processes adopted. Finally, attention focuses on the reliability and construct validity of the refined SSMQ.

8.2 Participant demographics

Data were analysed using the Statistical Package for Social Sciences (SPSS) software version 20.0 (IBM corp, 2011). 87 responses to the questionnaire pack were returned. Data were first coded and entered into SPSS. 62 participants (72%) opted to participate in the study using on-line completion, via advertisement on the Different Strokes and Stroke Association charity websites and social media pages. The remainder of the sample were recruited via the sources outlined in chapter seven (section 7.6.3). The regional locations of the on-line participants were not collected as part of this study. The regional locations, using the locations defined by the Stroke Association, of respondents who completed the paper questionnaire pack are presented in table 8.1.

UK region	No. of respondents (n=33)	UK Region	No. of respondents (n=33)
South Central	6	Scotland	2
South East	8	North East	3
South West	8	North West	3
Midlands	3		

Table 8.1 Regional location of sample using returned paper completion

A summary of the sample characteristics is presented in table 8.2. The following sections consider the key characteristics of the sample.

8.2.1 Age

The UK average age for a male experiencing stroke is reported as 71 years of age and 77 years for a female (Lee et al., 2011). Within this sample, the average age of females was 67 years, and males 57 years. The mean age of the sample was 59.40years (SD 14.66). This suggests that the study sample is younger, (particularly for males), than the typical UK stroke population. A spread of ages were recruited within the sample; the youngest respondent was 27 years old; the oldest 89 years.

Questionnaire				
	SSMQ*	**SSEQ***	**SIS***	**All Q.s***
No. of complete responses (% of all responses)	78 (90)	83 (95)	74 (85)	71 (81)
Age range (years) Mean [SD]	(27-89) 58.40 [14.74]	(27-89) 59.20 [14.74]	(27-89) 57.99 [14.66]	(27-89) 59.40 [14.66]
Male gender (%)	40 (51)	43 (52)	37 (50)	46 (53)
Mean months since stroke [SD] range#	55 [63.36] 319#	59 [63.82] 319#	51 [56.29] 273#	60 [63.74] 319#
Mode of completion (%)				
Paper	28	26	27	25
Online	72	74	73	75
Social circumstances (%)				
Live with spouse/partner	53	55	52	54
Live alone	19	21	22	20
Live with family	9	7	8	8
Live with dependents	17	16	18	16
Unknown	2	1	0	2
Ethnicity (%)				
White European	90	90	89	90
Asian descent	3	3	3	2
Afro-Caribbean descent	2	2	2	1
Arabic descent	5	5	6	5

Table 8.2- Summary of questionnaire respondents’ characteristics. ***SSMQ**- Stroke self-management questionnaire, **SSEQ**- Stroke self-efficacy questionnaire, **SIS**- Stroke Impact Scale. **All Q.s**- combined information for all outcome measures.

8.2.2 Duration since stroke

Table 8.2 depicts that the mean time since stroke was approximately 60 months (SD 63.26). Large variations in duration since stroke were observed across the sample. The shortest duration since stroke was three months; the longest was 26 years. Figure 8.1 illustrates the variation in the respondents' time since stroke.

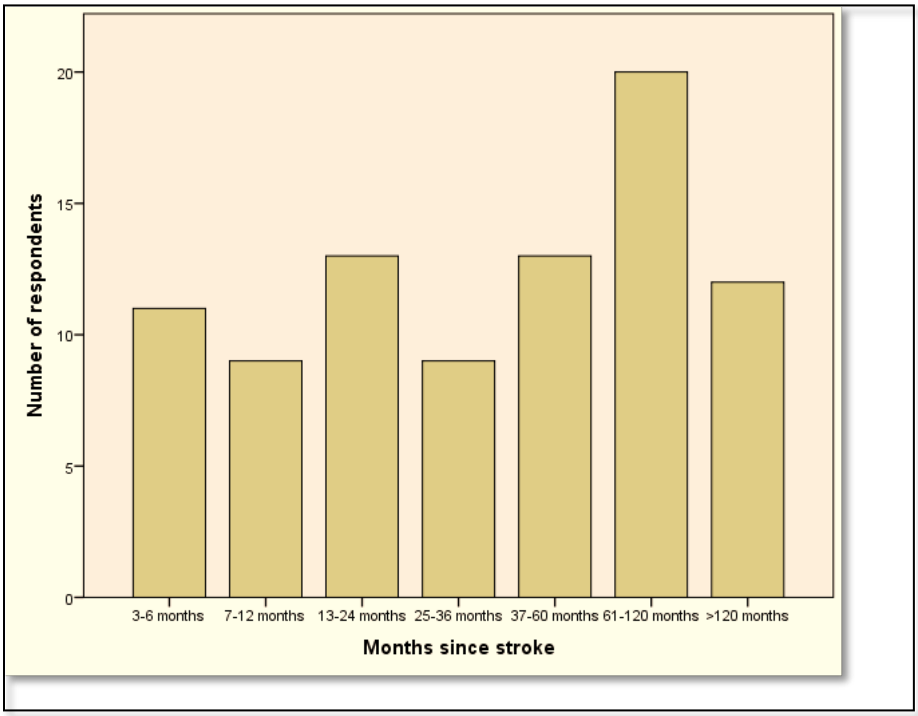


Figure 8.1 – Sample duration since stroke (n=87)

8.2.3 Social circumstances

Approximately 60% of the sample lived with a partner or family member(s). The remaining 40% lived alone, around half of which also had dependents to support. Of the respondents who lived alone, the mean self-rated perceived level of recovery since stroke as measured by the Stroke Impact Scale was 64 (SD 26.37) (maximum 100), compared to 54 (SD 21.79) for those who lived with partners or family members. One way analysis of variance (ANOVA) tests suggest that the difference in mean perceived recovery since stroke between those who lived alone or with others, was not statistically significant (*p*=0.06). Mean self-efficacy as measured by the Stroke Self-

efficacy Questionnaire was also not statistically significant between those who lived alone or with others (*p*=0.216). The mean age of respondents who lived alone was significantly younger (*p*=0.037) at 53 years (SD 15.24) compared to 61 years (SD 14.22).

8.2.3 Ethnicity

Stroke incidence in people with an ethnic minority heritage accounts for approximately 4% of all strokes in England, Scotland and Wales (Wild et al., 2007). Using this as an estimate, respondents from ethnic minority groups were representative of UK trends, although the sample was predominantly from a white European background (table 8.2).

8.2.4 Mode of completion

The majority of the sample (75%) completed the SSMQ and additional questionnaires by using the on-line completion method. The average time taken to complete the on-line pack was 22 minutes and 39 seconds (SD 11.07). ANOVA tests reveal that respondents who completed online were significantly younger (*p*= 0.004, mean 51.5 years, SD 14.99) compared to those who completed the paper version (62 years, SD 13.69).

8.3 Mokken Scale Analysis of the SSMQ

Mokken Scale Analysis (MSA) was used to examine the psychometric performance of the SSMQ. All analyses were conducted in *R* (R Development Core Team, 2010) a free language and environment portal for statistical computing. The Mokken package (van der Ark, 2007; 2012) was used to perform MSA in *R*. Data were first saved in a comma-delimited format using Excel, for import into *R*, before conversion to an *.Rdata file for analysis.

MSA follows a step-like procedure (van der Ark, 2011). The first step was to determine whether items within the SSMQ form a hierarchy. This step allows for verification that any unidimensional scales exist within the SSMQ item pool and if so, determines which items ‘fit’ which scale. Secondly, the Item step response functions (ISRFs) for each item, and within each scale, are examined to determine if they meet the Monotone Homogeneity model

(MHM) (section 7.10.1). Scales that meet the model can finally be examined for reliability and for evidence of construct validity.

8.4 Scale structure

Within MSA, unidimensional scales are formed using a ‘bottom up’ hierarchical clustering procedure, whereby the two items with the strongest correlation *H* coefficient are first selected for the scale, before adding further items to the scale which satisfy the scalability coefficient criteria (van Schuur, 2003). Using scalability coefficient (*Hij*, where *i* and *j* refer to the item pair), the pair of items with the highest values is first selected (Sijtsma &Molenaar, 2002). Once the first pair of items has been extracted, the item with the next highest *Hij* values is selected.

Loevinger’s coefficient *H* is used to indicate the extent to which items form a cumulative scale. In a cumulative scale, items can be ordered in terms of the probability they will be endorsed, relative to the level of the construct the respondent possesses. Loevinger’s coefficient *H* is represented mathematically as follows:

$$H = 1 - \frac{\text{Error (observed)}}{\text{Error (expected)}}$$

The observed error refers to the number of respondents who endorse a more difficult item, and then give a negative response to an easier item (also known as a Guttman error). The expected error refers to the number of errors expected by chance (Meijer & Baneke, 2004). A *H* value of 1 would indicate a perfect model, without any cumulative, or Guttman scaling errors (van Schuur, 2011). Conventionally, scales with *H* values of >0.3-0.4 are said to form acceptable Mokken scales, values between >0.4-0.5 moderate Mokken scales and values >0.5, strong Mokken scales (Mokken, 1971).

Items are said to form a Mokken scale if several conditions are met, as follows:

- For all item pairs, scalability coefficient H*ij* is greater than zero.
- Loevinger's coefficient *H* is greater than 0.3 (Watson et al., 2012).
- A single item is included within the scale if it increases the overall *H* value of the previously selected items (van Schuur, 2011).

Examination of the SSMQ began with investigation of the 44 item scores relative to one another. In *R* scalability coefficients were calculated for all item pairs within the SSMQ. This analysis suggested that 12 items from the 44 did not meet the criteria outlined above for a Mokken scale (*H* <0.3). The remaining 32 items possessed individual *H* coefficients which ranged from 0.96-0.39. The *H* coefficient for the 32-itemed SSMQ was 0.274, indicating a borderline Mokken scale (Meijer & Baneke, 2004). This low overall figure in comparison to acceptable pairwise *H* coefficients, suggested that some items were not acceptable indicators of a unidimensional latent trait, and thus the scale warranted further examination. Section 8.4.3 details the determination of scale structure.

8.4.1 Discarded items

The items in the SSMQ44, were generated following in-depth inductive work with the target population. However, the nature of MSA suggests that not all items are sufficient indicators for the latent trait(s) under investigation. 12 items did not possess a *H* coefficient >0.3 (appendix 18). Three items (1,21,41) displayed negative correlations, therefore clearly violating the criteria for a Mokken scale (van Schuur, 2011). The remaining nine items had very low *H* values (just above zero, or one in all cases) indicating that they were highly unlikely to form part of a cumulative scale, the values being indicative of a very high number of Guttman scaling errors.

Van Schuur (2011) argues that Mokken scaling errors occur both as a result of the items, and of the respondents. Error may be attributed to respondents, for example, when respondents overlook items, or when the items mean something different to respondents than the measure developers. Attempts to minimise such error have been countered by adopting a rigorous cognitive interviewing phase in this research. Since the aim was to develop a PROM that was useful with different stroke populations, a pragmatic approach to scale development was adopted which focused upon reducing potentially problematic items, but retaining the maximum amount of accurate indicators of stroke self-management. A tension then potentially exists between the items, which were inductively generated and considered important to potential users, and the Mokken criteria for discarding items that do not function well in a scale. Nonetheless, Mokken scaling represents a measurement model with the least criteria in this respect (section 7.10.1) and is the method most likely to resolve this tension in favour of retaining items. This is further debated in chapter nine.

Following the elimination of 12 items which did not meet the criteria for a Mokken scale, the remaining 32 items were investigated for the presence of any homogenous scales. Before detailing the next steps in the analysis, the approach to missing data is first outlined.

8.4.2 Approach to missing data.

Nine respondents (10%) returned questionnaires containing incomplete responses to the SSMQ (table 8.2). This compares to four incomplete responses from the Stroke self-efficacy questionnaire (SSEQ) (5%) and 13 (15%) from the Stroke Impact Scale (SIS). All of the nine cases with missing data on the SSMQ utilised completion via the paper version of the questionnaire packs. Most often, an entire page of responses on the SSMQ were left blank, suggesting that items were perhaps missed accidently as respondents overlooked a page. Nonetheless, identification of consistently missed items was important to consider, being potentially indicative of item incoherence.

In line with accepted guidance, where 50% or more of responses to the SSMQ were missing, cases were excluded from the analysis (n=3) (Sijtsma & van der Ark, 2003). During subsequent analyses, responses from complete data sets for the SSMQ were first used (n=78). As scale configuration emerged missing cases were revisited. Completed responses to items that were subsequently contained in one of the scales were added and the scales reanalysed. For successive analyses, the number of complete responses utilised is stated accordingly. Of note, is that several missing responses refer to seven items from the SSMQ44 that did not meet the criteria for a Mokken scale, and were subsequently excluded from analysis (58% of those excluded). It is plausible that respondents intentionally missed these items, because they were unclear, providing further evidence that these items were problematic and hence justifiably excluded.

8.4.3 Determination of scales

Scale structure was investigated using the Automated Item Selection Procedure (AISP) for MSA within *R* (van der Ark, 2007). AISP was implemented to investigate if the remaining 32 items together formed a cumulative scale, measuring one unidimensional construct. Within AISP, items rejected from the first derived scale are next investigated to see if they meet the criteria for a second scale. The process continues until all of the items have been used or specifically excluded due to failure to fulfil inclusion criteria. AISP is a useful procedure to examine the potential latent domains within a proposed construct (van Schuur, 2011), and as such is a useful procedure for new potential measures such as the SSMQ.

Within *R,* the user has the potential to set different threshold values for the *H* coefficient using the "search.normal" function. The conventional threshold is >0.3 (section 8.4). Higher threshold values may be selected based on the judgement that a higher level of homogeneity is required in the scale (Meijer and Baneke, 2004). Testing at different thresholds may also enable determination of which items are the most appropriate indicators of any underlying domains within a construct (Watson et al., 2012). After an initial screen of the SSMQ32 at >0.3, threshold values were incrementally increased by .05 from >.35 to >.5, inclusive to examine how the items performed at differing thresholds (table 8.3).

Threshold	**No. of excluded items (items)**	**No. of potential scales**	**Emerging description of scales** (SM= self-management, HCP= healthcare professional)
>0.3	0	4	Scale 1- Predominantly reflect SM capacity (attitudes or behaviours). Scale 2- Predominantly reflect communicating with HCPs (attitudes or behaviours). Scale 3- Confidence in engaging others for SM support (non-HCP). (Attitudes). Scale 4- Predominantly SM Skills (Behaviours).
>0.35	2 (22,24)	4	As per >0.3 threshold
>0.4	4 (7,13,16,44)	6	Item 22 added to scale 3, item 24 to scale 2. Scale 1- Capacity for managing health Scale 2– Confidence at communicating with HCPs Scale 3- No obvious relationship between items Scale 4- Confidence in engaging others Scale 5- Confidence at managing health Scale 6 – Confidence, vicarious experience
>0.45	5 (13,15,16,24,44)	7	Scale 1- Controlling Health & motivation Scale 2- Confidence for managing health Scale 3- Having effective relationships with HCPs Scale 4- Readiness to try different SM strategies Scale 5- HCPs as the sole source of SM support Scale 6- Confidence to engage others to facilitate SM Scale 7- Confidence- vicarious experience
>0.5	8 (13,15,16,20,24, 29,39,44)	7	Scale 1– Controlling Health Scale 2-Motivation & readiness for SM Scale 3- Confidence for managing health Scale 4- HCPs as the only source of SM support Scale 5- Confidence in the ability of HCPs Scale 6- Confidence to engage others to facilitate SM Scale 7- No obvious relationship

Table 8.3. Summary of the AISP for the 32 itemed SSMQ (SSMQ32)

As the threshold levels increased, more items were deemed ‘un-scalable’ and individual scales contained fewer items. Smaller scales may provide important information pertaining to a latent construct, that are not adequately covered by the larger scales (van Schuur, 2011). For example, ‘scale 2’ at the >0.3 threshold contained six items thought to capture a respondent’s attitudes and behaviours towards engaging health care professionals (HCPs). At larger thresholds these items formed smaller sub-scales, which related to different aspects of relationships with HCPs, such as confidence in their ability, or HCPs as the sole self-management resource. At threshold >0.45, five items formed a scale related to attitudes and behaviours towards effective relationships with HCPs (scale 3). A two-itemed scale formed which related to the value of HCPs as an important source for successful self-management (scale 5). At the >0.5 threshold, two items formed a scale relating to respondent’s confidence in the ability of HCPs (scale 5).

Items that are grouped together at different thresholds may represent an importantly different aspect of self-management (van Schuur, 2011). However, items may also be grouped together for seemingly theoretically unrelated reasons such as appearing near each other in the SSMQ44, or containing similar wording (van Abswoude et al., 2004). Scales with few items may reflect that the aspects they cover were not adequately explored in the qualitative development phases. Alternatively, there may be limited ways to ask about a particular aspect of self-management within the scale, which a small number of items sufficiently cover.

To explore which of these scenarios was most likely, a new clustering procedure was conducted (van Schuur, 2011). 15 items common to scale one at the >0.3, >0.35 and >0.4 thresholds were re-examined. The 15 items were collectively referred to as 1A and appeared to broadly reflect an individual’s capacity for self-management (appendix 19). Completed responses (n=82) corresponding to these items were imported into *R.* The overall scalability coefficient for 1A was 0.464, indicating a moderate Mokken scale. Individual coefficients ranged from 0.356-.561. The items remained as one scale at the >0.35 threshold, but split as thresholds increased. A review of 1A enabled removal of items which were worded similarly and which shared the same *H* coefficient to another item. Judgements on which item to remove were informed by which items appeared easier to interpret according to the prior cognitive interviewing data. Three items were removed to reduce future respondent burden; Loevinger's coefficient *H* for the resulting 12-itemed scale (labelled 1B, appendix 20) was slightly increased at 0.474, providing justification for modifying the scale. 1B did not split into further scales at the >0.45 threshold, suggesting a robust homogenous scale.

The conceptual properties of 1B were next considered. 1B predominantly contained items that captured attitudes and behaviours contributory to an individual's capacity for self-management, focusing upon the role of impairment, health literacy and determination. However, not all items appeared to 'fit' this scale, and other items which sat in different scales appeared to conceptually 'fit' better in scale 1B. For example, item 24 '*I find it difficult to tell health care professionals what I want or need*' appeared to be more relevant to an emerging scale two, which focused upon interaction with health professionals. To refine the scale structure further, individual items were removed and added and corresponding data sets were analysed. Outputs from the various item arrangements were evaluated in terms of the effect on the overall Loevinger's coefficient and interpretability of the scale, extracting the most interpretable solution, at the highest possible threshold. This resulted in a ten-itemed scale, characterised as self-management capacity (appendix 21).

The procedure was repeated with responses for items common to the emerging scales two and three, at the >0.3 threshold. At larger thresholds, items from the SSMQ32 began to separate into scales with fewer items. Responses from items not included in any of the three scales were then re-examined collectively as a separate scale, to check for the presence, or absence, of an additional homogenous scale. Analyses were conducted in *R* using the "search.normal" function. A further scale appeared to be formed. Once all analyses for scale structure were completed, the items were analysed as a 'whole' scale in *R*. Following MSA, the SSMQ forms a unidimensional scale, which consisting of 28 items with an overall Loevinger's coefficient of 0.353 (>0.35 threshold) (table 8.4). If the SSMQ is subject to higher threshold limits (>0.40), six-seven separate scales are observed.

Scale one, conceptualised as ‘Capacity’, consists of nine items that provide information about an individuals’ overall capacity to perform or engage in self-management following a stroke. Items within the scale measure the importance of determination, health literacy and stroke-related impairment on an individuals’ capacity to self-manage. Scale two characterised as ‘Interaction confidence’, provides six indicators of individual confidence at communicating with health professionals. Scale three, ‘Strategies’ consists of seven indicators of individual readiness and skills to carry out self-management strategies. Scale four, ‘Professional guidance’, identifies the reliance that individuals place on professional advice as a resource for successful self-management. Each scale measures a unidimensional concept. At a lower threshold (>0.35), but still a high standard by MSA criteria, a 28-itemed scale forms which measures a latent construct labelled stroke self-management competencies. Investigation of the evidence for the construct validity of the SSMQ and the separate scales which form at higher thresholds is set out in section 8.7. A finalised item list for the SSMQ is found in appendix 22.

Following determination of the scale structure, the next step using MSA investigated whether the SSMQ scale met the Monotone Homogeneity Model.

Scale (threshold)	**Title**	**Conceptual description**	**No. of items** (number of responses)	**Scale *H* coefficient** (standard error)
SSMQ **(>0.35)**	Self-management competency	Indicators of the combined elements required to be a competent self-manager following stroke	28 (n=82)	0.353 (0.067)
1 **(>0.45)**	Capacity	Indicators of the impact of impairment, determination and health literacy on self-management.	9 (n=82)	0.502 (0.049)
2 **(>0.4)**	Interaction confidence	Indicators of confidence at communicating with health professionals	6 (n=84)	0.447 (0.074)
3 **(>0.4)**	Strategies	Indicators of readiness, self-efficacy and skills to enact self-management strategies	7 (n=79)	0.325 (0.053)
4 **(>0.4)**	Professional guidance	Indicators of the value placed on health professionals as a resource for successful self-management	6 (n=81)	0.400 (0.063)

Table 8.4. Summary of scale structure of the final proposed SSMQ

8.5 Monotone Homogeneity Model

Originally developed in relation to dichotomous response scales, the Monotone Homogeneity Model (MHM) was later extended for measures with polytomous items (Molenaar, 1982), such as the SSMQ. Scales that meet the MHM consist of items which produce monotonically non-decreasing characteristic curves (i.e. scores from items broadly increase in relation to the level of the construct measured). The curves are functions of the latent construct under measurement (Stochl et al., 2012). Monotonicity is a principal attribute. If a scale is monotonic, total scores (from the summed items within the scale) allow respondents to be ordered on a supposed continuum (i.e. higher summed scores indicate higher levels of the latent construct). Therefore, if the MHM holds, totalled item scores from the SSMQ can confidently be used as an indicator of an individuals' level of self-management competency. Conversely, if the MHM does not hold, item scores

cannot confidently be totalled. This represents a major advantage of the Mokken model over other measurement models.

Responses from the 28-itemed SSMQ, plus each of the subscales which formed at higher thresholds were imported into *R* to investigate monotonicity. Monotonicity of an item *x*, is assessed by replacing the unobserved latent construct value with a restscore (van der Ark, 2007). The restscore refers to the total score of all of the items, except *x*. Within the MHM, If item *a* is considered easier to endorse than item *b*, in a group of persons with restscore *b,* a higher proportion will endorse the item step than in a group of persons with restscore *a*. If this predicted order is reversed, this represents a scaling violation (Sijtsma & Molenaar, 2002). Summaries of the results for each scale were generated (appendix 23). Figure 8.2 depicts an example summary output.

```
Item  H   #ac #vi #vi/#ac maxvi sum sum/#ac zmax #zsig
V1  0.42  31   0       0     0   0     0    0     0
V2  0.51  27   0       0     0   0     0    0     0
V3  0.39  30   0       0     0   0     0    0     0
V4  0.42  42   0       0     0   0     0    0     0
V5  0.41  24   0       0     0   0     0    0     0
V6  0.53  22   0       0     0   0     0    0     0
```

Figure 8.2. Summary output of monotonicity investigation for scale 2 (n=84). H represents the Loevinger's coefficient; #ac, the number of active pairs; #vi the number of violations of monotonicity; maxvi, largest violation of monotonicity; zsig the number of violations that are significantly greater than zero (van der Ark, 2007).

Summaries of monotonicity outputs indicated that the SSMQ nor other scales derived at higher threshold values, contained items which violated the MHM. Therefore, the SSMQ can be said to form a cumulative unidimensional scale, consisting of 28 items, that measures self-management competency. The additional scales which formed at higher thresholds also form cumulative unidimensional scales. A summed score from items within the SSMQ indicates the level of the proposed latent construct self-management competency that the respondent possesses. MSA suggested that if higher thresholds are adopted, four separate scales form. Summed scores from each of these scales can be used to indicate the level of the concept, measured by the scale, which each respondent possesses.

To observe the extent to which each item within the SSMQ reflected the latent construct, Item-step response functions (ISRFs) were next plotted in *R*. Figure 8.3 provides an example of an item (SSMQ, item 24) with a non-decreasing ISRF plot. (NB The plot is labelled V4, since it relates to the fourth variable within the data set under examination in *R,* not necessarily the fourth item*)*. Plots of each item displayed the results for the five 'steps' on the SSMQ response scale (from 1-2, 2-3, 3-4, 4-5 and 5-6). All ISRF plots for the SSMQ are displayed in appendix 24.

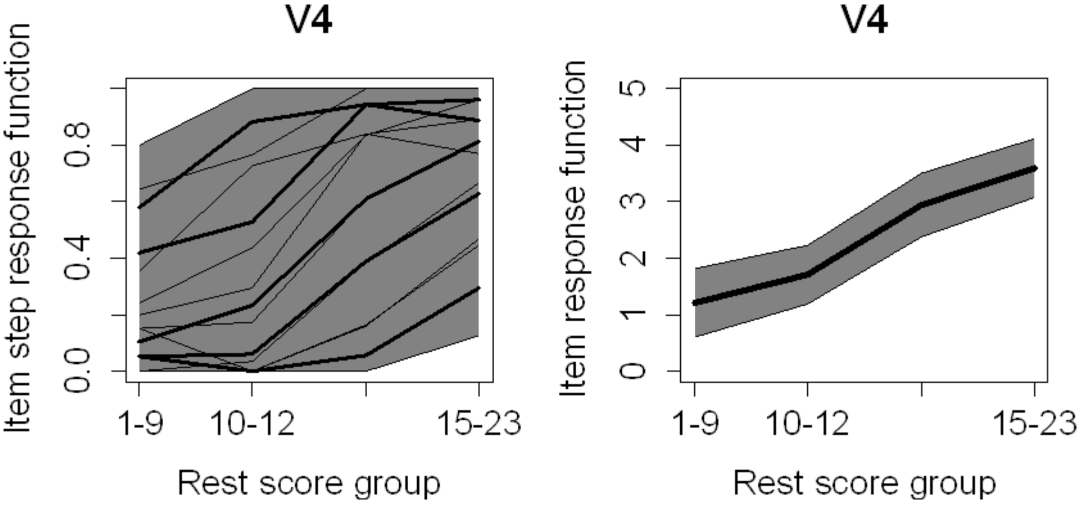


Figure 8.3. Item step and response functions for item 24, Professional guidance scale ''I am concerned that the things I do to manage stroke may cause harm if not guided by health care professionals'' (n=81).

The majority of ISRFs illustrated a non-decreasing relationship between the underlying latent trait thought to be represented in the SSMQ and the total item score. Of 28 item plots, 22 plotted non-decreasing ISRFs. The remaining six items plotted violations between 1 item-step only. Figure 8.4 illustrates an example where the function curve appears to decrease between step 4-5 (score 5-6 on the response scale). However, none of these violations were significant enough to warrant exclusion of the item from the scale, according to the criteria set (van der Ark, 2007). The SSMQ therefore meets the requirements of the monotone homogeneity model.

The next sections explore the reliability and validity of the SSMQ.

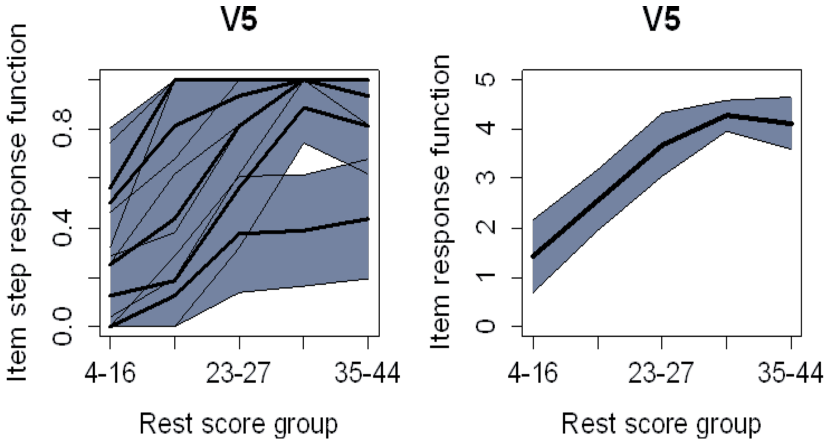


Figure 8.4. Item step and response functions for item 5, scale 1 '' Item: The physical effects of stroke mean that I cannot manage my health as I would like'' (n=82).

8.6 Reliability

Internal consistency reliability of the SSMQ, and of the four scales which formed at higher thresholds, were examined using Cronbach's alpha, α (Cronbach, 1951) and Mokken's estimation of reliability, denoted *r* (Mokken, 1971). Conventionally, internal consistency reliability is measured with Cronbach's alpha where values of >0.7 indicate acceptable reliability, values >0.8 indicate good reliability (Kline, 2000, Streiner & Norman, 2008). Values exceeding 0.9, may indicate that some items are redundant as they may be manifestations of the same item (Streiner, 2003). Alpha coefficients are affected by the number of items in a scale. More items can increase the α value, since there are more chances for the items to be manifestations of the same construct (Nunnally & Bernstein, 1994). Cronbach's alpha is therefore not a consistent indicator of homogeneity. Mokken's estimation of reliability assumes the scale meets the criteria of a Mokken Model (van Schuur, 2011). In this case, the number of items does not affect homogeneity of the scale. A fundamental assumption of internal consistency reliability, is that all items within the scale reflect the same unidimensional concept (Tavakol & Dennick, 2011). Both reliability coefficients were calculated for the SSMQ and for the four scales which formed at higher thresholds. All scales have acceptable to good internal consistency reliability (table 8.5).

Scale	**Cronbach's α**	**Mokken's *r***
SSMQ	0.89	0.89
Scale 1. Capacity	0.88	0.89
Scale 2. Interaction confidence	0.81	0.82
Scale 3. Strategies	0.73	0.73
Scale 4. Professional guidance	0.77	0.79

Table 8.5. Summary of reliability coefficients for the SSMQ and additional scales (n=84)

8.6.1 Test-retest reliability

Test retest reliability seeks to investigate the extent to which scores from the SSMQ are consistent over time, given no underlying change in self-management competency. 46 people were randomised to take part in the test re-test phase, from which 39 completed responses were returned (85%). The mean time between the first and second test was 14.51 days (SD 5.8). Mean age of the test-retest sample was 60.13 years (SD 14.28); 64% of the sample was of male gender.

Two methods are commonly used to calculate test–retest reliability by examining consistency between scores; Pearson's product-moment correlation and the intraclass correlation (ICC). Both methods are acceptable, however Pearson's product-moment correlation cannot determine test-to-test variation when multiple tests are administered (Yen & Lo, 2002). When a concept is measured three times repeatedly, three scores are obtained. Using Pearsons' method, three correlation coefficients for every two of the three scores are calculated and examined. However, the correlation coefficient of all three scores cannot be generated at the same time. Intra-class correlations resolve this problem. Since the SSMQ may be used to evaluate changes in self-management competency over more than two time points, the ICC was selected to investigate stability.

Item total scores for the 28-itemed SSMQ were calculated for time one and time two. To assess test-retest reliability, Intraclass correlation coefficients (ICC) were calculated at the 95% confidence level. ICC for the SSMQ was 0.928

indicating a high degree of consistency between test completions (de Vet et al., 2011). ICCs were next calculated for the additional scales obtained at higher thresholds (table 8.6).

	SSMQ	Scale 1 Capacity	Scale 2 Interaction confidence	Scale 3 Strategies	Scale 4 Professional guidance
ICC (significance)	0.928 (0.005)	0.590 (0.004)	0.824 (0.001)	0.947 (0.001)	0.867 (0.001)

Table 8.6. ICCs for time 1 and 2 for the additional scales

Fleiss describes values of ICCs from 0.40 to 0.75 as 'fair to good' (Fleiss & Cohen, 1973) while Streiner and Norman recommend values > 0.75 for scales used in health research (Streiner & Norman, 2008). Only the capacity scale did not meet the criteria set by Streiner and Norman, although this scale meets the criteria set by Fleiss and Cohen. Further work may be required to investigate the stability of this scale over time. ICC estimates suggest that the SSMQ provides stable estimates of self-management competency over time. The hypothesis presented in chapter seven (section 7.4.1) *'Stroke self-management behaviour and attitudes scores are stable over time'* is therefore upheld. The next step in the psychometric evaluation of the SSMQ was to examine the validity of the emerging construct *self-management competency*.

8.7 Construct Validity

MSA suggested that the SSMQ forms a unidimensional scale that measures the latent construct of stroke self-management competency. MSA suggested that, as the threshold for the degree of error in the scale increased, four additional unidimensional scales formed conceptualised as; Capacity; Interaction confidence; Strategies and Professional guidance. The Stroke Impact Scale (SIS) and Stroke Self-Efficacy Questionnaire (SSEQ) provide information about factors of theoretical conceptual importance to stroke self-management, such as self-efficacy, impairment and quality of life. Investigation of construct validity, by comparing responses from the newly

derived SSMQ, with those from the SIS and SSEQ enables further exploration of the emerging construct. Comparison of responses from the additional measures with the four additional scales, which form at higher thresholds, enables exploration of the potential unidimensional concepts measured by the individual scales. Prior to evaluation of the relationship between the SSMQ and other variables, the next sections provide a summary of the variables of interest.

8.7.1 Self-efficacy

Self-reported self-efficacy was captured using the SSEQ. Within the SSEQ, item scores are totalled to give a combined score out of a maximum of 130. The mean self-efficacy rating was 100 (SD 88.23) (range 10-130) (n=83).

Feasibly, level of impairment, time since stroke, age and whether a person lives alone may influence self-efficacy. Linear regression modelling was conducted in SPSS to assess the impact of those variables on self-efficacy. Scatterplots were first constructed to test the assumption that linear relationships held; an example is illustrated in figure 8.5. Neither time since stroke (-.973), age (-0.056) nor living alone (-0.973) appeared to affect self-efficacy (*p*=.762, .288, .690 respectively). However, self-rated perceived recovery was positively related to self-efficacy (0.992, CI 0.986-0.995) at the 99% confidence level. More clearly, this suggests that for every one point increase on self-rated recovery, self-efficacy increases respectively by 0.992.

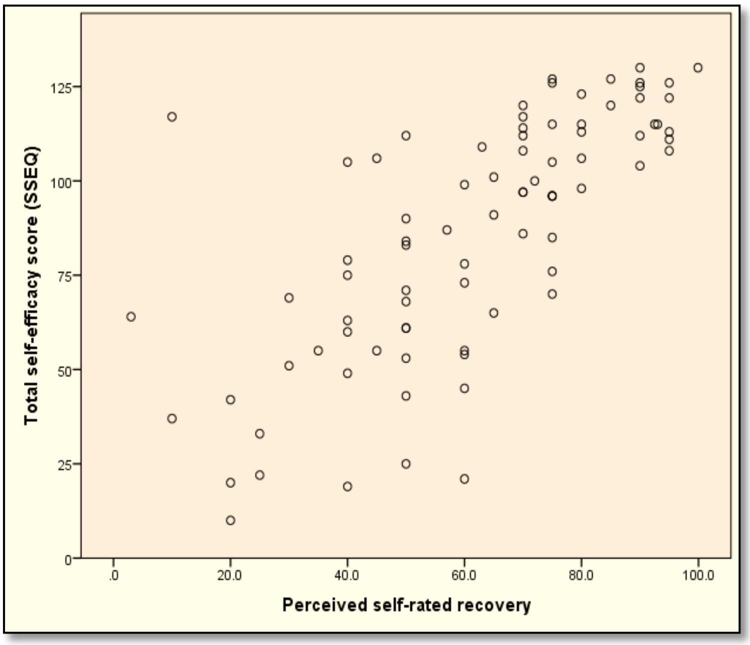


Figure 8.5. Linear relationship between total self-efficacy score and perceived recovery (n=83)

score is typical for an individual three months post-stroke (mean age 68.6 years) (Duncan et al., 2003). In this sample, no respondents were less than three months post-stroke and were largely past the acute phases of stroke (mean 60 months).Therefore statistical comparisons with the suggested normative score of 50, derived from a sample all three months post-stroke, are imprecise. Mean scores for the individual SIS domains are illustrated in table 8.7 and suggest that this sample has better function overall than a normative sample.

	Age (years)	**Memory**	**Communication**	**Participation**	**ADL**
Mean score (SD)	58.0 (14.97)	67.76 (26.33)	77.80 (24.05)	58.61 (25.10)	71.50 (24.21)
	Hand function	**Mobility**	**Emotion**	**Strength**	**0-100 perceived recovery**
Mean score (SD)	58.22 (34.51)	70.66 (25.36)	63.51 (20.27)	62.59 (27.45)	61.63 (23.03)

Table 8.7. Means and standard deviations for the domains of the Stroke Impact Scale (n=74)

Time since stroke may feasibly affect the impact of stroke. In this sample, there was no linear relationship between the duration since stroke and perceived recovery following stroke, measured using the Stroke Impact Scale (SIS) (figure 8.6). Accordingly, a nonparametric procedure, the Spearman's rank order correlation coefficient (i.e., Spearman's *rho*) was performed to assess any correlation. The Spearman's rho revealed a statistically significant negative relationship between time since stroke and 0-100 self-rated perceived recovery at the 95% confidence level (*rho* = -.234, CI -0.423- -0.025, n=87). This suggests that in this sample, self-rated perceived recovery decreases as time following stroke increases.

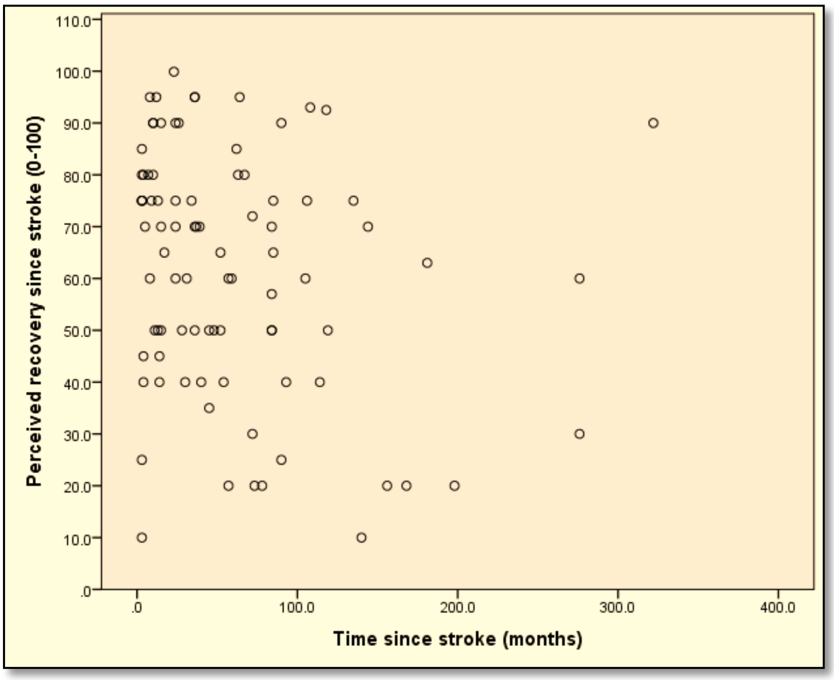


Figure 8.6 Relationship of duration since stroke to perceived self-rated recovery (n=87)

Age, living alone and individual stroke self-efficacy may also have a bearing on the self-reported impact of stroke. To evaluate the influence of these variables on self-rated perceived recovery, stepwise regression modelling was performed in SPSS. Stepwise regression modelling is a process that aims to create a model to explain the relationships between variables of importance. In stepwise regression modelling, variables without statistical

significance are removed, before re-estimating the relationships between the remaining variables.

In this sample, there appeared to be no statistically significant relationship between scores from the SIS perceived recovery domain, age nor living alone; subsequently these variables were removed from the model. In this sample, there was no significant difference in total self-efficacy scores as measured by the SSEQ, or 0-100 perceived recovery between those who live alone, or with others (section 8.2.3); living alone did not appear to be a confounding factor in relation to the impact of stroke. Total self-efficacy was the single best predictor of self-rated perceived recovery, accounting for 57.2% of the variance.

The relationship between total self-efficacy and the remaining individual domains of the SIS were explored using Spearman correlations (table 8.8). Total self-efficacy positively associated with all domains of the SIS, suggesting that in this sample, increased self-efficacy is associated with better physical function, memory, mood, communication and participation.

SIS domain	**Memory**	**Communication**	**Participation**	**ADL**
Total self-efficacy (significance)	.365 *p*=.001 CI 0.077-0.596	.335 *p*=.004 CI 0.116-0.523	.519 *p*=.0001 CI 0.263-0.706	.834 *p*=.0001 CI 0.715-0.906
SIS domain	**Mobility**	**Emotion**	**Strength**	**Hand Function**
Total self-efficacy (significance)	.814 *p*=.0001 CI 0.683-0.894	.462 *p*=.0001 CI 0.192-0.667	.623 *p*=.0001 CI 0.401-0.776	.761 *p*=.0001 CI 0.6-0.862

Table 8.8. Spearman rho correlations of total self-efficacy and the Stroke Impact Scale domains (n=74). CI = confidence interval associated with significance level.

The relationships between the individual domains of the SIS, SSEQ and the SSMQ scale are further investigated in the following section.

8.7.2 Hypothesis testing

To guide investigation of construct validity, chapter seven set out several hypotheses in relation to the theoretically related concepts of importance to stroke self-management (7.4.1). These are now revisited. An example of how the hypotheses were tested is first set out, before summarising the results in tables 8.9-8.15.

Example of Hypothesis testing

Hypothesis: '*Stroke self-management behaviour and attitudes are positively associated with self- efficacy'*

The hypothesis was tested by assessing the relationship between total scores from the completed 28-itemed SSMQ and completed total SSEQ scores (80 responses). In SPSS, scatterplots were first constructed to observe if a linear relationship between the variables held (figure 8.7). Since the correlations were between variables where at least one consisted of ordinal level data, there was a low probability that linear relationships held. Spearman's rank-order correlations (Greek *rho*, denoted ρ) for non-parametric data were accordingly performed (Kline, 2000). A significant positive correlation was found between total self-efficacy and total SSMQ score (*rho*=.624, CI 0.411-0.772, *p*=<0.01) (table 8.9). More clearly, for every 1 point increase on the SSEQ, the SSMQ total raw score appears to increase by 0.624. Therefore, the hypothesis is upheld.

For the remaining hypotheses, total scores from the relevant domain of the SIS were used to perform correlation analyses using the procedure outlined above. Summaries of the analyses are presented in tables 8.10-8.15. Since both perceived recovery and total self-efficacy are advocated as global indicators by the authors of those measures, correlations for both and the individual domains of the SIS are reported in each of the summary tables.

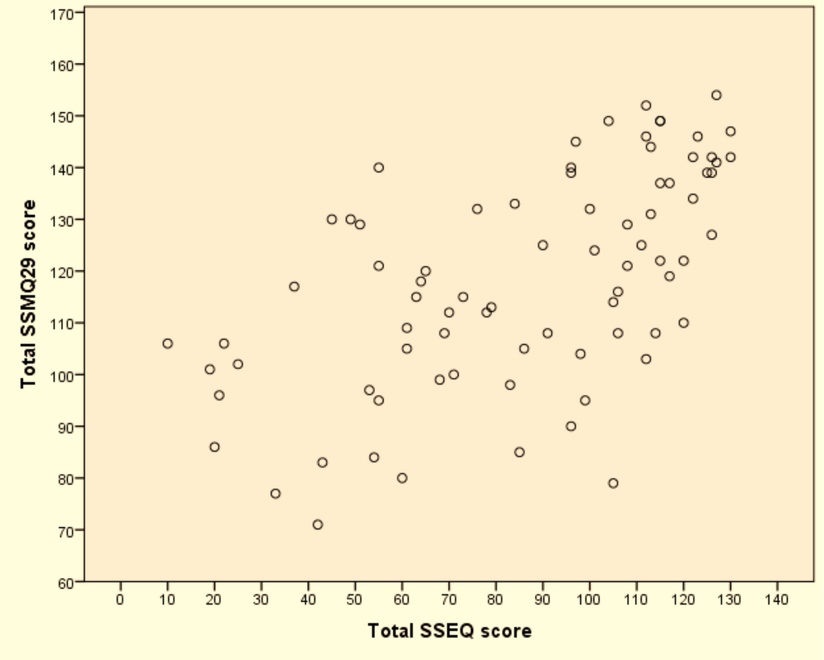


Figure 8.7. Non-linear relationship between SSMQ scores and self-efficacy (n=78)

8.7.3 Self-efficacy and the SSMQ

Stepwise regression modelling highlighted that total stroke self-efficacy, as measured by the SSEQ, appears to be a key factor to the self-rated impact of stroke (8.7.2). Total self-efficacy scores correlated positively and significantly (*p*=<0.01) with all of the SIS domains. The highest correlations with total self-efficacy were observed in the physical function domains of the SIS. The SIS physical function domains are considered to be more reliable and discriminative than the other domains in the SIS by the measure developers (Duncan et al., 2003b). The SSEQ consists of 13 items, ten of which relate to self-efficacy to perform physical function-related tasks. One inference of the correlations with the physical function domains of the SIS may be that the SSEQ measures physical recovery self-efficacy. Significant correlations between the SSEQ scores and the SSMQ were also observed (table 8.9), suggesting that those with higher levels of stroke self-efficacy possess better self-management competency following stroke.

Scale (n=80)	Hypothesis: *Stroke self-management behaviour and attitudes are positively associated with self- efficacy*		
	Spearman's rho co-efficient	Confidence interval	Significance level (*p* <)
SSMQ	.624	0.469-0.741	0.01
Capacity	.703	0.523-0.823	0.01
Interaction confidence	.259	0.042-0.452	0.05
Strategies	.263	0.046-0.456	0.05
Professional guidance	.438	0.242-0.599	0.05
Perceived recovery	.757	0.602-0.857	0.01

Table 8.9. Summary of Spearman rank-order correlations for SSEQ scores and the SSMQ.

8.7.4 Impact of stroke

Perceived recovery since stroke, is rated by respondents on the SIS by completing a 0-100 visual analogue scale (100 equates to maximum perceived recovery). Significant positive correlations were observed between self-rated perceived recovery and the SSMQ (total score) and the Capacity, Professional guidance and Strategies scales (table 8.10). The results suggest that individuals with higher rated levels of perceived recovery are more likely to score highly on the SSMQ, indicative of better self-management competency. A negative but not statistically significant correlation, was observed between the Interaction confidence scale and perceived recovery.

Scale (n=80)	0-100 perceived recovery		
	Spearman's rho co-efficient	Confidence Interval	Significance level (*p*=<)
SSMQ	.613	0.398-0.764	0.01
Capacity	.588	0.364-0.747	0.01
Interaction confidence	-.026	-	N/S
Strategies	.277	0.061-0.468	0.05
Professional guidance	.482	0.228-0.674	0.01

Table 8.10 Summary of Spearman rank-order correlations for perceived recovery and the SSMQ.

<table>
<tr><td rowspan="3">Scale
(n=73)</td><td colspan="3">Hypothesis: <i>Stroke self-management behaviour and attitudes are positively associated with communication</i></td></tr>
<tr><td colspan="3">Domain: Communication</td></tr>
<tr><td>Spearman’s rho co-efficient</td><td>Confidence interval</td><td>Significance level (<i>p</i>= <)</td></tr>
<tr><td>SSMQ</td><td>.383</td><td>0.096-0.611</td><td>0.01</td></tr>
<tr><td>SSEQ</td><td>.344</td><td>0.051-0.582</td><td>0.01</td></tr>
<tr><td>Perceived recovery</td><td>.226</td><td>-</td><td>N/S</td></tr>
<tr><td>Capacity</td><td>.405</td><td>0.122-0.627</td><td>0.01</td></tr>
<tr><td>Interaction confidence</td><td>.198</td><td>-</td><td>N/S</td></tr>
<tr><td>Strategies</td><td>.285</td><td>0.059-0.483</td><td>0.05</td></tr>
<tr><td>Professional guidance</td><td>.193</td><td>-</td><td>N/S</td></tr>
</table>

Table 8.11. Spearman correlation coefficients for SIS communication domain scores, the SSMQ and additional scales.

Positive Spearman correlations were observed between scores from the communication domain of the SIS, the SSMQ and the additional scales formed at higher thresholds. Only correlations between the communication domain and SSMQ, Capacity and Strategies scales were significant (table 8.11). This suggests that capacity, skills and readiness for self-management is related to self-rated communication ability. How confidence in communication with health care professionals and perceived reliance on professional advice for self-management is affected by communication impairment, is less clear.

Scores from the Memory domain of the SIS positively and significantly correlated with the SSMQ and additional scales except the Professional guidance scale (table 8.12). This suggests that memory and self-management competency may be related, as conceivably expected. The professional guidance scale relates to the perceived reliance upon health professionals for successful self-management, thus it is perhaps expected that a significant relationship was not observed with memory.

The Emotion domain of the SIS correlated positively and highly significantly (p=<0.01) with the SSMQ and the additional scales (table 8.13). This suggests that improved mood augments self-management competency, or potentially vice versa. Mood may influence individual capacity and readiness for effective self-management and modify reliance upon health professionals (Professional guidance scale), and confidence in communicating with health professionals (Interaction confidence scale). Conversely, the results may also suggest that self-management competency and its component parts influence mood.

Scale (n=73)	Hypothesis: *Stroke self-management behaviour and attitudes are positively associated with memory*		
	Domain: Memory		
	Spearman's rho co-efficient	Confidence Interval	Significance level (*p*=<)
SSMQ	.487	0.221-0.685	0.01
SSEQ	.376	0.088-0.606	0.01
Perceived recovery	.273	0.046-0.473	0.05
Capacity	.444	0.168-0.655	0.01
Interaction confidence	.286	0.06-0.484	0.05
Strategies	.453	0.179-0.661	0.01
Professional guidance	.015	-	N/S

Table 8.12. Spearman correlation coefficients for SIS memory domain scores, the SSMQ and additional scales.

Significant positive correlations between the SIS participation domain and SSMQ scores, as well as Capacity and Strategies scale scores were observed (*p*=<0.01) (table 8.14). Positive correlations between the Interaction confidence and Professional guidance scale scores were also observed, although these were not statistically significant. This suggests that effective self-management following stroke may be related to better social participation or vice versa.

Only scores from the capacity scale of the SSMQ significantly correlated with scores from the Hand function and Strength domains of the SIS (table 8.15). It is perhaps unsurprising that relationships were not found between these

domains of the SIS and the additional scales formed at higher thresholds, which focus upon the perceived value of professional advice, readiness for self-management and communication confidence. The relationship with the capacity scale suggests that

Scale (n=73)	Hypothesis: *Stroke self-management behaviour and attitudes are positively associated with mood*		
	Domain: Emotion		
	Spearman's rho co-efficient	Confidence interval	Significance level (*p*=<)
SSMQ	.586	0.349-0.752	0.01
SSEQ	.467	0.196-0.671	0.01
Perceived recovery	.365	0.075-0.598	0.01
Capacity	.619	0.394-0.774	0.01
Interaction confidence	.330	0.035-0.572	0.01
Strategies	.359	0.068-0.593	0.01
Professional guidance	.472	0.202-0.675	0.01

Table 8.13. Spearman correlation coefficients for SIS emotion domain scores, the SSMQ and additional scales.

Scale (n=73)	Hypothesis: *Stroke self-management behaviour and attitudes are positively associated with participation*		
	Domain: Participation		
	Spearman's rho co-efficient	Confidence interval	Significance level (*p*=<)
SSMQ	.361	0.071-0.595	0.01
SSEQ	.481	0.214-0.681	0.01
Perceived recovery	.528	0.273-0.713	0.01
Capacity	.529	0.274-0.714	0.01
Interaction confidence	.203	-	N/S
Strategies	.355	0.064-0.59	0.01
Professional guidance	.164	-	N/S

Table 8.14. Spearman correlation coefficients for SIS participation domain scores, the SSMQ and additional scales.

ability to perform self-management is affected by Hand and physical function of limbs. A non-significant negative correlation was found between the Strategies scale and Hand function. Positive correlations were observed with the remaining variables, but they were not statistically significant. The analyses suggest that limb and hand function appear to affect self-management capacity.

Significant positive correlations were observed between total scores from the Mobility domain of the SIS and the SSMQ, Capacity and Professional guidance scales (table 8.15). Positive correlations were observed with the Interaction confidence and Strategies scales, but which were not statistically significant. These relationships suggest that mobility is important to self-management competency.

Scores from the SSMQ and Capacity scales positively and significantly correlated with total scores from the ADL domain of the SIS, suggesting that self-rated ability to perform activities of daily living and self-care relates to an ability to perform self-management. Perhaps not unsurprisingly, considering what the additional scales measure, the Interaction confidence, Strategies and Professional guidance scales did not significantly correlate with scores from the ADL domain of the SIS.

Examination of the relationships between total scores from the SSEQ and SIS and the SSMQ provided emerging evidence in support of the construct of stroke self-management competency and the associated domains in the SSMQ. Further consideration is given to the evidence and associated theoretical implications in chapter nine.

Table 8.15. Spearman correlation coefficients for SIS function domains (n=73)

	Hypothesis: *Stroke self-management behaviour, attitudes are positively associated with functional ability*		
	Domain: Hand Function		
	Spearman's rho	Confidence interval	Significance level (*p*=<)
SSMQ	.100	-	N/S
SSEQ	.766	0.607-0.866	0.01
Perceived recovery	.557	0.311-0.733	0.01
Capacity	.309	0.012-0.556	0.01
Interaction confidence	.055	-	N/S
Strategies	-.033	-	N/S
Professional guidance	.233	0.004-0.439	0.05
Domain: Mobility			
SSMQ	.252	0.024-0.455	0.05
SSEQ	.816	0.685-0.896	0.01
Perceived recovery	.439	0.162-0.652	0.01
Capacity	.435	0.157-0.649	0.01
Interaction confidence	.134	-	N/S
Strategies	.194	-	N/S
Professional guidance	.244	0.015-0.448	0.05
Domain: Strength			
SSMQ	.049	-	N/S
SSEQ	.630	0.409-0.781	0.01
Perceived recovery	.493	0.229-0.689	0.01
Capacity	.288	0.063-0.485	0.05
Interaction confidence	.076	-	N/S
Strategies	.008	-	N/S
Professional guidance	.141	-	N/S
Domain: ADL			
SSMQ	.242	0.013-0.447	0.05
SSEQ	.834	0.714-0.906	0.01
Perceived recovery	.667	0.461-0.805	0.01
Capacity	.408	0.125-0.629	0.01
Interaciton confidence	.157	-	N/S
Strategies	.132	-	N/S
Professional guidance	.221	-	N/S

8.8 Limitations

There are several limitations with this study which are important to consider. Firstly, the sample size of 87, whilst adequate for the purposes of this PhD, may be considered insufficient by some health measurement theorists for a full examination of scale structure of the SSMQ. The sample may not fully represent a UK stroke population, being younger overall, despite there being a spread of ages represented within the sample. This may be indicative of the nature of the study, i.e. the completion of questionnaires, which may not be so accessible, nor appealing to older populations. Furthermore, participants were a broad range of duration since stroke, the average being 60 months. Due to the relatively small sample size, this means the effect of time since stroke may not be adequately examined.

Determination of construct validity is an on-going process, therefore further testing of the SSMQ would enable further examination of the hypotheses outlined in the study. Further examination of the SSMQ scale with a larger and more diverse sample is recommended.

8.9 Chapter Summary

The aim of analysis was to examine and refine the unidimensional scale structure of the SSMQ and provide preliminary evidence for reliability and validity. The use of Mokken Scale Analysis to investigate the psychometric properties of the SSMQ revealed a 28-itemed cumulative scale that measures the latent construct of self-management competency. At higher thresholds, the SSMQ forms four separate unidimensional scales that reflect self-management capacity, confidence in communicating with health professionals, perceived reliance upon health professionals for self-management and readiness to perform self-management. SSMQ and additional scales, all possess good reliability and emerging evidence of construct validity. The SSMQ can be used to measure self-management competency following stroke. The presence of additional scales at higher

Mokken thresholds, suggest that the four separate scales can be used individually to measure different facets of stroke self-management.

Chapter nine revisits the preliminary conceptual model in light of the findings from this final phase of the research. Further consideration is given to the theory which supports the SSMQ, and the additional scales present at higher thresholds.

9. Chapter Nine- Discussion

9.1 Overview

The research methods employed, findings and justifications for methodological developments regarding the development of the SSMQ have been addressed in their respective chapters. This chapter seeks to consider the key findings of the thesis and the implications for the future measurement of self-management following stroke. A brief summary of the findings is presented. Next, arguments are made to set out how the findings from this thesis relate to the existing knowledge regarding stroke self-management. Attention is given to the importance of the qualitative inquiry as a vehicle for informing the SSMQ. An exploration of the emerging construct of self-management competency follows. Consideration is given to how the findings relate to existing models and theories of self-management. Next reflections are made on the mixed methods approach. Finally, recommendations are suggested for the use of the SSMQ in future research and clinical practice.

9.2 Summary of findings

Measuring self-management through an appropriately conceptualised PROM is important for capturing patient experience, particularly within the context of the drive towards care which is more patient-centred and for services to deliver outcomes that matter most to patients. Following a systematic review of the literature (Boger et al., 2013), the problem of measuring and conceptualising stroke self-management was identified. Existing evaluations of stroke self-management relied upon indicators whose relation to the patient experience of self-management following stroke was unclear. The use of indicators which possess questionable validity in stroke populations, cast questions over the robustness of reported results and the potential theoretical foundations of self-management following stroke. This indicated a clear need for the development of an appropriate measurement tool and subsequent inception of this thesis.

This research consisted of three distinct phases which contributed to the development of a PROM to measure stroke self-management. Phase one employed focus group methodology. The development of PROMs is reliant upon robust conceptualisation to ensure the appropriate measurement of outcome which matter to patients (FDA, 2009, Lasch et al., 2010). There was a paucity of literature regarding the experience of self-management following stroke for patients. Qualitative enquiry was needed to identify the salient concepts of relevance to patients, and which might be appropriately measured with a PROM. Therefore, qualitative enquiry was essential as a basis for the inception of the PROM.

Data from five focus groups were organised in a conceptual model, presenting three key themes which affect the experience of self-management following stroke; *Individual capacity*, *Support for self-management* and *Self-management environment* (section 4.7). The theme of Individual capacity and its' related sub-themes denote how well individuals are able to respond to the demands of self-management following stroke. Since features that affect individuals are central to self-management and most often targeted in self-management interventions, the theme of *Individual capacity* was identified as fundamental to the patient-reported measurement of stroke self-management (section 4.5.1, 4.7). The aspects identified in individual capacity directly impact upon, and potentially may be mediated by individuals or by appropriate support and interventions, to provide insight into the perspectives of patients and are therefore appropriate for a PROM. The theme of individual capacity was used to inform the content (items) of an item pool which, following cognitive interviewng and psychometric evaluation, was developed into the stroke self-management questionnaire (SSMQ).

Phase two presented an item pool, focused on the theme of individual capacity and comprising of 57 items, to 11 people following stroke. Cognitive Interviewing (CI) sought to examine the processes involved for respondents in approaching the potential items. CI enabled careful consideration of the wording of items to reflect participants' interpretations, the response format and the layout to minimise participant burden and ensure the items had maximum clarity. CI guided revision of the preliminary item pool for the SSMQ to 44 items (chapter six).

The concepts of importance identified in the two qualitative enquiries were further explored using psychometric analyses. Phase three followed the procedure for Mokken scale analysis (MSA) to examine and refine the scale structure of the SSMQ. Following MSA, a unidimensional scale consisting of 28 items was formed. At higher thresholds, the SSMQ formed four homogenous scales. The individual scales and SSMQ possess good – excellent internal consistency reliability and test-retest reliability (section 8.6). Further analyses were conducted to obtain preliminary evidence of the validity of a proposed emerging construct measured by the SSMQ, labelled stroke self-management competency. Evidence in support of this construct is presented in section 9.4. The final psychometric phase demonstrated a useful example of how appropriate quantitative methodology can complement qualitative work. Section 9.6 further considers the operation of the mixed methods approach. The next section considers how the findings from this research add to the current knowledge regarding self-management following stroke.

9.3 Extending the knowledge base

This research has generated two manifest although related outputs; firstly a preliminary conceptual model for stroke self-management based on the perspectives of people following stroke, (section 4.7) and secondly a new PROM for stroke self-management the SSMQ (appendix 25). How the findings generated from this thesis augment the existing knowledge of stroke self-management is next argued in sections 9.3.1 to 9.3.3.

9.3.1 Conceptualising stroke self-management

The focus group enquiry represents the first research to explore what self-management might entail from the perspectives of people with stroke, including which factors influence or hinder self-management. As such, the findings expand upon the current theoretical foundations of stroke self-management. Moreover, some qualitative researchers contend that a vital goal of qualitative research is to influence the opinion of decision-makers, whose actions affect people's health and well-being (Groleau et al., 2009). The applicability of these findings beyond the particular people who participated therefore has importance.

The existing literature highlighted uncertainty about the optimal theoretical premises which support self-management following stroke (section 2.7.2). Where stated in studies, the most prevalent theoretical base was self-efficacy. The limitations of adopting self-efficacy theory, such as the potential for over-emphasising the role of the individual in succeeding at self-management, have been discussed in this thesis (section 2.4). The findings from the focus group study suggest that self-efficacy, or in the language of participant's, self-confidence, is an important element to stroke self-management (section 4.5.2). However, participant accounts suggest that self-efficacy alone is not a sufficient intermediary of stroke self-management. Participant accounts identified five other elements that contribute to an individual's capacity to self-manage following stroke (section 4.5.1): finding resources; determination; impairment; decision making and communication skills. The identification of these additional factors of importance which, to date, have not been specifically targeted or measured in stroke self-management interventions (SMIs) may, in part, help to illuminate the relatively disappointing outcomes observed following stroke SMIs.

Physical function constitutes the most frequently measured concept used to evaluate stroke self-management (2.7.7.1) and is assumed to be an outcome of successful self-management (Boger et al., 2013). The degree to which physical function relates to, or is indicative of, self-management following stroke has not been clearly articulated in the literature. Participants in the focus group study reported that physical function *does* impact on the ability to perform self-management; poor function presented many practical barriers to performing activities important to self-management, such as an inability to use the telephone or participate in social activities. However, participants identified that physical impairment alone was not the only arbitrator of successful self-management, extending to emotional, social and cognitive facets of impairment (section 4.5.6). Few stroke SMIs have evaluated the role that this more holistic experience of impairment, as described by participants, has on the ability to perform self-management and have not demonstrated improvements in impairment (Guitdetti & Yterrberg, 2011, Marsden et al., 2010). The focus group findings highlight the need for broader interpretations of impairment, including cognitive, language and emotional facets, to be considered in the design of future interventions and their evaluation.

An additional finding of importance associated with impairment, was that individuals with stroke-related impairment have additional difficulty in enacting self-management and are often reliant on others for assistance with relevant activities, such as self-care or performing therapies (section 4.5.10). This challenges current conceptualisations of self-management, which focus upon the self and the role of the individual in managing their long-term condition (Bandura, 2005, DoH, 2001, 2010a, Lorig et al., 2006a). The findings question how “self”, in self-management for those with impairment, should be perceived by stroke care services and providers.

Disability may be viewed as the result of negative interactions that take place between a person with impairment and their social environment (Oliver, 1996). Within this view, societal structures may be seen as creating disability for individuals with impairment, due to the restrictive way in which it operates. For example, some individuals following stroke report feeling over-whelmed with their new situation, and as a result do not engage fully with rehabilitation opportunities (Barker & Brauer, 2005). Once they are ready to seek further rehabilitation, provision is often no longer available to them. In line with the work of others, the focus group findings suggest that the potential impact of wider societal influences on self-management are not adequately considered (Vassilev et al., 2011).

Recently, attention has been directed towards the relationship between the workload attributed to patients and their capacity to manage health (Shippee et al., 2012). The findings from the focus group study support the notion that self-management may involve work for a patient. Stroke-related impairment both increases the workload and reduces the self-management capacity of individuals and their care-givers resulting in potentially higher treatment burdens. In accordance with Shippee and colleague’s model, a consequence of stroke-related impairment may be that the workload of self-management is beyond the capacity of the patient and their family and therefore does not occur, often with deleterious consequences for health. For example, if health professionals do not explore whether an individuals' therapy goals are relevant to them or achievable within the demands of his/her life, this may result in the goals not being enacted and possible deterioration or disillusionment (section 4.5.9). Further debate is required regarding the potential additional burden of self-management in relation to impairment.

The extent to which enlisting others in enacting stroke self-management facilitates or hinders self-management has not been considered in existing conceptualisations of self-management. There is a paucity of literature that considers the impact of impairment upon self-management of long-term conditions generally. In part, this may be a consequence of the exclusion of people with cognitive impairment from trials of self-management interventions (Damush et al., 2011, Lorig et al, 2001, 2006b), or that cognitive impairment is not evaluated by interventions (Harwood et al., 2011, Johnston et al., 2007, Kennedy et al., 2007). Work from diabetes suggests that cognitive impairment negatively affects the ability to self-manage (Feil et al., 2012); the extent to which this is also the case in stroke remains unknown. The impact of impairment upon self-management following stroke has not been debated within the literature; the focus group findings therefore add an important consideration for future research and practice.

Of note, is that only two stroke self-management intervention studies (of 17 identified) (Allen et al., 2004; Harwood et al., 2012) evaluated the implications of self-management on informal carers (section 2.7, appendix one). The study by Allen and colleagues used an un-validated measure to assess carer satisfaction, reporting improvements in the intervention group. Harwood and colleagues reported significant reduction in carer strain in the intervention group (p=0.034). Both interventions tested were aimed at the individual but also involved informal carers. No study explored the relationship between the existence, quantity or quality of carer support or social networks on self-management outcomes. The impact upon informal care-givers following stroke, and how they may facilitate self-management, remains largely unexplored. The finding in the focus group study, that carers are a vital component of self-management in light of stroke-related impairment, is therefore of importance for the future design and evaluation of interventions.

Within the stroke self-management literature, the measurement of desirable self-management behaviours is considered to be an important indicator of successful self-management (section 2.7). Some interventions focused upon modifying behaviours considered to augment health, such as the modification of lifestyle to reduce risk factors (Allen et al, 2004, Damush et al., 2011, Marsden et al., 2010, Sit et al., 2007). In contrast, the focus group findings identified that decision making (4.5.3) and finding resources (4.5.7) were also valued behaviours to people following stroke. Determination was identified as a crucial attribute of self-management following stroke (4.5.4), which has not been explicitly considered in the literature. All represent new areas for researchers and clinicians to target in future interventions.

In addition to identifying factors which may be helpful to target in future SMIs, the focus group enquiry provides evidence that successful self-management following stroke also requires factors that cannot be directly modified at the individual level. Existing stroke self-management interventions are predominantly targeted at the individual (appendix one). The well-established and prevalent Stanford CDSMP model (modified in the UK as the Expert Patient Programme) (section 2.5) does not focus upon the role of societal or health systems support, instead concentrating upon developing management strategies directed at the individual. However, the focus group enquiry emphasises that the wider influences of formal and informal support (4.5.8) and a prevailing environment (4.5.12) are necessary to foster successful stroke self-management. These findings are resonant of other existing models of health which make the distinction between individual and environmental determinants of health, such as the Health Action model, developed by Tones (1981) or the Chronic Care Model (CCM) (Wagner, 1999). The Health action model contends that people’s health behaviour is largely dependent upon the conditions of their lives. The CCM (2.7.5) is based on the premise that effective chronic disease programs are delivered in partnership with health systems and communities.

One stroke self-management intervention (SMI) study identifed in the literature review, cited the CCM as a theoretical base (Allen et al., 2004). Other models exist which acknowledge that self-management extends beyond the individual. For example, the WISE model (Whole system Informing Self-management Engagement) advocates that self-management cannot be separated from an individuals' socio-cultural environment, health services, family and the wider community (Kennedy et al., 2007). However, to date, only the CCM, as a model to acknowledge actors beyond the individual, remains tested in stroke SMIs. The findings from the focus groups verify the view that there is currently inadequate acknowledgement of the contribution of social influences on illness and self-management experience in existing self-management support provision (Paterson et al., 2001, Taylor & Bury, 2007, Vassilev et al., 2011). An argument is then presented for future stroke SMIs to be based on models that acknowledge the influences of society and health systems on self-management, and not solely upon psychological interventions focused at the individual.

The focus group findings provide evidence to challenge SMIs which solely target the individual, without acknowledging the role of a prevailing self-management enviroment and support identified in the model (4.7). Participants overwhelmingly reported that the level of resources and services following stroke did not meet their needs. Self-management appeared to be hindered by a lack of resources and access to appropriate professional support (sections 4.5.9-11), impeding the ability of participants to self-manage to their full potential. For example, a lack of equipment meant that self-managed therapy was not performed optimally (section 4.5.11) or reduced contact with professionals meant that confidence diminished (section 4.5.9). The focus group study evidences that people following stroke may be unable to successfully self-manage, in the absence of appropriate support. Comparable to the findings of the focus group study, Kielman and colleagues (2010) identified that people with respiratory conditions encounter system-related barriers to self-management and report feeling abandoned by health services. Similarly, the failures of support systems following stroke, has been documented previously (Hart, 2001). Harts' study highlighted how failures thought to be because, at least from a medical model perspective, of patient factors such as ‘lack of motivation’, were actually a failing of the health systems themselves. A paradox then exists between the increased policy focus upon self-management, and the reality that the support and resources to enable patients to effectively self-manage following stroke are largely absent. This research then evidences a conceptual and ethical disparity between the reality and the policy rhetoric of stroke self-management.

In summary, the findings suggest that factors considered to be modifiable by individuals affect the success, or otherwise, of self-management following stroke. However factors which remain largely out of the control of the individual, such as resources and services, are also key to successful self-management.

9.3.2 Experiences of support for self-management

The experience of participating in self-management interventions for a person with stroke has been documented in the literature (Catalano et al., 2003, Hirsche et al., 2011). Both studies were conducted to provide insights regarding the future content and delivery of interventions. No study, to date, has considered self-management for people following stroke, who may be described as having received ‘typical’ care (i.e. have not participated in a formal self-management intervention). The focus group study outlined in this thesis constitutes the first study to explore self-management from the perspectives of people following stroke, and thus offers useful insights.

The focus group findings suggest that support systems and healthcare structures do not currently meet the expectations of individuals to give genuine choice and control over their health following stroke (section 4.5.8). Despite policy guidance intended to foster equal sharing of power between health professionals and patients (DoH, 2008), the findings suggest that stroke self-management still appears to favour professional agendas. Currently, the dominant approach to self-management centres upon psychological mechanisms of behavioural change directed at the individual to initiate and sustain self-management, which may not acknowledge the social perspectives of those living in disadvantaged circumstances

(Protheroe et al., 2012). Similar to the focus group findings, others have highlighted that the social, cultural, economic and political influences on health are ignored within current conceptualisations of self-management (Vassilev et al., 2011, Wilkinson & Whitehead, 2009).

Participants in this study reported how health professionals were key to supporting self-management, often indicating that they were fearful of not performing therapy correctly without professional support (4.5.9). However, the specific responsibilities of professionals in supporting self-management following stroke often appeared unclear to participants. For example, therapy often ended without participants having a clear understanding of why, leaving them feeling abandoned. Similar to existing findings (CQC, 2011, McKevitt et al., 2011) many participants reported feeling ill-prepared to manage their long-term health following stroke independently (sections 4.5.2, 4.5.9, 4.5.11, 4.5.15). This suggests that professionals may not explicitly prepare people following stroke to self-manage, instead following professional agendas regarding what is considered to be self-management.

Such agendas may be implicit to professionals, such as a belief that professionals are 'more' expert than patients, and therefore patients should adopt their advice (Norris & Kilbride, 2013, Wilson et al., 2006). Moreover, participant accounts' suggested uncertainty regarding what is considered to be the responsibility of professionals, and what is self-management (4.5.11). Arguably, opportunities for health professionals to provide care in a manner which promotes self-management and which also contributes to embedding a prevailing self-management environment in practice exist. For example, setting goals important to the individual, adapting advice to life situation, promoting confidence, being proactive about the patients concerns and so forth. The findings suggest that the dynamic between patient and professional requires shifting so that each person brings their own expertise to the dialogue; professionals with condition expertise and patients with expertise on themselves.

Individuals in the qualitative phases of this research often perceived they were fulfilling their self-management responsibilities, but that the responsibilities of support services and health professionals were largely unreciprocated. This represents a barrier to effective self-management, whereby there is limited incentive for patients to '*play their part*' in self-management. An additional barrier appears to be that following stroke, individuals are not adequately informed or skilled to be able to self-manage. The role of health professionals in promoting effective self-management following stroke is therefore crucial, and arguably, the promotion of self-management needs to be considered in all interactions with patients. However, the focus group findings suggest that existing support for self-management following stroke, at least in this sample, is scarce, variable and access is reliant largely upon the determination of the individual.

The findings suggest that self-management is an unavoidable part of life for a person following stroke, but that individuals often feel unprepared by professionals to self-manage. Further work is required to investigate how people can be best prepared to self-manage following stroke and to explore the tacit expectations of self-management by differing stakeholders.

9.3.3 Measuring stroke self-management

Prior to this research, no appropriate instrument with which to specifically measure self-management following stroke, existed (2.8.18). Existing measures used to evaluate stroke specific SMIs were limited by unclear conceptual relationships to self-management and unknown reliability and validity for use with stroke populations (Boger et al., 2013). Moreover, limitations with tools to measure self-management for generic health conditions were identified (2.9). The SSMQ represents the first credible, patient derived measurement tool to assess self-management competency following stroke.

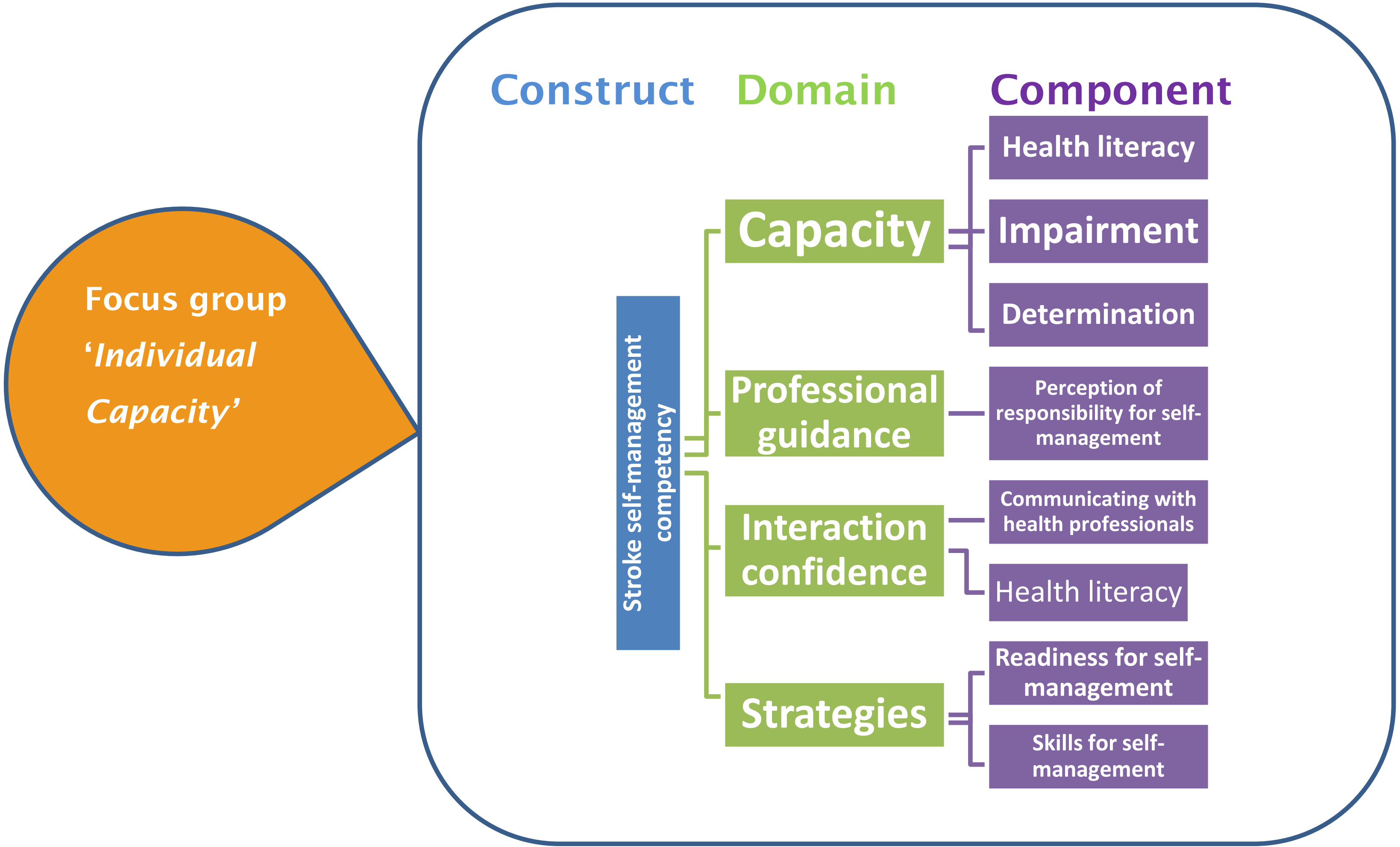
The content of the SSMQ was developed using the experiences of people following stroke. Conventionally, the perspectives of service users are often not incorporated in the development of new outcome measures. This is despite the fact that their perspectives may differ from researchers and clinicians regarding what counts as 'good' outcomes (Rose et al., 2011). Moreover, outcome measures which are condition specific and developed with input from their target population are more likely to focus on health aspects important to that patient group and may be more valid at detecting meaningful change (Wiebe et al., 2003). For someone following a stroke, self-management may encompass a range of tasks and strategies, which are likely to vary for each individual and at different time points after stroke (e.g. goal-setting to improve walking distance, negotiating transport to social events or managing fatigue or medication side effects). This variation in relevant self-management strategies, has arguably presented difficulty to date in the evaluation of stroke SMIs. Previous measurement of self-management has focused upon aspects of stroke recovery considered important to professionals and researchers, such as physical function and mood, as opposed to what might be important to self-management as described by people with stroke. The focus group enquiry was absolutely fundamental in identifying the concepts of importance to people following stroke, hence translated into a meaningful measure of stroke self-management.

The relationship between the preliminary conceptual model of stroke self-management and the SSMQ is represented in figure 9.4. It is important to highlight that the SSMQ does not claim to measure the additional elements important to self-management as highlighted by the focus group enquiry (i.e. support for self-management and self-management environment), which align with the view that social and environmental factors affecting self-management are not adequately acknowledged in current provision and interventions (Bury et al., 2005, Vassilev et al., 2011). In a patient-reported outcome measure it is arguably only appropriate to measure aspects which directly affect patient experience; those which pertain to individual capacity.

Specifically, each item within the SSMQ relates to either an attitude or behaviour considered important to self-management by people who have had a stroke. Attitudes are thought to influence self-management behaviour (section 1.2) and are therefore useful to measure as a way of evaluating self-management interventions (SMIs). To date, attitudes towards self-management have not been explicitly measured in stroke SMIs (appendix one). Existing stroke SMIs have measured behaviours considered important to lifestyle modification (section 2.7), however the SSMQ measures behaviours, or skills, such as decision-making and finding resources which are considered important to people following stroke (table 6.5). The SSMQ is therefore based on a broader understanding of self-management following stroke than was previously considered in the literature.

The SSMQ is unidimensional, measuring the construct of self-management competency, the combined attitudinal and behavioural elements required of an individual to successfully self-manage following stroke. The SSMQ forms a cumulative scale which meets the monotone homogeneity model required of a Mokken scale (section 8.5). Items within the SSMQ scales can thus be ordered in terms of the probability that they will be endorsed, relative to the level of self-management competency the respondent possesses. A summated score from the SSMQ, therefore, can be used to indicate the level of self-management competency that an individual possesses at the time of measurement. Mokken scale analysis suggests that, once the SSMQ is subject to higher threshold requirements, four individually unidimensional subscales (capacity, interaction confidence, strategies and professional guidance) form. These individual scales may be useful to measuring difference aspects of stroke self-management competency. A preliminary item hierarchy for each scale is presented in appendix 22.

Figure 9.4 Proposed relationship between the theme of Individual capacity and the SSMQ



Loevinger's coefficient *H* is used to indicate the confidence with which items can be judged to form a cumulative scale, and hence the confidence with which summed scores can be used as indicators of the level of self-management competency. A value of 1 indicates a perfect model, without any cumulative errors. More clearly, for example, if item 4 in a given perfect scale, is endorsed by a respondent then items 1-3 will also be endorsed (see figure 9.1). Assuming the example scale is a perfect scale, a cumulative error would occur if a respondent endorsed item 3, but not item 2.

1. I am happy for pizza to be sold in my town
2. I am happy to see a pizza
3. I am happy to smell pizza
4. I am happy to eat pizza
5. I am happy to eat pizza for every meal

Figure 9.1 Example of a theoretically perfect Guttman scale

The psychometric study established that there is a unidimensional hierarchical arrangement of items from the SSMQ. The SSMQ and additional scales all possess acceptable *H* coefficient values (table 8.4); the capacity scale meets the criteria of a strong Mokken scale (0.502), the interaction confidence and professional guidance scales meet the criteria for moderately strong scales (0.447 and 0.400, respectively). The strategies scale meets the criteria for an acceptable Mokken scale (0.325). Scales with higher *H* coefficients possess fewer scaling errors; summed item scores from scales with higher coefficients can more confidently be used to measure the corresponding level of the characteristic the respondent possesses. Given the study limitations (section 9.7), the preliminary *H* coefficient of the SSMQ and additional scales compare favourably with other Mokken scales used with stroke populations. The Hospital Anxiety and Depression scale (HADS) (Zigmond & Snaith, 1983) has a *H* coefficient of 0.41 (n=893) (Cosco et al., 2012); the Rivermead Motor Assessment (Lennon & Johnson, 2000) 0.36 (n=107) (Kurtais et al., 2009) and the Subjective Index of Physical and Social Outcome (SIPSO) (Trigg & Wood, 2000) 0.51 (n=445) (Kersten et al., 2010).

Theoretically, scales which possess higher *H* coefficients have a stronger hierarchy of items. According to their respective *H* coefficients, items in the capacity scale form a ‘stronger’ hierarchy, than items in the strategies scale; item 1 in both scales represents the ‘easiest’ item to endorse (figure 9.2). Further work is necessitated to examine the conceptual hierarchy of items as identified by the preliminary analysis. Investigation with larger sample sizes and a further exploration of Mokken models is required (see 10.3.2). According to some experts, the relationship of item hierarchies to the latent construct measured is often not fully elucidated and, similar to construct validity, examination is viewed as an on-going process (van Schuur, 2011). Evidence from this thesis suggests that the SSMQ is potentially a useful instrument for ordering individuals in terms of self-management competency, on the basis of their total mean scale score.

Capacity scale (0.502)

1. The effects of stroke mean that I cannot manage my recovery and health
2. When things do not go well with my stroke, it is hard to stay positive
3. It is not up to me to decide what the best ways to manage my stroke are
4. The physical effects of stroke mean that I cannot manage my health as I would like

Strategies scale (0.325)

1. I plan my day so I can get things done without being tired (16)
2. I feel confident asking family members to help me do things important to my health (43)
3. I manage things related to stroke as well as other people with stroke (39)
4. I try different ways of doing things, until I find out what works for me (19)

Figure 9.2 Comparison of item hierarchy on the capacity and strategies scale

The psychometric evidence outlined in this thesis suggests that the SSMQ provides a consistent estimate of self-management competency over time (test-retest reliability) and possesses good internal consistency reliability (section 8.6). Figure 9.3 illustrates that the preliminary reliability of the SSMQ is favourable in comparison to other proposed outcome measures of self-management. As well as being reliable, the SSMQ possesses good preliminary evidence of construct validity. Section 9.4 discusses the evidence for construct validity in detail. Overall the findings of the psychometric

evaluation detailed in this thesis provide evidence that the SSMQ is a reliable and valid scale of stroke self-management competency and the first PROM of stroke self-management attitudes and behaviours.

Items within the SSMQ were derived from the theme of Individual capacity, described following the focus group enquiry (4.5.1). The subsequent psychometric evaluation of the concepts identified from the qualitative enquiry can be considered to strengthen the preliminary conceptual model (4.7). The theme of individual capacity may be further supported in light of the component parts of self-management competency measured by the SSMQ. The extent to which a person is ready and able to respond to the demands of self-management, i.e. their individual capacity, can be considered to impact upon their self-management competency. The direction of causality cannot confidently be stated, and it may conversely be that self-management competency has an impact upon individual capacity. Further evidence, which will be derived from further testing of the SSMQ, is required to understand how the additional scales extrapolated at higher thresholds affect Individual capacity and vice versa.

Since 80-90% of self-management in long-term conditions, including stroke occurs away from health care professionals (De Silva, 2011) it follows that self-management cannot conceivably be measured without patient evaluation. The SSMQ then represents the first PROM, acceptable to people following stroke which measures self-management behaviours and attitudes following stroke.

This section has discussed how the findings of this thesis contribute to the existing conceptualisation and measurement of self-management following stroke. Section 9.4 discusses the proposed construct of self-management competency in further detail.

Measure	Sample	Internal consistency Reliability (Cronbach's alpha)	Test-retest Reliability
BSMQ	156 (>65yrs, more than one long-term condition)	0.38-0.92	Not reported
HeiQ	591 (long-term health conditions, 59% arthritis)	0.7-0.8	Not reported
PAM	100 (unspecified long-term health conditions)	0.87	93% of sample scored within 0.05 predicted confidence interval (n=30)
SES	292 (unspecified long-term health conditions)	0.77-0.90	ICCs 0.72-0.88 (n=51)
SIS	91 (mean 3 months post-stroke)	0.83-0.90	0.56-0.92 (n=25)
SSEQ	40 (<4 weeks post-stroke)	0.90	Not reported
SSMQ	87 (mean 60 months post-stroke)	0.73-0.88	ICCs 0.59-0.947 (n=39)

Figure 9.3. Comparison of reliability of potential outcome measures of self-management. BSMQ- Barriers to self-management questionnaire (Bayliss et al., 2003); HeiQ – Health education impact Questionnaire (Osborne et al., 2007); PAM – Patient Activation Measure (Hibbard et al., 2004); SES - Self-efficacy to perform self-management behaviours scale (Lorig, 1996); SIS- Stroke Impact Scale (Duncan et al., 1999); SSEQ- Stroke Self-Efficacy Questionnaire (Jones et. al, 2008).

9.4 The construct of stroke self-management competency

Construct validity is a unifying form of validity incorporating both content and criterion validity (Strauss & Smith, 2009). It represents an overall argument in support of the interpretations of a score from a PROM. Determination of construct validity cannot be achieved in one single study. Construct validation is viewed as an on-going process (de Vet et al., 2011); refinement of the construct evolves with the continual testing of proposed theory supporting the construct with different samples over time. Each new exploration verifies or challenges the theory, developing the evidence in support of, or for refinement of construct validity. Construct validity of the SSMQ was investigated by exploring the relationships between scores from the SSMQ and associated scores on the SSEQ and SIS. What follows is an overview of the proposed construct of *self-management competency,* measured by the SSMQ.

9.4.1 Components of the SSMQ

Each item within the SSMQ can be described as an attitude, behaviour or skill that provides information about the self-management competency of an individual. Attitudes describe the '*evaluation of an object, concept or behaviour'* within a continuum of like or dislike, favour or disfavour (Ajzen & Fishbein, 2000 p.3). Attitudes are thought to be modifiable at a sub-conscious level, according to an individual's mood, the context in which an issue or attitude is presented or expressed and by cognitive processing goals (Ajzen & Fishbein, 2000, Gross, 2010). Attitudes are thought to influence subsequent health behaviour(s) and may be modifiable in interventions (Armitage & Christian, 2003, Hardeman et al., 2002). Measurement of attitudes using the SSMQ may help researchers to understand their causal relationships to self-management behaviours (Fazio & Olson, 2003, Oppenheim, 2000). Fredrickson (2003) has presented a model illustrating how positive attitudes can affect health by increasing the cognitive, physical, and social resources of the individual. Feasibly in people following stroke, those with more positive attitudes may be able to draw on personal resources, which, in turn, may increase the chances of successful self-management.

In the context of this research, self-management behaviours refer to the activities that people following stroke do to promote health and prevent further complications. For example, goal-setting or performing therapy exercises may be desired behaviours for successful self-management. In addition to possessing the attitudes that influence desirable self-management behaviours, performance of desirable behaviours may require the development of new skills. For example, carrying out tasks with limited limb function, or returning to work with a cognitive impairment.

Measurement of self-management attitudes and behaviours may help researchers and clinicians understand the mechanisms underpinning successful self-management following stroke.

9.4.2 Additional scales

When the SSMQ was subject to higher threshold requirements, four individual scales formed (chapter eight). These additional scales may provide unique information about self-management competency following stroke. The scales are unidimensional and distinct from each other, individually revealing a different aspect of stroke self-management (table 9.1). The proceeding sections describe each scale in further detail.

9.4.3 The capacity scale

The capacity scale contains reliable indicators of an individuals' capacity to perform or engage in self-management following a stroke (test-retest Intraclass Coefficient 0.590, CI 0.427-0.716; Mokken reliability coefficient 0.89). Scores on this scale indicate several things about an individuals' capacity for stroke self-management. Higher scores characterise someone who is determined not to let stroke control their life, and overcomes impairment related barriers to self-management. Three items indicate the impact of stroke-related impairment on an individuals' capacity for self-management (appendix 22, items 1, 4, 7). Six items are indicators of the degree of patient determination to self-manage (items 2, 3, 5, 8, 9). One item provides information about the patients' health literacy (item 6).

The findings suggest that health literacy may be of importance to stroke self-management. Health literacy has been defined as a person's capacity to seek, understand and utilise health information to participate in decisions about their health (US Department of Health and Human Services, 2010). Deficient levels of health literacy have been associated with poor understanding about health (Williams et al., 1998), worse health (Rothman et al., 2002; Sudore et al., 2006) and higher mortality (Baker et al., 2007). Health literacy is consequently likely to be essential to self-management and has been shown to be predictive of ability to engage in self-management in

elderly adults with hypertension (Gerber et al., 2011), asthma (Paasche-Orlow et al., 2005) and diabetes (Williams et al.,1998). The sustainability of self-management interventions and support services may be, in part, reliant upon patients' capacity to participate, which conceivably is affected by their health literacy (Jordan et al., 2008). The interaction confidence scale also contains items which pertain to health literacy (10, 15).The items thought to reflect health literacy is therefore of significance, since health literacy has not been evaluated to date in existing stroke self-management interventions, nor has been a key consideration in the prevalent self-management models. Further validation work exploring correlations with existing measures of health literacy would enable expansion concerning the relationship between self-management competency, capacity and health literacy.

Scale	**Items** (raw score range)	**Definition**	**Interpretation**
SSMQ	28 (28-168)	Indicators of the elements required to be a competent self-manager following stroke.	Higher scores characterise someone who is competent at responding to the demands of managing health after stroke.
Capacity	9 (9-54)	Indicators of the impact of impairment and determination on self-management.	Higher scores characterise someone who is determined not to let stroke control their life, and overcomes impairment-related barriers to self-management.
Interaction confidence	6 (6-36)	Indicators of the confidence and ability of an individual in communicating with health professionals, and the confidence in the response of health professionals to get self-management needs met.	Higher scores characterise someone who is confident in their communication skills with health professionals. Scores also indicate an individuals' confidence in the responses of health professionals with regard to self-management needs.
Professional guidance	6 (6-36)	Indicators of the perceived input required from health professionals to enable self-management.	Higher scores characterise someone who is comfortable with taking responsibility for self-management.
Strategies	7 (7-42)	Indicators of an individuals' readiness and skills to enact self-management strategies.	Higher scores characterise someone who possesses skills in symptom management and enacting self-management strategies.

Table 9.1 Conceptual construct and addtitonal scale definitions of the SSMQ

The capacity scale indicates the extent to which individuals are determined not to allow stroke to take over their lives and can overcome stroke –related barriers, such as impairment. The focus group findings suggest that determination or motivation to engage in self-management is a key facet of stroke self-management capacity. To date, this important concept to people following stroke has not been measured or evaluated in stroke SMIs (Boger et al., 2013).

Determination and self-efficacy are thought to be related theoretical constructs (Bandura, 1997). Therefore the significant correlations of the capacity scale with the stroke self-efficacy scale, provide further evidence that determination is measured by the capacity scale (table 8.9). Feasibly, the relationship can be described thus; self-efficacy enhances capacity to self-manage, or conversely self-management capacity enhances self-efficacy. This finding provides further evidence of the mediating role of self-efficacy in successful self-management.

Physical function has previously been a focus for measurement and evaluation in stroke SMIs (2.7.7.1) Cognitive impairment has been reported to negatively impact upon the self-management of diabetes (Feil et al., 2012), but has not been reported upon in stroke. In people who have both cognitive and physical impairment, physical function is more likely to decline (Fultz et al., 2003), arguably resulting in increased difficulties with self-management for these individuals. This is of particular relevance to stroke, where individuals may experience a range of impairments that are physical, cognitive and participative in nature, thus potentially affecting capacity to self-manage. Previous studies have focused on physical function which, as evidenced by the focus group findings (4.5.6), represents a narrow view of stroke-related impairment. The capacity scale positively correlated with all domains of the Stroke Impact Scale (SIS), including the participation, emotion, memory and communication domains (tables 8.10-8.15). This suggests that the degree of different manifestations of impairment following stroke, and not just physical function, relate to capacity for self-management. Therefore the capacity scale provides a useful indicator of the role of impairment upon self-management, by measuring the ability of individuals to overcome impairment-related barriers.

9.4.4 The interaction confidence scale

The SSMQ interaction confidence scale contains reliable indicators of confidence for interactions with health professionals (test-retest Intraclass coefficient 0.824, CI 0.741-0.882; Mokken reliability coefficient 0.82). Scores on this scale (appendix 22, items 10-15) chiefly indicate an individuals' confidence in their interactions with health professionals. Higher scores characterise someone who is confident in their communication skills with health professionals. Scores also indicate an individuals' confidence in the responses of health professionals with regard to self-management needs.

Several items within this scale potential also reflect health literacy. As noted in section 9.4.3, health literacy is important to communiction with health professionals. Further validation of this scale is required with an appropriate measure of health literacy to explore this potential theoretical relationship.

This scale appears to represent the patient perspective of communication with health professionals relating to self-management. Arguably, effective interaction requires the participation of health professionals, which is, to a large degree, outside of the patients' control. Effective communication to support self-management requires skills on the part of the professional too. The extent to which health professionals are skilled at placing patients at the heart of interactions has been questioned (Bury, 2004). Moreover, it has been argued that many health professionals lack the necessary expertise for promoting self-management (Kosmala-Anderson et al., 2010, Légaré et al., 2012, Wilson et al., 2006). A recent study highlighted that stroke professionals who received training on the promotion of self-management, remained challenged by empowering patients, being most comfortable where therapy followed professional agendas (Norris & Kilbride, 2013). A need for a cultural change to facilitate self-management within professional groups and health service providers was highlighted by the study authors. Similarly, the focus group research within this thesis identified that a prevailing self-management environment is an important aspect of successful self-management from the patients' perspective (4.5.12).

The interaction confidence scale did not significantly correlate with total stroke self-efficacy, as measured by the stroke self-efficacy questionnaire

(SSEQ), to the same statistical degree as the other scales ($p=<0.05$ v. $p=<0.01$, table 8.9). The SSEQ consists of 13 items, ten items of which relate to confidence to perform physical function-related tasks. That the SSEQ focuses upon self-efficacy for physical function is further emphasised by the highly significant correlations with all of the physical function domains of the Stroke Impact scale (SIS) (table 8.15). It is plausible that the SSEQ in fact measures stroke self-efficacy related to physical function recovery, as opposed to a more holistic view of stroke self-efficacy. The focus upon physical function may in part relate to the views exhibited by participants in the development phase of the SSEQ. Those participants were at a relatively acute stage following stroke (average four weeks), where, conceivably, physical function was a priority for participants. In contrast, the interaction confidence scale was developed with individuals a longer duration since stroke (mean 60 months, table 8.2) and may be reflective of evolving health priorities.

Communication skills, memory and emotion are likely to be very important for self-management focused interactions with health professionals. Communication impairment following stroke has been linked to increased emotional distress (Thomas & Lincoln, 2008) and reduced quality of life (van der Gaag et al., 2005). Improved mood is thought to enhance recovery of physical function (Saxena et al., 2007), whilst post-stroke memory loss has been linked to reduced quality of life and coping (Aben et al., 2008). The interaction confidence scale correlated significantly with the communication, memory and emotion domains of the SIS (tables 8.12-8.14). The findings suggest that these elements are of importance to a persons' confidence to interact with health professionals, and relate to self-management competency.

The interaction confidence scale appears to be unrelated to physical function (no significant correlations with the perceived recovery or any physical domain from the SIS) (table 8.15). Given that the literature with regard to stroke self-efficacy focuses upon physical function (Korpershoek et al., 2011), the scale potentially measures a different aspect of stroke self-efficacy of importance to patients.

9.4.5 The strategies scale

The strategies scale contains reliable indicators of readiness (appendix 22, items 17-20) and skills (items 15, 16, 21) required to enact self-management strategies (test-retest intraclass coefficient 0.90, CI 0.85-0.934; Mokken internal consistency reliability coefficient 0.73). Scores on this scale indicate a persons' readiness to engage in self-management following stroke. Higher scores characterise someone who possesses skills in symptom management and in enacting self-management strategies.

The strategies scale correlated positively with total stroke self-efficacy, as measured by the SSEQ, and the perceived recovery, communication, emotion, memory and participation domains of the SIS (tables 8.9-8.15). Conceptually, it follows that someone who has higher self-efficacy and mood function may be better at enacting self-management strategies (Jerant et al., 2005, Jones & Riazi 2011, Korpershoek et al., 2011). There is a paucity of literature with regard to communication, memory and self-management following stroke, however it might be supposed that such impairments would impede self-management. Surprisingly, since it might be expected that someone who has a better degree of physical recovery following stroke may be better able to enact self-management strategies, the strategies scale appears to be unrelated to physical function as measured by the SIS in this sample. The strategies scale correlated with perceived recovery, as measured by the SIS, suggesting that possibly 'recovery' was interpreted holistically by respondents, in addition to physical recovery. This provides further evidence that physical function is not the only important self-management outcome for patients.

Self-management may involve individuals developing a wide range of skills to manage their condition effectively, for example goal-setting, symptom management, monitoring, problem-solving and communication (Bodenheimer et al., 2002a). Arguably, communication skills are, to some degree, also elicited in the interaction confidence scale, since confidence in interaction may relate to communication skill. Items 21 and 22 in the strategies scale relate to engaging others to enable stroke self-management an aspect of key importance identified in the qualitative work.

Some studies suggest that appropriate self-management support may help people make health behaviour change by progressing them through the change continuum (Daley et al., 2009, Parchman et al., 2010). A measure that indicates readiness to change behaviour may be useful to stroke self-management, as it may enable the targeting of intervention strategies for people at different stages of change. For example, a person that scores low on item 16 *'I plan my day so I can get things done without being tired'* may benefit from an exploration of any fatigue symptoms or strategies to enhance planning. Further work is required to explore the validity of the strategies scale in relation to behaviour change theories.

The focus group data suggested that learning to cope and adjusting behaviours to accommodate living with stroke, in addition to dealing with possible therapy, treatment and lifestyle changes, is a difficult endeavour. The self-management strategies that people engage in may be affected by a person's readiness to engage in self-management. There is paucity in the literature with regard to the relationship between readiness for change and stroke, however some commentators acknowledge that readiness is a key requirement for successful stroke self-management (Jones et al., 2013).

9.4.6 The professional guidance scale

The professional guidance scale contains reliable indicators of the reliance participants place on health professionals as a resource for successful self-management (test-retest intraclass coefficient 0.867, CI 0.803-0.911; Mokken reliability coefficient 0.79). The professional guidance scale indicates the extent to which individuals are comfortable with taking ownership of self-management following stroke (appendix 22, items 24-28) and by inference, the extent to which they perceive professionals should guide self-management. Conceptually, higher scores characterise someone who is comfortable with taking responsibility and control for self-management.

The increasing prevalence of self-management interventions has been partly driven by the assumption that self-management is of benefit to patients and can improve their quality of life (Barlow et al., 2002a, De Silva, 2011). However, not all patients may wish to take the responsibility, nor may be ready, for self-management (Rogers et al., 2005), instead preferring care to remain at the direction of professionals. The professional guidance scale potentially gives researchers and clinicians a useful way of considering the extent to which individuals are prepared to self-manage following stroke. This may facilitate the provision of support for individuals who place a high reliance on professional guidance. Additionally the scale could help the targeting and evaluation of interventions. This is further considered in section 9.5.

The professional guidance and interaction confidence scales from the SSMQ provide information about respondents' perceptions of health professionals and their role in self-management. Therefore, changes in scores on these scales may, in part, reflect professional and organisational cultures and indicate areas which could be targeted in service models.

In summary, the SSMQ measures stroke self-management competency. Self-management competency represents the features an individual requires to be competent and capable of self-management following stroke. However, four separate scales can be derived from the SSMQ at higher Mokken thresholds. The scales may individually be useful to clinicians and researchers wishing to focus upon measuring a different aspect of stroke self-management competency. Collectively the SSMQ and individual scales represent new facets of self-management, as identified by people with stroke. Further refinement of the emerging construct of self-management competency and of the concepts measured by the individual scales, is inevitable as the theory surrounding self-management develops and the SSMQ is further validated.

9.4.7 Relationship between the SSMQ and additional measures

In chapter seven, hypotheses about the potential theoretical relationships between scores in the SSMQ and additional measures were set out. Tests of these theoretical relationships provide information about the construct captured in the SSMQ and are therefore fundamental to assessing the evidence for the construct of self-management competency measured by the

SSMQ. The following sections explore the relationship between the SSMQ and the additional measures used in the psychometric evaluation.

9.4.7.1 Relationship to stroke self-efficacy

Within stroke self-management, self-efficacy is the most prevalent purported theoretical base to interventions (Jones & Riazi, 2011, Lennon et al., 2013).The Stroke Self-Efficacy Questionnaire (SSEQ) (Jones et al., 2008b) remains the only stroke specific PROM of self-efficacy, and was thus used to explore construct validity. However, some limitations exist with the SSEQ (7.7.2) which are first important to consider.

Questions exist concerning the relevance of the development sample for the SSEQ. Data were generated with people a relatively short time frame since stroke (mean time after stroke was 4.2 weeks and 16 days for the phases involving people with stroke). This may not represent sufficient time for individuals to adequately appraise their situation since stroke, especially as some participants were still in hospital. How self-management operates in hospital environments, where the autonomy of patients is arguably limited, is unknown. Individual levels of self-efficacy and engagement in relevant self-management activities or strategies may vary with time following stroke. The SSEQ may therefore not comprehensively reflect self-efficacy levels at longer different durations since stroke.

In this study, neither time since stroke, age nor living alone appeared to affect self-efficacy as measured by the SSEQ. This may possibly be explained by a lack of validity of the SSEQ to evaluate self-efficacy at longer durations since stroke, as outlined above (in comparison the mean duration since stroke in the psychometric phase sample was 60 months). Moreover, the extent to which the SSEQ expansively measures self-efficacy following stroke may be questioned. Ten of thirteen items contained in the SSEQ relate to performing physical function-related tasks, which may provide a narrow representation of self-efficacy following stroke. A clear increasing linear relationship between the scores from self-rated perceived recovery and self-efficacy was observed (figure 8.5). Conceptually, it is feasible that those with better perceived recovery, as measured by the SIS, possess greater confidence in enacting tasks related to physical function, as predominantly measured by the SSEQ.

As hypothesised, all items on the SSMQ positively correlated with total stroke self-efficacy, as measured by the SSEQ (table 8.9). More clearly, higher self-efficacy scores were related to increased SSMQ scores and thus more successful self-management behaviours, attitudes and skills. This finding is consistent with the existing literature regarding the impact of self-efficacy and effective self-management (sections 2.4, 2.7.3). Advocates of the role of self-efficacy in self-management believe it mediates desirable health behaviours, for example, following a healthy lifestyle, taking prescription medication, leading to improved motivation, treatment adherence, function and better clinical outcomes (Kendall et al., 2007, Marks & Allegrante, 2005). Following stroke, self-efficacy appears to relate to potential outcomes of self-management (Jones & Riazi, 2011), such as recovery and physical function (Hellström et al., 2003, Le Brasseur et al., 2006), community reintegration (Pang et al., 2007). Lower levels of self-efficacy are associated with lower mood and coping skills after stroke (Aben et al., 2008).

The findings of this research cautiously suggest, given the limitations identified with the SSEQ, that increased stroke self-efficacy is related to enhanced competency for self-management following stroke, providing evidence for the construct.

Section 9.3.1 sets out how self-management capacity, used to inform the content of the SSMQ, may not be affected by self-efficacy alone. As described in the focus groups by people following stroke, impairment, decision-making, determination, finding resources and communication skills are also key to self-management capacity. The role of impairment in stroke self-management appeared to be particularly salient to participants and therefore of potential theoretical importance to determining the construct validity of the SSMQ. To explore this further, the Stroke Impact Scale (SIS) was used to examine the relationship between mood, communication, memory, participation and functional impairment to provide evidence for the emerging construct of self-management competency.

As hypothesised, items on the SSMQ correlated positively with the physical function, mood, communication, memory and participation domains in the SIS. Higher function following stroke appears to be related to increased self-management behaviours, attitudes and skills. The following sections offer possible explanations for these findings.

9.4.7.2 Relationship to Physical function

The SSMQ positively correlated with all of the physical function domains of the SIS, although correlations with the Hand function and Strength domains were not significant (table 8.15). The correlations evidenced in this research between the physical function domains of the SIS and the SSMQ imply that effective self-management is associated with improved physical function. However, it is not possible to deduce if higher function causes improved self-management, or vice versa. Conceivably, physical impairment may limit an individuals' ability to perform some desirable self-management behaviours, such as exercising. Attitude may also be important to how individuals following stroke respond to impairment-related barriers by influencing the perception that physical function has improved, or the extent to which impairment is bothersome to the individual (Lewis et al., 2001, Johnston et al., 1999, Ostir et al., 2008).

Arguably, patients' attitudes toward their stroke and related behaviours change over time and may be associated with their level of physical function. For example, someone who recovers a great deal of physical function in the early months may possess a more positive attitude one year following stroke than someone with a stroke of similar severity, who does not recover as much function. Contrary to what might be expected, in this sample, there appeared to be no linear relationship between self-rated perceived recovery, as measured by the SIS, and duration since stroke (figure 8.6). The longer time since stroke respondents were, the lower their level of self-rated recovery was (rho = -.234, CI -0.423 to -0.025, n=87). One explanation might be that as time since stroke increases, people's expectations of continued recovery change as improvements become less obvious. Alternatively, the sample in this study was not sufficiently powered to determine statistical differences in self-rated perceived recovery at different time points since stroke; the finding may be indicative of a type one error (false positive).

9.4.7.3 Relationship to Emotion

An assumption exists within the literature that better self-management leads to improved well-being and mood (Catalano et al., 2003) (section 2.7). Mood is thought to be significant to recovery following stroke (White et al., 2008) and low mood has been identified as a barrier to self-management in long-term conditions (Bayliss et al., 2003, 2007). It follows that mood may be an important outcome to investigate in stroke self-management intervention studies, although to date, no significant effects on mood following such interventions have been reported in the literature (Lennon et al., 2013).

The SIS emotion domain positively correlated with the SSEQ. If the SSEQ is accepted as a valid measure of stroke self-efficacy, this suggests that increased stroke self-efficacy is associated with better mood. Such associations between self-efficacy and mood have been documented in the stroke literature (Robinson-Smith et al., 2000) and in other long-term conditions (Jerant et al., 2005, Marks et al., 2005). This research then provides further evidence of the relationship between self-efficacy and mood following stroke.

As predicted, scores from the SSMQ and additional scales derived from the SSMQ, correlated positively with scores on the emotion domain of the SIS (table 8.13). This suggests that, in this sample, individuals with lower mood, exhibit fewer desirable self-management behaviours and attitudes. Improved mood may augment self-management competency, or potentially vice versa. One explanation for this might be the accepted convention that positive attitudes are associated with better mood (Gross 2010). The SSMQ measures self-management attitudes and behaviours, it follows that higher scores should correlate with measures of mood, to provide further evidence of construct validity.

9.4.7.4 Relationship to communication, memory and participation

No significant changes have been reported to communication mood or social participation following self-management interventions (Lennon et al., 2013), although many of the studies included in the systematic review were powered inadequately to detect change in these domains. However, trends for improvement in the communication and participation domains of the SIS were observed following a pilot group self-management intervention (n=25) (Marsden et al., 2010), suggesting that effective self-management may have the potential to impact upon these domains.

The SSMQ correlated positively with the communication, memory and participation domains of the SIS, suggesting that, these elements are important to self-management competency. There is a paucity of literature with regard to memory, communication, social roles and self-management following stroke. Some studies suggest greater satisfaction with social role function following generic self-management interventions (Lorig et al., 1999, 2001). Conceptually, it might be expected that effective communication skills would enable successful enacting of self-management.

9.4.7.5 Relationship to Quality of life

The SIS was developed as a measure of health status after stroke (Duncan et al., 1999, 2001, 2003b), although it has been used to measure quality of life (QoL) related to stroke self-management by some researchers (Guidetti & Yterrberg, 2011, Marsden et al., 2010). Reviews of QoL measures for use with stroke populations, identified the SIS as a comprehensive measure of impairment (Geyh et al., 2007, Salter et al., 2008) and questioned if the SIS, is a sufficient measure to describe QoL expansively. Section 7.7.2 highlighted some limitations associated with the development of the SIS, which question its validity as a measure of QoL after stroke.

There is a suggestion within the literature that as people develop the coping skills to adjust to and manage their life post-stroke their quality of life will consequently improve (Catalano et al., 2003, Lorig et al., 2006a). Seven (39%) stroke self-management intervention studies adopted measures of QoL suggesting that there is support for this premise in the design of such interventions, although few studies explicitly stated why QoL might be an outcome of successful self-management or reported significant changes to QoL (2.7.7, 2.9.9).

Section 7.7.2 highlighted that it remains unclear how the SIS domains align with the views of people with stroke. As discussed this may, in part, be due to a lack of clarity regarding the concept of quality of life following stroke, and hence a lack of suitably valid instruments to measure it (Salter et al., 2008).

The SSMQ significantly (p=<0.05) and positively correlated with all physical function domains of the SIS except for the Hand function and Strength domains (table 8.15). Significant (p=<0.01) positive correlations were found with the Memory, Communication, Emotion, Participation and Perceived recovery domains. Assuming the SIS is a potentially valid measure of quality of life, the correlations with the SSMQ and subscales corroborate the view that successful self-management is associated with improved quality of life. Conceptually, QoL may be important to self-management; gaining more control over health and well-being can feasibly be considered to improve QoL. Conversely, those who possess greater QoL may be more likely to exhibit the skills necessary to self-manage competently. However, these findings must be considered with caution owing to the possible limitations of the SIS as a measure of QoL.

The psychometric findings provide preliminary evidence of the construct validity of the SSMQ in several ways. Firstly, the predicted hypotheses made with regard to the relationship of scores from the SSMQ and additional measures were borne out. Secondly, that the SSMQ correlates with the measures of theoretically related importance suggest that self-management competency is consistent with the existing knowledge of stroke self-management. Finally, the evidence suggests that the SSMQ measures concepts of importance to people following stroke.

9.5 Anticipated use of the SSMQ

The literature highlights that the optimal content, target outcomes, and mechanisms for change in self-management interventions remain unclear (Jones et al., 2013, Lennon et al., 2013). Measurement of an individuals' self-management competency, their attitudes towards self-management and relevant behaviours relies upon patient report. The findings from this thesis then augment the existing knowledge by providing an instrument, grounded in the views of patients with which to evaluate self-management following stroke. Moreover, the findings provide a basis for further consideration of the content of interventions and the outcomes of importance to patients. Judgements regarding the quality of the SSMQ will ultimately inform researchers and clinicians regarding its' utility. The next section considers the preliminary properties of the SSMQ, how its' quality might be enhanced and the implications for clinical and research practice.

9.5.1 Quality of the SSMQ

The systematic review produced in relation to this research, utilised a standardised checklist (COSMIN) with which to judge the quality of outcome measures (Boger et al., 2013). The COSMIN (COnsensus-based Standards for the selection of health status Measurement Instruments) checklist (Mokkink et al., 2010b) was developed following an international Delphi study of 57 psychometric experts and is advocated as a guide to enhancing methodological rigour in the development of outcome measures. Applying the COSMIN standards to the SSMQ provides a useful indicator of its' preliminary quality and use as a potential research tool.

The properties examined by COSMIN consist of nine items: Internal consistency; Reliability; Measurement error; Content Validity; Structural validity; Hypothesis testing; Cross-cultural validity; Criterion Validity and Responsiveness. Where the COSMIN item has not been investigated, the item is not scored. Criterion validity, responsiveness and cross-cultural validity of the SSMQ has yet to be determined; these items are therefore not scored. Each item is rated as excellent (++++), good (+++), fair (++) or poor (+) (table 9.2). Within the COSMIN scoring method, the lowest score in any given category is taken as the score.

	Internal consistency	Reliability	Measurement error	Content Validity	Structural Validity	Hypothesis testing
COSMIN rating	+++	+++	+++	++++	+++	+++

Table 9.2 Summary of COSMIN property scores of the SSMQ Key: excellent (++++), good (+++), fair (++) or poor (+)

Ratings of the SSMQ using the COSMIN checklist are encouraging. The methods employed in the development of the SSMQ resulted in scores of ‘good’ in each applicable category, bar content validity where a rating of ‘excellent’ was attained. Content validity is of particular importance when trying to capture the essence of self-management, since the experience of patients is vital in determining what is valued from their perspective. COSMIN operates a ‘lowest score counts’ scoring system which may account for why the SSMQ did not score ‘excellent’ in the additional categories. The methods adopted were judged to be appropriate in the additional categories, but were rated as ‘good’ due to inadequate sample size. For example, for the SSMQ to be rated as ‘excellent’ in the other categories, a sample size of >100 is required, highlighting an important direction for the future enhancement of the SSMQ.

To give context for future research, the SSMQ compares favourably with the other outcome measures used to evaluate stroke self-management interventions. 43 outcome measures were used by the studies identified in a systematic review, 49% (n=21) of which demonstrated some of the COSMIN properties with stroke populations (the remainder had not been tested for validity or reliability in stroke populations) (Boger et al., 2013). The majority of measures which were eligible to be scored, scored either ‘fair’ or ‘poor’. The SSMQ then represents a soundly developed measure, which can be objectively selected by other researchers to evaluate stroke self-management, and adopted into clinical preactice subject to further investigation of validity.

9.5.2 Mokken measurement properties of the SSMQ

Within a Mokken measurement model, the ability of a scale to discriminate via its component items and subsequently differentiate and order respondents is determined by the scale's *H* coefficient value (Meijer & Baneke, 2004). This preliminary work, reveals that the SSMQ possesses an overall *H* coefficient of 0.353. According to convention this indicates an acceptable Mokken scale (0·40–0·50 indicates a medium scale; >0·50 a strong scale) (van Schuur, 2011). If higher thresholds are applied, the SSMQ forms four separate scales also with acceptable *H* coefficients. The strategies scale is classified as an acceptable scale (0.325). The interaction confidence and professional guidance scales are classified as moderate Mokken scales (0.447; 0.40 respectively) and the capacity scale is classified as a strong Mokken scale.

Given the limitations associated with this research (section 9.7) these results are an encouraging basis for future research (chapter ten presents suggestions to further strengthen and enhance the existing SSMQ). The findings suggest that the SSMQ meets the monotone homogeneity model meaning that respondent scores increase with an increasing level of self-management competency. This allows for respondents with different levels of self-management competency to be categorised using a summed total score derived from the SSMQ. Similarly respondent scores for the additional scales increase with respective increasing levels of capacity, confidence, strategies or professional guidance.

Each item on the SSMQ is scored on a 1-6 scale; higher scores indicate greater self-management competency. The potential range of scores on the SSMQ is therefore 28-168. Within this research, the mean score on the SSMQ was 118 (SD 20.99), the lowest score was 67 and the highest 157 suggesting that a breadth of self-management competency was exhibited in this sample, without any obvious floor or ceiling effects.

To avoid a potential response pattern bias, some items are reversed scored. In these cases, higher raw scores indicate fewer desirable attitudes, skills or behaviours. Raw scores refer to the original score from the item before it is adjusted. Prior to interpretation, raw scores from negatively worded items are then adjusted so that low scores equal less desirable attributes. For example, within the Interaction confidence scale one item is worded negatively (‘*I find it difficult to tell health care professionals what I want or need*’), where a score of ‘6’ (Always True) would indicate a less favourable skill. This is adjusted prior to interpretation, so a score of ‘6’ is then interpreted as ‘1’. Within the capacity scale, nine items are worded negatively and require reverse scoring prior to interpretation. No items in the strategies scale are worded negatively. All items in the professional guidance scale are worded negatively and require reverse scoring prior to interpretation.

Questions exist with regard to the burden that a combination of negative and positive wording, plus the requirement to adjust raw scores in some items prior to interpretation, places on potential users of the SSMQ. An aim of this research was to develop a PROM that could be adopted in clinical and research practice. The SSMQ might be further enhanced and better incorporated into practice through the development of a scoring pro forma for clinicians that would facilitate ease of use. The cognitive interviewing findings suggested that the wording of items was acceptable to potential respondents, and completion rates for the SSMQ items were good (93%). Moreover, the Flesch-Kincaid Reading Ease index of the SSMQ is 80.4 (0-100 scale, scores of 100 equate to easiest text) indicating that the scale would be understood by most 11 year olds (Flesch, 1948). However, as part of on-going investigation of validity the response burden of the SSMQ, including attention to the mix of negatively and positively worded items, might be revisited.

9.5.3 Evaluation of interventions

Section 9.4.1 outlined that the SSMQ measures attitudes, behaviours or skills in relation to self-management competency. The findings of this research suggest that the SSMQ might be used to evaluate interventions designed to improve patients’ self-management skills. Self-management competency may be a key leverage point for understanding change in people's health behaviours and improving their well-being. The SSMQ could be included as an outcome measure for stroke specific SMIs, providing researchers, clinicians and other stakeholders with information about intervention effectiveness.

The SSMQ provides an estimate of individual self-management competency. The additional scales derived from the SSMQ may provide useful information for clinicians with regard to directing appropriate support at an individual level. For example, individuals with low capacity scale scores may benefit from tailored therapy to address impairment related barriers to self-management or from advice on how to monitor health. In addition to enabling more individualised communication for patients, the interaction confidence scale may provide health professionals with knowledge of how their own communication abilities are perceived. Scores from the strategies scale may facilitate interventions that aim to develop self-management skills or explore readiness for self-management. The professional guidance scale may enable the exploration of individual attitudes towards self-management and open discussions about the expectations of patients and health professionals. The SSMQ then represents a potentially useful patient-centred tool to enhance clinical dialogue and the individualising of self-management support. These assumptions are reliant upon further examination of the validity of the scale in clinical practice (chapter ten).

Information about the patient experience of self-management is vital as a contribution towards the provision of appropriate self-management support and services that meet patients' needs. Aspects relating to health service provision and community support, which may provide information regarding experience of self-management support and services, were intentionally omitted from the SSMQ. However, information from the SSMQ may facilitate understanding from stakeholders regarding the aspects of self-management relevant to patients. The SSMQ also provides information for researchers seeking to develop new stroke SMIs regarding the aspects of self-management which are most important to target for patients.

The SSMQ may help clinicians estimate the self-management competency of individuals following stroke. It may also help inform the extent to which self-management can be tolerated by an individual. The burden of self-management may outweigh the perceived benefits of self-management from the patients' perspective. As previously mentioned, not all individuals may wish to take responsibility for self-management. Within the drive for patient-centred care this is vital to consider so that self-management support can be appropriately targeted; the SSMQ provides a tool to enable this consideration.

This section has outlined ways in which the SSMQ can facilitate further understanding of stroke self-management by validly and reliably representing the complexity of stroke self-management from the perspectives of potential users. The next section provides reflection on the methodology adopted within this thesis.

9.6 Reflections on the mixed methods approach

Three key stages employing both qualitative and quantitative methodologies contributed to the development of the SSMQ. Within a mixed methods paradigm, neither quantitative nor qualitative methods are viewed as being superior (Teddlie & Tashakkori, 2008). In the context of developing this PROM, the qualitative and quantitative methods shared a symbiotic relationship, where each method relied upon the other to ensure development of a robust PROM. Nonetheless, potential tensions existed between the methodologies employed within this research.

The first tension existed in selecting which of the qualitative findings were most conducive to inclusion in a PROM that would measure stroke self-management. The qualitative inquiry insightfully represented the aspects of stroke self-management important to participants. The generation of item statements were sufficient to describe their experience, however were not adequate to measure experience without further exploration using quantitative methods. Pragmatic judgements were necessary regarding which aspects of the proposed conceptual model were potentially amenable to measurement in a PROM. In addition, for the purposes of future clinical and research application, consideration was given to which aspects of the model may be modified following an appropriate self-management intervention. Consequently, not all aspects of the focus group findings could be included in the preliminary item pool. Some aspects that participants discussed were felt to be problematic to encapsulate in a PROM, such as policy influences (section 4.7).

Participants were able to offer opinions on health service provision or policy and funding issues, but were considered unlikely to be able to directly influence these factors. While the data suggested that these factors do affect peoples' self- management, it is unlikely that patient-focused interventions would affect them. A judgement was made to exclude these aspects of the focus group data which did not directly reflect individual self-management capacity. Selection of elements of the data appropriate to measurement using a PROM prevented the creation of an overly complex outcome measure that may be burdensome to users.

Cognitive Interviewing (CI) is a robust qualitative technique used to enhance the wording and content of items on the PROM. However, in part quantitative judgements, including the frequency with which statements were judged as problematic, informed which items were revised or excluded. Decisions were made on the basis of the majority of participants' views, in line with accepted guidance (Willis, 2005). Questions exist with regard to how comprehensively such judgments represented the views of all people following stroke. Possibly, there is potential for salient elements of the data to be overlooked from 'minority' interpretations. The sampling strategy adopted for the CI research (section 5.6.4), which sought to reflect a broad range of experience since stroke, perhaps counterbalanced this tension. In the absence of a definitive analysis strategy for cognitive interviewing (Drennan, 2003) this approach appears to be accepted convention.

A further tension existed in relation to the reduction of the rich qualitative findings to those statements (items) which eventually fitted the Mokken measurement model. Items were selected based on their requirements to meet a Mokken scale, according to an arbitrary cut-off coefficient value (H=>0.3). There appears to be no clear explanation in the literature with regard to why this figure should be convention, and not for example >0.2, or >0.4. However, setting any cut-off value will invariably reduce some of the

content of the qualitative data. The compromise in developing a scale using MSA, or other measurement models appears to be a reduction of the qualitative content of the final PROM.

The retention of as much qualitative data as possible is essential to producing a PROM grounded in user perspectives, and one of the key reasons that MSA was selected as a method. The use of MSA enabled greater retention of the qualitative work enquiry compared to other methodologies such as Rasch or classical test theory (CTT) (Chapters seven and eight). Figure 9.5 compares the SSMQ with three stroke specific measures which employed 'excellent' qualitative methodology in their development as rated by COSMIN (Boger et al., 2013), but which adopted other measurement models. The SSMQ retained appreciably more of the qualitative work compared to the other measures. It is therefore feasible to argue that the possible tension of reducing qualitative findings was minimalised, as far as possible, by the use of MSA methodology.

Measure	No. of items generated from Qualitative work	No. of items following statistical modelling	% of Qual data items discarded
SSQoL	**78**	**49**	**38**
SSEQ	**29**	**13**	**55**
SA-SIP30	**90**	**30**	**67**
SIPSO	**97**	**10**	**89**
SSMQ	**44**	**28**	**36**

Figure 9.5. Comparison of qualitative work eliminated following statistical modelling in stroke specific PROMs. SSQol – Stroke Specific Quality of Life questionnaire (Williams et al., 1999); SSEQ- Stroke Self-Efficacy Questionnaire (Jones et. al, 2008); SA-SIP30 - Stroke Adapted Sickness Impact Profile 30 (van Straten et. al, 1997); SIPSO -Subjective Index of Physical and Social Outcome (Trigg & Wood, 2000)

Within a mixed methods paradigm the strengths of qualitative and quantitative methods are exploited while simultaneously countering their limitations (Johnson & Onwuegbuzie, 2004, Moffatt et al., 2006). For example, the identification and understanding of the concepts of importance through the qualitative work ensured that the concepts pertinent to potential users were targeted within the SSMQ. The resonant data from 28 people in the

South region of the UK was explored in a larger, more nationally representative sample, through the quantitative work. The conceptual model has been explored in further depth through the examination of construct validity. Hence, the methodological differences between the qualitative phases and the psychometric phase have generated more insights about the measurement of stroke self-management than would be possible for either method alone.

9.7 Limitations of the research

Although this research met its overriding aim to develop an appropriate PROM for stroke self-management, there were some unavoidable limitations. In addition to those already highlighted with regard to each study within this thesis, the following points are necessary to consider.

The first limitations relate to the study sample. The sample size for the psychometric evaluation phase (n=87) may be considered relatively small. To investigate validity and reliability of a measurement tool, some advocate sample sizes in excess of 200 (Frost et al., 2007), although others suggest that sizes of 100 are sufficient (Mokkink et al., 2010). To further investigate the extent to which the SSMQ meets the criteria of the Mokken model, larger sample sizes are required. Ethnic diversity was not well represented in the qualitative study phases. Moreover, the SSMQ and study information was only available in English, which may have further prevented or dissuaded those who do not have English as a first language from taking part. The SSMQ would therefore further benefit from extended evaluation and investigation of validity, including cross-cultural applications, in a larger, more diverse sample.

The sample for the psychometric evaluation may not be fully transferrable to wider stroke populations, since people who are less articulate or have communication impairments may have been discouraged from completing questionnaires. However, pleasingly this research incorporated the views of eleven participants with impaired communication during the two qualitative phases, and over 60 % of the psychometric evaluation sample experienced a moderate communication impairment (transformed scores <60, 0-100 scale), according to scores from the communication domain of the Stroke Impact Scale (mean score 77, SD 24).

The second limitation relates to the investigation of construct validity. This was challenging, since the theoretical underpinnings of stroke self-management are not well delineated. Therefore, selection of appropriate outcome measures with which to investigate theoretical relationships within the PROM focused on the most prevailing theory of self-efficacy, despite the limitations associated with the theory highlighted in this thesis (section 2.5.5). Self-efficacy was measured using the SSEQ. Questions have been raised with regard to the properties of stroke self-efficacy the SSEQ captures (sections 9.3.3, 9.4.7). Further exploration of construct validity with additional measures may further enhance the strength of the construct of self-management competency. For example measures appropriate to stroke that capture health literacy, decision-making and burden of self-management are likely to be of significance.

The final limitation relates to the representation in the SSMQ of the themes identified as important to self-management by potential users. It may be that as self-management support changes in response to policy direction and health and social care service provision, the self-management priorities for people following stroke may also change. As part of on-going validation of the SSMQ, such priorities may be necessary to revisit.

9.8 Summary

While there is still further work that can be done to improve the SSMQ, the findings from this thesis suggest the SSMQ scale is a promising PROM for measuring self-management competency following stroke. The final chapter offers conclusions and recommendations for the direction of further research.

10. Chapter Ten – Conclusions and recommendations

10.1 Introduction

This chapter draws conclusions before presenting recommendations for the direction of future research.

10.2 Conclusions

The primary aim of this research was to develop a new PROM for stroke self-management. A review of the literature identified that no valid nor reliable measure of stroke self-management existed and that existing measures used in the evaluation of stroke self-management were related or proxy indicators possessing questionable validity. The self-management aspects of importance to people affected by stroke had not been included in a reliable, valid outcome measure. This suggested a need for an appropriate outcome measure, grounded in the perspectives of potential users, for assessing self-management. Given the limitations identified in the literature with regard to the conceptualisation of stroke self-management, this work was the first to explore the patient perspective of stroke self-management and use this to develop a PROM that measures issues of importance to patients. A PROM to measure self-management attitudes and behaviours in people following stroke was developed and examined for preliminary validity and reliability. Development and evaluation methods were adopted that are accepted in the wider field of health measurement.

The research makes several critical contributions to the existing knowledge regarding stroke self-management. Firstly, the preliminary conceptual model of stroke self-management can be considered a starting point to understanding of stroke self-management from the patients' perspective. This has not previously been explored. Secondly, the model can be used to inform the development of future interventions that support self-management following stoke and which target areas relevant to patients. Finally, stroke self-management interventions can be evaluated with a reliable and valid instrument, from the perspectives of people following stroke. This represents the first instrument for the specific evaluation of stroke self-management which employed user perspectives.

10.2.1 Qualitative findings

The qualitative phases employed in this research generated rich insights into the perspectives of people following stroke regarding self-management. Principally, the following conclusions are offered:

- Self-management following stroke encompasses three themes, *Individual capacity*, *Support for self-management* and *Self-management environment*
- *Individual capacity* is affected by an individuals' decision-making, self-confidence, level of impairment, ability to seek resources, determination and communication skills
- Successful self-management following stroke appears to be facilitated by appropriate support and a prevailing culture that is supportive of self-management

The findings from the focus group study have implications for the discourse around self-management support and related policy initiatives. Participants accounts suggested that existing support for self-management following stroke is scarce and reliant largely upon the determination of the individual. Many individuals following stroke feel ill-prepared to successfully self-manage following discharge from formal services. Additionally, stroke-related impairment presents an additional barrier to successful self-management, which has not been fully considered by existing conceptualisations of self-management.

10.2.2 Psychometric findings

The SSMQ is valid to measure self-management competency in adults living in the community, three months or more following stroke. The SSMQ contains 28 indicators of self-management competency. Item scores can be summed, subject to the reassignment of scores in negatively worded items, to indicate the level of individual self-management competency. Four additional scales (Capacity, Interactional confidence, Professional guidance and Strategies) can be derived from the SSMQ if subject to higher thresholds. The SSMQ and the additional scales meet the criteria for a Mokken scale (section 8.5). Therefore, total scores from the SSMQ, or from each individual scale, can be summed to indicate the corresponding level of attribute represented by each scale. Individual scales can be selected for use, depending on the nature of research. For example, studies where patient communication confidence in healthcare professional interactions is considered a variable, may select the interaction confidence scale (table 9.1). This research presents several conclusions with regard to the Mokken properties of the SSMQ:

- The SSMQ meets the criteria for the Monotone Homogeneity model.
- The SSMQ is unidimensional, and measures the construct of stroke self-management competency.
- Summed scores from the SSMQ can be used to indicate an individuals' level of self-management competency following stroke.

The SSMQ and the strategies scale meet the criteria for an acceptable Mokken scale, the Interaction confidence and Professional guidance scales meet the criteria for moderately strong scales and the Capacity scale meets the criteria for a strong Mokken scale. In addition, the following conclusions are proposed with regard to the reliability and validity of the SSMQ:

- The SSMQ and the additional scales possess good internal consistency reliability (Mokken reliability coefficients 0.73-0.89).
- Test-retest reliability of the SSMQ is excellent (ICC 0.928, p=<0.005)
- The SSMQ possess excellent content validity.
- Good supporting evidence exists for the construct validity of self-management competency, measured by the SSMQ.

This research also makes important contributions to the wider health measurement field. The findings demonstrate that a mixed-methods approach, including Mokken Scale measurement theories were a suitable methodology to developing a PROM. The methodological quality adopted in the development of the SSMQ has been rated as 'good –excellent' by a standardised checklist (table 9.2). The methodological approaches set out in this thesis are thus appropriate for the on-going development of the SSMQ.

The preliminary results presented in this thesis indicate that the SSMQ has the prerequisite qualities for a valid and reliable psychometric instrument. The psychometric properties of the SSMQ therefore provide a confident means for researchers, clinicians and other stakeholders to:

- Comprehensively assess self-management competency following stroke
- Quantify the benefits of self-management interventions from the patients' perspective, thus far lacking in the area.

Subject to further work, as outlined next in this chapter, the SSMQ is a promising tool to inform practitioners, researchers and other stakeholders regarding the effectiveness of self-management interventions for stroke and determine whether stroke self-management interventions promote health and well-being.

10.3 Future research

10.3.1 Development of the SSMQ

Further psychometric evaluation in a larger, more diverse sample is warranted to enable continuing investigation of the scale structure and validity of the SSMQ. Verification of the findings from the preliminary psychometric evaluation of the SSMQ in additional samples is required to provide further evidence of construct validity.

Further exploration in larger samples is recommended to explore the strength and conceptual relationship of the Mokken scales derivable from the SSMQ. A high threshold was set for the development of the SSMQ (>0.35) (thresholds of >0.3 are conventionally adopted), since scales which form at higher thresholds permit fewer scaling errors. At higher thresholds (>0.4->0.5) the SSMQ items 'split' into four separate scales, which have conceptual relevance to stroke self-management (table 9.1). Although the SSMQ and the additional scales meet the criteria for a Mokken scale, the SSMQ and strategies scale possess Loveinger's *H* coefficient consistent with an 'acceptable' Mokken scale (table 8.6) (Meijer & Baneke, 2004). Pleasingly, the remaining scales possess *H* coefficients consistent with 'moderate- strong' Mokken scales (table 8.6). Given the limitations of the psychometric phase that have been identified (section 8.8), the potential strength of the SSMQ as a Mokken scale, subject to further investigation, is promising.

Further work investigating the construct validity of the SSMQ will involve the examination of correlations with other theoretically related concepts. Appropriate indicators of concepts thought to be related to stroke self-management, such as readiness to change and health literacy suggested by the emerging conceptual properties of the SSMQ (section 9.4.8, 9.4.10), may provide further elaboration regarding the construct of stroke self-management competency. Sections 7.7.2 and 9.4.6 highlighted the potential importance of quality of life to self-managment following stroke, but noted the limitations of the Stroke Impact Scale as a measure of quality of life. Additional investigation of construct validity using correlations with well-conceptualised and valid measures of stroke specific quality of life is warranted to confirm the preliminary positive relationship of self-management competency to quality of life.

The extent to which the additional unidimensional scales which can be derived from the SSMQ, relate to the construct of self-management competency has not been explored. On-going investigation of construct validity will enable examination of these additional scales and the extent to which they are theoretically related.

Currently the direction of causality within the SSMQ is uncertain. Section 7.3 provided an outline of the differences in causality in reflective and formative measurement models. The extent to which the item scores affect the level of self-management competency (formative model), or alternatively the extent to which self-management competency is reflected in the item scores (reflective model) is unclear. The distinction between the two models with regard to the SSMQ currently appears ambiguous. Further examination of the SSMQ may enable conceptualisation of the direction of causality that flows, either from the construct to the item scores, or vice versa. This would enable promotion of the SSMQ as a tool to explore causality in research applications.

Measurement using PROMs needs to become more commonplace in the self-management arena to realise the goal of enhancing and maintaining health and well-being of people following stroke. To examine the potential usefulness of the SSMQ in clinical and research practice, responsiveness, the validity of any change score, needs to be evaluated in future research. Determination of the ability of the SSMQ to accurately detect change is essential, if it is to be used to evaluate the effectiveness of stroke self-management interventions. Responsiveness can be considered an extension of validity, since a valid measure should implicitly reflect change in the underlying construct. To investigate responsiveness, or this aspect of validity, a longitudinal study is required whereby changes in the construct of self-management competency can be expected. One example would be measurement of self-management competency, using the SSMQ, pre and post a self-management intervention. Hypotheses with regard to the expected and magnitude of changes in the SSMQ, and other theoretically related variables are tested by examining the correlations between the variables.

Currently, how such scores from the SSMQ relate to clinically desirable outcomes is unknown. Further investigation is required to examine the meaning and relevance of normative, low, mid-range and high self-management competency scores to practice. There is therefore a need for longitudinal studies to enable interpretation of scores from the SSMQ and the clinical significance of any change scores.

The SSMQ may be useful for facilitating patient-professional communication and the setting of goals and priorities for self-management support. A pertinent question for health professionals working with people affected by stroke is the appropriateness of using the SSMQ for clinical decision-making regarding the type and provision of self-management support. Such decisions will be subject to on-going investigation of validity of the SSMQ including responsiveness and the testing of hypothesised changes. The extent that the additional scales, which can be derived from the SSMQ contribute to the overall construct, will enable scale scores to be weighted as appropriate. Work drawing on these findings would seek to develop a scoring algorithm for clinicians to enable easier interpretation of scores to assist clinical-decision making.

The SSMQ is considered valid for use with people who were represented in the development process. Although 11 people with communication impairments were included in the development phases of the SSMQ, one of the limitations of self-report outcome measures remains that many people following stroke with cognition and communication problems would be discouraged from completing a questionnaire. The development and investigation of a version of the SSMQ that could be completed by a nominated proxy, to enable those people whose impairment is sufficient to prevent self-report use of the SSMQ, is therefore advocated. Development of a proxy measure could reduce the probability of missing data within clinical trials and promote the inclusion of the opinions of people who may otherwise be omitted. The relationship between proxy and patient self-reports of the SSMQ, in terms of reliability and validity, needs to be assessed. An alternative may be validation of the SSMQ for carer- assisted completion.

Furthermore, communication impairment is a key concern to many people following stroke. There is a need for an appropriately developed version of the SSMQ to facilitate inclusion of people affected by this issue. Further investigation may focus upon the use and validity of ‘text-light’ versions of the SSMQ.

A final recommendation is the investigation of cross-cultural validity of the SSMQ, for example for people from differing ethnic backgrounds. The study samples contained relatively few participants from ethnic minority groups. Since the UK is a culturally diverse nation, there is a need for an appropriate PROM to assess self-management competency in people from ethnic minority groups. Furthermore, there is a need for the SSMQ to be validated for use in cross-national, multi-centred or multi-country studies. As patient perception of self-management competency may be affected by cultural background, content and construct validation studies are required to assess appropriateness for cross-cultural application.

10.3.2 Methodological research

This thesis demonstrated that the SSMQ meets the requirements of the Monotone Homogeneity Model (MMH) (section 8.5). The next stage of the Mokken scaling procedure is to investigate whether the items on the SSMQ fit the double monotonicity model (DMM) (Mokkan & Lewis 1982). The DMM is more restrictive in that it assumes, in addition to the assumptions of the MMH, that the order of the probabilities of endorsing items is the same for all respondents (van Schuur, 2011). This means that each respondent will have a probability of endorsing an item with a certain 'difficulty' in relation to self-management competency that is higher than, or equal to, the probability of responding to items with greater difficulty (i.e. people are more likely to endorse 'easier' items than more 'difficult' items). If the SSMQ meets the assumption of the DMM, all respondents, independent of their level of self-management competency, agree about the order of difficulty of the items.

If the SSMQ meets the requirements of the DMM, respondents can more confidently be ordered, in terms of their level of self-management competency, by the sum score. The items within the SSMQ could also be more confidently ordered in terms of their level of difficulty, or how likely a respondent is to endorse an item based on their level of self-management competency. This is known as Invariant Item Ordering (IIO). IIO will be crucial to further understanding the discriminative properties of the SSMQ.

The rationale for using a Mokken scaling approach in this research has been set out in the thesis. Other approaches to evaluate the psychometric performance of the PROM, such as factor analysis or Rasch modelling, could have been adopted, each approach being associated with a particular set of assumptions. Different approaches to the investigation of the SSMQ could be explored in conjunction with Mokken analysis to determine the extent to which the SSMQ meets the assumptions of different measurement models. If the SSMQ meets the assumptions of additional models, this provides robust evidence for the reliability and validity of the scale. For example, Rasch modelling could be used to further test the ordering of items within the SSMQ. Exploration of the SSMQ using differing measurement models may provide further validation evidence for the construct of self-management competency.

A further area to consider in the on-going development of the SSMQ is the notion of ceiling or floor effects. Outcome measures with ceiling and/or floor effects may be insensitive to changes at either end of the spectrum they measure (Fries et al., 2011). Failure to adequately address floor and ceiling effects therefore can result in suboptimal assessment and an inability to discriminate between individuals who are at the extremes of the construct. The SSMQ has a minimum score of 28 and a maximum of 168; the preliminary psychometric study reported in this thesis the lowest score was 67, the highest 157, suggesting in this sample an absence of ceiling or floor effects.

Finally, an area for further development is exploration of the response format. Following the cognitive interview study, participants expressed preference for the six-point scale currently employed in the SSMQ. However, it is imprudent to suppose this preference would be replicated in a different and larger sample. In light of the need to reduce response burden as far as possible for future respondents, and given the possibility for users of the scale to be affected by cognitive impairment, there is an argument to re-examine the response format. Investigation is warranted to explore the optimal number of points in the response format that offer an acceptable level of precision, in terms of providing discriminating information, but which represents the minimum burden for respondents.

10.3.3 Intervention development

The arguments presented in this thesis highlight the need for the emerging conceptual model of stroke self-management, from the perspectives of people with stroke, to be considered in the future design of interventions to promote self-management. Despite stroke self-management interventions focusing primarily on the individual, the views of people with stroke regarding self-management have not been elicited before. The conceptual model represents significant content to aid the design of interventions. Elements contributing to the themes of *individual capacity*, *support for self-*

management and *self-management environment* (4.5.1) represent the aspects of self-management that are important to people following stroke. The discussion chapter highlighted how these aspects have not, thus far, been adequately considered in stroke self-management interventions (9.3.1).

Since informal family care–givers have been identified as crucial to stroke self-management, further qualitative work is crucial to enable exploration of whether carers' experiences of supporting self-management are consistent or divergent with those affected by stroke. Such work would enable the development of instruments which may be beneficial to further understanding self-management following stroke, for example the measurement of carer capacity to support self-management. The design of interventions that provide people following stroke and their families with on-going self-management support represents an important area for future research.

Evidence with regard to how the professional priorities of stroke self-management differ to those of people following stroke, is emerging (Norris & Kilbride, 2013), but requires further exploration. Despite the recent changes to the identification and provision of NHS services through the advent of clinical commission groups (DoH, 2012), there remains a paucity of knowledge with regard to how commissioners, and other decision makers, prioritise stroke self-management. Although guidance recommends that all people following stroke should receive self-management training (Intercollegiate Stroke Working Party, 2012a), recent guidance for commissioners of stroke services makes no explicit mention of self-management, paradoxically suggesting that it remains a low priority (Intercollegiate Stroke Working Party, 2012b). Research to examine the priorities of differing stakeholders will facilitate the development of consensus building to foster equal partnerships in self-management, and identify the key features of importance to target in interventions. Developing interventions which provide people following stroke and their families with on-going self-management support plus provide professionals with the skills to facilitate support, represent important areas for future research.

The SSMQ can be included in research evaluating stroke self-management interventions subject to further validation. The SSMQ will potentially enable the investigation of how self-management competency is affected by other factors, both internally related to the individual (some examples include, impairment, duration since stroke, determination and psychosocial factors), and externally (e.g. their family members or informal care-givers and the nature and strength of relationships) and factors associated with the experience of care (e.g. satisfaction, perceived professional competence). Such studies may allow for the modelling of the factors that modify high or low self-management competency.

Finally, within the context of finite resources, there is a need for an appropriate PROM for use in economic evaluations of stroke self-management interventions. Subject to on-going validity evaluations, the SSMQ can be used to generate self-management scenarios, (for example, 'individuals sustain improved self-management competency six months post-intervention') for use in economic evaluations.

10.3.4 Qualitative research

The focus group methodology employed was appropriate for the purposes of providing content for a PROM and for presenting a preliminary conceptual model of self-management following stroke. Section 4.8 suggested that, given the potentially sensitive and complex nature of stroke self-management, the focus group findings might be augmented by additional individual interviews. Case studies of individual accounts of self-management following stroke might be employed to provide detailed understanding of the perceptions, opinions, beliefs, and attitudes towards self-management of people following stroke. Furthermore, the experiences of people who are in the acute phases following stroke with regard to self-management, who may be undergoing active rehabilitation have yet to be elicited. Questions remain regarding how self-management is promoted, or enacted in acute settings and within different models of stroke rehabilitation. Such questions may be facilitated using an ethnographic approach in addition to interviews with key stakeholders (e.g. patients, relatives, clinical staff and managers). Further qualitative work will also be crucial to understanding if there is a need for a version of the SSMQ appropriate to acute settings.

This final chapter has provided conclusions and recommendations for the future direction of research. The research has succeeded in developing the SSMQ; a novel, valuable, reliable and valid PROM, grounded in the perspectives of users, that seeks to inform researchers, clinicians and other stakeholders about the self-management competency of people following stroke.

Appendix A – Published systematic review paper

BOGER, E., DEMAIN, S. & LATTER, S. 2013. Self-management: A systematic review of outcome measures adopted in self-management interventions for Stroke. Disabil Rehabil, 35 (17), 1415-28.

Disability & Rehabilitation, 2013; 35(17): 1415–1428
© 2013 Informa UK, Ltd.
ISSN 0963-8288 print/ISSN 1464-5165 online
DOI: 10.3109/09638288.2012.737080

informa
healthcare

REVIEW ARTICLE

Self-management: a systematic review of outcome measures adopted in self-management interventions for stroke

Emma J. Boger, Sara Demain & Sue Latter

Faculty of Health Sciences, University of Southampton, Southampton, UK

Purpose: To systematically review the psychometric properties of outcome measures used in stroke self-management interventions (SMIs) to (1) inform researchers, clinicians and commissioners about the properties of the measures in use and (2) make recommendations for the future development of self-management measurement in stroke. *Methods*: Electronic databases, government websites, generic internet search engines and hand searches of reference lists. Abstracts were selected against inclusion criteria and retrieved for appraisal and systematically scored, using the COSMIN checklist. *Results*: Thirteen studies of stroke self-management originating from six countries were identified. Forty-three different measures (mean 5.08/study, SD 2.19) were adopted to evaluate self-SMIs. No studies measured self-management as a discreet concept. Six (46%) studies included untested measures. Eleven (85%) studies included at least one measure without reported reliability and validity in stroke populations. *Conclusions*: The use of outcome measures which are related, indirect or proxy indicators of self-management and that have questionable reliability and validity, contributes to an inability to sensitively evaluate the effectiveness of stroke self-SMIs. Further enquiry into how the concept of self-management in stroke operates, would help to clarify the nature and range of specific self-management activities to be targeted and aid the selection of existing appropriate measures or the development of new measures.

Keywords: Stroke, self-management, outcome measures, COSMIN, reliability, validity

Implications for Rehabilitation

- The evaluation of complex interventions such as self-management interventions is aided by clear outcome expectations and valid and reliable measurement.
- This review demonstrates a lack of outcome measures that specifically measure self-management of stroke. A minority of outcome measures that were used as proxy indicators for SM fulfill some of the criteria for quality outlined in the COSMIN checklist.
- Clinicians should select measures which appropriately reflect expected outcomes, giving due consideration to the theoretical underpinnings of the intervention. Further work is required to establish which measures currently in use, if any, accurately reflect stoke self-management.
- In the meantime, researchers should seek to develop psychometrically sound measures of stroke self-management to assist effective evaluation of such interventions in stroke.

Introduction

Stroke is a major cause of death and disability world-wide [1]. By 2020 stroke, together with coronary-artery disease, are predicted to be the leading causes of global lost healthy life-years [2]. Stroke represents an often devastating disruption to life [3], the majority of survivors experiencing some degree of impairment requiring additional care or support 1 year post-stroke [4].

Stroke is an acute event, but may result in significant long-term impact for the individual, such as social isolation, mood disturbance, communication difficulties and reduction in mobility and life roles [5,6]. Recovery following stroke is complex and multidimensional [3,7,8], encompassing biomedical, psychological and sociological elements [9–11]. Engagement in self-management practices by individuals with long-term conditions has been suggested as key to promoting recovery [12] and is cited as a means of empowerment and facilitator of improved health outcomes [13,14].

Self-management is a prominent issue in UK health policy [15–17] and has been identified as a key priority for health

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Correspondence: Emma J. Boger, Faculty of Health Sciences, University of Southampton, Building 45, Highfield, Southampton SO17 1BJ, UK.
E-mail: e.j.boger@soton.ac.uk
(Accepted October 2012)

by organisations independent of the UK government [18,19]. Self-management can be defined as the "active management by individuals of their treatment, symptoms, lifestyle, physical and psychological consequences inherent with living with a chronic condition" [20]. Self-management is an attractive initiative in managing the increasing burden on health and social care resources and reducing associated costs; the assumption being that effective self-management by an individual reduces their healthcare utilisation [21–23]. Healthcare professionals are well placed to promote the effective self-management of stroke [9,24,25].

Self-management interventions (SMIs) are designed to enable people to manage their health more effectively. Evaluation therefore must consider two key areas; firstly whether people develop the skills to manage their own health and secondly, if this consequently results in better health. SMIs operate over multiple dimensions and within different contexts. As such evaluation is complex, not least due to variation in delivery, culture of the sponsoring healthcare organisation and anticipated goals and outcomes [26,27].

The UK Medical Research Council advocates establishing the theoretical basis of an intervention as a first step in estimating its possible outcomes [27]. Currently, evidence suggests that the mediators of change and theoretical premises in SMIs are unclear [28–30]. This poses difficulty in the evaluation and operation of interventions for two key reasons. Firstly, doubt exists regarding the appropriate outcome(s) to monitor to assist evaluation of the intervention and aid determination of cost-effectiveness and clinical impact. Secondly, if the theoretical premises underpinning the intervention are uncertain, intervention fidelity is difficult to monitor and maintain. Questions then exist regarding *what* influences change and how this can be appropriately measured and SMIs evaluated.

SMIs may be evaluated by examining the effect on health outcomes that potentially change as a consequence of better self-management. Using patient reported outcome measures (PROMs) (e.g. functional status, symptom control, mood and health-related quality of life) is an important way of to ensuring evaluation considers outcomes important to patients. Preliminary investigation of self-management suggests that effective self-management corresponds with positive changes in health behaviour [20,28]. More recently there has been a focus upon measuring attitudes since these are thought to modify health behaviour [29–31]. Additionally, measurement may facilitate understanding of the relationships between attitudes and behaviour [32,33]. PROMs endeavor to capture information that is not directly observable and unmediated by healthcare professionals; consequently accurate measurement is contingent on the extent that the PROM is an accurate reflection of the variable in question [34]. Therefore, it is vital to evaluate whether the measures adopted in SMI studies provide legitimate information to evaluate self-management, both the process and obtaining of skills to better manage health and subsequent potential improvements in health.

Before using an outcome measure in research or clinical practice, it should be assessed and considered to possess adequate psychometric properties. Despite the recognised value of reliable and valid outcome measures and the increasing importance of identifying effective SMIs in stroke, we know of no review that has systematically evaluated international research for the quality of outcome measures used in stroke self-management. The purpose of this article is to systematically review outcome measures used in stroke self-SMIs, with the aim of informing researchers, healthcare professionals and policy-makers and making recommendations for the design of future outcome measures suitable for use in stroke self-management.

Methods

This review seeks to systematically examine the outcome measures adopted in stroke SMIs in terms of the methodology adopted in their development and subsequent strength of their psychometric properties for use with stroke populations. Differing criteria have been adopted to evaluate the psychometric properties of outcome measures [34,35]. Often the methodology adopted in reviews of outcome measures, use differing assessment standards, creating confusion for researchers and clinicians [36].

A recent international Delphi study of 57 experts (63% response rate) resulted in a tool to assess the methodological quality of studies on measurement properties, referred to as the COnsensus-based Standards for the selection of health status Measurement INstruments (COSMIN) checklist [37]. The COSMIN list has good inter-rater agreement and reliability [38] and represents the first critical appraisal tool that is based on the consensus of experts in psychometric theory. COSMIN has been used in other systematic reviews examining the measurement properties of outcome measures in a range of health conditions [39–41]. The Delphi study consisted of four rounds and sought to reach consensus on the terminology and definitions to be adopted with regard to psychometrics. This consensus offers both researchers and clinicians guidance with regard to some of the complexities of measurement properties. COSMIN also addresses modern psychometric theory methodology, such as Item Response Theory, as well as Classical Test Theory. Further information on COSMIN can be accessed via www.cosmin.nl

The properties examined in this systematic review are defined by COSMIN [42] and consist of nine items: Internal consistency; Reliability; Measurement error; Content Validity; Structural validity; Hypothesis testing; Cross-cultural validity; Criterion Validity and Responsiveness.

The purpose of the review is not to make a judgement on the quality of the SMI studies, or to synthesize findings to answer questions regarding the effectiveness of the interventions in the review. Instead the review focuses upon the value of the outcome measures adopted within stroke SMI studies according to their methodological quality, reliability and validity for stroke populations as outlined by COSMIN [42].This is vital since judgments about the results and impact attributed to SMIs are dependent on valid and reliable measurement.

In order to examine the properties of the outcome measures used in stroke SMIs, it was first necessary to identify which measures were used to evaluate the SMIs. Stroke self-management literature was systematically searched on the following electronic databases by one author (E.J.B.): Medline, PsychInfo, Science Direct, Web of Science and CINAHL. The following terms were used to identify existing stroke SMI studies:

- self-management
- self-care
- intervention*
- program* AND stroke
- rehabilitation
- outcome*
- education*

Search terms were chosen to represent concepts often linked to self-management (education, rehabilitation), however, studies were excluded unless they specifically stated their purpose was to enhance self-management. Article reference lists, website of UK government health department, generic internet search engines, and stroke-specific organisations were also searched. Dissertations and conference abstracts were excluded, however, searches for publications by dissertation or conference abstract authors were conducted. Selected articles described either (1) stroke-SMI development and/or implementation or (2) presented outcomes of stroke SMIs. Identified interventions and associated outcome measures were extracted and tabulated. Authors screened each abstract to eliminate articles that were not relevant, based on the following inclusion criteria:

(1) the study was published in English;
(2) the article addressed self-management specific to stroke; and
(3) was published between January 1990 and June 2011, to examine the current and most relevant evidence for practice.

One reviewer (E.J.B.) assessed all relevant full text articles obtained and a second reviewer (S.D.) assessed 10% to check reliability. Outcome measures included in studies were then identified and recorded (the version adopted by the SMI was selected for review). A second literature search then sought to find evidence for the measurement properties (as outlined by COSMIN) of those outcome measures identified. The following electronic databases were used: Medline, PsychInfo, Science Direct, Web of Science and CINAHL. The following search terms were used in conjunction with the title of the identified outcome measure:

- Valid*
- Reliable AND stroke
- Responsive*
- Sensitive

For example, for a search on the validity of the Geriatric Depression Scale, the search terms "Stroke" AND "Validity" AND "geriatric depression scale" was performed. Search terms were chosen to represent the properties of outcome measure quality as outlined by the COSMIN checklist. No time limitations were set as advocated by COSMIN, since older literature on measurement properties is still relevant. Searches were conducted to specifically find evidence of those properties with stroke populations. This is crucial since a measure's reliability and validity are on-going properties, dependent upon the context and population with which it is used [34,43]. For example, a measure developed to assess quality of life with a traumatic brain injury population will not necessarily possess acceptable content validity for stroke populations, since the issues faced by both populations may have similarities and differences.

Article reference lists from the originating studies and generic internet search engines were also searched. Discussion between the authors sought to clarify any issues regarding terminology and interpretation of the COSMIN checklist and preceded scoring of the identified measurement tools. Studies were excluded if they investigated postal or proxy reliability and validity unless this was how they were used in the SMIs. For outcome measures with more than one result per COSMIN criteria, the article stating the most robust results was reviewed. Where it was not clear that the study populations were specifically stroke, articles were excluded. One reviewer (E.J.B.) assessed all relevant full text articles using a standard data extraction form advocated by COSMIN. To ensure consistency of interpretation and scoring, a second reviewer (S.D.) independently scored a random 10% of the articles, with discussion between the two reviewers regarding the scores attained. Disagreement regarding interpretation of COSMIN terminology was resolved through consensus meetings. Agreement between scores was consistent.

Identified interventions and associated outcome measures were extracted and tabulated. Paper authors were contacted for further details where the study reported on early phases, or cited unpublished work. Outcome measures included in identified stroke SMIs were rated using the COSMIN checklist [37]. COSMIN consists of four steps and 12 items with different categories for scoring. Ten items are used to assess whether a study meets the standard for good methodological quality. Two items contain general requirements for articles in which Item Response Theory (IRT) methods and general requirements for the generalisability of the results are applied. Where a published paper does not report on a COSMIN item, the item is not scored. For example, if the responsiveness of the measure has yet to be determined, this item is not scored. Each item is rated as excellent (++++), good (+++), fair (++) or poor (+). Full details of the scoring system are available at www.cosmin.nl. The overall score per item is determined by the category with the lowest score.

Results

Search results

Eighty nine records for possible stroke SMIs were identified. Of those, 43 abstracts were identified as potentially relevant studies and were screened (46 duplicate records were excluded). From these, 19 articles were retrieved and reviewed for inclusion criteria and data extraction (studies were excluded because they did not meet the detailed criteria or if they reported on an earlier phase of the same study). Outcome measures within each study were then identified and grouped conceptually into different themes, using content analysis. A total of 13 studies met the eligibility criteria (Table I).

Profiles of stroke SMIs

All studies included participants over 18 years of age who had experienced a stroke. Three studies of stroke-SMIs originated from the UK; three from Australia; two from Canada; two from the USA; two from Sweden and one from Hong Kong. Nine studies reported upon interventions aimed at community-dwelling participants; two upon the acute recovery phase (<3 months post-stroke); one upon recovery for care home residents and one study did not report details of the setting. Four studies delivered individualised interventions; three utilised workbook interventions; four tested group SMIs designed specifically for stroke and two tested existing self-management programs adapted for stroke. Interventions were delivered primarily; by Allied Health Professionals (six); Nurse specialists (four); researcher (two) and lay experts (one).

Concepts measured

Four studies identified primary outcomes; *Health-related Quality of Life* [44]; *self-efficacy* [45]; *physical functioning* [46] and *feasibility* [47]. Although all studies focused upon stroke self-management, none measured stroke self-management as a discrete concept. Instead, a range of concepts were measured which presumably were selected to reflect the expected outcomes or process of self-management. Evaluation relies upon judgements concerning the process of the SMI and the outcome expected following participation in the SMI. The majority of measures used sought to measure health outcomes e.g. physical functioning, mood, quality of life (Figure 1). Attitudes were also measured which could be considered to more readily reflect the process of self-management e.g. healthcare utilization, medication compliance although the theoretical mechanisms linking self-management to these concepts was not elucidated by the authors.

Unreported measures

The term "unreported" is used in this review to describe an outcome measure that has not, at time of writing, been published in peer reviewed publicly available media. Unreported measures relate to those developed either by the study authors or through modifications made to existing measures without examination to ensure such assumptions or modifications were valid. Therefore, it is not possible to determine if unreported measures meet any of the COSMIN criteria. Six studies adopted unreported measures of concepts presumably (although the theoretical links were not explicitly stated by the authors), relating to the process of self-management, that had unknown reliability, validity, responsiveness.

Allen et al. [48] included an unreported measure to assess condition management and patient and carer satisfaction with the intervention. Two studies used 10 point visual analogue rating scales (VASs) to assess usefulness and intelligibility [49] and satisfaction [50] related to the intervention. Whilst VASs are brief and simple to administer and minimal in terms of respondent burden, without established reliability or validity relating to the underlying construct purported to be measured, they remain of limited value. Ljungberg and colleagues [51] designed four questions to assess life satisfaction pre- and post-participation in the SMI and Sit and colleagues [52] modified an existing stroke knowledge scale; details of the modifications were absent in the paper. Marsden and colleagues [44] used a measure of stroke knowledge test, but stated clearly they were not basing inferences from the data obtained using this measure.

Quality of outcome measures

Forty-three different outcome measures were adopted by studies in this review of measures used in stroke SMIs. Of these, 21 measures (49%) demonstrated some properties in stroke populations, according to the COSMIN checklist [42] (Table II). For the remaining measures no evidence could be found for any of the COSMIN properties in *stroke populations* (n = 16, 39%), or the measures were observer-based assessments (n = 5, 12%).

A summary of how the measures included in the stroke SMI studies scored according to COSMIN, when examined for their measurement properties with stroke populations,

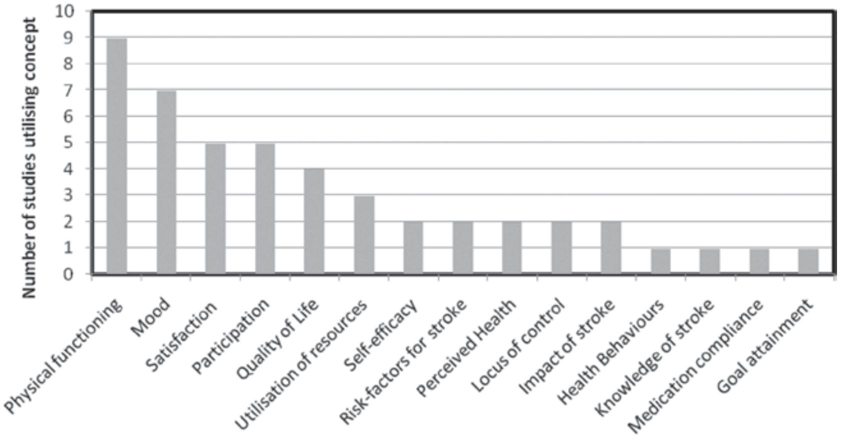


Figure 1. Summary of concepts used by studies (n = 13).

Table I. Summary of included studies.

Author (years) Country in which study conducted	Sample *Mean age in years	Theoretical premise of intervention	Intervention
Allen et al. (2004) [48] USA	Other details regarding sample absent ($n = 96$)	Chronic care model [88].	Strategies to enhance post-stroke care and recovery (STEPS CARE) Regular telephone and home follow-up by a specialist nurse (ANP) for 6 months post-discharge to implement and review care plan agreed by multidisciplinary stroke specialist team (core team-General practitioner, Geriatrician, ANP, Physiotherapy. Occupational therapy, speech and language therapy, dietician, social work and psychology, as required)
Cadilhac et al. (2011) [47] Australia	Stroke ≥3 months, >18 years old, English as a first language, living in community, no prior participation in Self-Management Programs. Recruited following discharge from acute or community care, or from stroke support clubs. Randomised to Stroke self-management program (SSMP) ($n = 48$) (56% female, *68) Or standard care (SC) ($n = 48$) (62% female, *71) Or Stanford Self-management program (generic) ($n = 47$) (60% female, *69)	None stated	Stroke-specific 8-week self-management programme (2.5 h per week). Health-care professional and trained lay co-led.
Frank et al. (2000) [49] Scotland	Patients with stroke ≤24 months, cognitive impairment and aphasia excluded Randomised to intervention ($n = 20$) (50% Male, *63.6) or usual care ($n = 19$) (53% Male, *64.3)	Locus of control [89] Self-efficacy [90]	5 week, workbook-based intervention and relaxation tape Delivered by researcher Weeks 1 and 2 involved face-to-face contact, weeks 3–5 phone contact Measures taken at baseline, 1-month post-completion of workbook (9 weeks for control group)
Guidetti & Yterrberg (2011) [91] Sweden	Confirmed stroke, ability to follow instructions, need for self-care intervention and referral to one of three rehabilitation clinics. People with dementia excluded. Randomised to intervention ($n = 19$, 42% male, *66) Or Control ($n = 21$, 43% male, *69)	None stated	Client-centred self-care intervention (CCSCI) Delivered by Occupational Therapists with additional training in intervention
Huijbregts et al. (2008) [92] Canada	Inclusion criteria-stroke ≥3 months, medically, physically and cognitively able to participate, able to dress and undress independently, active rehabilitation finished Sample given information on both programs and cost ($30 MOST, $20 Living With Stroke, LWS) then contacted research team with preference (able to request subsidy) MOST ($n = 18$) (77% male, *71) LWS ($n = 12$) (58% male, 63*)	Social Cognition Theory [59]	MOST (Moving on After Stroke) self-management program. 17 two hour, twice weekly, group based sessions (8 weeks) plus booster session 6 weeks post-completion. Discussion and exercise. Delivered by 3 health-care professionals, a physiotherapy assistant and 3 volunteers

(Continued)

Table I. (*Continued*).

Author (years) Country in which study conducted	Sample *Mean age in years	Theoretical premise of intervention	Intervention
Huijbregts et al. (2009) [93]	Inclusion criteria- stroke, living in community, finished active rehabilitation.	Self-efficacy [59]	Telehealth (video-conferencing) delivery of a stroke self-management program, Moving on after stroke (T-MOST).
Canada	Exclusion criteria—Cognitive impairment and severe aphasia		Co-led by two trained health-care professionals at two different remote sites
	Intervention received briefing to ensure they understood self-management model.		9 weekly sessions, each session—1 h of discussion, 1 h of exercise to focus upon coping skills problem solving & goal setting
	T-MOST ($n = 8$, 50% male, *61.8) Waiting list control ($n = 7$, 37.5% male, *65.6)		
Johnston et al. (2007) [50]	Sampling Frame- English speaking patients and their carers discharged following admission to 1 Hospital for acute stroke.	Cognitive behavioural Therapy theory	5 week, workbook-based intervention to enhance control cognitions, coping and recovery from disability
Scotland	Sample randomised to Intervention ($n = 103$, *68.96, 61% male)		Week 1, 2, and 5 involve face-to-face contact, week 3 and 4 phone contact
	Or		
	Usual care control ($n = 100$, *68.79, 61% male)		
Jones et al. (2009) [45]	Purposive sampling of medically stable participants discharged following first stroke (12 weeks-18 months post-stroke) ($n = 10$) (70% male, *61.5).	Social Cognition Theory [59] (self-efficacy as a predictor of behaviour change)	Four-week workbook-based intervention to enhance mastery, vicarious experience and feedback.
England	Participants with severe memory and language limitations, depression and emotionalism excluded.		Contact to introduce intervention and at each measurement point.
	Recruited from the registers of either an acute hospital stroke unit or community stroke team.		
Kendall et al. (2007) [76]	Sampling frame—in-patient acute urban hospitals. 1st stroke ≤6 months.	Self-efficacy [59]	6 week Stanford Chronic Disease Self Management Program (CDSMP) plus 1 stroke-specific session (7 weeks total).
Australia	Excluded if unable to communicate sufficiently in English, or previous strokes/dementia, or lack of support person to attend course, or if discharge was not to their own (or family members') home.		7 week intervention conducted between 3 and 6 month data collection points.
	Randomised to Intervention group ($n = 58$, 70.6% male, *66.58)		Both arms received usual care and rehabilitation
	Or Usual care control ($n = 42$, 62% male *66.36)		
Ljungberg et al. (2001) [51]	Confirmed stroke, estimated rehabilitation time of 4 weeks, able to transfer from bed to chair with 1 person and communicate by telephone.	Orem's Self-care theory [94]	Collaborative rehabilitation with patients and caregivers on neurology ward and then for 4 weeks in patients own home, followed by 5 2 h educational sessions 3 months post.
Sweden	Dementia and inability to swallow fluids, excluded.	Motor relearning programme [95]	Provided by Nurses, Nursing assistants, Occupational Therapists, Physiotherapist, Social welfare officer and Neurologist
	Non-randomised		
	Intervention group ($n = 32$, *72, 44% male)		
	Control group ($n = 9$, *72, 66% male)		

(Continued)

Table I. *(Continued).*

Author (years) Country in which study conducted	Sample *Mean age in years	Theoretical premise of intervention	Intervention
Marsden et al. (2010) [44]	Randomised, assessor blind, cross-over, controlled trial.	None stated	"Community Living After Stroke for Survivors and Carers" (CLASSiC) programme
Australia	Community-dwelling, chronic stroke survivors (n = 25) and carers (n = 17), discharged from therapy and English speaking.		(weekly, 2 1/2 h, seven-week group programme combining physical activity, education, self-management principles and "healthy options")
	Recruited via self or physician referral.		Delivered by physiotherapist, social worker, dietician, clinical nurse consultant, speech pathologist and OT
Sackley et al. (2006) [46]	Residents of 12 care homes in one area of England, with moderate-severe stroke related disability cluster randomised to Intervention (n = 63) (83% female, *88.6)	None stated	Occupational Therapy (OT) client-centred intervention to improve self-care among care home residents following stroke.
England	Or Usual care (n = 55) (82% female, *86.3		Delivered by one OT over a period of 3 months in each home.
Sit et al. (2007) [52]	Participants were >18 years, had a minor stroke, living in the community, independent in ADLs and cognitively able.	None stated	Community-based Stroke prevention programme. 8 weekly 2 h sessions delivered by 3 community nurses.
Hong Kong	Exclusion—hemorrhagic stroke, pending surgery, non-Cantonese speaking		Aimed to improve self-management for secondary Stroke prevention
	Non-randomised to intervention (n = 77) or usual care (n = 70)		

is shown in Figure 2. Not every measure scored in each category on COSMIN. Of 21 measures, none scored in every category of COSMIN. Where more than one paper addressed a COSMIN category, the article which stated the most robust results was scored. The majority of measures scored either "fair" or "poor" in each category. The only category to obtain an "excellent" rating was content validity. Three measures scored "excellent" in this category as follows; the Stroke Adapted Sickness Impact Profile (SA-SIP30); the Stroke Self-Efficacy Questionnaire (SSEQ) and the Subjective Index of Physical and Social Outcome (SIPSO).

Discussion

This review examined the methodological quality of studies determining the psychometric properties of outcome measures, used in stroke SMIs according to criteria outlined by the COSMIN checklist. Consistent with measurement theory we explored the validity and reliability of these measures for use in people with stroke, not their general use in broader populations. To our knowledge, this is the first review to systematically appraise and summarize the evidence on the quality of outcome measures used in stroke SMIs. Since no study adopted a measure of stroke self-management attitudes or behaviours, the theoretical concepts utilised by studies in the review to measure self-management will first be addressed.

Theoretical concepts of self-management

The range and number of different published outcome measures adopted by studies in this review [42] may suggest a current lack of consensus regarding the appropriate measures to assist evaluation of stroke SMIs. Alternatively, the use of heterogeneous measures may be reflective of recognition by researchers that self-management embraces a range of differing concepts. The current absence of consensus may in part reflect an underlying lack of consensus about the concept and operation of self-management in stroke. In addition, most SMIs have been developed for generic audiences, which may partly explain the lack of specific measures developed for stroke self-management. An argument exists for research to investigate the conceptual properties of stroke self-management, to examine which measurement concepts currently being used, if any, are appropriate.

A range of concepts were measured. Some captured health outcomes, such as physical functioning, which the study authors anticipated may be affected by the SMI; others attempted to capture behaviours, such as resource utilisation or attitudes, such as changes in self-efficacy thought to be associated with self-management processes (Figure 2). However, how the concepts measured align with the patient experience of stroke self-management remain unknown. Physical function (PF) was most often used as an indicator of effective self-management. Of the 21 measures possessing at least one property of the COSMIN checklist in this review, 11 related to PF (52%). This is potentially suggestive of an assumption that effective self-management results in improved PF, or that improved PF is a desired outcome. PF appears to remain a dominant concept within stroke rehabilitation, despite increasing evidence of the role of psychosocial factors in recovery [53–55]. For example, the measurement

Table II. COSMIN property scores in stroke populations of outcome measures used in stroke self-management interventions.

Measure (author, year) (additional measurement property studies in stroke populations)	Study(s) adopting Measure	No studies with stroke populations identified	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Hypothesis testing	Cross-wcultural validity	Criterion validity	Responsiveness
Activities-specific Balance Confidence scale (ABC) [96,97]	[92]	4	++	+++	+	+	++	++	–	+++	–
Assessment of Quality of Life (AQoL) [98,99]	[47]	2	+++	–	–	+	+++	+	–	++	–
(The) Barthel Index [100–104]	[48,50]	37	–	++	–	+	–	–	–	+	+
(The) Barthel Index (Raschmodelled) [105]	[91]	1	+++	–	+++	–	+++	+++	–	–	+++
(The) Barthel ADL Index [106,107]	[46]	12	+	–	+	+	–	++	–	–	+
Berg Balance Scale (BBS) [108–113]	[93]	16	++	+	+	+	–	++	–	++	+
Center for Epidemiologic Studies Depression Scale (CES-D) [114–117]	[48]	5	+++	++	–	+	–	+++	–	++	–
Quality from the patients perspective Questionnaire (CFPP) [118]	[51]	0	–	–	–	+	+	–	–	–	–
Chedoke McMaster Stroke Assessment (CMSA) [119,120]	[92,93]	2	–	++	–	++	–	++	–	–	++
Frenchay Activities Index (FAI) [101,121–127]	[91]	18	+	++	–	+	+++	–	–	++	++
Functional Independence Measure (FIM) [124,128–133]	[51,91,92]	31	++	+++	+	+	++	++	–	++	++
Geriatric depression Scale Short-from (GDS) [115,134,135]	[92,93]	3	++	++	–	+	+	+	–	++	++
Hospital Anxiety and Depression Scale (HADs) [136–138]	[45,49]	2	+	–	+	+	+	+++	–	–	–
Modified Rivermead Mobility Index (MRMI) [101,103,139–141]	[45,46]	13	+	+	–	+	–	+	–	–	+
Recovery Locus of control (RLoC) [142,143]	[45,50]	2	+	+++	–	+	++	++	–	–	++
Reintegration to Normal Living Index (RNL) [144–146]	[92,93]	9	++	+	–	+++	++	+	–	+	–
Rivermead Activities of Daily Living (RADL) [147–150]	[45]	5	–	+	–	–	–	+	–	+	–
Stoke Adapted Sickness Impact Profile (SA–SIP30) [151] [124,152,153]	[92]	5	++	–	–	++++	++	+++	–	–	+++
Stroke Impact Scale version 2.0 (SIS) [154–156]	[91]	8	+	+	+	_	+	++	_	++	++
Subjective Index of Physical and Social Outcome (SIPSO) [157–159]	[45]	5	+++	+++	–	++++	+++	+	–	++	+
Stroke Self-efficacy Questionnaire (SSEQ) [160]	[45]	1	+	–	–	++++	+	+	–	+++	–
Stroke-Specific Quality of Life (SSQoL) [161,162]	[48,76]	3	+	–	–	++	+	++	–	++	++

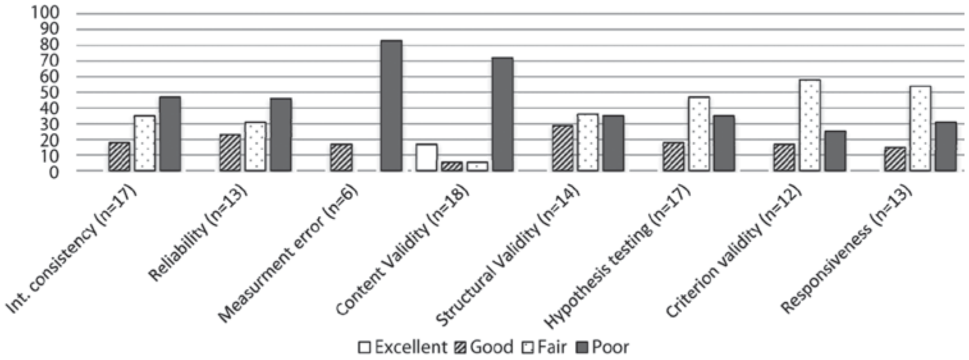


Figure 2. Percentage of studies with COSMIN quality rating ($n = 21$).

of PF is of limited value in studies that target speech disorder, depression, social participation or cognitive function [56], debatably all factors in effective stroke self-management. Questions regarding the differing priorities of rehabilitation between healthcare professionals and those affected by stroke have been raised before [57]. Effective self-management extends beyond the ability to perform certain tasks, encompassing decision making and choices regarding health and behaviour [14]. The role of PF in stroke self-management requires further clarification before it can be adopted as a robust indicator of effective self-management.

Six studies collected information on health behaviours and healthcare resource utilisation. However, issues of potential greater importance to patients, for example a change in confidence or increased awareness about how to manage fatigue, may not be captured in measures focused upon management of health behaviours or resource utilisation. There is a need to further conceptualise stroke self-management to ensure that self-management strategies pertinent to people recovering from stroke are captured in existing or new outcome measures.

Eight of the studies in this review explicitly cited a theoretical basis to the intervention adopted in the study (Table I). The most commonly cited theory was psychologist Albert Bandura's Social Cognition Theory and the concept of Self-Efficacy ($n = 4$ studies). Self-efficacy can be described as the belief in one's capabilities to organise and execute the course of action required, to produce given achievements[58,59]. The validity of outcome measures is contingent upon using them for the purpose they were intended for.

Of the four studies citing self-efficacy as a theoretical premise underpinning the intervention, only two studies utilised outcome measures to reflect change attributed to this theoretical concept in the interventions [45,60]. The measure adopted by Kendall and colleagues, The Self-Efficacy Scale [61], has unknown psychometric properties in stroke populations, and therefore requires further examination to establish its validity for use in these populations. The Stroke Self-efficacy Scale adopted by Jones and Colleagues [45] was developed with stroke populations. However questions exist concerning the relevance of the sample. Data were generated with people a relatively short time frame since stroke (mean duration was 4.2 weeks and 16 days post-stroke for two of the development phases). This may not represent sufficient time since stroke for individuals to adequately appraise their situation, especially as some were still in hospital.

The relationship to self-management of any of the measures in this review was not explicitly stated by any of the study authors. This suggests that further clarification is required to determine the extent to which they reflect the process or outcomes of self-management. Whilst potential theoretical bases for the self-management of long-term conditions, such as self-efficacy, have gained increasing acknowledgement, the role in stroke self-management remains unclear. This is in part due to a lack of robust outcome measures and, in addition, a lack of clarity regarding the purported theoretical foundations of stroke self-management [20,62].

Quality of outcome measures

A paucity of measures scored "excellent" or "good" for quality according to the criteria outlined by COSMIN (Figure 2). The COSMIN checklist does not advocate summarising the quality criteria into one overall quality score, as is often the case in other systematic reviews. An overall quality score would assume that all measurement properties are of equal importance. Since measurement properties are in part affected by the context in which they have been determined, this approach would be misleading. For example in our review, no measure was scored on *cross-cultural validity*, since the purpose of the review was not to assess how well a measure had been developed and validated in other languages or cultures.

Outcome measures should be developed with involvement of the target population to identify what is meaningful from their perspective and hence enhance content validity and clinical utility [61,63,64]. Three measures scored "excellent" in the content validity category (SSEQ; SIPSO; SA-SIP30). Measures that did not include involvement of users in the development of the measure scored "poor" on the COSMIN checklist, regardless of other aspects of the content validity process which may have been classed "fair" "good" or "excellent". This is partly as a result of the COSMINs scoring method in which the lowest score in any given category counts, but is also indicative of the importance of involving potential users in measurement development. Arguably, measures developed without user-involvement have questionable meaning and other types of validity, since without steps in the design to capture the experience of the population to be measured, the context of the measure remains largely that of the measure developers [65,66]. More recently techniques such as cognitive interviewing [67], have been used by researchers [68,69] to ensure the content validity of new measures is optimal.

Difficulty exists in determining which measures used in the stroke SMIs in this review reflect self-management with validity since most measures did not score well according to the COSMIN criteria.

Several studies included unreported measures, designed specifically by the authors for the purpose of the SMI study [44,48–52]. With the exception of Marsden et al., studies utilised data from unreported measures as indicators of outcomes. An absence of psychometric data confounds the ability to draw reliable inferences from studies adopting those measures. In addition, a lack of information regarding the development or modification of unreported measures limits the ability to make judgments upon the validity and appropriateness of the measure. A further possible limitation on interpreting data from unreported measures may be a tendency for reporting positive results [70]. Without establishment of reliability and validity the outcome measure is little more than a collection of items that have meaning to the developer alone [33,71]. Given the lack of consensus of how stroke self-management operates in the literature, and a lack of consensus upon the theoretical premises grounding stroke SMIs, the assumptions underpinning unreported measures remain speculative. Researchers and clinicians should exercise caution in considering findings from studies adopting unreported measures.

Of note is that 11 studies (85%) within this review adopted at least one outcome measure without reported validity and reliability with stroke populations. The reporting of minimal, or non-significant, observed changes following stroke SMIs in those studies including measures without established psychometric properties in stroke populations may be indicative of a lack of relevance and meaningfulness of those measures to stroke populations. Problems exist in using unreported measures when determining whether change occurred as a result of an ineffective intervention or due to imprecise measures.

Measures developed with intended user populations, facilitate the gaining of information about health, illness and the effects of health-care interventions from the perspective of the patient [72,73]. As well as enhancing content validity, this can also facilitate shared decision making with healthcare professionals. This is of particular relevance to those involved in promoting self-management and increasing patient autonomy, such as nurses and therapists.

Responsiveness is a necessary property of instruments intended for measuring clinically meaningful change, such as in stroke self-SMIs [74,75]. Involvement of users in the development of outcome measures promotes the responsiveness of measures. Arguments exist that responsiveness should focus upon detecting change that is valued by the person rather than the clinician or researcher [72]. This is of particular relevance to self-management.

Change attributed to an intervention is an important aspect of evaluating clinical effectiveness. In this review, 13 measures included information on responsiveness in stroke populations. None of these measures scored “excellent” for this property, and only 15% scored “good”. Aside from inadequate sample sizes, a common finding was that studies often were not clear about what happened to study populations between testing. Additionally, authors often did not specify how missing items from respondents were handled. The result is that judgments regarding responsiveness data were difficult to substantiate. This also affected how well measures scored for reliability and other areas of validity. There is, therefore, a need for future measurement developers to specify these overlooked aspects of development more clearly in subsequent reporting.

The majority of SMI study populations within this review experienced stroke <24 months previously, with a number of studies using populations experiencing stroke no more than 6 months previously [48,50,51,76]. This may be a result of sampling to reduce the influence of additional factors upon study outcomes, such as the development of unhelpful coping behaviours, the likelihood of which might increase over time, and out of an assumption that more change may be observed in those early in their recovery. However, in reality the number of people living in the community and recovering from stroke extends beyond those who are 6–24 months post-stroke. As engagement in self-management activities varies during recovery, particularly following adjustment to stroke as a long-term condition, there is a future need to consider outcome measures sensitive to change(s) at different durations since stroke.

The role of PROMs, developed using rigorous investigation with the population to be measured extends beyond validating patient experience [77]. PROMs may improve the quality of interactions between health professionals and patients, assess levels of health and need, and provide evidence of outcomes of services, for the purposes of audit, quality assurance and comparative performance evaluation [78,79]. This is of particular importance when trying to capture the essence of self-management, since the experience of clients is vital in determining what is valued from their perspective. There is a need to focus upon the development of measures of self-management developed with people recovering from stroke.

Limitations of review

This review focused upon the current state of measurement in stroke self-management. Consensus between reviewers was used to determine eligibility and inclusion of SMI articles. Whilst we were in agreement, there is the possibility for selection bias. Our aim was not to make judgments on the quality of the SMIs identified. However, the use of a standardized critical appraisal tool may assist the selection of articles for future reviews. Where interpretation of the COSMIN criteria differed, agreement was reached by discussion and consensus. Additional reviewers may have further validated this process however the criteria within COSMIN are explicitly stated and differences were quickly resolved. Data extraction was facilitated by a standardized tool advocated by COSMIN, with extraction and scoring checked in a random 10% of articles. We acknowledge that checking of 10% may be viewed as a limitation of this review, however, assert that a systematic process using a standard data extraction tool was followed throughout.

That COSMIN operates a "lowest score counts" scoring system may account for the lack of measures scoring well in the measurement property criteria. Some studies used otherwise appropriate methodologies, but were rated as "poor" due to inadequate sample sizes for analyses. For example, for a measure to be rated as "good" for reliability, measurement error, criterion validity and responsiveness, a sample size of $n = 50–99$ is required. To score "good" for internal consistency and structural validity, the sample size required increased to five times the number of items within a measure (and ≥100 OR 5–7* #items but <100). Therefore, if those studies were repeated with larger sample sizes, their ratings according to COSMIN could change dramatically. The tendency for measures to score poorly may be reflective of a floor effect of the COSMIN checklist. COSMIN was developed following consensus of experts in health measurement, therefore if its stringent criteria is to be adopted this is indicative of a need to debate the rigorous methods for measure development required. It is fair to comment that some of the measures in this review were developed before the focus upon involving potential users in measure development. It may be that the measures examined in this review require further development and investigation to establish adequate measurement properties for use with stroke populations.

Our review points to existing limitations in the evaluation of stroke self-SMIs. Our recommendations for clinicians and researchers seeking to evaluate such interventions would be firstly to clarify the theoretical premise of the intervention in question, as advocated elsewhere [27,80,81]. Without this step, it is difficult to identify the mechanisms by which the intervention may influence outcomes, and thus difficult to select an outcome measure which appropriately captures the potential outcome. Potential outcome measures should be selected on the basis that they appropriately reflect and capture the expected outcome change.

This review highlights that the reported theoretical drivers within stroke SMIs are unclear, not least because they are often not explicitly stated by researchers. The heterogeneity of the outcome measures utilised by SMIs in this review may indicate a difficulty in determining the expected outcomes of stroke SMIs. A systematic review demonstrated that interventions with specific aims, such as reduced systolic blood pressure in Hypertension or glycosylated haemoglobin levels in Diabetes, produced greater effect sizes than those without defined outcomes [82]. Further work is therefore warranted to conceptualise stroke self-management and examine the theoretical premises supporting such interventions, and expected outcomes so that appropriate outcome measures which accurately reflect the concept can be selected and/or developed. Until such clarification, researchers and clinicians should, where possible, select outcome measures with reliability and validity data in the population to be tested in the intervention. The selection of outcome measures developed with involvement from the target population is also advocated. This ensures that what is meaningful to the patient is more likely to be captured appropriately, thus enhancing content validity [83].

In the meantime, researchers must support clinicians by conducting further work to examine the concept and theoretical premises of self-management and developing appropriate measures if required.

Conclusion

This is the first systematic review of international research on outcome measures used and selected in stroke self-SMI studies. We have identified important limitations in the measures used to evaluate the effectiveness of stroke self-SMIs, which has significant implications for the inferences we are currently able to draw about the evidence base. None of the measures used in studies of stroke SMIs, purported to specifically measure self-management as a discrete concept. This is indicative of the difficulty in conceptualisation and operation of this concept, a view expressed elsewhere [13,84]. Further work is required to determine how the measures identified in this review, align with the concept of self-management. The range of outcomes adopted, the lack of observed changes in outcomes following stroke SMIs and the lack of consensus surrounding which outcome measures to utilise, indicates that the causal mechanisms of stroke SMIs remain imprecise. Stroke SMIs have raced ahead of the evidence to support their theoretical basis, operation and effective evaluation [85,86]. Work to conceptualise stroke self-management is required to help identify which outcomes are most appropriate for evaluating interventions, to further inform the theoretical basis for SMIs [87] and to assist the development of interventions. There is a need for studies to explore the theoretical underpinnings of SMI in stroke and for the development of robust outcome measures to enable evaluation of stroke SMIs.

Declaration of Interest: This work was supported by a University of Southampton research studentship. The authors report no declarations of interest.

References

1. Feigin VL, Lawes CM, Bennett DA, Barker-Collo SL, Parag V. Worldwide stroke incidence and early case fatality reported in 56 population-based studies: a systematic review. Lancet Neurol 2009;8:355–369.
2. NAO, National Audit Office. Reducing brain damage: faster access to better stroke care. London: Stationary Office, 2005
3. Ellis-Hill C, Payne S, Ward C. Using stroke to explore the life thread model: an alternative approach to understanding rehabilitation following an acquired disability. Disabil Rehabil 2008;30:150–159.
4. Horgan NF, O'Regan M, Cunningham CJ, Finn AM. Recovery after stroke: a 1-year profile. Disabil Rehabil 2009;31:831–839.
5. McKevitt C, Redfern J, Mold F, Wolfe C. Qualitative studies of stroke: a systematic review. Stroke 2004;35:1499–1505.
6. Young J, Murray J, Forster A. Review of longer-term problems after disabling stroke. Rev Clin Gerontol 2003;13:55–65.
7. Ch'ng A, French D, McLean N. Coping with the challenges of recovery from stroke: long term perspectives of stroke support group members. J Health Psychol 2008;13:1136–1146.
8. Mukherjee D, Levin RL, Heller W. The cognitive, emotional, and social sequelae of stroke: psychological and ethical concerns in post-stroke adaptation. Top Stroke Rehabil 2006;13:26–35.
9. Dowswell G, Lawler J, Dowswell T, Young J, Forster A, Hearn J. Investigating recovery from stroke: a qualitative study. J Clin Nurs 2000;9:507–515.
10. Ellis-Hill CS, Payne S, Ward C. Self-body split: issues of identity in physical recovery following a stroke. Disabil Rehabil 2000;22:725–733.
11. Vanhook P. The domains of stroke recovery: a synopsis of the literature. J Neurosci Nurs 2009;41:6–17.

12. de Ridder D, Geenen R, Kuijer R, van Middendorp H. Psychological adjustment to chronic disease. Lancet 2008;372:246–255.
13. Battersby M, Lawn S, Pols R. Conceptualisation of self-management. In: Kralik D, Paterson B, Coates V (eds). Translating chronic illness research into practice. Chichester: John Wiley and Sons Ltd., 2010.
14. Kralik D, Koch T, Price K, Howard N. Chronic illness self-management: taking action to create order. J Clin Nurs 2004;13:259–267.
15. DoH. White paper 'Equity and excellence: liberating the NHS'. Health, Do. (ed). London: Department of Health, 2010.
16. DoH. White paper. healthy lives, healthy people: our strategy for public health in England. London: The Stationary Office, 2010.
17. DoH. The health and social care bill. Health, Do. (ed). London: Department of Health, 2011.
18. Imison C. et al. Transforming our health care system: Top ten priorities for commissioners. London: The King's Fund, 2011.
19. Foundation H. Evidence: helping people help themselves. A review of the evidence considering whether it is worthwhile to support self-management. London: The Health Foundation, 2011.
20. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. Ann Behav Med 2003;26:1–7.
21. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. JAMA 2002;288:2469–2475.
22. Glasgow RE, Funnell MM, Bonomi AE, Davis C, Beckham V, Wagner EH. Self-management aspects of the improving chronic illness care breakthrough series: implementation with diabetes and heart failure teams. Ann Behav Med 2002;24:80–87.
23. Rogers A, Bury M, Kennedy A. Rationality, rhetoric, and religiosity in health care: the case of England's Expert Patients Programme. Int J Health Serv 2009;39:725–747.
24. Robinson-Smith G. Self-efficacy and quality of life after stroke. J Neuroscience Nursing 2002;34:91–98.
25. Western H. Altered living: coping, hope and quality of life after stroke. Br J Nurs 2007;16:1266–1270.
26. Du S, Yuan C. Evaluation of patient self-management outcomes in health care: a systematic review. Int Nurs Rev 2010;57:159–167.
27. MRC. A framework for development and evaluation of RCTs for complex interventions to improve health. London: Medical Research Council, 2000.
28. Lorig KR, Sobel DS, Stewart AL, Brown BW Jr, Bandura A, Ritter P, Gonzalez VM, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. Med Care 1999;37:5–14.
29. Ajzen I, Fishbein M. The influence of attitude on behaviour. In: The Handbook of Attidues. Albarracín D, Johnson B, Zanna M (eds.). New Jersey: Lawrence Erlbaum Ltd., 2005, 173–221.
30. Hardeman W et al. Application of the theory of planned behaviour in behaviour change interventions: a systematic review. Psychology & Health 2002;17:123–158.
31. Hirsche RC, Williams B, Jones A, Manns P. Chronic disease self-management for individuals with stroke, multiple sclerosis and spinal cord injury. Disabil Rehabil 2011;33:1136–1146.
32. Fazio RH, Olson MA. Implicit measures in social cognition. research: their meaning and use. Annu Rev Psychol 2003;54:297–327.
33. Oppenheim A. Questionnaire design, interviewing and attitude measurement. 2nd edn., 2000, London: Pinter.
34. Lohr KN, Aaronson NK, Alonso J, Burnam MA, Patrick DL, Perrin EB, Roberts JS. Evaluating quality-of-life and health status instruments: development of scientific review criteria. Clin Ther 1996;18:979–992.
35. Valderas JM, Ferrer M, Mendívil J, Garin O, Rajmil L, Herdman M, Alonso J; Scientific Committee on "Patient-Reported Outcomes" of the IRYSS Network. Development of EMPRO: a tool for the standardized assessment of patient-reported outcome measures. Value Health 2008;11:700–708.
36. Mokkink LB, Terwee CB, Stratford PW, Alonso J, Patrick DL, Riphagen I, Knol DL, et al. Evaluation of the methodological quality of systematic reviews of health status measurement instruments. Qual Life Res 2009;18:313–333.
37. Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Knol DL, Bouter LM, de Vet HC. The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. Qual Life Res 2010;19:539–549.
38. Mokkink LB, Terwee CB, Gibbons E, Stratford PW, Alonso J, Patrick DL, Knol DL, et al. Inter-rater agreement and reliability of the COSMIN (COnsensus-based Standards for the selection of health status Measurement Instruments) checklist. BMC Med Res Methodol 2010;10:82.
39. Elbers RG, Rietberg MB, van Wegen EE, Verhoef J, Kramer SF, Terwee CB, Kwakkel G. Self-report fatigue questionnaires in multiple sclerosis, Parkinson's disease and stroke: a systematic review of measurement properties. Qual Life Res 2012;21:925–944.
40. Schellingerhout JM, Heymans MW, Verhagen AP, de Vet HC, Koes BW, Terwee CB. Measurement properties of translated versions of neck-specific questionnaires: a systematic review. BMC Med Res Methodol 2011;11:87.
41. Smit S, Lamping D, Maclaine G. Measuring health-related quality of life in diabetic peripheral neuropathy: A systematic review. Diabetes Res Clin Practice, 2012;96:261–270.
42. Terwee CB, Mokkink LB, Knol DL, Ostelo RW, Bouter LM, de Vet HC. Rating the methodological quality in systematic reviews of studies on measurement properties: a scoring system for the COSMIN checklist. Qual Life Res 2012;21:651–657.
43. DeVellis R. Scale development. Theory and applications. Bickman L, Rog D (eds.). Applied social research methods series. Vol. 26. 2nd edn., 2003, Sage Publications: Thousand Oaks.
44. Marsden D, Quinn R, Pond N, Golledge R, Neilson C, White J, McElduff P, Pollack M. A multidisciplinary group programme in rural settings for community-dwelling chronic stroke survivors and their carers: a pilot randomized controlled trial. Clin Rehabil 2010;24:328–341.
45. Jones F, Mandy A, Partridge C. Changing self-efficacy in individuals following a first time stroke: preliminary study of a novel self-management intervention. Clin Rehabil 2009;23:522–533.
46. Sackley C, Wade DT, Mant D, Atkinson JC, Yudkin P, Cardoso K, Levin S, et al. Cluster randomized pilot controlled trial of an occupational therapy intervention for residents with stroke in UK care homes. Stroke 2006;37:2336–2341.
47. Cadilhac DA, Hoffmann S, Kilkenny M, Lindley R, Lalor E, Osborne RH, Batterbsy M. A phase II multicentered, single-blind, randomized, controlled trial of the stroke self-management program. Stroke 2011;42:1673–1679.
48. Allen K, et al. Improving stroke outcomes: implementation of a postdischarge care management model. J Clin Outcomes Manag 2004;11:707–714.
49. Frank G, et al. Perceived control and recovery from functional limitations: Preliminary evaluation of a workbook-based intervention for discharged stroke patients. British J Health Psychol 2000;5:413–420.
50. Johnston M, Bonetti D, Joice S, Pollard B, Morrison V, Francis JJ, Macwalter R. Recovery from disability after stroke as a target for a behavioural intervention: results of a randomized controlled trial. Disabil Rehabil 2007;29:1117–1127.
51. Ljungberg C, Hanson E, Lovgren M. A home rehabilitation program for stroke patients: a pilot study. Scandinavian J Caring Sciences 2001;15:44–53.
52. Sit JW, Yip VY, Ko SK, Gun AP, Lee JS. A quasi-experimental study on a community-based stroke prevention programme for clients with minor stroke. J Clin Nurs 2007;16:272–281.
53. Chau JP, Thompson DR, Twinn S, Chang AM, Woo J. Determinants of participation restriction among community dwelling stroke survivors: a path analysis. BMC Neurol 2009;9:49.
54. Saxena SK, Ng TP, Koh G, Yong D, Fong NP. Is improvement in impaired cognition and depressive symptoms in post-stroke patients associated with recovery in activities of daily living? Acta Neurol Scand 2007;115:339–346.
55. Whyte EM, Mulsant BH, Vanderbilt J, Dodge HH, Ganguli M. Depression after stroke: a prospective epidemiological study. J Am Geriatr Soc 2004;52:774–778.
56. Quinn T, Langhorne P, Stott D. Barthel index for stroke trials: development, properties, and application. Stroke 2011;42:1146–1151.
57. Cott C, Wiles R, Devitt R. Continuity, transition and participation: preparing clients for life in the community post-stroke. Disabil Rehabil 2007;29:1566–1574.
58. Jerant A, von Friederichs-Fitzwater M, Moore M. Patients' percieved barriers to active self-management of chronic conditions. Patient Education and Counseling 2005;57:300–307.
59. Bandura A. The nature and structure of self-efficacy. In: Bandura A (ed). Self-efficacy: The exercise of control, New York: WH Freeman and Company, 1997, pp 3–5.
60. Kennedy A, Reeves D, Bower P, Lee V, Middleton E, Richardson G, Gardner C, et al. The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with long-term conditions: a pragmatic randomised controlled trial. J Epidemiol Community Health 2007;61:254–261.

61. Bowling A. What things are important in people's lives? A survey of the public's judgements to inform scales of health related quality of life. Soc Sci Med 1995;41:1447–1462.
62. Bury M, Newbould J, Taylor D. A rapid review of the current state of knowledge regarding lay-led self-management of chronic illness. London: National Institute for Health and Clinical Excellence, 2005.
63. Vogt D, King D, King L. Focus groups in psychological assessment: enhancing content validity by consulting members of the target population. Psychol Assess, 2004;16:231–243.
64. McDowell I, Newell C. Measuring health: a guide to rating scales and questionnaires. 2nd edn, New York: Oxford University Press, 1996.
65. Switzer GE, Wisniewski SR, Belle SH, Dew MA, Schultz R. Selecting, developing, and evaluating research instruments. Soc Psychiatry Psychiatr Epidemiol 1999;34:399–409.
66. 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 2007;60:34–42.
67. Willis GL, Moore C, Armstrong SM. Breaking away from dopamine deficiency: an essential new direction for Parkinson's disease. Rev Neurosci 2012;23:403–428.
68. Beck SL, Towsley GL, Berry PH, Brant JM, Smith EM. Measuring the quality of care related to pain management: a multiple-method approach to instrument development. Nurs Res 2010;59:85–92.
69. Rosal M, Carbone E, Goins K. Use of cognitive interviewing to adapt measurement instruments for low-literate Hispanics. Diabetes Educ 2003;29:1006–1017.
70. Marshall M, Lockwood A, Bradley C, Adams C, Joy C, Fenton M. Unpublished rating scales: a major source of bias in randomised controlled trials of treatments for schizophrenia. Br J Psychiatry 2000;176:249–252.
71. Raykov T, Marcoulides GA. Introduction to psychometric theory. Taylor & Francis, New York, USA, 2010.
72. Fitzpatrick R, et al. Evaluating patient-based outcome measures for use in clinical trials. Health Technol Assess 1998;2:1–74.
73. O'Donnell AB, Lutfey KE, Marceau LD, McKinlay JB. Using focus groups to improve the validity of cross-national survey research: a study of physician decision making. Qual Health Res 2007;17:971–981.
74. Beaton DE, Bombardier C, Katz JN, Wright JG. A taxonomy for responsiveness. J Clin Epidemiol 2001;54:1204–1217.
75. Liang MH, Lew RA, Stucki G, Fortin PR, Daltroy L. Measuring clinically important changes with patient-oriented questionnaires. Med Care 2002;40:II45–II51.
76. Kendall E, Catalano T, Kuipers P, Posner N, Buys N, Charker J. Recovery following stroke: the role of self-management education. Soc Sci Med 2007;64:735–746.
77. Greenhalgh J, Long AF, Flynn R. The use of patient reported outcome measures in routine clinical practice: lack of impact or lack of theory? Soc Sci Med 2005;60:833–843.
78. Darzi A. Our NHS our future: High quality care for all in NHS next stage review final report. London: Department of Health, 2008.
79. Jenkinson C, Gibbons E, Fitzpatrick R. A structured review of patient-reported outcome measures in relation to stroke. Oxford: Department of Public Health University of Oxford: P.-r.O.M. Group, 2009.
80. Campbell M, Fitzpatrick R, Haines A, Kinmonth AL, Sandercock P, Spiegelhalter D, Tyrer P. Framework for design and evaluation of complex interventions to improve health. BMJ 2000;321:694–696.
81. Redfern J, McKevitt C, Wolfe CD. Development of complex interventions in stroke care: a systematic review. Stroke 2006;37:2410–2419.
82. Warsi A, Wang PS, LaValley MP, Avorn J, Solomon DH. Self-management education programs in chronic disease: a systematic review and methodological critique of the literature. Arch Intern Med 2004;164:1641–1649.
83. Lasch KE, Marquis P, Vigneux M, Abetz L, Arnould B, Bayliss M, Crawford B, Rosa K. PRO development: rigorous qualitative research as the crucial foundation. Qual Life Res 2010;19:1087–1096.
84. Blakeman T, Bower P, Reeves D, Chew-Graham C. Bringing self-management into clinical view: a qualitative study of long-term condition management in primary care consultations. Chronic Illn 2010;6:136–150.
85. Bury M, Pink D. The HSJ debate. Self-management of chronic disease doesn't work. Health Serv J 2005;115:18–9, 1.
86. Jones F, Riazi A. Self-efficacy and self-management after stroke: a systematic review. Disabil Rehabil 2011;33:797–810.
87. Cano SJ, Hobart JC. The problem with health measurement. Patient Prefer Adherence 2011;5:279–290.
88. Wagner E. Care of older people with chronic illness. In: Calkins E et al. (eds). New ways to care for older people: building systems based on evidence. Springer: New York, 1999.
89. Rotter JB. Generalized expectancies for internal versus external control of reinforcement. Psychol Monogr 1966;80:1–28.
90. Schwarzer R. Self-efficacy in the adoption and maintenance of health behaviours: Theoretical approaches and a new model. In: Schwarzer R (ed). Self-efficacy: Thought control of action. Hemisphere: London, 1992, pp. 217–243.
91. Guidetti S, Ytterberg C. A randomised controlled trial of a client-centred self-care intervention after stroke: a longitudinal pilot study. Disabil Rehabil 2011;33:494–503.
92. Huijbregts MP, Myers AM, Streiner D, Teasell R. Implementation, process, and preliminary outcome evaluation of two community programs for persons with stroke and their care partners. Top Stroke Rehabil 2008;15:503–520.
93. Huijbregts M, McEwen S, Taylor D. Exploring the Feasibility and Efficacy of a Telehealth Stroke Self-Management Programme: A Pilot Study. Physiotherapy Canada 2009;61:210–220.
94. Orem D. Nursing: concepts of practice. St Louis, USA: Mosby, 1995.
95. Carr J, Sheppard R. A motor relearning programme for stroke. 2nd edn. London: Heinemann, 1987.
96. Powell LE, Myers AM. The Activities-specific Balance Confidence (ABC) Scale. J Gerontol A Biol Sci Med Sci 1995;50A:M28–M34.
97. Botner E, Miller W, Eng J. Measurement properties of the Activities-specific Balance Confidence Scale among individuals with stroke. Disabil Rehabil 2005;27:156–163.
98. Hawthorne G, Richardson J, Osborne R. The Assessment of Quality of Life (AQoL) instrument: a psychometric measure of health-related quality of life. Qual Life Res 1999;8:209–224.
99. Sturm JW, Osborne RH, Dewey HM, Donnan GA, Macdonell RA, Thrift AG. Brief comprehensive quality of life assessment after stroke: the assessment of quality of life instrument in the north East melbourne stroke incidence study (NEMESIS). Stroke 2002;33:2888–2894.
100. Mahoney FI, Barthel DW. Functional evaluation: The Barthel Index. Md State Med J 1965;14:61–65.
101. Green J, Forster A, Young J. A test-retest reliability study of the Barthel Index, the Rivermead Mobility Index, the Nottingham Extended Activities of Daily Living Scale and the Frenchay Activities Index in stroke patients. Disabil Rehabil 2001;23:670–676.
102. Jacob-Lloyd H. et al., Effective measurement of the functional progress of stroke clients. British J Occupat Ther 2005;68:253–259.
103. Hsueh IP, Wang CH, Sheu CF, Hsieh CL. Comparison of psychometric properties of three mobility measures for patients with stroke. Stroke 2003;34:1741–1745.
104. Duncan PW, Samsa GP, Weinberger M, Goldstein LB, Bonito A, Witter DM, Enarson C, Matchar D. Health status of individuals with mild stroke. Stroke 1997;28:740–745.
105. van Hartingsveld F, Lucas C, Kwakkel G, Lindeboom R. Improved interpretation of stroke trial results using empirical Barthel item weights. Stroke 2006;37:162–166.
106. Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. Int Disabil Stud 1988;10:61–63.
107. Hsueh I, Lee M, Hsieh C. Psychometric characteristics of the Barthel activities of daily living index in stroke patients. J Formos Med Assoc 2001;100:526–532.
108. Berg K. Measuring balance in the elderly: preliminary development of an instrument. Physiotherapy Canada 1989;41:304–311.
109. Berg KO, Wood-Dauphinee SL, Williams JI, Maki B. Measuring balance in the elderly: validation of an instrument. Can J Public Health 1992;83 Suppl 2:S7–11.
110. Berg K, Wood-Dauphinee S, Williams JI. The Balance Scale: reliability assessment with elderly residents and patients with an acute stroke. Scand J Rehabil Med 1995;27:27–36.
111. English CK, Hillier SL, Stiller K, Warden-Flood A. The sensitivity of three commonly used outcome measures to detect change amongst patients receiving inpatient rehabilitation following stroke. Clin Rehabil 2006;20:52–55.
112. Stevenson TJ. Detecting change in patients with stroke using the Berg Balance Scale. Aust J Physiother 2001;47:29–38.
113. Salbach NM, Mayo NE, Hanley JA, Richards CL, Wood-Dauphinee S. Psychometric evaluation of the original and Canadian French version of the activities-specific balance confidence scale among people with stroke. Arch Phys Med Rehabil 2006;87:1597–1604.
114. Radloff L. The CES-D Scale: a self-report depression scale for research in the general population. Appl Psychol Meas 1977;1:385–401.

115. Agrell B, Dehlin O. Comparison of six depression rating scales in geriatric stroke patients. Stroke 1989;20:1190–1194.
116. Shinar D, Gross CR, Price TR, Banko M, Bolduc PL, Robinson RG. Screening for depression in stroke patients: the reliability and validity of the Center for Epidemiologic Studies Depression Scale. Stroke 1986;17:241–245.
117. Kim JH, Park EY. Rasch analysis of the Center for Epidemiologic Studies Depression scale used for the assessment of community-residing patients with stroke. Disabil Rehabil 2011;33:2075–2083.
118. Wilde B. Quality of care: models, instruments and empirical results among elderly. In: Department of Geriatric Medicine. University of Gothernburg, Gothenburg, Sweden, 1994.
119. Gowland C, Stratford P, Ward M, Moreland J, Torresin W, Van Hullenaar S, Sanford J, et al. Measuring physical impairment and disability with the Chedoke-McMaster Stroke Assessment. Stroke 1993;24:58–63.
120. Huijbregts M, Gowland C, Gruber R. Measuring clinically important change with the Activity Inventory of the Chedoke-McMaster Stroke Assessment. Physiotherapy Canada, 2000;52:295–304.
121. Holbrook M, Skilbeck CE. An activities index for use with stroke patients. Age Ageing 1983;12:166–170.
122. Wade D, Legh-Smith J, Langton Hewer R. Social activities after stroke: measurement and natural history using the Frenchay Activities Index. Int Rehabil Med 1985;7:176–181.
123. Piercy M, Carter J, Mant J, Wade DT. Inter-rater reliability of the Frenchay activities index in patients with stroke and their careers. Clin Rehabil 2000;14:433–440.
124. Schepers VP, Ketelaar M, Visser-Meily JM, Dekker J, Lindeman E. Responsiveness of functional health status measures frequently used in stroke research. Disabil Rehabil 2006;28:1035–1040.
125. Pedersen PM, Jørgensen HS, Nakayama H, Raaschou HO, Olsen TS. Comprehensive assessment of activities of daily living in stroke. The Copenhagen Stroke Study. Arch Phys Med Rehabil 1997;78:161–165.
126. Schuling J, de Haan R, Limburg M, Groenier KH. The Frenchay Activities Index. Assessment of functional status in stroke patients. Stroke 1993;24:1173–1177.
127. Hsueh IP, Lin JH, Jeng JS, Hsieh CL. Comparison of the psychometric characteristics of the functional independence measure, 5 item Barthel index, and 10 item Barthel index in patients with stroke. J Neurol Neurosurg Psychiatr 2002;73:188–190.
128. Dodds TA, Martin DP, Stolov WC, Deyo RA. A validation of the functional independence measurement and its performance among rehabilitation inpatients. Arch Phys Med Rehabil 1993;74:531–536.
129. Cavanagh SJ, Hogan K, Gordon V, Fairfax J. Stroke-specific FIM models in an urban population. J Neurosci Nurs 2000;32:17–21.
130. Daving Y, Andrén E, Nordholm L, Grimby G. Reliability of an interview approach to the Functional Independence Measure. Clin Rehabil 2001;15:301–310.
131. Segal ME, Schall RR. Determining functional/health status and its relation to disability in stroke survivors. Stroke 1994;25:2391–2397.
132. Brock K, Goldie P, Greenwood K. Evaluating the effectiveness of stroke rehabilitation: choosing a discriminative measure. Arch Phys Med Rehabil 2002;83:92–99.
133. Ottenbacher KJ, Hsu Y, Granger CV, Fiedler RC. The reliability of the functional independence measure: a quantitative review. Arch Phys Med Rehabil 1996;77:1226–1232.
134. Sheikh, J, Yesavage J. Geriatric Depression Scale (GDS): Recent evidence and development of a shorter version. Clin Gerontologist, 1986;5:165–172.
135. Wancata J, Alexandrowicz R, Marquart B, Weiss M, Friedrich F. The criterion validity of the Geriatric Depression Scale: a systematic review. Acta Psychiatr Scand 2006;114:398–410.
136. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand 1983;67:361–370.
137. Aben I, Verhey F, Lousberg R, Lodder J, Honig A. Validity of the beck depression inventory, hospital anxiety and depression scale, SCL-90, and hamilton depression rating scale as screening instruments for depression in stroke patients. Psychosomatics 2002;43:386–393.
138. Johnston M, Pollard B, Hennessey P. Construct validation of the hospital anxiety and depression scale with clinical populations. J Psychosom Res 2000;48:579–584.
139. Lennon S, Johnson L. The modified rivermead mobility index: validity and reliability. Disabil Rehabil 2000;22:833–839.
140. Johnson, L, Selfe J. Measurement of mobility following stroke: a comparison of the Modified Rivermead Mobility Index and the Motor Assessment Scale. Physiotherapy, 2004;90:132–138.
141. Hsieh C, Hsueh I, Mao M. Validity and responsiveness of the Rivermead Mobility Index in stroke patients. Scand J Rehab Med, 2000;32:140–142.
142. Partridge C, Johnston M. Perceived control of recovery from physical disability: measurement and prediction. Br J Clin Psychol 1989;28 (Pt 1):53–59.
143. Johnston M et al., Perceived control, coping and recovery from disability following stroke. Psychology & Health, 1999;14:181–192.
144. Wood-Dauphinee SL, Opzoomer MA, Williams JI, Marchand B, Spitzer WO. Assessment of global function: The Reintegration to Normal Living Index. Arch Phys Med Rehabil 1988;69:583–590.
145. Daneski K, Coshall C, Tilling K, Wolfe CD. Reliability and validity of a postal version of the Reintegration to Normal Living Index, modified for use with stroke patients. Clin Rehabil 2003;17:835–839.
146. Stark SL, Edwards DF, Hollingsworth H, Gray DB. Validation of the Reintegration to Normal Living Index in a population of community-dwelling people with mobility limitations. Arch Phys Med Rehabil 2005;86:344–345.
147. Whiting, S, Lincoln N. An ADL assessment for stroke patients. British J Occup Ther 1980;43:44–46.
148. Lincoln NB, Edmans JA. A re-validation of the Rivermead ADL scale for elderly patients with stroke. Age Ageing 1990;19:19–24.
149. Nouri, F, Lincoln N. An extended activities of daily living scale for stroke patients. Clin Rehabil 1987;1:301–305.
150. Rossier P, Wade DT, Murphy M. An initial investigation of the reliability of the Rivermead Extended ADL index in patients presenting with neurological impairment. J Rehabil Med 2001;33:61–70.
151. van Straten A, de Haan RJ, Limburg M, Schuling J, Bossuyt PM, van den Bos GA. A stroke-adapted 30-item version of the Sickness Impact Profile to assess quality of life (SA-SIP30). Stroke 1997;28:2155–2161.
152. van de Port I et al., Monitoring the functional health status of stroke patients: the value of the Stroke-Adapted Sickness Impact Profile-30. Disability & Rehabilitation, 2004;26:635–640.
153. van Straten A, de Haan RJ, Limburg M, van den Bos GA. Clinical meaning of the Stroke-Adapted Sickness Impact Profile-30 and the Sickness Impact Profile-136. Stroke 2000;31:2610–2615.
154. Duncan PW, Wallace D, Lai SM, Johnson D, Embretson S, Laster LJ. The stroke impact scale version 2.0. Evaluation of reliability, validity, and sensitivity to change. Stroke 1999;30:2131–2140.
155. Duncan PW, Bode RK, Min Lai S, Perera S; Glycine Antagonist in Neuroprotection Americans Investigators. Rasch analysis of a new stroke-specific outcome scale: the Stroke Impact Scale. Arch Phys Med Rehabil 2003;84:950–963.
156. Lin KC, Fu T, Wu CY, Wang YH, Liu JS, Hsieh CJ, Lin SF. Minimal detectable change and clinically important difference of the Stroke Impact Scale in stroke patients. Neurorehabil Neural Repair 2010;24:486–492.
157. Trigg R, Wood VA. The Subjective Index of Physical and Social Outcome (SIPSO): a new measure for use with stroke patients. Clin Rehabil 2000;14:288–299.
158. Trigg R, Wood VA. The validation of the Subjective Index of Physical and Social Outcome (SIPSO). Clin Rehabil 2003;17:283–289.
159. Kersten P, Ashburn A, George S, Low J. The subjective index for physical and social outcome (SIPSO) in stroke: investigation of its subscale structure. BMC Neurol 2010;10:26.
160. Jones F, Partridge C, Reid F. The Stroke Self-Efficacy Questionnaire: measuring individual confidence in functional performance after stroke. J Clin Nurs 2008;17:244–252.
161. Williams LS, Weinberger M, Harris LE, Clark DO, Biller J. Development of a stroke-specific quality of life scale. Stroke 1999;30:1362–1369.
162. Williams LS, Weinberger M, Harris LE, Biller J. Measuring quality of life in a way that is meaningful to stroke patients. Neurology 1999;53:1839–1843.

Appendix One- Summary of stroke self-management intervention studies

Author (year) country	Study design and Sample	Theoretical premise of intervention	Intervention	Outcome measures	Results
(Allen et al., 2004) USA	Preliminary reporting of data from a pilot RCT. STEPS CARE v. Usual care Details regarding sample absent (n=96)	Chronic care model (Wagner, 1999).	Strategies to enhance post-stroke care and recovery (STEPS CARE) Regular telephone and home follow-up by a specialist nurse (ANP) for 6 months post-discharge to ensure implementation and review of care plan agreed by multi-disciplinary stroke specialist team (core team- General practitioner, Geriatrician, ANP, Physiotherapy. Occupational therapy, speech and language therapy, dietician, social work and psychology, as required)	Primary outcome measure not identified Barthel Index (BI) (Mahoney and Barthel, 1965) Questionnaire to determine stroke management (author designed) Stroke specific QoL (SSQol) (Williams et al., 1999) Patient, carer and physician satisfaction (author designed) Health-care utilisation and post-stroke complications Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977) Biomedical measures of risk (Blood pressure, cholesterol, incontinence, falls, anti-coagulation, blood sugars)	Satisfaction levels higher in intervention group (statistics unreported) 'Well-being' significantly better in STEPS CARE group (p=<0.001) Self-management and risk management significantly better in STEPS CARE group (p=<0.001 Health care utilisation, physical functioning and QoL significantly better in STEPS CARE group (p=<0.03)
(Cadilhac et al., 2011 Australia	Single blinded, Phase II multi-centred RCT. Stroke ≥3 months, >18 years old, English as a first language, living in community, no prior participation in Self-Management Programs. Recruited following discharge from acute or community care, or from stroke support clubs.	None stated	Stroke specific 8 week (2.5 hours per week), Health care professional and trained lay co-led self-management programme. Randomised to Stroke self-management program (SSMP) (n=48) Or standard care (SC) (n=48) Or Stanford Self-management program (generic), (n=47)	Primary - Feasibility – levels of participation, Assessment of QoL (AQoL) (Hawthorne et al., 1999) Engagement with life (domain of Health education impact Q, HeiQ) (Osborne et al., 2007) Irritability, depression and anxiety scale (IDA) (Snaith et al., 1978) Self-report diary of health utilisation.	SSMP (n=48) (56% female, mean age 68 yrs) SC (n=48) (62% female, mean age 71 yrs) Generic (n=47) (60% female, mean age 69 yrs) Self-report diary omitted due to 'inconsistent and missing data'. Primary outcomes – 52% completed SSMP (>90% who started), 38% GSMP (69% who started)

					(*p*=0.18). Secondary outcomes- increases seen across all domains, though not statistically significant.

Author (year) country	Study design and Sample	Theoretical premise of intervention	Intervention	Outcome measures	Results
(Catalano et al., 2003) Australia	Concurrent Qualitative analysis of a single-blinded longitudinal study (Kendall et al., 2007) Structured interviews (n=37) with participants who had attended at least 4 sessions of a stroke self-management programme.	Self-efficacy (Bandura, 1997)	See Kendall et al., 2007	Transcribed data to four open questions: What concerns you most about your present situation? Do you think your condition has changed? What do you think might change in the upcoming months? Who provides you with the most help at the present time?	Six themes: Importance of social contact and comparison Increased knowledge and awareness of stroke Motivation to pursue goals and activities Sense of achievement Maintenance of gains Paradoxical nature of social support
(Damush et al, 2011) USA	Randomised trial. Intervention v. placebo group. Sample enrolled within 1 month of an ischaemic stroke (n=63) Cognitive impairment excluded life expectancy of > 12 months 62 participants were male (98%)	Self-efficacy (Bandura, 1997)	6 week modified CDSMP intervention focused on improving self-efficacy, delivered by 20 minute biweekly telephone calls. Placebo group also received phone calls	Primary outcome measure stroke specific QoL (SSQoL) (Williams et al., 1999) Self-Management Behavior Frequency (Lorig et al., 1996) (exercise, social & recreation activities & cognitive/mental relaxation) Self-efficacy scale (Lorig et al., 1996) Patient Health Questionnaire (PHQ-9) (Kroenke et al., 2001) Data collected pre, 3/12s and 6/12s post intervention	SSQoL (Family roles) significantly improved (p=<0.06) & SSQoL Social roles improved (p=<0.05) at 3-months. No difference at 6 months No significant difference in self-management behaviour frequency. Self-efficacy re communicating with physician improved in the intervention group at 6 months (p=<0.02). No other changes to self-efficacy highlighted in paper.
(Frank et al., 2000) Scotland	Single blinded RCT – Intervention v. waiting list control. Patients with stroke ≤24	Locus of control (Rotter,1966) Self-efficacy	5 week, workbook-based intervention and relaxation tape. Delivered by researcher Weeks 1 &2 involved face to face	Primary outcome measure not identified Functional limitations Profile (FLP) (Patrick and Peach, 1989, Pollard and	Intervention (n=20) (50% Male, mean age 63.6) Control (n=19) (53% Male Mean age 64.3)

	months, cognitive impairment and aphasia excluded. Randomised to intervention (n=20) Or usual care (n=19)	(Schwarzer, 1992)	contact, weeks 3- 5 phone contact. Measures taken at baseline, 1 month post completion of workbook. (9 weeks for control group)	Johnston, 1997) Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983) Perceived health competence scale (PHCS) (Smith et al., 1995) Intervention group rated usefulness and intelligibility (0-10 VAS) (author designed)	Workbook rated as 7.8/10 for usefulness and 9.2/10 for ease of understanding. No statistically significant difference in FLP, HAD scores. Perceived control positively associated with functional independence (*p*=<0.01).
Author (year) country	Study design and Sample	Theoretical premise of intervention	Intervention	Outcome measures	Results
(Guidetti & Ytterberg, 2011) Sweden	Pilot single-blinded RCT Confirmed stroke, ability to follow instructions, need for self-care intervention and referral to one of three rehabilitation clinics. Dementia excluded. Randomised to intervention (n=19) Or Control (n=21)	None stated	Client-centred self-care intervention (CCSCI) Delivered by Occupational Therapists with additional training in intervention	Primary outcome measure not identified Feasibility Barthel Index (BI) (Mahoney and Barthel, 1965) Functional Independence Measure (FIM) (Grimby et al., 1996 Frenchay Activities Index (FAI) (Wade et al., 1985) Stroke Impact Scale (SIS) (Duncan et al., 1999 Occupational Gaps questionnaire (OGQ) (Eriksson et al., 2006) Life satisfaction (LiSat-11) (Fugl-Meyer et al., 2002) Care-giver burden Scale (CBS) (Elmstahl et al., 1996) Self-reported use of home help & health care	Intervention (n=19, 42% male, mean age 66 yrs) Control (n=21, 43% male, mean age 69yrs) No statistically significant differences in BI, FIM, SIS, FAI, LiSat-11, OGQ and Caregiver Burden at 12 months Both groups showed significant within group improvements in BI, FIM and SIS (p=<0.001-p=<0.002) at 12 months
Harwood et al., 2012) New Zealand	Prospective Randomised, controlled parallel group 2×2 trial. Adults (>15 years) 6 - 12	None-stated	A DVD of 4 inspirational stories by Maori and Pacific people with stroke A 'Take Charge Session' – a single structured risk factor and activities of	Primary outcomes SF-36 (Ware et al., 1993) (Physical Component Summary (PCS) & Mental Component Summary (MCS) 12 months	12 months (n=139) No effect on MCS from either intervention (*p*=0.28)

	weeks after stroke, living outside of institutional care and self-identifying as being of Maori or Pacific ethnicity (n=172).		daily living assessment, designed to facilitate self-directed rehabilitation Control group (30 minute home visit plus written material about stroke delivered by a trained research assistant of the same ethnic group) Participants randomly received one, both or neither of the interventions.	from randomisation. Secondary outcomes Barthel Index (BI) (Mahoney & Barthel,1965) Frenchay Activities Index (FAI) (Wade et al., 1985) Carer Strain Index (CSI) (Robinson, 1983) Modified Rankin score (MRS) (van Swieten et al., 1988)	Take charge session higher PCS (p=0.004). DVD nor Take Charge Session effected FAI (p=0.86). (MRS >2) in the Take Charge Session intervention group (odds ratio (OR) 0.42, 95% CI 0.2 to 0.89, P = 0.023) but not the DVD group. Take Charge Session intervention improved scores on the CSI (p = 0.034). DVD no effect on CSI Strain Index (p=0.89) Neither intervention had an effect on BI (p=0.31)
Author (year) country	**Study design and Sample**	**Theoretical premise of intervention**	**Intervention**	**Outcome measures**	**Results**
(Hirsche et al., 2011) Canada	Exploratory study Semi-structured interviews (n=22) with individuals with stroke (n=13), spinal cord injury (n=4) or multiple sclerosis (n=5) 1 week following participation in the CDSMP. Inclusion criteria: community dwelling individuals, ≥18 years, able to converse in English and able to attend the 6-week CDSMP.	None-stated	Chronic Disease self-management programme protocol (aimed at generic health conditions). 6-weekly 2.5 h sessions, led by lay leaders. Subjects included: techniques to deal with problems such as frustration, fatigue, pain and isolation; appropriate exercise; appropriate use of medications; communication; nutrition and how to evaluate treatments	Transcribed interview data	Five primary categories evolved from data analysis, with 12 sub-categories. Primary categories: (1) pre-programme influences; (2) group; (3) factors affecting learning opportunities; (4) workshop content and (5) outcomes. CDSMP was enjoyable, perceived behavioural changes made were made by participants.
(Huijbregts et al., 2008) Canada	Prospective mixed methods longitudinal cohort design Inclusion criteria- stroke ≥3 months, medically, physically and cognitively able to participate, able to	Social Cognition Theory (Bandura, 1997)	MOST (moving on after stroke) self-management program. 17 two hour, twice weekly, group based sessions (8 weeks) plus session 6 weeks post-completion. Discussion and exercise.	Primary outcome measure not identified Reintegration to Normal Living (RNL) Index (Wood-Dauphinee et al., 1988) Activity-specific Balance Confidence scale (ABC) (Powell and Myers, 1995)	MOST (n=18) (mean age, 71yrs, 77% male) LWS (n=12) mean age 63 yrs, 58% male) Between group differences not

	dress and undress independently, active rehabilitation finished Sample given information on both programs and cost ($30 MOST, $20 Living With Stroke, LWS) then contacted research team with preference (able to request subsidy) MOST (n=18) LWS (n=12)		Delivered by 3 health-care professionals, 1 physiotherapy assistant and 3 volunteers	Functional Independence measure (FIM) (Grimby et al., 1996) Geriatric Depression Scale (GDS) (Yesavage et al., 1983) Activity Inventory of the Chedoke McMaster Stroke Assessment (CMSA-AI) (Gowland et al., 1993) Goal Attainment Scale (GAS) (Stolee et al., 1992)	significant for all measures. Participants were largely attracted to MOST due to exercise component.
Author (year) country	**Study design and Sample**	**Theoretical premise of intervention**	**Intervention**	**Outcome measures**	**Results**
(Huijbregts et al., 2009) Canada	Mixed methods exploratory study. Inclusion criteria- stroke, living in community, finished active rehabilitation Exclusion criteria – Cognitive impairment and severe aphasia Intervention received briefing to ensure they understood self-management model. T-MOST (n=8) V. Waiting list control (n=7)	Self-efficacy (Bandura, 1997(	Telehealth (video-conferencing) delivery of a stroke self-management program, Moving on after stroke (T-MOST). Co- led by two trained health care professionals at two different remote sites 9 weekly sessions, each session - 1 hour of discussion, 1 hour of exercise to focus upon coping skills problem solving & goal setting	Primary outcome measure not identified Reintegration to normal living Index (RNL) (Wood-Dauphinee et al., 1988) Stroke Adapted Sickness Impact Profile (SA-SIP30) (van Straten et al., 1997) Geriatric Depression Scale (GDS) (Yesavage et al., 1983) Berg Balance Scale (BBS) Chedoke-McMaster Stroke Assessment— Activity Inventory only (CMSA-AI) (Gowland et al., 1993) Goal Attainment Scale (GAS) (Stolee et al., 1992)	T-MOST (n=8, 50% male, mean age 61.8 yrs) Control (n=7, 37.5% male, mean age 65.6 yrs) 84% attendance BBS changes significant only (p=<0.05) Patients perceived MOST to be helpful and less isolating
(Johnston et al., 2007) Scotland	RCT – intervention arm v. control arm. English speaking patients and their carers discharged following admission to 1 Hospital for acute stroke. Sample randomised to	Cognitive behavioural Therapy theory	5 week, workbook-based intervention to enhance control cognitions, coping and recovery from disability Week 1,2 &5 involve face to face contact, week 3&4 phone contact. Independent interviews with patients and carers plus completion of measures at 2 weeks (baseline), 8	Primary outcome measure not identified Barthel Index (BI) (Mahoney and Barthel, 1965) Observer Assessed Disability (OAD) (Partridge et al., 1987) Hospital Anxiety and Depression Scale	Intervention group (n=103, mean age 68.96, 61% male) Control group (n=100, mean age 68.79, 61% male) Intervention group demonstrated significant

	Intervention (n=103) Or Usual care control (n=100)		weeks post-discharge (after completion of workbook) and 6 months.	(HADS) (Zigmond and Snaith, 1983) Satisfaction with treatment (0-10 Visual analogue scale, VAS) (author designed) Recovery Locus of Control Scale (RLoCS) (Partridge and Johnston, 1989) Confidence in recovery (0-10 VAS) (Lewin et al., 1992)	improvements in recovery from disability (p=0.019). No significant effect on anxiety and depression (p=0.40), confidence in recovery (p=1.14), perceived control (p=0.17) or satisfaction with treatment (p=0.15)

Author (year) country	Study design and Sample	Theoretical premise of intervention	Intervention	Outcome measures	Results
(Jones et al., 2009) England	Single subject design. Purposive sampling of medically stable participants discharged following first stroke (12 weeks-18 months post stroke) (n=10) (70% male, mean 61.5years) Participants with severe memory and language limitations, depression and emotionalism excluded. Recruited from the registers of either an acute hospital stroke unit or community stroke team.	Social Cognition Theory (Bandura, 1997)	4 week workbook based intervention to enhance mastery, vicarious experience and feedback. Contact to introduce intervention and at each measurement point.	Primary outcome- self-efficacy Stroke self-efficacy questionnaire (SSEQ) (Jones et al., 2008b) General Self-Efficacy Scale (GSES) (Schwarzer & Jerusalem, 1995) Recovery Locus of Control Scale (RLoCS) (Partridge & Johnston, 1989) Rivermead Mobility Index (RMI) (Lennon & Johnson, 2000) Rivermead Activities of Daily Living Scale (RADLs) (Whiting & Lincoln, 1980) Subjective Index of Physical and Social Outcome (SIPSO) (Trigg &Wood, 2000) Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983)	n=10 (70% male, mean age 61.5) Significant increase in self-efficacy observed (p=<0.05) No statistically significant change in other variables
(Kendall et al., 2007) Australia	Single blinded Longitudinal RCT. Sampling frame - in-patient acute urban hospitals. 1st stroke ≤ 6 months. Excluded if unable to communicate sufficiently in English, or previous strokes/dementia, or lack	Self-efficacy (Bandura, 1997)	6 week Stanford Chronic Disease Self Management Program (CDSMP) plus 1 stroke specific session (7 weeks total). 7 week intervention conducted between 3 and 6 month data collection points. Both arms received usual care and rehabilitation	Primary outcome measure not identified Stroke Specific Quality of Life (SSQoL) (Williams et al., 1999) Self-efficacy Scale (SES) (Lorig, 1996)	Intervention group (n=58, 70.6% male, mean age 66.58) Control (n=42, 62% male mean age 66.36) Self-efficacy lower in control group for all time points (p=0.003), including pre-intervention. Self-

	of support person to attend course, or if discharge was not to their own (or family members') home Randomised to Intervention group (n=58) Or Usual care control (n=42)				efficacy levels did not change over time for either group. Intervention group increased in Self-Care domain of SSQoLS (p=<0.5). Effect of intervention across all domains diminished at 12 months, when effects equalled control group

Author (year) country	Study design and Sample	Theoretical premise of intervention	Intervention	Outcome measures	Results
(Ljungberg et al., 2001) Sweden	Quasi-experimental Confirmed stroke, estimated rehabilitation time of 4 weeks, able to transfer from bed to chair with 1 person and communicate by telephone Dementia and inability to swallow fluids, excluded. Non-randomised Intervention group (n=32) Control group (n=9)	Orem's Self-care theory (Orem, 1995) Motor relearning programme (Carr & Sheppard, 1987)	To support self-management decision making, collaborative rehabilitation with patients and care-givers on neurology ward and then for 4 weeks in patients own home, followed by 5 2 hour educational sessions 3 months post. Provided by Nurses, Nursing assistants, Occupational Therapists, Physiotherapist, Social welfare officer and Neurologist	Primary outcome measure not identified Functional Independence measure (FIM)) (Grimby et al., 1996) Quality from the patients perspective questionnaire (CFPP) (Wilde, 1994) Life Satisfaction questions (author generated)	Intervention group (n=32, mean age 72yrs, 44% male) Control group (n=9, mean age 72yrs, 66% male) No significant difference between groups over any variable. Intervention group significantly more active at making rehabilitation decisions (p=<0.05) and receiving appropriate information from staff (p=<0.05) Significant difference between groups for satisfaction (p=<0.05) and self-care activities (p=<0.05)
(Marsden et al., 2010) Australia	Randomised, assessor blind, cross-over, controlled trial. Community-dwelling, chronic stroke survivors	None stated	'Community Living After Stroke for Survivors and Carers' (CLASSiC) programme (weekly, 2 1/2 hour, seven-week	Primary - Stroke Impact Scale (Duncan et al., 1999) Health Impact Scale (carers) (Lai et al., 2002)	Participants attended ≥ 4 sessions. 88% attended 6 or 7 sessions. Non-statistically significant

	(n=25) and carers (n=17), discharged from therapy and English speaking Recruited via self or physician referral		group programme combining physical activity, education, self-management principles and 'healthy options') delivered by physiotherapist, social worker, dietician, clinical nurse consultant, speech pathologist and OT	Six Minute Walk Test (Hill et al., 2001) Timed Up and Go (TUG) (Hill et al., 2001) Caregiver Strain Index (Robinson, 1983) Stroke Knowledge (unpublished measure)	improvements observed in intervention group, except memory (SIS). Knowledge of stroke and risk factors increased. Measures remained above baseline12 weeks post programme, except for memory and IADL/ADL.
(Mawson & Mountain, 2011) England	Case-study Community dwelling, IT literate stroke survivors with upper limb dysfunction recruited from private physical therapy clinic (n=4) Motor function was recorded pre and post therapy	None stated	'SMART' telehealth rehabilitation system for upper limb recovery following stroke. Delivered remotely. Participants had system set up in their own homes and wore sensor systems administering therapy for 2 weeks.	Timed Up and Go (TUG) (Hill et al., 2001) Motor Assessment score (Poole & Whitney, 1988) Qualitative interviews	Non-statistically significant results. Functional improvements observed in 50% of items measured, with 40% unchanged and 10% deterioration.
Author (year) country	**Study design and Sample**	**Theoretical premise of intervention**	**Intervention**	**Outcome measures**	**Results**
(Sackley, et al., 2006) England	Cluster RCT Residents of 12 care homes in one area of England, with moderate-severe stroke related disability cluster randomised to Intervention (n=63) Or Usual care (n=55)	None stated	Occupational Therapy (OT) client-centred intervention to improve self-care among care home residents following stroke. Delivered by one OT over a period of 3 months in each home.	Primary- Barthel Index (BI) (Mahoney and Barthel, 1965) Rivermead Mobility Index (RMI) (Lennon & Johnson, 2000) Poor Global Outcome (defined as deterioration in BI or death)	Intervention (n=63) (83% female, mean age 88.6 yrs) Control (n=55) (82% female, mean age 86.3 yrs) difference between groups BI 3 months (p=0.07) 6 months (p=0.12) Global outcome 3 months (p=0.05) 6 months (p=0.03)
Author (year) country	**Study design and Sample**	**Theoretical premise of intervention**	**Intervention**	**Outcome measures**	**Results**

(Sit et al., 2007) Hong Kong	Quasi-experimental Participants were >18years, had a minor stroke, living in the community, independent in ADLs and cognitively able. Exclusion – haemorrhagic stroke, pending surgery, non-Cantonese speaking Non-randomised to intervention (n=77) or usual care (n=70)	None stated	Community based Stroke prevention programme. 8 weekly 2 hour sessions delivered by 3 community nurses. Aimed to improve self-management for secondary Stroke prevention	Primary outcome measure not identified Stroke Knowledge Scale (modified by authors) Medication Compliance scale (Morisky et al., 1986) Self-report info on diet, smoking and alcohol consumption Exercise scale Self-report info on health monitoring practices (blood sugar, blood pressure, cholesterol, urinary glucose and albumin testing)	Intervention group (n=77) Control group (n=70) Final population characteristics not reported Intervention group – significant positive difference in identifying stroke warning signs (p=<0.001), medication compliance (p=<0.004), BP monitoring (p=<0.001) Control group - significantly decreased level of exercise (p=<0.001) 30 participants withdrew from intervention group

Appendix Two – Summary of outcome measures used to capture self-management

Measure, (Author, Year)	Methodology	Sample/setting	Validation measures	Measure description	Results
Barriers to self-management tool (Bayliss et al., 2003;2005b)	Semi-structured interviews (n=16) (Bayliss et. al, 2003). Responses analysed for frequency, content and range of description. Used to inform domains. New and existing items from other measures used to construct tool. Face validity- 1:1 interviews conducted with sample following completion of measure. Retest reliability - Two consecutive mailings of measure to main sample. Reliability –internal consistency calculated for each domain	Interview study – Denver, USA, selected from 4 family doctor practices, participants identified through advertisements with 2 or more long-term conditions. USA, Health maintenance organisation (provides primary, secondary and specialist care). Pre-testing sample >65yrs, more than 1 chronic condition (n=156). Validity sample >65yrs with at least one chronic health condition. Selected using stratified randomisation, (those with >3 conditions over-sampled intentionally, 69% sample)	Participant demographics For criterion validity –SF-36 (Ware et al., 1993), Disease burden scale (Bayliss et al., 2005a)	Details of number of items, absent. 13 domains. Details of response type, absent. 2 domains are represented by a single item. Some items contain dichotomous responses	Response rate, 28% Mean age of sample 75yrs, mean no. of conditions =5.9 Incomplete data in 47 respondents (30%). 2 domains represented by single items, so internal consistency for those items not calculated. Internal consistency α0.38-0.92 Validity- correlations between majority of domains and additional measures significant (*p*=<0.05).
Therapeutic Self-care Scale (TSCS) (Doran et al., 2002;2006) (Chaboyer et al., 2012)	<u>Conceptualisation of model</u> (Doran et al., 2002) Cross-sectional design – comparison of patient reported data at discharge with Nurse reported data. Structural equation modelling (SEM) used to test if data fits model.	Ontario, Canada Patients (n=372) and Nurses (n-254) from 26 general surgical-medical and cardiac units in a tertiary hospital (n=372).	Patient perception of quality of nursing care, Judgement of Hospital Quality Scale (Chachamovich et al., 2009) Nurses' perceived time to perform nursing activities (un-validated) Nurses' Role tension	13 items with a 5 point Likert-style response format	Nurse independent role and nurse communication positively predicted patient Therapeutic self-care (TSC). Nursing interventions predicted functional status, but not mood or TSC α0.93. Unclear from paper if reporting test-retest reliability or internal consistency

	Study 1 (Doran et al., 2006) Repeated measures design – data collected on admission and discharge by nursing staff. Scale validation 2 (Chaboyer et al., 2012) Longitudinal correlational design- collected 3 & 6 months post discharge	Study 1 - Convenience sample of patients (n=574) from general medical and surgical units from 1 tertiary teaching, 1 rural and 2 community hospitals. Scale validation 2 Patients, aged >18years admitted with trauma via A&E to 2 metropolitan hospitals, Queensland, Australia. (n=125) 3 months (n=103) 6 months	scale (Lyons,1971) and Job autonomy (Hackman & Oldham, 1980). Un-validated measure of patient readiness to resume usual role and social functioning Mood (Sutherland et al., 1989) Study 1 Patient demographics Functional status- activities of daily living items (Hirdes et al., 2003) Nursing interventions (review of documentation) Scale validation 2 Patient demographics Injury severity		Study 1 Authors state this is a 'usability study' only. No psychometric data available Scale validation 2 PCA performed on responses from 3 months. 3 factors emerged, two items were deleted: Taking medications Recognising and managing symptoms Managing changes in health conditions Reliability reported as 0.76

Measure, (Author, Year)	Methodology	Sample/setting	Validation measures	Measure description	Results
Patient Activation Measure (PAM) (Hibbard et al., 2004)	Phase – 1. Conceptualise activation using Literature, Focus Groups and expert panel consensus. 80 item pool generated 2. Preliminary testing of psychometric properties through cognitive interviewing and subset of experts 3. Instrument refinement &	USA. Phase 1- Expert panel consisted of prominent people in the field (n=21). FG participants (n=19) had at least 1 long-term condition. Details on how selected absent. Phase 2 – Cognitive interviewing sample details absent except for presence of chronic condition (n=20). Phase 3 local sample (n=100)	Phase 4- Survey of health behaviours, designed by authors SF-8 (Ware et al., 2001) Healthcare utilisation (patient reported)	22-items. Guttman-like scale, difficulty rated on a 0-100 scale.	Rasch modelling - items infit values between .76 and 1.32, (within the range required for a uni-dimensional measure.) The Rasch person reliability was between .85 (real) and .88 (model), α.87. Phase 4 - activation correlates with better health (*r*5.38, *p*<.001), and negatively correlates with

	testing with pilot population. Rasch analysis used to assess item difficulty. 4. Testing in wider population via telephone administration	recruited through advertisements (19-79yrs). Phase 4 national sample (n=1515) (>45yrs of age), accessed through random digital dialling (up to 12 times call back)			healthcare utilisation (r=, -.07, p<.01).
Measure, (Author, Year)	Methodology	Sample/setting	Validation measures	Measure description	Results
Strategies used by people to promote health (SUPPH) (Lev & Owen, 1996)	Study 1 – Interviews to generate 36 itemed measure. Panel of experts used to validate items. Measure tested with oncology pts (n=114) as part of battery of measures at baseline and 2-4/52s later. Study 2 – item reduced to 29 items using Manalanobis distance of scores significant at p<.0005. Participants completed measures in the treatment setting (setting unspecified). Confirmatory Factor Analysis.	USA Oncology and End Stage Renal patients. Study 1- 4 ambulatory care units at hospital outpatient settings and 3 private physician offices across 4 states. Interview participants all oncology patients (n=47). Experts were post-graduate nurses (n=6). Study 2- Pts receiving chemotherapy (n=64) and haemodialysis for ESRD (n=97) plus participants from study 1 (n=107).	Study 1 – Pt demographics Beliefs about health behaviours , *Grief* (Lev, 1993) Study 2 – Brief symptom Inventory (Derogatis and Spencer, 1982, Functional Assessment of Cancer Treatment, (Cella et al., 1993) Profile of mood states (McNair et al., 1971), Somatic Symptom Distress Scale (Burton et al., 1986)	36 items of self-care self-efficacy 5-point Likert-style rating format (*very little confidence* (1) to *quite* a *lot of confidence (5))*	Study 1- response rate 36%, Internal consistency α 0.93 Retest reliability α0.95 Higher SCSE correlated with positive health beliefs (.61 *(p =<* .001), and less grief (-.38 *p=* <0.01). Study 2- CFA revealed a 4 factor solution (81% of the variance) - coping, stress reduction, making decisions and enjoying life. 'coping' and 'stress reduction' correlated less consistently with health outcome data. 'making decisions' did not significantly correlate with any measures. 'enjoying life' correlated with health outcome data in ESRD pts.
Measure, (Author, Year)	Methodology	Sample/setting	Validation measures	Measure description	Results
Exercise of Self-care agency Scale (ESCAS)	Kearney & Fleischer (1979) - Scale developed following review of Orem's theory of self-care and following Nursing development conference proceedings	USA Internal consistency determined with psychology and nursing students (n=237) Content validity nurse experts (n=11)	Concurrent validity - Adjective Check List (Gough & Heilbrum, 1965) Locus of Control Scale	20 items- 4 constructs. Items are oriented positively toward	Test-retest reliability α0.77 40% of the variance attributed to a four-factor solution. 8 items loaded less than 0.40 on any factor and were excluded. 12

(Kearney & Fleischer, 1979; Riesch & Hauck, 1988)	(1973). Scale administered twice to students. Reisch & Hauck (1988) - Factor analysis to examine construct validity, ANOVA to determine discriminant validity. Data from three prior studies that used the ESCAS were pooled (n=506). Results of factor analyses reviewed by experts to name factors.	Study 2 - Sample consisted of pregnant women and their labour partners (n=100), healthy adolescents (n=110), University staff and students (n=296). Experts in self-care were nurses with clinical or theoretical expertise (n=5).	(Silverman, 2001)	self-care on a 0-4 scale Likert-style response format. 11 items have reverse scoring. Following Riesch and Hauck research, reduced to 12 items.	items loaded between 0.40- 0.63
Self-efficacy to perform self-management behaviours scale (Lorig, 1996)	Focus groups to inform tool terminology. Scale mailed to participants, non-returners were reminded once by post, and then contacted by telephone. Incomplete responses were contacted by telephone. Scale constructed by authors and tested using Multitrait scaling analysis	USA. FG sample, more than one unspecified long-term condition Scale sample (n=1130), selected from those participating in CDSMP. 75% female, 91% white ethnicity, mean age 64.3yrs. Sub-sample (n=51) completed scale twice	Other measures were developed simultaneously by the authors, and correlations of responses on these were used to examine construct validity.	11 items (4 constructs) 10 point Likert-type rating scale	Response rate stated as >90% Internal consistency α0.77-0.88 Item correlations *r*-0.1 – 0.41
Health Education Impact Questionnaire (HeiQ) (Osborne et al., 2007)	Item development – synthesis of current Self-Management programme practice, obtained through semi-structured interviews with stakeholders (n=?) & thematic analysis of transcripts. Concept mapping to derive appropriate language of items, and a hierarchy of concepts key to self-management programmes.	Australia. Interviews with stakeholders– sample not described. Program logic model- expert sample (n=?) did not include patients. Concept mapping – chronic illness group previous attendees of a SM programme (n=8), professional group (n=9), leaders of SM programmes, HCPs, program managers, policy makers.	Initial questionnaire reviewed by stakeholders and medical editor (purpose not stated). No other measures	51 items. 4 point Likert-style response format (8 constructs).	Construct validity - CFA revealed good – excellent item fit. Test-retest reliability not reported. α0.70 - 0.89 for 8 domains. Rasch statistics for each item reported upon in paper, all fit model.

	Tool calibration – tested with community sample and hospital sample, telephone interviews unclear procedures. Telephone interviews conducted to explore responses. CFA and Rasch Analysis used to explore item characteristics	Tool calibration (n= 591) members of Arthritis Foundation across Australia, 84% female, 59% had arthritis, 31% had participated in a SM course. Unclear how sample accessed and selected. Hospital sample drawn from city hospital outpatient depts (n=598). Telephone interviews - purposively selected sub-sample (n=30) relating to extreme, missing or erroneous responses. PLUS 2 FGs (n=17), 1 with pts who had attended SM program, 1 with leaders of SM program and HCPs. Questionnaire testing (n=598). Recruited from out-patient depts of public hospital (46%) remainder not specified. 58% female.			

Appendix three - Confirmation of Ethical approval and Research Governance

UNIVERSITY OF Southampton

E04/Mar 2011/ v2.0

Emma Boger
Faculty of Health Sciences

23 June 2011

Dear Emma

Ethics Submission No: FoHS-ETHICS-2011-054
Title: Item generation for an (self-management self-efficacy) instrument

I am pleased to confirm **full approval** for your study has now been given. The approval has been granted by the Faculty of Health Sciences Ethics Committee.

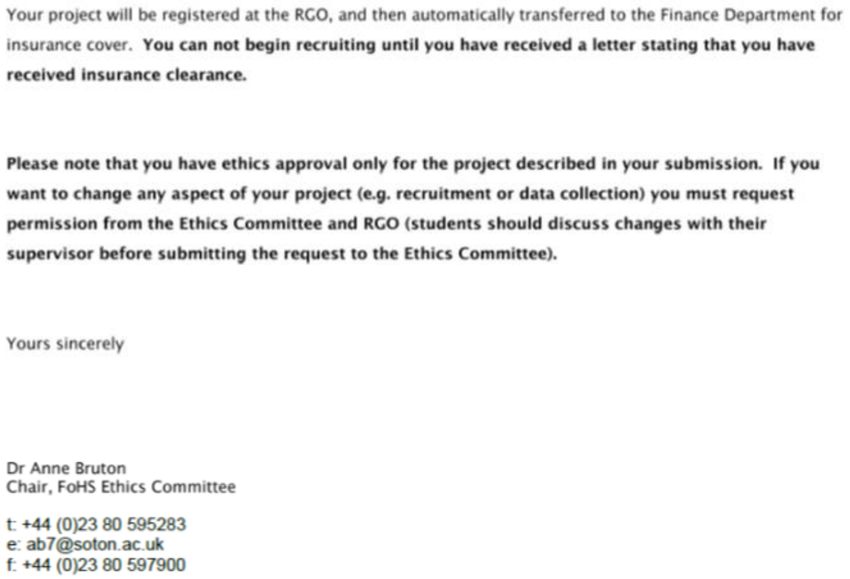
You are required to complete a University Insurance and Research Governance Application Form (IRGA) in order to receive insurance clearance before you begin data collection. The blank form can be found at http://www.soton.ac.uk/corporateservices/rgo/regprojs/whatdocs.html

You need to submit the following documentation in a plastic wallet to Dr Martina Prude in the Research Governance Office (RGO, University of Southampton, Highfield Campus, Bldg. 37, Southampton SO17 1BJ):

- Completed IRGA Research Governance form
- Copy of your research protocol/School Ethics Form (final and approved version)
- Copy of participant information sheet
- Copy of SoHS Risk Assessment form, **signed**
- Copy of your information sheet and consent form
- Copy of this SoHS Ethical approval letter

Continued overleaf

Building 67
Faculty of Health Sciences, University of Southampton, Highfield Campus, Southampton SO17 1BJ United Kingdom
Tel: +44 (0)23 8059 7979 Fax: +44 (0)23 8059 7900 www.southampton.ac.uk/healthsciences



Your project will be registered at the RGO, and then automatically transferred to the Finance Department for insurance cover. **You can not begin recruiting until you have received a letter stating that you have received insurance clearance.**

Please note that you have ethics approval only for the project described in your submission. If you want to change any aspect of your project (e.g. recruitment or data collection) you must request permission from the Ethics Committee and RGO (students should discuss changes with their supervisor before submitting the request to the Ethics Committee).

Yours sincerely

Dr Anne Bruton
Chair, FoHS Ethics Committee

t: +44 (0)23 80 595283
e: ab7@soton.ac.uk
f: +44 (0)23 80 597900

NB – The University of Southampton made changes to its Ethical approval and Research Governance procedures in 2012. Following this time, confirmation of ethical approval and goverance was gained via an online portal (ERGO) (www.ergo.soton.ac.uk).

UNIVERSITY OF
Southampton

RGO Ref: 8160

Mrs Emma Boger
School of Health Sciences
University of Southampton
University Road
Highfield
Southampton
SO17 1BJ

01 July 2011

Dear Mrs Boger

Project Title Item Generation for an (Self-Management Self-Efficacy) Instrument

This is to confirm the University of Southampton is prepared to act as Research Sponsor for this study, and the work detailed in the protocol/study outline will be covered by the University of Southampton insurance programme.

As the sponsor's representative for the University this office is tasked with:

1. Ensuring the researcher has obtained the necessary approvals for the study
2. Monitoring the conduct of the study
3. Registering and resolving any complaints arising from the study

As the researcher you are responsible for the conduct of the study and you are expected to:

1. Ensure the study is conducted as described in the protocol/study outline approved by this office
2. Advise this office of any change to the protocol, methodology, study documents, research team, participant numbers or start/end date of the study
3. Report to this office as soon as possible any concern, complaint or adverse event arising from the study

Failure to do any of the above may invalidate the insurance agreement and/or affect sponsorship of your study i.e. suspension or even withdrawal.

On receipt of this letter you may commence your research but please be aware other approvals may be required by the host organisation if your research takes place outside the University. It is your responsibility to check with the host organisation and obtain the appropriate approvals before recruitment is underway in that location.

May I take this opportunity to wish you every success for your research.

Yours sincerely

Dr Martina Prude
Head of Research Governance

Tel: 023 8059 5058
email: rgoinfo@soton.ac.uk

Corporate Services, University of Southampton, Highfield Campus, Southampton SO17 1BJ United Kingdom
Tel: +44 (0) 23 8059 4684 Fax: +44 (0) 23 8059 5781 www.southampton.ac.uk

Appendix four – Charity permissions to approach community stroke groups

22nd March 2011

The Stroke Association
3rd Floor, Roman Landing
35-37 St.Mary's Place
Kingsway
Southampton SO14 1AF
Phone
02380 720420
Fax
02380 632765

Dear Emma
Research study -"What is the experience of stroke survivors living in the community with regard to self-management?'

To confirm, subject to ethical approval I would be happy to advertise your study through our services in the area and also to our affiliated stroke clubs.

Yours Sincerely

Katherine Staley
Head of Operations – South Central
Tel. 02380 720 422
katherine.staley@stroke.org.uk

<u>Different Strokes</u>
Self-Management Study
Eileen Gambrell [eileen@differentstrokes.co.uk]
You replied on 17/03/2011 14:22.
Sent: 08 February 2011 10:35
To: boger e.j. (ejb1c09)
Attachments:

Hi Emma
Thanks for your message – subject to your study receiving ethical approval, we will be happy to help advertise it for you.

Keep in touch!
Thanks, Eileen

Thanks, Eileen
Eileen Gambrell, Services Manager, Different Strokes, 9 Canon Harnett Court,
Wolverton Mill, Milton Keynes MK12 5NF Tel 0845 130 7172 Fax 01908 313501

Stroke Support Group
Xxxxxxxxxxxxxx
Xxxxxxxxxx
xxxxxxxxxxx
info@XXXstrokesupport.org.uk

21st March 2011
Dear Emma

Re: Research Project

Thank you for giving us an opportunity to contribute to your research project concerning stroke self-management. I have spoken about this with our members and am pleased to say that we would be more than happy to co-operate with you on this project.

We understand that you need ethical approval for this project to go ahead, and therefore offer our conditional approval pending ethical approval.

We should be pleased if you would let us know when you receive ethical approval to proceed with the project, and we can arrange dates for you to visit our group.

I look forward to hearing from you,

Yours sincerely

XXXX XXXX

Secretary Stroke Support Group (xxxxxxxxxxx)

Appendix five - Participant information sheets (focus groups)

UNIVERSITY OF
Southampton

Study Information Sheet

My name is Emma Boger, I am a registered nurse and post-graduate researcher at the Faculty of Health Sciences, University of Southampton. I would like to invite you to participate in a research study titled *"What is the experience of people who have had a stroke, with regard to self-management?'* This study is part of a larger study titled *'The development of a new outcome measure of self-management self-efficacy for Stroke'.*

Before you decide it is important for you to understand why the research is being done and what it will involve. We know that some people have difficulty reading after a stroke, so we have included a picture representation to help everyone understand what taking part would involve. Please take time to read the following information carefully and discuss it with friends, relatives or your GP if you wish. Please contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this information sheet.

What is the purpose of the study?

This study is interested in finding out how people who have had a stroke manage their condition, health and well-being. Sometimes this is referred to as 'self-management'.

This study is part of a larger research study that aims to develop a new measurement questionnaire for self-management following a stroke. Finding out the experiences of people who have had a stroke is crucial. It is important so the new measurement questionnaire is relevant to people who have had a stroke.

The questionnaire will be used to help people who have had a stroke, healthcare professionals and researchers measure their progress since having a stroke and/or having rehabilitation. It may be used to help healthcare professionals provide the right treatment, rehabilitation and support.

Why have I been chosen?

You have been chosen because you have previously had a stroke. Your experience of having a stroke is therefore very valuable to this study.

Do I have to take part?

No, taking part is voluntary. It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time. If you decide not to take part you do not have to give a reason, nobody will be upset and the standard of any care you receive will not be affected.

What will I be asked to do if I take part?

If you decide to take part I will ask some questions about you and ask you to complete a questionnaire about your physical ability over the telephone. This will take around 15-25 minutes. You will then be asked to attend a discussion group with other stroke survivors (maximum 12). You will be asked to sign a consent form at the group, before it starts.

During the discussion group, you will be asked to talk freely about topics relating to managing your condition, health and well-being after having a stroke. The group discussion will last between 60-90 minutes. **The discussion will be tape-recorded and notes will be taken during the session.**

If you usually have someone who attends the stroke group with you to help you with communication and speaking, they can also attend the discussion group to help you. If you usually have someone who attends the stroke group with you to assist you in any other way, they will be offered refreshment, but asked to wait while you participate in the discussion.

The discussion group will be lead by the researcher (Emma Boger). Another colleague will also attend to help the running of the group. The discussion group will be held in a local venue depending on the needs of those attending. Light refreshments will be provided.

What are my responsibilities?

I would be very grateful if you could contact me should you like to take part. I will then contact you to answer any queries you may have and to discuss suitable arrangements for the group session. **My contact details can be found at the bottom of this information sheet.**

The study would like to include everyone in the research, however no more than 12 people can take part in each discussion group. In the event that more than 12 people want to take part, the discussion group will be chosen so that a range of people attend with differing gender, age, physical ability and length of time since stroke.

Unfortunately, if there are lots of people with a similar experience to you who agreed to participate before you, it may mean that you will be unable to participate in this group. You may be offered the chance to participate in a different group or be involved in the later parts of the research study, if you would like to.

What are the possible side effects of taking part?

The research study consists of group discussion therefore we do not expect any side effects. While every effort will be made to avoid upset, there is a possibility that some of the things discussed might be upsetting for you. If you were to become upset you would be asked whether or not you wanted to continue. If you wished to continue you would be given some time to collect yourself. If you wished to leave the discussion the research assistant would be available to accompany you and make sure you were all right. After the discussion finishes the researcher would be available to give information on possible sources of support or advice.

What are the possible benefits in taking part?

There is no personal benefit for you in taking part. However, your participation in the study can potentially help others. Your experience is very valuable and will help researchers develop a new questionnaire measure that could help future stroke survivors and healthcare professionals.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. Please discuss with the researcher (Emma Boger) in the first instance to see if the problem can be resolved. If you would prefer not to discuss with the researcher, you should contact the Head of Research & Enterprise Services, at the Faculty of Health Sciences (Address: University of Southampton, Building 67, Highfield, Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 7912; Email: sohsreso@soton.ac.uk). If you remain unhappy and wish to complain formally Susan Rogers can provide you with details of the University of Southampton Complaints Procedure.

Will my taking part in this study be kept confidential?

I (Emma Boger) will not reveal that you have taken part in this study, or what you have said to anyone. However, as this is a group discussion the other people attending will know that you have taken part and be aware of what you have said. Everyone who attends will be asked to maintain the confidentiality of the other people in the discussion group. Your contribution to the group is highly valuable. However you do not have to make comments on any topic you don't feel comfortable with.

All written and recorded information collected will be kept securely and confidentially. Any information concerning you, or comments made by you, will have your name removed and not be identifiable to you. When the study finishes the audio tapes and study data will be kept securely at the University of Southampton for ten years.

What will happen to the results of the research study?

The results of this study will help determine the key things important to people managing their condition, health and well-being after a stroke. The findings will be used to help develop a questionnaire to measure how confident people are at self-managing following a stroke. The results may be reported in professional publications or meetings, but you will not be identified by name. You may like to receive a copy of the summary of the research, and can indicate this when you participate.

Who is organising and funding the research?

This study is being funded by the Faculty of Health Sciences at the University of Southampton and organised by the researcher (Emma Boger) as part of a post-graduate degree at the University of Southampton.

Who has reviewed the study?

The University Research Governance department and Faculty of Health Sciences at the University of Southampton have approved the study. It has been subject to ethical review by the Faculty of Health Sciences ethics committee.

What do I do now?

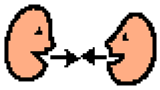
Thank you for considering taking part in this research. **If you would like to take part, please contact me via email at** E.J.Boger@soton.ac.uk. **Or contact me via telephone on (0)23 8059 8XXX or 07XXX XXXXXX**. Please leave your name and telephone contact number if you are happy for me to contact you by telephone, and any availability or other requirements. **Or if you prefer, return the reply slip on the last page of this information sheet.**

I will then contact you to discuss with you any queries you may have and arrangements for the group session.

Thank you again for reading this.

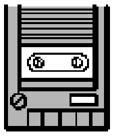
Managing after a stroke: How do people who have had a stroke manage their health?

I would like to talk to you about your stroke



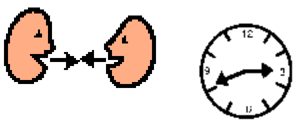
I would like to do this as part of a group discussion

I would like to tape-record it



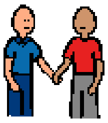
An assistant will write notes about this discussion

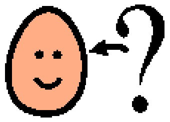
We will talk for about 1 hour



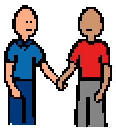
1hour

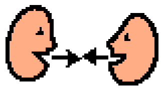
You can have a friend or relative with you

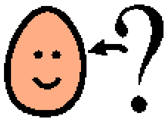


You can ask questions about the research 

You can talk to your friends and family about taking part





If you want to take part, or ask questions  you can contact Emma Boger:

<u>(0)23 8059 8XXX</u> or <u>07XXX XXXXX</u>

Appendix six – The Barthel Index

THE
BARTHEL
INDEX
FEEDING
0 = unable
5 = needs help cutting, spreading butter, etc., or requires modified diet
10 = independent
BATHING
0 = dependent
5 = independent (or in shower)
GROOMING
0 = needs to help with personal care
5 = independent face/hair/teeth/shaving (implements provided)
DRESSING
0 = dependent
5 = needs help but can do about half unaided
10 = independent (including buttons, zips, laces, etc.)
BOWELS
0 = incontinent (or needs to be given enemas)
5 = occasional accident
10 = continent
BLADDER
0 = incontinent, or catheterized and unable to manage alone
5 = occasional accident
10 = continent
TOILET USE
0 = dependent
5 = needs some help, but can do something alone
10 = independent (on and off, dressing, wiping)
TRANSFERS (BED TO CHAIR AND BACK)
0 = unable, no sitting balance
5 = major help (one or two people, physical), can sit
10 = minor help (verbal or physical)
15 = independent
MOBILITY (ON LEVEL SURFACES)
0 = immobile or < 50 yards
5 = wheelchair independent, including corners, > 50 yards
10 = walks with help of one person (verbal or physical) > 50 yards
15 = independent (but may use any aid; for example, stick) > 50 yards
STAIRS
0 = unable
5 = needs help (verbal, physical, carrying aid)
10 = independent

TOTAL (0–100): ______

Appendix seven - Focus group interview schedule

Checklist – Comfortable seating; comfortable temperature; fire procedure and emergency exits; Mobile phones switched off; encourage movement if uncomfortable; Remind participants to leave room quietly, should they need to do so (no need to ask permission).

Example Group reminders – ''I am recording this discussion and my colleague will be making notes throughout our discussion. My colleague is noting the order of who is speaking to help me remember the discussion once we've finished. I am interested in what you all have to say or feel. Everybody's view is valid so please allow everyone the chance to have their say. Please can I assure you that neither I, nor my colleague, will be judging you, or repeating what you personally have said today to anyone else. To make everyone feel comfortable with the discussion, we ask each of you to also respect this right to privacy and confidentiality by not repeating our discussion outside of this room.

Summary and Close

The researcher summarised the different views and opinions covered, plus attempted to elicit anything that might not have been said in the main discussion.

Discussion topics	**Rationale**	**Example prompts**
Tell me what you've heard about the term 'self-manage' or 'self-management' before?	Qualify knowledge/ awareness of terms. Identify relevance of term to people following stroke.	If those terms are unfamiliar to you, what do you think they mean? If no recognition of term, suggest it might mean involvement with care, decision making, monitoring condition, etc.
How relevant do you think self-management is to someone who has had a stroke?	Establish knowledge/ awareness of terms and identify value placed on SM activities by individual. Is SM viewed as relevant/feasible for people who has a stroke	Why might this be? 'How' and 'why' prompts to elicit thoughts if necessary
Tell me about the kinds of things you already do as part of self-management?	As above.	How did you come to do this? (to understand the motivation and circumstances behind SM activity.
Imagine that we lived in an ideal world, perfect in every way, but you still had had your stroke. Tell me about the kinds of things you would like to do to help manage your condition?	Explore the potential for SM post-stroke.	What would you like most involvement with or control over? 'Why?' 'How?' To elicit view as necessary
What kinds of things get in the way of these activities?	Identify actual or perceived barriers to effective SM	'How' and 'why' to elicit why the barriers might exist
In what ways has SM changed since you first had your stroke?	Explore effect of time since stroke on SM and SM opportunities	'Why' and 'how' to explore change as necessary Has your confidence in your ability to manage changed?
What support, or changes, might help you to self-manage in the way you would ideally like to?	Explore factors which might enable SM. Explore the degree to which participants would like to SM. Are participants happy with current level of SM?	How might SM be made better for future people after stroke? How might your confidence or belief in your ability to manage your condition be increased?

Appendix eight- Participant information sheets (cognitive interviewing)

'Interviewing people recovering from stroke to help design a new questionnaire'.

Study Information Sheet

My name is Emma Boger, I am a registered nurse and post-graduate researcher at the Faculty of Health Sciences, University of Southampton. I would like to invite you to participate in a research study titled **'Interviewing people recovering from stroke to help design a new questionnaire'.** This study is part of a larger study titled *'The development of a new outcome measure of self-management for Stroke'.*

Before you decide it is important for you to understand why the research is being done and what it will involve. We know that some people have difficulty reading after a stroke, so we have included a picture representation to help everyone understand what taking part would involve. Please take time to read the following information carefully and discuss it with friends, relatives or your GP if you wish. Please contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this information sheet.

What is the purpose of the study?

In this study we are interested in finding out what people who have had a stroke think about a new questionnaire. The questionnaire has been developed after talking to people recovering from stroke.

Finding out what people who have had a stroke think of the questionnaire is crucial. It is important in case we need to make changes to the questionnaire to make it more relevant, understandable and acceptable to people who have had a stroke.

The questionnaire will be used to help people who have had a stroke. Healthcare professionals and researchers will use the questionnaire to measure the progress of people who have had a stroke. It may be used to help healthcare professionals provide the right treatment, rehabilitation and support.

Why have I been chosen?
You have been chosen because

- you have previously had a stroke. Your experience of having a stroke is therefore very valuable to this study, and
- you took part in a previous discussion group study lead by the researcher (Emma Boger).

Do I have to take part?

No, taking part is voluntary. It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time. If you decide not to take part you do not have to give a reason, nobody will be upset and the standard of any care you receive will not be affected.

What will I be asked to do if I take part?

If you decide to take part, I will ask some questions about you and ask you about your physical ability, to make sure you are able to take part in the study. We will then arrange a convenient time and place to meet and for me to conduct the interview (usually in your own home). At the interview, you will be asked some questions about the new questionnaire. In particular, I will ask questions to find out how easy it is to understand the new questionnaire. I will also ask you about how it might be worded better. You will be asked to sign a consent form before the interview. The interview will last no longer than 60 minutes. **The interview will be tape-recorded and notes may be taken during the session.**

If you usually have someone who helps you with communication and speaking, they can also be present at the interview to assist you.

The interview will be conducted by me, the researcher (Emma Boger).

What should I do if I want to take part?

I would be very grateful if you could contact me should you like to take part. I will then contact you to answer any queries you may have and to discuss suitable arrangements for the interview. My contact details can be found at the bottom of this information sheet.

The study would like to include everyone in the research, however no more than 15 people can take part in this study. In the event that more than 15 people want to take part, people will be chosen so that a range of people with differing gender, age, physical ability, length of time since stroke and experience of managing after a stroke take part.

Unfortunately, if there are lots of people with a similar experience to you who agreed to participate before you, it may mean that you will be unable to participate in this study. You will be offered the chance to be involved in the later parts of the research study, if you would like to.

What are the possible side effects of taking part?

The research study involves an interview therefore, we do not expect any side effects. While every effort will be made to avoid upset, there is a possibility that some of the things discussed might be upsetting for you. If you were to become upset you would be asked whether or not you wanted to continue. If you wished to continue you would be given some time to collect yourself. If you wished to stop the interview, no one will be upset and the researcher would be available to give information on possible sources of support or advice.

What are the possible benefits in taking part?

There is no personal benefit for you in taking part. However, your participation in the study could potentially help others. Your experience is very valuable and will help researchers develop a new questionnaire measure that could help future stroke survivors and healthcare professionals.

In case of complaint

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. Please discuss with the researcher (Emma Boger) in the first instance to see if the problem can be resolved. If you would prefer not to discuss with the researcher, you should contact Martina Prude, Research Governance Office at the Faculty of Health Sciences (Address: University of Southampton, Building 67, Highfield, Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 7912; Email: sohsreso@soton.ac.uk). If you remain unhappy and wish to complain formally, details of the University of Southampton Complaints Procedure will be provided by this office.

Will my taking part in this study be kept confidential?

I (Emma Boger) will not reveal that you have taken part in this study, or what you have said to anyone. Your contribution to the study is highly valuable. However you do not have to make comments on any topic you don't feel comfortable with.

All written and recorded information collected will be kept securely and confidentially. Any information concerning you, or comments made by you, will have your name removed and not be identifiable to you. When the study finishes the audio tapes and study data will be kept securely at the University of Southampton for ten years.

What will happen to the results of the research study?

The results of this study will help the questionnaire be relevant and acceptable to people recovering from stroke. The results may be reported in professional publications or meetings, but you will not be identified by name. You may like to receive a copy of the summary of the research, and can indicate this when you participate.

Who is organising and funding the research?

This study is being funded by the Faculty of Health Sciences at the University of Southampton and organised by the researcher (Emma Boger) as part of a post-graduate degree (PhD) at the University of Southampton.

Who has reviewed the study?

The University Research Governance department and Faculty of Health Sciences at the University of Southampton have reviewed and approved the study. It has been subject to ethical review by the Faculty of Health Sciences ethics committee.

What do I do now?

Thank you for considering taking part in this research. **If you would like to take part, please contact me via email at** E.J.Boger@soton.ac.uk. **Or contact me via telephone on (0)23 8059 8XXX or 07XXX XXXXXX.** Please leave your name and telephone contact number if you are happy for me to contact you by telephone, and any availability or other requirements. **Or if you prefer, return the reply slip on the last page of this information sheet.**

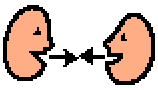
I will then contact you to discuss with you any queries you may have and arrangements for the interview.

Thank you again for reading this information sheet.

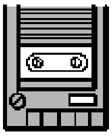
Emma Boger Email – E.J.Boger@soton.ac.uk

Interviewing people recovering from stroke to help design a new questionnaire

I would like to talk to you about a questionnaire

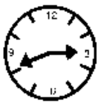


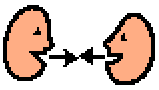
I would like to tape-record this discussion



I will write notes about this discussion

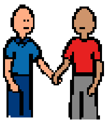
We will talk for about 1 hour



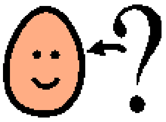


1hour

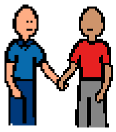
You can have a friend or relative with you

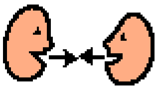


You can ask questions about the research



You can talk to your friends and family about it





<u>(0)23 XXXX XXXX</u> or <u>07XXX XXXXXX</u>

Appendix nine- Preliminary item pool

1. It is worth trying things that work for other people with stroke
2. I have useful information or advice to give to others regarding stroke self-management
3. I cannot rely on others to help me recover from stroke
4. It is easy for me to do things to help the people I care about
5. My physical limitations mean that I cannot manage my condition as I would like
6. My communication limitations mean that I cannot manage my condition as I would like
7. I don't like asking for help from others to help me with my condition
8. I am able to control all other aspects of my health
9. Self-care of my condition is important to me to stay as healthy as possible
10. My limitations due to stroke mean that I cannot manage my condition at all
11. My condition might change if I received more professional advice
12. I have too much going on in life to pay as much attention to self-care as I should
13. Activities or strategies that I do without the input of professionals, may worsen my condition (e.g. doing independent physiotherapy exercises)
14. I don't understand why some people with stroke seem to do better than me
15. I need professional advice to self-care to my best ability
16. No matter how hard I try, managing my stroke doesn't turn out the way I would like
17. The advice given by professionals is often not relevant to my situation
18. I do not let treatment and therapy regimes rule my life
19. Sometimes performing therapy exercises is a low priority
20. Whatever I do, I will not improve my condition

21. When things do not go well with my stroke, I still think positively
22. I worry that my own self-care activities may make me worse (e.g. doing exercise)
23. I don’t feel comfortable asking others to help me with my condition
24. I am confident in asking family members or friends to help me perform activities important to managing my condition
25. It is not up to me to decide what the best ways to manage my stroke are
26. I am able to manage things related to my stroke as well as most other people
27. My limitations due to stroke mean that I cannot manage any aspect of my condition, by myself
28. Healthcare professionals should make most of the decisions about my condition
29. I find it difficult to find solutions that work for problems with managing my stroke
30. I am able to tell professionals what I want or need
31. There is little point in carrying out exercises as my condition will not change
32. I cannot affect what my healthcare professionals decide to do about my problem(s)
33. I feel confident in asking healthcare professionals questions about my stroke
34. I have developed ways to remember the advice given to me by healthcare professionals
35. I always follow professional advice about my condition, to the letter
36. I am confident in asking family members or friends to help me perform activities important to my recovery
37. I adapt professional advice so it is relevant to my situation
38. I pay equal attention to my physical and emotional health

39. I try new therapies or ways of doing things in case it helps me manage my condition better
40. I plan my day so I can get things done without becoming tired
41. I have found ways to remember a certain treatment or therapy regime
42. The lifestyle choices that affect my health (for example, smoking, diet, alcohol) have not changed since having a stroke
43. I know how to get help if I am concerned about my condition
44. I can work out problems I have about my condition without asking for professional advice
45. I am not sure what signs or symptoms might mean my condition is changing
46. I have worked out ways of managing my stroke together with healthcare professionals
47. I understand what my prescribed medication is for
48. I know what symptoms to look out for that might show I need professional advice
49. I always ask healthcare professionals to explain things that I don’t fully understand
50. I feel confident in disagreeing with healthcare professionals, if their advice seems irrelevant to me
51. I take more care with my diet to stay healthy since having a stroke
52. I feel able to access the information I need to make decisions about my condition
53. I make sure that I find time to relax and enjoy life
54. I generally succeed in the strategies I use to manage my stroke
55. I use technology, such as the internet to seek advice or information about my condition
56. I feel sure that the efforts I take to manage my condition have a real positive effect
57. Support from other people who have had a stroke is important to my own recovery

Appendix ten Summary of first round of Cognitive Interviewing

1. It is worth trying things that work for other people with stroke

Notes: ID 2 understood this item to mean trying new therapies or strategies, but felt it could be clearer if worded as follows '*'post your stroke, do you think it would be useful to share ideas about how you can improve your quality of living*". ID1 said it depended on what the things were and would not try anything felt to be patronising. ID 6 felt it hinted at not giving up hope. ID 5 did not like the item as 'things' was felt to be too vague. He preferred the item to be phrased as a question rather than a statement to agree or disagree with. A dichotomous response format was the preferred format (2/4). When 'yes' was endorsed, the participants all chose the extreme ends of the other two scales (Strongly agree) (3/4). The original wording is not very definitive (worth trying) so this item may always be readily endorsed.
Suggestion: *Ideas and strategies that work for other people with stroke are helpful to my recovery*

2. I have useful information or advice to give to others regarding stroke self-management

Notes: All participants felt this was worded clearly and would be answered honestly. It was understood as sharing knowledge about stroke recovery or being helpful to other people who have had a stroke. ID5 used experience of helping others following stroke to respond to the item. ID1 pointed that you might have useful information but you can't always say what you want because of aphasia.

3. I cannot rely on others to help me recover from stroke

Notes: This was understood literally by participants. 1 participant felt the wording was very clear. 1 participant felt that the approach to this item depended on your stroke. However, 2/4 felt recovery was dependent upon help from others, citing advice from HCPs, other people who have had a stroke and family members which therefore made this item difficult to answer. 1 participant also said how it takes effort on the part of the PwS too, and suggested re-wording as below. 1 participant answered 'yes and no' depending on what the help was.

Suggestion: *Following advice from healthcare professionals is the only way I will recover from stroke*
Plus add an additional item to be more specific about who may provide assistance
I am dependent upon the help of others to help me perform tasks important to my recovery
I cannot rely solely on others to help me recover from stroke
(participant suggestion)

4. It is easy for me to do things to help the people I care about

Notes: 2 participants chose to answer this by comparing to life pre-stroke and felt this could therefore be sensitive for some respondents. 1 participant would like an example of the kinds of 'things' the item refers to. 1 participant felt that this '*had absolutely nothing to do with strokes*'. Participants found this difficult to answer and focused upon how stroke had changed life. There is a risk this item could cause distress. The social participation information may be best interpreted from other items. Suggestion: remove item

5. My physical limitations mean that I cannot manage my condition as I would like

Notes: Physical limitations was understood as physical problems, such as walking or exercise. All participants felt this was relevant to them, however 1 participant said that physical limitations mean you are forced to adapt, rather than having any choice (ID 5)
Suggestion: More probing is required to interpret how 'manage my condition as I would like' is understood

6. My communication limitations mean that I cannot manage my condition as I would like

Notes: 2 participants with aphasia answered this item the other participants felt this was irrelevant to them. 'Communication limitations' was understood by 1 participant to mean talking and more, but she was unable to elaborate on '*and more*'. 'Limitations' was thought to be overly complicated (2/2). 1 participant did not like the statement format of this item (preferred question). He felt it was a 'trick' question rather than being 'straightforward'.

Suggestion: *My communication problems mean that I cannot manage my condition as I would like*

7. I don't like asking for help from others to help me with my condition

Notes: ID1 said she wasn't allowed to ask for help from family members and was '*left to get on with it*' therefore the issue was more about being permitted to ask. In addition, she didn't like asking, but felt for her that this wasn't a big issue. 1 participant found this confusing, because it was hard to think who the 'others' could be and then generalise an answer. ID2 said that you only go back to family members who have offered help previously, and therefore you don't mind asking them. 1 participant compared how she used to be pre-stroke and now in terms of asking for help to answer the item and commented that it was difficult to adjust between the differences (ID 6). ID5 felt this was 'personal to every person' and therefore hard to answer, and he didn't like asking for help but that you are forced to. Suggestion: this item is similar to item 23 which asks about how comfortable a PwS is at asking for help. Most people will probably not like asking, so this item doesn't really evoke much else. Remove item.

8. I am able to control all other aspects of my health

Notes: 'Aspects' appears too vague ¼ and could not answer this item as it '*tries to cover too many things*'. This was interpreted as health issues unrelated to stroke by ID 2. ID5 viewed this as controlling things related to post-stroke health. It may be hard to differentiate between what is stroke or non-stroke health.

Suggestion: *I am able to control my general health*

9. Self-care of my condition is important to me to stay as healthy as possible

Notes: Self-care was interpreted as having the ability to look after yourself, doing washing, diet, surviving, doings basics and smoking were cited as examples. ID6 felt that she couldn't say self-care was important because she smoked; it made her feel like her pre-stroke self . ID5 felt it was too vague and that 'my condition' covered too many variables. 'My condition' was felt to be a confusing term – e.g.my stroke, or my health or what condition?
Suggestion: *General self-care is important to me to stay as healthy as possible*

10. My limitations due to stroke mean that I cannot manage my condition at all

Notes: This item appeared confusing for ¼ participants who gave responses contrary to their statements. 'Limitations' was felt to be a negative word (1/4). 1 participant said that once you accept limitations they become normal things again so are not perceived as limitations. Participants felt that there were some things that were manageable despite disability e.g. medication. 'Condition' was also hard to define. ID5 felt it was 'way too vague' as a condition has so many aspects to it. Being healthy after a stroke was viewed as preventing further strokes (ID 6).
Suggestion: *The effects of stroke mean that I cannot manage any aspect of my recovery and health*

11. My condition might change if I received more professional advice

Notes: This item reflects very strong views from the focus groups. Professional advice was perceived as HCP advice by ¼ participants, physiotherapy (1/4 '*what else is there?*') and social advice by ¼ participants. Change was interpreted as improve. 1 participant said 'it might', and then answered strongly agree suggesting a mis-interpretation of the scale. 1 participant pointed out that it is difficult to answer if you don't know what advice is available '*ignorance is bliss'*. This item currently appears to be one that would be condoned by the majority of respondents, including someone very proficient at self-management. More definitive re-wording may elicit a range of responses
Suggestion: *My condition would improve if I received more professional advice*

12. I have too much going on in life to pay as much attention to self-care as I should

Notes: This item was not interpreted with ease. 2/4 participants understood self-care to mean day to day tasks to stay well. 1 participant felt she was '*too lazy to change*' (but not too busy), and that self-care was not high on her priorities as it '*should*' be, suggesting that the item can be answered honestly. ID5 felt this was a '*pointless statement'* and '*it doesn't mean anything'*.
Suggestion: remove item

13. Activities or strategies that I do without the input of professionals, may worsen my condition (e.g. doing independent physiotherapy exercises)

Notes: 1 participant could not answer this because she felt she needed help to perform physiotherapy exercises (focused upon example). 1 participant liked the example but again focused upon physiotherapy and then stated how it could lead responders. Help of professionals was felt key to avoid worsening the condition (1/4). 1 participant couldn't see how doing things yourself would make you any worse. 1 participant felt it could be shorter and more to the point (no example).

Suggestion: ***Activities or strategies that I do without the input of professionals, may worsen my condition***

14. **I don't understand why some people with stroke seem to do better than me**

Notes: 3/4 participants felt they did understand and talked about differences between individuals and individual strokes. 1 participant found this difficult to articulate an answer, but could point to a response. There appears to be clear knowledge regarding the differences between individual strokes. However, 1 participant said that you are left to explain it to yourself, as no one bothers to explain it to you (ID 5). The item may be best re-worded to encourage comparison with perceived 'similar' PwS.

Suggestion: ***I don't understand why some people who have similar problems following stroke do better***

15. **I need professional advice to self-care to my best ability**

Notes: 2 participants felt this was dependent on the self-care situation. Professional advice was felt to be from medical and occupational therapists (1/4).1 participant felt you needed professional advice initially and then support should focus more upon monitoring. However, another participant felt that the things that had had the biggest impact were those he'd learnt himself and not from others (ID 5). 4/4 felt this was a clear item.

16. **No matter how hard I try, managing my stroke doesn't turn out the way I would like**

Notes: 1 participant felt this was clear and condoned the statement readily and quickly. However, 1 participant thought that 'no matter how hard I try' was an extreme phrase. Answering this was difficult for the participant because it meant reviewing a time period that has passed and was felt to be effected by your expectations of recovery. 1 participant felt there was nothing to manage, since the stroke had happened already (ID6). 1 participant found the response options

difficult to use without input for this item. 1 participant said that he doesn't try anything again if it doesn't work the first time, and that that is fine. Therefore even if things do not work as expected, it is '*no big deal'*.
Suggestion: *Generally speaking, my efforts to manage the consequences of stroke turn out the way I would like*

17. The advice given by professionals is often not relevant to my situation

Notes: 3 participants felt this was true and said they would ignore anything felt irrelevant. 1 participant felt it was less easy to dismiss the advice of a stroke specialist HCP than a generalist and felt that this could be differentiated in the item. 1 participant talked about how she has kept asking (HCPs) until she got answers. 'Given' may suggests an implicit direction by a HCP. This item appears difficult to answer with the dichotomous response option
Suggestion: *Advice offered by stroke professionals is easily applicable to my situation* AND
Advice offered by professionals generally is not relevant to my situation

18. I do not let treatment and therapy regimes rule my life

Notes: '1 participant said that he as he didn't have any treatment of therapy he could not answer this item. 'Take over my life' was preferred to 'rule my life' (1/4). This item was felt to be relevant based on the interpretation that therapy is in the patients' best interests (and therefore treatment should dominate SM strategies) (2/4). However,1 participant said this was not the case, suggesting that the item could be answered from a range of perspectives. However, both perspectives (and answers) could be viewed as being key to successful self-management as the patient employs decision-making skills– does the item therefore differentiate?
Suggestion: *When I have treatment or therapy regimes, I do not let them take over my life*

19. Sometimes performing therapy exercises is a low priority

This depends on pain, tiredness and other commitments (1/4). 'Therapy exercises' was interpreted as doing physio exercises as well as other physical activity (2/4). 1 participant interpreted this as things that 'therapists give you to do'. 2 participants could not answer as they had not been given any. This was appeared to be a

hard item to endorse because of the perception that doing exercises is a desired social norm.
Suggestion: re-word item to talk about motivation generally
It is difficult to stay motivated to do tasks or strategies important to my recovery

20. Whatever I do, I will not improve my condition

Notes: This was a clear item (3/4). The desire to keep going and stay motived appears to be a desired quality and may affect responses.

21. When things do not go well with my stroke, I still think positively

Notes: This was a clear item (2/4). However 1 participant felt it was more relevant to the earlier phases of stroke recovery. 1 participant felt this was hard to answer if you have reached 'plateau'.
Suggestion: *When things do not progress with my recovery, I still think positively*

22. I worry that my own self-care activities may make me worse (e.g. doing exercise)

Notes: The example was liked (2/4). Self-care was interpreted as being busy with activities. (2/4). 'Worry' was felt to be a negative term (1/4). All participants focused upon the example provided in approaching this item which may lead to a narrow interpretation. Participants felt that this would be answered honestly (4/4).
Suggestion: *I am concerned that my own self-care activities may worsen my condition*

23. I don't feel comfortable asking others to help me with my condition

Notes: 3 participants felt this depended on who you are asking. 1 participant felt that you had to learn to be comfortable to help your recovery. 1 participant left this blank because it was difficult to generalise an approach dependent upon who was being asked. 'With my condition' was felt to be too vague (1/4).
Suggestion: *I don't feel comfortable asking family to help me do things helpful to my recovery that I find difficult by myself*

AND

I don't feel comfortable asking friends to help me to things helpful to my recovery that I find difficult by myself

24. I am confident in asking family members or friends to help me perform activities important to managing my condition

Notes: 1 participant was not confident because she felt she had been told not to ask for help. 2/4 participants felt the item was clear. 'my condition' was felt to be vague (2/4). Activities important to managing my condition were cited as washing, cooking, cleaning, eating (1/4)
Suggestion: *I feel confident to ask family members or friends to help me do activities important to my recovery*

25. It is not up to me to decide what the best ways to manage my stroke are

Notes: 4/4 participants felt this was clear. '*Of course it's up to you*!'

26. I am able to manage things related to my stroke as well as most other people

Notes: 3/4 felt this clear. 1 participant did not know anybody else with a stroke so found it hard to compare and therefore formulate an answer. Things related to my stroke was interpreted as medication, coping with day to day disability and seeing HCPs. 1 participant commented how she liked to give '*top marks'* (when completing questionnaires), suggesting that answers might be subject to a response pattern. Participants were able to compare themselves to others in giving responses.
Suggestion: *I probably manage things related to stroke as well as most other people*

27. My limitations due to stroke mean that I cannot manage any aspect of my condition, by myself

Notes: 1 participant suggested changing 'any' to 'many' too make the item less sensitive. Thinking about what my condition means is difficult. 1 participant talked about 'managing' in terms of getting by and coping
Suggestion: *The effects of stroke mean that I cannot control many aspects of my health, by myself.*

28. Healthcare professionals should make most of the decisions about my condition

Notes: Shared decision making and co-operation with professionals was preferred (2/4) however 1 participant felt strongly that the decisions should be made by yourself. 1 participant gave responses that were incongruous to his comments, however most appeared to find this a straightforward item to answer.

29. I find it difficult to find solutions that work for problems with managing my stroke

Notes: 1 participant said there were '*no solutions'* since you '*can't turn back time*' [and not have had a stroke]'. It can be difficult to find solutions because they may not be easily available. This is different to finding it difficult due to personal factors such as motivation. 1 participant felt this was more relevant to the early stages of stroke and now it is more about managing the consequences of stroke.
Suggestion: *It is hard to be motivated to seek out and try solutions to problems relating to my stroke*

30. I am able to tell professionals what I want or need

Notes: Depends on being able to find the right words (ID 1), or being able to speak (ID5). This item is clearly worded (4/4)

31. There is little point carrying out exercises as my condition will not change

Notes: This item was clearly understood (4/4), but was less easy to endorse due to the extreme position in the statement and need to be viewed in a social desirable way. The focus upon exercise may be too narrow a view to capture motivation.
Suggestion: *There is little point in trying new ways of managing my stroke, as my condition will not change*

32. I cannot affect what my healthcare professionals decide to do about my problem(s)

Notes: Cleary understood (3/4) and felt to be relevant. 1 participant felt you could obviously affect this by telling professionals what you want. Another participant felt that this could only work if the healthcare professional moved away from 'standard procedure'. 1 participant wanted to be taught how to recover by therapists and felt that therapy was not personalised. Another participant said you had to bow to HCP expertise and be guided by their recommendations.

33. I feel confident in asking healthcare professionals questions about my stroke

Notes: Easy to understand and quick to answer and endorse item, therefore it is unclear how useful this item will be. 1 participant said he doesn't expect much in return, as his experience is that Healthcare professionals are '*vague'* (ID5).

34. I have developed ways to remember the advice given to me by healthcare professionals

Notes: Felt to be a clear item, however, ID1 said she developed ways but they were ineffective. ID5 said she can remember advice but it didn't mean whether or not she '*took any notice'*. On reflection, it is unclear how much this item tells us regarding self-management.
Suggestion: remove item

35. I always follow professional advice about my condition, to the letter

Notes: ID1 said she did not do this, however this was because she couldn't remember the advice rather than a deliberate decision not to do so. ID5 said '*no*' because she smoked (and had been advised to give up).

36. I am confident in asking family members or friends to help me perform activities important to my recovery

This item was identified as a repeat of item 24 by ¾ participants. Answers were the same for both items Suggestion: remove item!

37. I adapt professional advice so it is relevant to my situation

Notes: Depends on how the advice sits with the respondents' life situation and prior experience of advice. 4/4 participants found this to be clearly worded.

38. I pay equal attention to my physical and emotional health

Physical health was understood to be walking and doing physical activity however ID1 did not understand 'emotional health'. ID2 felt this item would be hard for other respondents to think about and answer. Participants thought it was important to pay equal attention overall but that there may be differing priorities for health at different times. 1 participant said that she paid little attention to

either, but yet this was still equal attention. This highlights how someone could endorse this item while actually be low at paying attention to physical and emotional aspects of health. 1 participant said that '*taking care'* [physical care] made him feel '*much better about everything*' [coping with his depression]
Suggestion: *It is important to pay similar attention to my physical and emotional health*

39. I try new therapies or ways of doing things in case it helps me manage my condition better

Notes: Easily understood by participants (3/4) and thought to be quite obvious to endorse, however, 1 participant said that she would (try new therapies) but has not due to a '*lack of motivation'*. 1 participant couldn't answer it because they had not been exposed to new therapies. This item may be more indicative of how receptive to change a person may be.
Suggestion: *Changing the way I do things might help me to better manage the consequences of stroke*

40. I plan my day so I can get things done without becoming tired

Notes: Depends on what is going on sometimes things cannot be planned. 1 participant strongly disagreed with this item due to a perception that she had nothing in her day to plan.
Suggestion: *Where possible, I plan my day so I can get things done without becoming tired*

41. I have found ways to remember a certain treatment or therapy regime

Notes: Thought it was clear (4/4) but not sure of relevance (2/4). 1 participant didn't have an existing treatment or therapy regime. On reflection what the item says about self-management may be quite limited, instead focusing on memory strategies.
Suggestion: remove item

42. The lifestyle choices that affect my health (for example, smoking, diet, alcohol) have not changed since having a stroke

Notes: Felt difficult to answer honestly (1/4). Examples thought to be good (3/4) but 1 suggested leaving them out to avoid leading people (1/4)
Suggestion: probe further for the influence of the examples on the responses given. ? remove examples to avoid leading

43. I know how to get help if I am concerned about my condition

Notes: Thought to be clear (3/4) by participants. All cited going to GP as a first point of call

44. I can work out problems I have about my condition without asking for professional advice

Notes: Clearly worded (2/4), but respondents felt that professional advice was necessary as a starting point. ¼ felt that the term 'my condition' was unclear, as having a stroke was '*not like being ill*' but instead was a '*brain accident*'.
Suggestion: *I can work out problems I have about the consequences of stroke without seeking professional advice*

45. I am not sure what signs or symptoms might mean my condition is changing

Notes: ID1 didn't know and felt the doctor would tell her if there was a problem (she attended for annual check-ups), but also talked about using the internet to find out information. 1 participant felt that health or situation would be a better substitute for 'my condition', and said she would not know if she was having another stroke.
Suggestion: *I am not sure what signs or symptoms might mean my health is changing*

46. I have worked out ways of managing my stroke together with healthcare professionals

Notes: 1 participant did not like the focus on stroke ('*that happened in the past, it's now that counts*') and would prefer health or situation to be used. 1 participant was not sure what was meant by 'healthcare professionals'.
Suggestion: *I have worked out ways of managing my health together with healthcare professionals* Probe for understanding of the term healthcare professionals

47. I understand what my prescribed medication is for

Notes: All participants felt the item would be answered honestly. However when 'understand' was probed more fully, the reasons given for the purpose of prescribed medication were difficult to articulate and participants felt they didn't really have much control over what was prescribed. This item is not intended to catch people out

regarding their knowledge, but rather to prompt them to think about the influence they have on prescribed medication.
Suggestion: *I feel consulted about any medication I am prescribed*

48. I know what symptoms to look out for that might show I need professional advice

Notes: Some participants were not sure what 'symptoms' meant (2/4). 1 participant would remove it as she found it difficult to answer. 1 participant found this hard because he didn't recognise his stroke before. 1 participant felt it was too vague. The item is intended to capture self-monitoring of health generally. However it may infer that PwS should know what to look out for to avoid stroke and will therefore be sensitive and inappropriate.
Suggestion: remove item

49. I always ask healthcare professionals to explain things that I don't fully understand

Notes: An assumption that HCPs would expect this ('*they are employed to help me*') and should be able to explain things in lay terms (2/4). 1 participant said that the way information is given affects the likelihood of you doing it- the rationale being explained behind advice.

50. I feel confident in disagreeing with healthcare professionals, if their advice seems irrelevant to me

Notes: Difficult to answer honestly (2/4). Prior experience of doing so influenced the response to item.

51. I take more care with my diet to stay healthy since having a stroke

Notes: Difficult to answer in a negative way. 1 participant said that many people will lie because they '*like to please*'. ID5 said that he had always taken care with his diet.
Suggestion: *I have made changes to my lifestyle since having a stroke to improve my health*

52. I feel able to access the information I need to make decisions about my condition

Notes: Interpreted as accessing information from the internet, from leaflets, pamphlets and books but not readily from HCPs (3/4). ID5 talked about the lack of a central point to find information out. 'Access' was interpreted as a physical place to gain information (1/4). Suggestion: further probe of the term 'access' and 'make decisions'

53. I make sure that I find time to relax and enjoy life

Notes: 4/4 felt this was important and relevant to recovery. Item clear, however 1 participant felt that he '*wasn't enjoying life, just getting by'*. Therefore questions exist regarding how someone experiencing low mood would respond to the item.
Suggestion: *Finding time to relax and enjoy life is important to my recovery*

54. I generally succeed in the strategies I use to manage my stroke

Notes: The item aims to tap into how confident someone is to self-manage. Confusion with the use of 'generally' and how to measure success (1/4). 1 participant suggested taking out 'generally'. 1 participant said her '*stroke was something in the past'*, and she is left with the '*residue'* therefore felt unable to answer this item. 1 participant said that you wouldn't use the strategies if they didn't succeed.
Suggestion: *I try different ways of doing things, or different strategies until I find out what works for me*

55. I use technology, such as the internet to seek advice or information about my condition

Notes: Item clear (3/4). Not sure how useful this item is, if you are unable to use technology (1/4 did not).
Suggestion: remove item

56. I feel sure that the efforts I take to manage my condition have a real positive effect

Notes: Complicated wording (2/4), what does '*effect*' mean? 'My condition' a difficult concept to describe
Suggestion: *The efforts I take to manage my health have a real positive effect*

57. Support from other people who have had a stroke is important to my own recovery

Notes: Understood literally (3/4) and felt to be important to recovery (2/4). 2/4 felt it was unimportant, suggesting this item could differentiate. Re-worded to make it clearer
Suggestion: *Advice from other people who have had a stroke is important to my recovery*

<u>Response format preferences</u>

ID 1 – Numerical anchored Likert response format and dichotomous scale were '*too black and white*' and did not appeal, use of faces would be too patronising. Colour and font size acceptable.
ID 2- Dichotomous scale and verbal Likert response format preferred. Font size acceptable. Would like response options as you go along and clear sections to break it up
ID 5 – Likert response format preferred. Larger font size.
ID 6 – Dichotomous scale preferred. Would like no more than 3 response options at most.

57 items seemed to be too long and burdensome for 2/4 participants. The other two participants appeared happy with this amount.
In summary, the item pool reduced from 57 – 53 items; 37 items were amended.

Appendix 11- Item pool for second round of cognitive interviewing

1. Ideas and strategies that work for other people with stroke are helpful to my recovery
2. I have useful information or advice to give to others regarding stroke self-management
3. Following advice from healthcare professionals is the only way I will recover from stroke
4. I am dependent upon the help of others to help me perform tasks important to my recovery
5. I cannot rely solely on others to help me recover from stroke
6. My physical problems mean that I cannot manage my condition as I would like
7. My communication problems mean that I cannot manage my condition as I would like
8. I am able to control my general health
9. General self-care is important to me to stay as healthy as possible
10. The effects of stroke mean that I cannot manage any aspect of my recovery and health
11. My condition would improve if I received more professional
12. Activities or strategies that I do without the input of professionals, may worsen my condition
13. I don’t understand why some people who have similar problems following stroke do better
14. I need professional advice to self-care to my best ability

15. Generally speaking, my efforts to manage the consequences of stroke turn out the way I would like
16. Advice offered by stroke professionals is easily applicable to my situation
17. Advice offered by professionals generally is not relevant to my situation
18. When I have treatment or therapy regimes, I do not let them take over my life
19. It is difficult to stay motivated to do tasks or strategies important to my recovery
20. Whatever I do, I will not improve my condition
21. When things do not progress with my recovery, I still think positively
22. I am concerned that my own self-care activities may worsen my condition
23. I don’t feel comfortable asking family to help me do things helpful to my recovery that I find difficult by myself
24. I don’t feel comfortable asking friends to help me to things helpful to my recovery that I find difficult by myself
25. I feel confident to ask family members or friends to help me do activities important to my recovery
26. It is not up to me to decide what the best ways to manage my stroke are
27. I probably manage things related to stroke as well as most other people

28. The effects of stroke mean that I cannot control many aspects of my health, by myself.
29. Healthcare professionals should make most of the decisions about my condition
30. It is hard to be motivated to seek out and try solutions to problems relating to my stroke
31. I am able to tell professionals what I want or need
32. There is little point in trying new ways of managing my stroke, as my condition will not change
33. I cannot affect what my healthcare professionals decide to do about my problem(s)
34. I feel confident in asking healthcare professionals questions about my stroke
35. I always follow professional advice about my condition, to the letter
36. I adapt professional advice so it is relevant to my situation
37. It is important to pay similar attention to my physical and emotional health
38. Changing the way I do things might help me to better manage the consequences of stroke
39. Where possible, I plan my day so I can get things done without becoming tired
40. The lifestyle choices that affect my health (for example, smoking, diet, alcohol) have not changed since having a stroke
41. I know how to get help if I am concerned about my condition

42. I can work out problems I have about the consequences of stroke without seeking professional advice
43. I am not sure what signs or symptoms might mean my health is changing
44. I have worked out ways of managing my health together with healthcare professionals
45. I feel consulted about any medication I am prescribed
46. I always ask healthcare professionals to explain things that I don’t fully understand
47. I feel confident in disagreeing with healthcare professionals, if their advice seems irrelevant to me
48. I have made changes to my lifestyle since having a stroke to improve my health
49. I feel able to access the information I need to make decisions about my condition
50. Finding time to relax and enjoy life is important to my recovery
51. I try different ways of doing things, or different strategies until I find out what works for me
52. The efforts I take to manage my health have a real positive effect
53. Advice from other people who have had a stroke is important to my recovery

Appendix 12 Summary of findings following second round of cognitive interviewing

1. Ideas and strategies that work for other people with stroke are helpful to my recovery (Round 1 'It is worth trying things that work for other people with stroke')

Notes: Felt to be a clear item (3/3). ID4 talked about not knowing if something was going to help but that it was '*worth a go'*. ID7 felt that there was some truth in the statement, but pointed out that people have different strokes and that differences in people (e.gs of age/gender/education were given) would depend on whether you could relate to their experiences or not. ID3 felt that she did not have the opportunity to draw on other peoples experience since her stroke was 'missed', however she felt it would have been useful.
Suggestion: item remains

2. I have useful information or advice to give to others regarding stroke self-management

Notes: Unchanged from round 1. ID4 talked about how '*keeping the brain working'* was important and how feeling useful was important to his psychological recovery. ID7 talked about the importance of having recovery goals. He used the example of a speaker he heard which he felt was motivating, and supposed that this kind of advice could also be motivating to others. ID3 perceives herself to currently do this in her role on various committees promoting equitable treatment for people with disabilities. Self-management was thought to involve being able to '*recognise, control and accept*' what has happened to you (ID 7) and '*taking control'* (ID 3).
Suggestion: item unchanged

3. Following advice from healthcare professionals is the only way I will recover from stroke (Round 1 - I cannot rely on others to help me recover from stroke)

Notes: ID4 was unconvinced that following advice was the only way to recover and notes that it depended on the expertise of the HCP. He felt strongly that it was very much up to the individual to persist with their recovery. HCPs were understood as being people trained and educated in stroke. 1 participant highlighted how disagreement between doctors means their word cannot be '*gospel*' (ID 7). Seeing professionals regularly was viewed as being

a '*confidence builder'*. Some felt that HCPs did not know enough about life pre-stroke to give you useful advice (ID 4). Experience and age enables you to '*recognise and realise your own body'* (ID 7). ID3 felt that HCP advice had to be taken with a '*pinch of salt'* as there are *'degrees of expertise'*. Participants 3 & 7 talked about how they would research things (e.g. medication was discussed) and then '*make up their own minds'*. Reword to avoid focus on recovery which may exclude some respondents.
Suggestion: Following advice from healthcare professionals is the only way I will manage stroke

4. I am dependent upon the help of others to help me perform tasks important to my recovery (developed as a result of round 1)

Notes: Need to be '*proactive*' to restore QoL (ID 4). To '*expand horizons'* you need to be persistent at pursuing new treatments or concessions for disabled people (ID 4). ID7 felt the answer depended when after stroke the question was asked, but was able to appraise his situation now and how it had changed. 'tasks important to my recovery' was described as '*things you needed to do to get on*' (ID4) and '*doing rehabilitation'*. ID3 felt this was hard to answer as she perceived herself to not be '*recovering*'. 'Dependent' was not a preferred term (2/3).
Suggestion: *I am reliant upon the help of others to help me do things important to my health and well-being*.

5. I cannot rely solely on others to help me recover from stroke (developed as a result of round 1)

Notes: Need for determination and pro-activism (ID 4). ID7 felt it was very important that you didn't rely on others to be independent. ID3 felt that you couldn't avoid relying on others, but probing of the word 'solely' led to an acknowledgement there were some things you could do yourself. ID7 felt that some people would not answer it honestly for fear of losing any help they currently had, or fear of not being able to get help when it was needed, especially in current economic climate. Reword to avoid focus on recovery which may exclude some respondents.
Suggestion: I cannot rely solely on others to help me manage the consequences of stroke

6. My physical problems mean that I cannot manage my condition as I would like (round 1 - My physical limitations mean that I cannot manage my condition as I would like)

Notes: ID4 answered this by summarising his physical limitations and the progress he has made and changes to his ability. 'Managing my condition' was viewed as being able to get to appointments, being unable to wash and get dressed (ID 4). Physical problems stop independence, which is '*frustrating*' (ID 4). However, this does not seem to stop effective self-management '*We work through it, progress is do-able, but it might mean going back before going forwards*' (ID 4). ID7 talked about his own limitations in order to answer this item. 'Physical disability', 'physical limitation' or 'physical condition' was preferred to 'physical problem'.
Suggestion: The physical effects of stroke mean that I cannot manage my condition as I would like

7. My communication problems mean that I cannot manage my condition as I would like (round 1- My communication limitations mean that I cannot my condition as I would like)

Notes: ID 4 did not answer as N/A. ID 3 and 7 felt this would be different according to '*where in recovery you were'*. This point (which is true in item 6 also) is likely to affect the responsiveness of the final scale. Reword to avoid attribution of problems to PwS.
Suggestion: My problems with communication mean that I cannot manage my condition as I would like

8. I am able to control my general health (round 1- I am able to control all other aspects of my health)

Notes: '*I am capable of living within a treatment regime, can contact a doctor or dentist, or initiate something if I feel the need to, so I think I am'* (ID 4). ID 4 talked about maybe buying a home BP monitor machine to '*keep tabs'*. ID7 talked about how he had made changes to his lifestyle to affect his health. General health was interpreted as 'weight' 'cholesterol' 'diet', 'exercise' and '*nothing complex'*. ID3 talked about how her disability (following stroke) made managing her other LTCs more problematic.
Suggestion: item remains

9. General self-care is important to me to stay as healthy as possible (round 1- Self-care of my condition is important to me to stay as healthy as possible)

Notes: Self-care understood as being disciplined in personal hygiene, toileting (ID 3,4,7). On further thought, exercise was also thought to be part of SC (ID 7). This was thought to be relevant to a PwS as an

indicator of when health might be deteriorating (lack of care with appearance) (ID 7).
Suggestion: item remains

10. The effects of stroke mean that I cannot manage any aspect of my recovery and health (round 1 - My limitations due to stroke mean that I cannot manage my condition at all)

Notes: '*don't buy that'* (ID 4). '*you could just exist, but you have to work within a regime, set by yourself* (to recover and not give up)' (ID 4). '*don't agree with that at all*' (ID 7). The use of 'any' promoted lots of discussion. Participants suggested using 'some' or 'many' instead of 'any'. Participants wanted to alter the statement so it best reflected their situation. All participants answered a definitive 'No' on the dichotomous scale, however gave differing answers using the other response formats, suggesting an appraisal of the statement and ability of the item to be discriminative. If 'some' or 'many' were used (instead of any) it may limit this variance in responses as both are subjective terms.
Notes: Depends on the accompanying response format. Dichotomous scales unlikely to be sensitive or responsive with this item. Item remains

11. My condition would improve if I received more professional help (round 1 - My condition might change if I received more professional advice)

Notes: There was a range of responses to this item. '*Perhaps, dependent upon how good the advice is how motivated I am to follow advice'* (ID 4). '*I am convinced I'd be worse off if I didn't have the private* (therapy)' (ID 4). '*Probably not*' (ID 7) as help that was received was perceived as being '*satisfactory*' as therapy was not provided 7 days a week. Nurses and therapists spent a '*lot of time on computers'*. '*Definitely, but the help is not there*' (ID 3). This item is likely to be affected by how long after stroke the respondent is.
Suggestion: item remains

12. Activities or strategies that I do without the input of professionals, may worsen my condition (round 1 - Activities or strategies that I do without the input of professionals, may worsen my condition (e.g. doing independent physiotherapy exercises)

Notes: ID 3 and 7 felt this needed to be re-worded to make it clearer. '*don't agree*' (ID 4). On probing, responses depended on the advice or

strategy given and on the degree of confidence had in carrying it out and also upon confidence in knowing what to do if '*things went wrong'*. ID7 said he wouldn't '*mess around with medication'* and that this item wasn't relevant to him, as if his condition was worsening he would consult a professional. He talked about managing his blood pressure through taking exercise, eating wisely, reducing his weight and measuring his BP at his local surgery. ID 3 felt this was about being '*sensible'* and not taking on '*anything daft'* (cited as exercise, or homeopathy) without advice (professional). The item aims to judge how 'risk' is assessed by a PwS, and levels of responsibility for their health they feel are attributed to HCPs/selves
Suggestion: Activities or strategies I do without the guidance of professionals may worsen my health

13. I don't understand why some people who have similar problems following stroke do better (round 1 - I don't understand why some people with stroke seem to do better than me)

Notes: Participants were all able to talk about differences in recovery from stroke and about personal factors ('*being dynamic', 'education levels' 'family who help'*). Hard to compare who is 'similar'. Answering the item depended on whether participants could compare with someone with the same type of stroke. Which prompts the question what is the same or similar, in terms of stroke? Not convinced this is either an attitude, behaviour or skill or what the item indicates.
Suggestion: remove item

14. I need professional advice to self-care to my best ability

Notes: ID 4 &7 disagreed with this statement. ID3 felt that help or advice was needed in the initial stages. Self-care was interpreted mainly as ADLs, which may affect responses to this item. Item could be reworded to focus upon self-management and the extent the respondent views the role of HCPs in SM.
Suggestion: I need constant professional advice to self-manage stroke

15. Generally speaking, my efforts to manage the consequences of stroke turn out the way I would like (round 1- No matter how hard I try, managing my stroke doesn't turn out the way I would like)

Notes: ID 4 & 7approached the item by thinking over the timeframe of their recovery and thinking of a summary. 'Consequences of stroke' was interpreted as resulting disability, including emotions. ID 7 preferred this term. ID3 felt that her efforts were usually thwarted.

Suggestion: reworded for clarity - Generally speaking, my efforts to manage the consequences of stroke turn out how I like

16. **Advice offered by stroke professionals is easily applicable to my situation (round 1- The advice given by professionals is often not relevant to my situation)**

Notes: ID 4 cited a practice nurse, physiotherapist and psychologist as his current stroke professionals. To answer this item people appeared to draw on those HCPs they currently see, not those they have ever seen. ID7 felt that HCPs were often not as '*well-versed'* as he thought they should be and also questioned why some HCPs give advice (talking at conferences) when they should be doing '*serious stuff'*. ID3 found it frustrating when your questions were not answered (e.g. when asking a therapist, 'what does salt do? How much can I have?') which gave an impression that the HCP knowledge base generally was not deep. This may be a desired SM attribute, however focuses more on the HCP role than the PwS, therefore is less reflective of pt experience of self-management
Suggestion: remove

17. **Advice offered by professionals generally is not relevant to my situation (developed following round 1)**

Notes: 'Advice' was interpreted as '*something less direct'* or a '*recommendation*' (ID 7). Again, this is less reflective of pt experience of self-management, as it depends more on the role of the HCP than the PwS's behaviour/attitudes.
Suggestion: remove

18. **When I have treatment or therapy regimes, I do not let them take over my life (round 1 - I do not let treatment and therapy regimes rule my life)**

Notes: ID 4 has adapted regimes so they have '*appeal*' and '*fit*' into lifestyle. Participants found it frustrating to be '*controlled*' by anything they didn't want to do. ID4 drew on his current physiotherapy, and negotiating within each session, to consider this item. ID 7 felt that he would either follow or challenge any regime, but not think about it all the time. ID 3 felt that all advice had to be taken with a '*pinch of salt'* and used the examples of avoiding taking BP readings when she knew she was '*stressed*'. Reword for clarity.

Suggestion: When I have treatment or therapy regimes, they do not take over my life

19. It is difficult to stay motivated to do tasks or strategies important to my recovery (round 1 - Sometimes performing therapy exercises is a low priority)

Notes: Participants readily understood this item. However, this item may arguably be hard to endorse (social desirability connotations)
Suggestion: item remains

20. Whatever I do, I will not improve my condition

Notes: ID 4 talked about a need to initiate concerns with his GP. He felt feeling this sentiment would be unwise. 'Whatever I do' was interpreted as being '*helpless*'. ID 3 felt that this statement resonated with her.
Suggestion: item remains

21. When things do not progress with my recovery, I still think positively

Notes: Readily endorsed by 2/3 participants. ID 3 felt that this didn't apply to her as she does not perceive herself to be '*still recovering'*. Item could be made clearer by using consistent meaning (there is confusing use of negative and positive phrases)
Suggestion: When things do not go well with my stroke, it is hard to stay positive.

22. I am concerned that my own self-care activities may worsen my condition (round 1- I worry that my own self-care activities may make me worse (e.g. doing exercise))

Notes: ID 4 interpreted self-care activities as personal care and therefore couldn't understand how this might worsen your condition, instead viewing it as a good thing to be taking responsibility for. ID 7 & 3 also did not understand the item.
Suggestion: I am concerned that things I do to manage stroke, may cause harm if not guided by healthcare professionals

23. I don't feel comfortable asking family to help me do things helpful to my recovery that I find difficult by myself (round 1- I don't feel comfortable asking others to help me with my condition)

Notes: Negatively worded item slightly problematic to interpret (2/3). 'Family' interpreted as '*nuclear family'* (spouse and children) (ID 4). Felt to be *'too long*' an item, with an over-complicated structure (ID 4). ID 7 would feel comfortable asking '*close*' family, but not other family members. ID 3 felt that this was emotional to answer since her relationship with her children had changed. All said they would not feel comfortable in asking for help, but would do it if they had to.
Suggestion: remove item

24. I don't feel comfortable asking friends to help me to things helpful to my recovery that I find difficult by myself (round 1- I don't feel comfortable asking others to help me with my condition)

Notes: Negative wording problematic (2/3). '*depends on the help'* (ID 4) ID 7 said he would ask friends he knew well. ID 3 said that you ask specific friends for specific things. Reword to avoid negative wording which appears problematic.
Suggestion: I feel comfortable asking friends to help me with activities important to my health that I find difficult

25. I feel confident to ask family members or friends to help me do activities important to my recovery (round 1 - I am confident in asking family members or friends to help me perform activities important to managing my condition)

Notes: Negative wording problematic (2/3) ID 7 felt that if there was something important to his recovery he would do it himself (and not ask others). ID 3 felt that she was not '*recovering*' in her view so this was difficult to answer. Suggestion: I feel confident asking family members to help me with activities important to my health that I find difficult

26. It is not up to me to decide what the best ways to manage my stroke are

Notes: ID4 used a 1-10 scale to explain his answer. He drew on his own upbringing where being self-sufficient had a high value, to answer the question. ID4 said there is a distinction between the '*medical' 'must do'* things to '*stay alive'* (e.g. medication) and therapy and recovery type decisions (using an exercise band). ID 3 talked about needing guidance initially to get you '*started on the right track'*.

Suggestion: item remains

27. I probably manage things related to stroke as well as most other people (round 1- I am able to manage things related to my stroke as well as most other people)

Notes: ID 4 felt this would make more sense if '*most*' was removed. Item relies on knowing '*most other people'*. ID 4 was able to compare himself to others. Clarification was needed re if this item meant most other people or most other people who had had a stroke.
Suggestion: I manage things related to stroke as well as other people with stroke

28. The effects of stroke mean that I cannot control many aspects of my health, by myself (My limitations due to stroke mean that I cannot manage any aspect of my condition, by myself)

Notes: Prompted a lot of discussion during CI. ID 7 felt that '*many'* is better than 'any' and interpreted 'aspects of my health' as '*health not being a single thing as health is affected by many different things*'. ID 3 and 4 felt that encouraged the PwS to look at the things they are doing to help themselves, and that not all people would '*like what they saw.*'
Suggestion: item remains

29. Healthcare professionals should make most of the decisions about my condition

Notes: ID4 felt there is a distinction between the advice of medical professionals '*interested in keeping you alive'* and therapists who are *'concerned with recovery'*. He would agree with medical professionals (GP and consultants) but question therapy advice more. ID 4 felt that therapy advice is more '*common sense'* and doesn't rely on '*specific knowledge'*. ID 3 also felt that she would more readily follow '*doctors orders'*. Re-word item to place emphasis on PwS.
Suggestion: I should make most of the decisions about how my stroke is managed

30. It is hard to be motivated to seek out and try solutions to problems relating to my stroke (round 1 - I find it difficult to find solutions that work for problems with managing my stroke)

Notes: Of 3 participants, 2 disagreed with this statement. Potentially response to this item may be affected by social desirability. Two

things were asked about in this item ‘seeking out’ and ‘trying’ complicating responses. Reword.
Suggestion: It is hard to be motivated to seek out solutions to problems relating to stroke.

31. I am able to tell professionals what I want or need

Notes: All participants felt they were able to do this and that this was very relevant to PwS. On further probing, it appeared that not all participants had actually been able to tell HCPs their needs. Reword to encourage item appraisal.
Suggestion: I find it difficult to always tell professionals what I want or need

32. There is little point in trying new ways of managing my stroke, as my condition will not change (round 1 - There is little point carrying out exercises as my condition will not change)

Notes: ID 4 & 7 readily disagreed with this statement, talking about how things do change using their own experience as examples. ID 3 felt that her stroke was in the past. ID 7 felt that the item ‘*encouraged the right answer, one way or another.’*
Suggestion: There is little point in trying new ways of managing the consequences of stroke, as it will not change my condition

33. I cannot affect what my healthcare professionals decide to do about my problem(s)

Notes: Participants used their own experiences to answer this. ‘I cannot affect’ was interpreted as being unable to change a recommended course of action (ID 4). ID 4 felt the item was a ‘*bit ambiguous’* and depends on ‘*how confident you are’* ID7 did not agree with the statement. He felt that the item referred to anything that could help him with decision making. ID3 felt that it is important to ‘*get your point across’*, but that ‘*they (HCP) also have to listen’*. Reword to change emphasis to stroke and avoid assumption of problems.
Suggestion: I cannot affect what my healthcare professionals decide to do about my stroke

34. I feel confident in asking healthcare professionals questions about my stroke

Notes: Understood by all participants. This item focused upon questions, which may not be the only information is obtained from a HCP (e.g. leaflets, reflexivity of HCP, manner of delivery etc).

Suggestion: reword - I feel confident in getting the information I need from healthcare professionals.

35. I always follow professional advice about my condition, to the letter

Notes: Participants were able to reflect on their own situation to answer the item. 'to the letter' was felt to be very clear, i.e. doing exactly what the advice asks.
Suggestion: item remains

36. I adapt professional advice so it is relevant to my situation

Notes: A distinction between medical and AHP advice, the purpose of the advice is thought to be different (ID 4). '*Adapting is one thing, asking is another*', advice would be questioned rather than adapted, which was perceived as being '*dodgy'* (ID7).
Suggestion: Reword- I apply professional advice so it is relevant to my situation

37. It is important to pay similar attention to my physical and emotional health (round 1 - I pay equal attention to my physical and emotional health)

Notes: Physical health was interpreted as physical well-being such as weight, balance and function (ID 4). ID4 found this difficult to answer he didn't perceive he had any '*emotional issues*', '*I am content*'. He then went onto talk about how he woke up early worrying about things on occasions. ID7 felt that emotional health was a problem for him, and they were more complex. However, following 2 rounds of CI, although this item appears relevant to stroke, it is not clear how this item would be a discriminator for stroke self-management.
Suggestion: remove item

38. Changing the way I do things might help me to better manage the consequences of stroke (round 1 - I try new therapies or ways of doing things in case it helps me manage my condition better)

Notes: '*Difficult to know – if you think they might help you will change, if you don't think they will you could go on as you are'* (ID 7). ID3 felt that there wasn't really much different that she could do. Item seems to have potential to be an indicator of SM, attitudes and behaviours.

Suggestion: item remains

39. Where possible, I plan my day so I can get things done without becoming tired (round 1- I plan my day so I can get things done without becoming tired)

Notes: Item prompted a range of responses. Participants had different interpretations of what ‘where possible means’, dependent upon context, experience etc.
Suggestion: re word - I plan my day so I can get things done without being tired

40. The lifestyle choices that affect my health (for example, smoking, diet, alcohol) have not changed since having a stroke

Notes: All participants felt this was relevant and important to health following stroke. The examples were again liked in this round.
Suggestion: leave item and examples

41. I know how to get help if I am concerned about my condition

Notes: The GP would be the first step or a neurophysio (ID4). ID7 would look at the internet first or talk to spouse and also talked about AHPs (e.g. visiting an optician for a visual disturbance). ID 3 would talk with family or friends before going to GP.
Suggestion: item remains

42. I can work out problems I have about the consequences of stroke without seeking professional advice (round 1 - I can work out problems I have about my condition without asking for professional advice)

Notes: over-complicated wording (2/3). Participants found this item too wordy.
Suggestion: I find answers to problems about stroke without seeking professional advice

43. I am not sure what signs or symptoms might mean my health is changing (round 1 - I am not sure what signs or symptoms might mean my condition is changing)

Notes: ID 4 cited *‘obvious’* red flags such as severe weight loss. ID3 felt that she knew her body ‘*inside out’*, and would not rely on check-ups to act on anything she felt was wrong.

Suggestion: item remains

44. I have worked out ways of managing my health together with healthcare professionals (round 1 - I have worked out ways of managing my stroke together with healthcare professionals)

Notes: ID4 talked about negotiating treatment and exercises or sometimes just not doing things that don't appeal without directly saying so to avoid causing offence. Healthcare professionals were described as someone you could *'respect'* (ID 7) with '*special knowledge'* (ID 3). ID 7 said he did not immediately think of doctors, but more those at a '*level lower'* such as *'physiotherapists and psychiatrists'*. Reword to change emphasis to stroke and avoid past tense.
Suggestion: I work out ways of managing my health following stroke together with healthcare professionals

45. I feel consulted about any medication I am prescribed (round 1- I understand what my prescribed medication is for)

Notes: ID4 talked about how he wasn't consulted about medication whilst in hospital (even when he could be included), but felt he was in the '*GP setting'*. ID 7 felt that he would research medication before taking it. ID 7 & 3 did not feel consulted about medication. This item might assume there was a problem or lack of understanding about medication, whereas the item aims to gauge the extent a PwS is involved in prescribing.
Suggestion: I talk about any medication I am prescribed with healthcare professionals

46. I always ask healthcare professionals to explain things that I don't fully understand

Notes: Participants all stated they would question things they didn't understand. To make this item more discriminative and to focus on the desired SM behaviour of negotiating with HCPs, item could be re-worded.
Suggestion: I always ask healthcare professionals to explain why I should follow their advice

47. I feel confident in disagreeing with healthcare professionals, if their advice seems irrelevant to me

Notes: ID4 felt he would be more able to disagree with a therapist (than a doctor or nurse), or just ignore their advice without overtly saying he disagreed. ID 7 said he would find out if the HCP understood what he was saying before disagreeing. ID 3 said she would be more likely to ignore their advice rather than disagree. Arguably the term disagree is too extreme and may affect responses. Item can be reworded to acknowledge there may be a different approach dependent upon the HCP (think previous item captures HCPs generally)
Suggestion: I feel confident at discussing any advice I don't understand, with Doctors.

48. **I have made changes to my lifestyle since having a stroke to improve my health (round 1 - I take more care with my diet to stay healthy since having a stroke)**

Notes: all participants drew on their experience to answer this item. They felt the item would not be sensitive to others (attributing blame). Smoking, drink, diet and social engagements were cited as lifestyle factors.
Suggestion: item remains

49. **I feel able to access the information I need to make decisions about my condition**

Notes: ID3 interpreted 'access' in the physical sense (i.e. being able to enter a health centre). Instead, the item aims to elicit the extent that a respondent can gain information to aid decision making.
Suggestion: I am confident that healthcare professionals can answer my questions.

50. **Finding time to relax and enjoy life is important to my recovery (round 1- I make sure that I find time to relax and enjoy life)**

Notes: ID 4 was uncertain of the relevance of the item (1/3). ID3 and 7 felt it was important to have something to '*apply yourself to*', and to '*enjoy life*'. ID 7 felt it was about moving on and doing things that stop you thinking about your situation. Not sure how much this item discriminates between those who are, or are not effective self-managers
Suggestion: remove item

51. I try different ways of doing things, or different strategies until I find out what works for me (round 1 - I generally succeed in the strategies I use to manage my stroke)

Notes: All participants felt they had the ability to try different strategies and used examples to illustrate.
Suggestion: item remains

52. The efforts I take to manage my health have a real positive effect (round 1- I feel sure that the efforts I take to manage my condition have a real positive effect)

Notes: ID 3 felt that she was often trying hard but to no '*real avail'*. ID 7 talked about the positive effect on his '*state of mind'* and used an example from his recovery to illustrate. ID 4 endorsed the item and felt that if he didn't perceive there to be a positive effect, he wouldn't make the effort. Reword to improve clarity
Suggestion: The efforts I take to manage my health have a positive effect

53. Advice from other people who have had a stroke is important to my recovery (round 1 - Support from other people who have had a stroke is important to my own recovery)

Notes: ID 4 answered '*yes*', but identified that he hadn't *'really found anyone who's had a stroke that has* (given advice)*'.* ID 7 felt he could give advice, but had not received advice, but that this would have been helpful in hospital. ID 3 talked about how responding depended on the advice and how it was given. The link between this item and self-management maybe unclear, as it depends on the PwS gaining 'useful' advice and that PwS wanting to seek a shared experience of stroke.
Suggestion: remove item

Format issues

Font size is fine (size 14)

Black, white or yellow are easy to read, '*but not red'*

Yellow or cream was preferred

Items should be grouped together in similar sections with headings

Response format:

Dichotomous options are '*too stark'* (ID 4,7,3)

Tick boxes would be nice, as a basis for discussion, would also like free text boxes to add additional comments
Scales without numbers are more understandable (3/3)
ID 7 felt that the numerical and strongly agree-strongly disagree scale was '*boring'* as you '*see it a lot'*.

ID 7 felt that after 45 minutes of the CI he could feel his concentration was going. 20-25 minutes was felt to be long enough to answer the final measure. Or suggested breaks to enable people to return to answering the measure

Appendix 13 Item pool for final round of cognitive interviewing

1. Ideas and strategies that work for other people with stroke are helpful to my recovery
2. I have useful information or advice to give to others regarding stroke self-management
3. Following advice from healthcare professionals is the only way I will manage stroke
4. I am reliant upon the help of others to help me do things important to my health and well-being
5. I cannot rely solely on others to help me manage the consequences of stroke
6. My physical effects of stroke mean that I cannot manage my condition as I would like
7. My communication problems mean that I cannot manage my condition as I would like
8. I am able to control my general health
9. General self-care is important to me to stay as healthy as possible
10. The effects of stroke mean that I cannot manage my recovery and health
11. My condition would improve if I received more professional help
12. Activities or strategies that I do without the input of professionals, may worsen my health
13. I need constant professional advice to self-manage stroke
14. Generally speaking, my efforts to manage the consequences of stroke turn out the way I would like
15. When I have treatment or therapy regimes, they do not take over my life
16. It is difficult to stay motivated to do tasks or strategies important to my recovery
17. Whatever I do, I will not improve my condition

18. When things do not go well with my stroke progress, it is hard to stay positive
19. I am concerned that things I do to manage stroke, may cause harm if not guided by healthcare professionals
20. I feel comfortable asking friends to help me with activities important to my health that I find difficult
21. I feel confident asking family members to help me with activities important to my health that I find difficult
22. It is not up to me to decide what the best ways to manage my stroke are
23. I manage things related to stroke as well as other people with stroke
24. The effects of stroke mean that I cannot control many aspects of my health, by myself.
25. I should make most of the decisions about how my stroke is managed
26. It is hard to be motivated to find solutions to problems relating to stroke
27. I find it difficult to always tell professionals what I want or need
28. There is little point in trying new ways of managing the consequences of stroke, as it will not change my condition
29. I cannot alter what my healthcare professionals decide to do about my stroke
30. I feel confident in getting the information I need from healthcare professionals
31. I always follow professional advice about my condition, to the letter
32. I apply professional advice so it is relevant to my situation
33. I regularly think about how I can change things to help me manage the consequences of stroke
34. I plan my day so I can get things done without being tired
35. The lifestyle choices that affect my health (for example, smoking, diet, alcohol) have not changed since having a stroke

36. I know how to get help if I am concerned about my condition
37. I find answers to problems about stroke without seeking professional advice
38. I am not sure what signs or symptoms might mean my health is changing
39. I have worked out ways of managing my health following stroke together with healthcare professionals
40. I talk about any medication I am prescribed with healthcare professionals
41. I always ask healthcare professionals to explain why I should follow their advice
42. I feel confident at discussing any advice I don't' understand with Doctors
43. I have made changes to my lifestyle since having a stroke to improve my health
44. I try different ways of doing things, until I find out what works for my health
45. The efforts I take to manage my health have a positive effect
46. I am confident that healthcare professionals can answer my questions

Appendix 14 Summary of findings following final round of cognitive interviewing

1. Ideas and strategies that work for other people with stroke are helpful to my recovery (Round 1 'It is worth trying things that work for other people with stroke')

Notes: ID 9 talked about wanting to try things that had worked for others, but that this was restricted by funding available locally. Item was understood as talking to other people who are stroke survivors and learning from them (ID 8, 10, 11). The term 'recovery' was understood as getting to your optimal level (ID 8, 10), but in addition not necessarily how you were before stroke but accepting how you are (ID 10,11).

2. I have useful information or advice to give to others regarding stroke self-management (unchanged from round 1)

Notes: ID9 & 11 had not heard of the term 'self-management', but thought it might mean what people do to help themselves recover. Self-management was also described as fighting to '*get what you need to help yourself'* (ID 8). ID 10 talked about passing information on (to other PwS, or to partners/carers), either via a group, or discussing places, resources and exercises which helped you. 'Self-management' was understood as taking info from HCP and learning to incorporate the advice, '*using and interpreting it* (advice) *to your needs'* . Also recognising improvements and finding out information for yourself (internet) (ID 10). This item was thought to be time dependent (ID 10), i.e. it might change at different time durations after stroke.

3. Following advice from healthcare professionals is the only way I will manage stroke (Round 1 - I cannot rely on others to help me recover from stroke, Round 2- Following advice from healthcare professionals is the only way I will recover from stroke)

Notes: ID 9 felt this was partly true and talked about '*one's own determination'* playing a big part. In the main, ID 9 felt he followed HCP advice. ID 9 felt it is '*obvious*' that a PwS would want to get better, and it followed that it was '*obvious*' you would try anything to get better. ID 9 felt that 'HCPs' meant '*hospital specialists, GP, nurses & physiotherapists'*, whereas ID 10 understood them to be more inclusive including OTs, stroke specialists, doctors, nursing staff and phlebotomists, '*somebody with an understanding of health and the body'*. ID 8 felt HCPs were doctors, nurses and physiotherapists. ID 9 felt that he would be more likely to follow the advice if a HCP with a specialist knowledge in stroke and felt he takes the lead in appointments with his GP. ID 10 felt that she would follow HCP advice regarding medication. ID 10 talked about being dubious of health supplements, and would check with her GP ('a particular GP who is brief') before taking anything. ID 8,10 and 11 did not think HCP advice was the only way to manage stroke.

3. I am reliant upon the help of others to help me do things important to my health and well-being. (developed as a result of round 1)

Notes: ID 9 talked about the frustrations of unsuccessfully gaining funding for FES (functional electrical stimulation) treatment, and felt that the budget-holders were '*determined not to help him'* and were very '*unhelpful*'. ID 10 felt she was reliant on others to do practical things (change light bulb, remove grass cuttings) which would otherwise impact upon well-being adding '*these things get you down*'. ID 10 talked about relying on two friends particularly in the event of a health emergency. ID 10 also thought about this item in the context of the quality of the existing HCP support in place from her local practice. ID 8 lives alone and therefore felt he could not be reliant. Item felt to be dependent on stage of recovery (ID 10, 8,9). ID 11 felt reliant upon her husband also her carer to provide emotional as well as practical support with medication and personal care.

4. I cannot rely solely on others to help me manage the consequences of stroke (developed as a result of rounds 1&2)

Notes: ID 9 felt that he was determined and motivated to recover, that he had done well so far, but wanted to do even better to '*beat it'* (disability). He felt it would be '*defeatist*' to rely solely on others. ID 8 & 10 (live alone) and agreed strongly with this '*otherwise you would just end up sitting, like in a care home'* (ID 10). 'Consequences of stroke' was understood as not being able to do what you could do prior to stroke (ID 10), to include the changes in family dynamics & impact on family (ID 11). ID 8 felt that 'consequences of stroke' meant the aftermath of stroke.

5. The physical effects of stroke mean that I cannot manage my condition as I would like (round 1 - My physical limitations mean that I cannot manage my condition as I would like, round 2- My physical problems mean that I cannot manage my condition as I would like)

Notes: ID 9 readily endorsed this item, but that progress was made through determination. He would like to walk unaided and drive again, but feels this is probably unlikely. He requires others to drive him to appointments, or take him on days out. He currently cannot play the piano, which makes him feel depressed. ID 10 was not sure what 'manage my condition as I would like' meant. ID 10 felt that generally she thought she managed her condition quite well, and felt this was a bit of an odd question, in so much that if there were problems, you '*just get around them'*- this is managing. ID 8 and 11 felt that over time this had changed as you get better, become more accepting and learn to adapt.

6. My problems with communication mean that I cannot manage my condition as I would like (round 1- My communication limitations mean that I cannot my condition as I would like, round 2- My communication problems mean that I cannot manage my condition as I would like)

Notes: ID 9 could not talk at first and found making himself understood very frustrating, following SALT this gradually returned and he perceives himself now to be as articulate as he was pre-stroke. Now he has no problems communicating, so he would not endorse this item. ID 8 did not have speech difficulties, but low confidence has prevented him from going back to work. ID 10 & 11 had difficulties with communication following stroke, but not now. They talked about being frustrated in getting wants and needs expressed. The term 'aphasia' was used to describe this difficulty. Item may therefore depend on the time since stroke. All participants felt that they currently 'manage my condition as I would like', otherwise they would change things.

7. I am able to control my general health (round 1- I am able to control all other aspects of my health)

Notes: ID 9 felt that 'general health' meant '*doing what the doctors and specialists recommended*' and gave '*taking tablets every day without fail'*, eating well & seeing specialists as examples. ID 10 felt she could control her health, and added she knew she did because of feedback from her GP to that effect. ID 8 felt there were certain things he was currently working on to try and improve his situation (move nearer family). ID 11 felt this meant eating well and making sure you followed HCP advice.

8. General self-care is important to me to stay as healthy as possible (round 1- Self-care of my condition is important to me to stay as healthy as possible)

Notes: Self-care was not a familiar term to these participants. When probed for what they thought it might mean, ID 9 felt it meant '*looking after yourself, taking the right advice from the doctor, doing the right exercises'*. Self-care was understood as '*doing everything the doctor says'* '*doing everything you can to encourage progress'* (ID 9). ID 8 &10 understood 'self-care' as carrying out personal care. ID 10 talked about paying for regular pedicures as she could no longer care for her feet and felt this was important to '*all senior citizens'* (not just PwS).

9. The effects of stroke mean that I cannot manage any aspect of my recovery and health (round 1 - My limitations due to stroke mean that I cannot manage my condition at all)

Notes: ID 10 felt this might change as she gets older, but she can manage this now. ID 9 felt stroke had '*restricted*' recovery. The weakness in his arm and leg, prevents him from doing activities important to him (piano, drama), and also prevents him from doing activities important to recovery e.g. he feels unconfident in walking outside without assistance, and feels unable to cook '*healthy*' meals. ID 8 felt if you weren't determined recovery would be limited following stroke. ID 11 felt that 'any aspect' meant being unable to do anything at all for yourself.

Participants in round 2 suggested using 'some' or 'many' instead of 'any'. Participants wanted to alter the statement so it best reflected their situation. All participants answered a definitive 'No' on the dichotomous scale, however gave differing answers using the other response formats, suggesting an appraisal of the statement and ability of the item to be discriminative. If 'some' or 'many' were used (instead of any) it may limit this variance in responses as both are subjective terms.

10. My condition would improve if I received more professional help (round 1 - My condition might change if I received more professional advice)

Notes: ID 9 felt despite having had ‘*the most and best professional advice he could have’* often people (but not HCPs) were ‘*determined not to help him’* (he unsuccessfully sought funding from the PCT for additional funding for FES treatment). He involved his MP in his request and felt that the PCT was ‘*very, very mean*’. ID 9 felt there wasn’t a ‘*magic formula’* for recovery, and he was satisfied with the advice he’d received. ID 8 & 11 felt that if more input had been given earlier on, recovery might be different. ID 10 felt she was ‘*past that’* (i.e. receiving professional help would not help her) because ‘*you wouldn’t get it*’ (help). However, when probed about her on-going OT assessment, she said it was unsatisfactory as no-one would come to her home, but acknowledged that she *could* pursue the OT for further help. ID 10 commented that ‘*I shouldn’t have to go through that’* (chasing help). Item may be affected by time since stroke.

11. Activities or strategies I do without the guidance of professionals may worsen my health (round 1 - Activities or strategies that I do without the input of professionals, may worsen my condition (e.g. doing independent physiotherapy exercises), round 2 - Activities or strategies that I do without the input of professionals, may worsen my condition)

Notes: ID 9 said he ‘*always does what the teacher says’* and ‘*always follows their* (HCP) *advice*’. On probing, he said he wouldn’t do anything he hadn’t been told to do, or that wasn’t part of the rehabilitation programme. ID 10, used her experience of deciding whether or not to take health supplements, and being wary of trying new things without them being sanctioned by HCPs (fear of altering INR). ID 10 felt she needed someone to talk to about her diet in relation to maintain a safe INR (but instead has had to find it out for herself, which she feels is ‘*wrong*’). ID 8 felt that it was important to try and get back to doing the activities you enjoyed pre-stroke and that you had to sometimes had to take HCP advice ‘*with a pinch of salt’*. ID 11 felt that she would seek HCP advice before changing medication or starting a new exercise programme ‘*I don’t want to go backwards’*. The item aims to judge how ‘risk’ is assessed by a PwS, and levels of responsibility for their health they feel are attributed to HCPs/selves

12. I need constant professional advice to self-manage stroke (round 2- I need professional advice to self-care to my best ability)

Notes: ID 9 felt that 'constant professional advice' meant going to your doctor regularly and taking and implementing their advice. ID 11 interpreted 'constant professional advice' as not making changes without professional help. ID 8 felt that the statement was true in the acute stages, but not '*further on down the line'*. ID 10 felt that she didn't need constant professional advice, but felt that if you were under the care of a stroke consultant '*obviously you'd still be getting that* (advice)'. Item may be affected by time.

13. Generally speaking, my efforts to manage the consequences of stroke turn out how I like (round 1- No matter how hard I try, managing my stroke doesn't turn out the way I would like, round 2- Generally speaking, my efforts to manage the consequences of stroke turn out the way I would like)

Notes: ID 8 & 9 endorsed this item and drew on experiences since having stroke to appraise this item. ID 11 felt this was hard to answer as she couldn't think about what her efforts were to manage stroke. ID 10 also condoned this she drew on her experience of struggling to go on holiday and go swimming and being determined (crawling along the poolside and being helped in (to the pool) by the caretaker, despite this being '*awful'* it was '*liberating'*). 'Generally speaking' was interpreted as '*most of the time'* (ID 10&11).

14. When I have treatment or therapy regimes, they do not take over my life (round 1 - I do not let treatment and therapy regimes rule my life, round 2- When I have treatment or therapy regimes, I do not let them take over my life)

Notes: ID 9 felt '*no, because I have got a lot of other interests'*. ID 10 felt '*definitely not'*. ID 8 said that in the early stages of stroke you do become *'engrossed'* in your therapy, making every effort to engage in recovery. 'Take over my life' was interpreted as being '*all encompassing'* '*not thinking about anything else'* (ID 8, 9,10,11).

15. It is difficult to stay motivated to do tasks or strategies important to my recovery (round 1 - Sometimes performing therapy exercises is a low priority)

Notes: ID 9 felt that you had to be motivated, '*otherwise it* (stroke) *would get the better of you'*. ID 10 joked that this item was aimed at '*people struggling with physio!'*. She expanded on this by saying how you need a good partner to encourage or help you with exercises recommended by Physios (she felt this was usually the female partner, assisting a male PwS). ID 10 felt this was more relevant in the early stages as '*you think you are never going to get better'*. ID 8 & 11 readily disagreed with this item.

16. Whatever I do, I will not improve my condition

Notes: ID 9 felt that endorsing this item would '*show a negative attitude'*. 'whatever I do' was interpreted as doing a range of activities, and 'improve' was interpreted as getting better (ID 9,11). ID 10 interpreted 'my condition' as '*my physical limitations'*, ID 8, 11 interpreted it as '*my stroke'*.

17. When things do not go well with my stroke, it is hard to stay positive. (round 1&2 When things do not progress with my recovery, I still think positively)

Notes: ID 9 felt that there was '*no good being negative'*. On probing regarding how he coped in a specific difficult situation (not being granted funding for FES), ID 9 relented, that he did feel negative, in a '*temporary dip'* and then '*overcame it'*. ID 10 agreed it was difficult to stay positive when things don't go well, and felt most people would answer in this way. She explained how she used reflection to consider further attempts at Nordic walking classes. ID 8 talked about being frustrated at having had the stroke as he was '*young, fit and active'*. ID 11 felt that staying positive was difficult, and it can be difficult to be honest about this when everyone around you was there trying to help you ('*don't want to seem ungrateful'*).

18. I am concerned that things I do to manage stroke, may cause harm if not guided by healthcare professionals (round 2 -I am concerned that my own self-care activities may worsen my condition (round 1- I worry that my own self-care activities may make me worse (e.g. doing exercise))

Notes: Clear Item (4/4). ID 9 & 11 felt you would be 'stupid' or 'daft' to not follow HCP guidance. ID 10 drew on her experience on taking health supplements, and seeking advice from her GP prior to doing so (fear of altering INR). ID 8 felt that he would check with a HCP if he was concerned about anything, however this was guided by his prior experience of HCP advice being 'vague' and 'not that helpful'.

19. I feel comfortable asking friends to help me with activities important to my health that I find difficult

Notes: ID 9 said he had no hesitation asking friends for help and gave specific examples. ID 10 talked about two very close friends (‘*with rent-a-husbands!’*) she could rely upon. ID 8 said that a lot of his friends had ‘*fallen by the wayside’* since his stroke. ID 11 wasn’t really sure what kinds of things ‘activities important to my health’ would be.

20. I feel confident asking family members to help me with activities important to my health that I find difficult (round 2- I feel confident to ask family members or friends to help me do activities important to my recovery, round 1 - I am confident in asking family members or friends to help me perform activities important to managing my condition)

Notes: ID 9 could not answer this as he doesn’t have many family members, who live nearby. ID 10 did not have family members living nearby. ID 8 felt he could rely upon his adult children, and was in the process of moving closer to them to feel more secure. ID 11 felt able to rely on her husband.

21. It is not up to me to decide what the best ways to manage my stroke are

Notes: 9 &11 felt that HCPs are the ‘*experts’*, and therefore they should *‘dictate how things are done’* . ID 10 felt it might not have been her decision in the past (when her stroke was very acute), however felt strongly it is now her decision to follow advice ‘*I would reserve the right to say no!’*. ID 8 talked about the distinction between ‘*medical’* advice and therapy and ‘*recovery type’* advice.

22. I manage things related to stroke as well as other people with stroke (round 2- I probably manage things related to stroke as well as most other people, round 1- I am able to manage things related to my stroke as well as most other people)

Notes: ID 8 & 9 did not know many other people with stroke, so felt they were making estimates to answer the item. ID 10 felt she managed ‘*better than most’* because of now living on her own and coping with a difficult relationship at the time of her stroke. ID 10 used other people she knew with stroke *(‘like me’*) to make this judgement. ID 11 used people from a stroke support group to think about this item.

23. The effects of stroke mean that I cannot control many aspects of my health, by myself (round 1&2, My limitations due to stroke mean that I cannot manage any aspect of my condition, by myself)

Notes: ID 9 felt that his arm and leg weakness meant he was reliant on others for transport for appointments and that he'd also given up many things important to him. He felt he could '*control what he was able to control'*. 'control many aspects of my health' was interpreted as '*those things you do to keep yourself healthy'* by ID 10. She drew on her attempts to lose weight since having a stroke, which frustratingly had become more difficult due to lower mobility, and an inability to exercise '*in the way I used to'* and ageing. ID 11 felt that it was not possible to control aspects of health, as this was '*up to the doctors to do*'. ID 8 felt that his general health (i.e. physical health) was good, but that his mental health was now more problematic.

24. I should make most of the decisions about how my stroke is managed (rounds 1&2- Healthcare professionals should make most of the decisions about my condition)

Notes: ID 9 did not endorse this item, and felt that professional advice was need regarding '*how best to manage'*. On probing, ID 9 said he would follow anything that was recommended to him, as it '*would be stupid, not to'*. ID 10 felt she had '*the right to say no'* and would take on board any advice, but ultimately make the final decision. ID 8 felt this was true, but might be different in the early stages of stroke. ID 11 felt that she should be involved in how decisions are made, but ultimately decisions should be professional lead '*they* [HCPs] *know best'*.

25. It is hard to be motivated to seek out solutions to problems relating to stroke.

(round 1 - I find it difficult to find solutions that work for problems with managing my stroke, round 2 - It is hard to be motivated to seek out and try solutions to problems relating to my stroke)

Notes: 'seek out' was thought to be a '*clumsy*' term by ID 9. The item was therefore re-phrased for participants 8 and 10 as follows: *It is hard to be motivated to find solutions to problems relating to stroke.* ID 10 felt she needed to think back to when she was less mobile to approach this item. ID 10 felt it was hard to be motivated then, as you don't see yourself getting any better, however now, because of that experience '*I am constantly thinking how well I have done*'. ID 8 felt that problems can be overcome with determination and reflected that there were points he felt like '*throwing the towel in'*. ID 11 found this a difficult item to understand.

26. I find it difficult to always tell professionals what I want or need (rounds 1&2 - I am able to tell professionals what I want or need)

Notes: All participants felt they were able to do this and that this was very relevant to PwS. Participants felt this depended on good relationships with HCPs. ID 9 was asked regarding some of the negative experiences with HCPs he had mentioned during the interview. He said would in future not discuss himself with anyone (HCP) he '*disliked*'. ID 10 felt she had a good relationship with everyone at the practice (Health centre)..*even the receptionist' 'they all know me'*. ID 11 felt that her '*GP and practice nurses'* knew her very well which made it talk to tell them. ID 8 was apprehensive about moving to a new practice and developing these relationships again.

27. There is little point in trying new ways of managing the consequences of stroke, as it will not change my condition (round 2 - There is little point in trying new ways of managing my stroke, as my condition will not change (round 1 - There is little point carrying out exercises as my condition will not change)

Notes: ID 9 felt this was a '*defeatist attitude'* and did not endorse this item. ID 10 felt she was '*constantly thinking what else can I do* (to improve)?' IDs 8 & 11 also found this item difficult to endorse.

28. I cannot affect what my healthcare professionals decide to do about my stroke (round 1&2- I cannot affect what my healthcare professionals decide to do about my problem(s)

Notes: ID 9 felt that 'affect' was '*odd'* wording. He interpreted this item to be about how well you put HCP advice into practice. We discussed the role of the PwS in this decision, and it was clear that he did not conceive the PwS to have any part to play in the decisions of HCPs. Item reworded for participants 8, 10 &11 as follows: *I cannot alter what my healthcare professionals decide to do about my stroke.* ID 10 felt that she could, and had altered the way HCPs thought because of her positive attitude. ID 10 felt that HCPs need to acknowledge that everyone's experience of stroke is different ('*as the stroke association are always saying*'), therefore PwS should be listened to. She felt that the statement reflected how some HCPs presume that because they don't hear from a PwS, that person is getting along fine. ID 8 felt that HCPs might judge you depending on how much '*effort*' you had put into your recovery. ID 11 readily endorsed this item.

29. I feel confident in getting the information I need from healthcare professionals. (round 1&2- I feel confident in asking healthcare professionals questions about my stroke)

Notes: ID 9 talked about a PT he had had whom he did not '*get along with'*, he felt the exercises she recommended were not helping him. ID 10 felt confident in getting information but pointed out that the problem was often in the length of time it takes to get that information. This was frustrating. ID 8 felt that sometimes often advice was '*vague'* and '*not that clear*.'

30. I always follow professional advice about my condition, to the letter

Notes: ID 9 used his experience with a PT, and felt you would be '*stupid'* not to follow their '*sound and helpful'* advice. This is interesting because he also talked in the interview about how, when he did not get on with one PT, he <u>did not</u> follow her advice. There appears to be different elements in judging whether or not to follow advice, based partly on professional knowledge, but also on the quality of the relationship and personal factors of the therapist. ID 10 agreed with this statement and talked about following the advice of a neighbour (who was a GP) regarding not going up ladders. So even when a professional was '*off-duty'* (and maybe did not know the history etc), there appears to be a value placed on their advice. ID 11 readily endorsed this item, and on probing if this was always the case, insisted she was a '*good patient'!* ID 8 talked about having to '*convince'* physiotherapists that he needed hydrotherapy as he perceived the therapy regime he did have to be unhelpful.

31. I apply professional advice so it is relevant to my situation (round 1&2 - I adapt professional advice so it is relevant to my situation)

Notes: ID 9 readily condoned this item and gave the example of using the FES exactly to the instructions of the HCP (i.e. no application, adaption of the advice). On probing, for examples where he had to change or modify advice to fit with his lifestyle/circumstances, he was unable to give an example. ID 10 talked about negotiating with HCPs and finding out what the '*parameters*' were with each piece of advice. ID 8 talked about '*having to'* otherwise you wouldn't *'get anywhere'* (make progress in recovery). ID 11 felt it might be '*risky'* to adapt advice, and found that most advice felt relevant to her.

32. Changing the way I do things might help me to better manage the consequences of stroke 'I regularly think about how I might change things to help me manage the consequences of stroke' (amended for participants 10 and 8) (rounds 1&2 - I try new therapies or ways of doing things in case it helps me manage my condition better)

Notes: ID 10 endorsed the revised item readily. ID 8 & 11 endorsed this item less readily. ID 8 felt that he still wanted guidance from HCPs or other people with stroke. ID 11 felt '*perfectly happy just going along'* (i.e saw no need to change things). Item may be difficult to endorse as if a PwS thinks change is needed, they will arguably have already implemented it.
Suggestion: I regularly think about how I might change things to better manage the consequences of stroke

33. I plan my day so I can get things done without becoming tired (round 1- I plan my day so I can get things done without becoming tired, round 2 where possible, I plan my day so I can get things done without becoming tired)

Notes: ID 8, 9 & 11 readily endorsed this item. ID 10 talked about trying to plan her day, but often this was not possible if her day was unexpectedly busy. ID 10 did say she was affected by tiredness. She used an example of a day where she had lots of activities and then had to '*flake out'* in the afternoon.

34. The lifestyle choices that affect my health (for example, smoking, diet, alcohol) have not changed since having a stroke

Notes: ID 9 said his appetite had decreased, therefore he had lost weight, but had not consciously tried to reduce his weight. ID 10 said her diet, and eating habits (smaller glasses & side plates) had changed, and her alcohol had reduced because of her INR. She talked about various diet plans which '*all talk about eating plenty of greens and drinking lots of water*'. She felt that if she followed this guidance she would '*wet myself'* and that '*eating too many greens* (would mean) *my INR would be so bad I would be in danger of internally bleeding*'. ID 11 felt that she was now less active than before her stroke. ID 8 said that his lifestyle has always been healthy, therefore had not changed.

35. I know how to get help if I am concerned about my condition

Notes: Readily endorsed (ID 8, 9, 10, 11).

36. I find answers to problems about stroke without seeking professional advice (round 2 - I can work out problems I have about the consequences of stroke without seeking professional advice, round 1 - I can work out problems I have about my condition without asking for professional advice)

Notes: ID 9 & 11 felt that help from HCPs was always needed, since they are the '*experts on stroke*'. ID 10 felt that if reading an article in a book or paper, she would not '*take it as gospel*' and would therefore ask her GP. ID 8 felt that going back to sport had helped him get a '*handle on things*' (although he had been advised by his GP to avoid his particular sport).

37. I am not sure what signs or symptoms might mean my health is changing (rounds 1&2 - I am not sure what signs or symptoms might mean my condition is changing)

Notes: ID 9 would rely on information from his GP and specialists to tell him when things are changing. ID 11 would '*go to the doctors*' if '*I didn't feel right*'. ID 10 felt that thinking back over her time since stroke, there were signs and symptoms that her health changed for the better (more stable BP and INR, being able to walk not crawl, reduced frequency of appointments). ID 8 felt that he knew which signs to '*look out for*', but that regular check-ups (from HCPs) would help him feel more confident.

38. I work out ways of managing my health following stroke together with healthcare professionals (Round 2- I have worked out ways of managing my health together with healthcare professionals, round 1 - I have worked out ways of managing my stroke together with healthcare professionals)

Notes: ID 9 felt that he did, in so much that he regularly saw a HCP and always implemented their advice. ID 10 talked about negotiating with HCPs and finding out the limits of their advice e.g. '*what about this? Can I do this instead?*'. ID 11 felt that she '*always had a good*

chat about things'**. ID 8 endorsed this item '*****to a degree'*****. On probing, he still felt some of his concerns were left unanswered.**

39. **I talk about any medication I am prescribed with healthcare professionals (round 2- I feel consulted about any medication I am prescribed (round 1- I understand what my prescribed medication is for**

Notes: ID 9 talked about and showed the medication he was currently prescribed (uses Dosset box). On probing, the HCPs always '***told me why I was having to take these'***** and has regular medication reviews where he could raise any concerns. ID 10 had just had a medication review. ID 8 & 11 felt they didn't really discuss medication and took what was prescribed, since '*****they***** (doctors) *****know best'*****.**

40. **I always ask healthcare professionals to explain why I should follow their advice (rounds 1&2- I always ask healthcare professionals to explain things that I don't fully understand)**

Notes: ID 9 felt he asked questions '***all the time'*****. On probing, he felt that he would only ask questions if he '*****got on'***** with the HCP, finding this more difficult to do if the relationship was tense. He said it was '*****silly*****' not to follow HCP advice, as '*****they know what they're doing'*****. ID 10 used an example with her GP, where her GP had said some information (from health supplements) was not *****'a load of rubbish however was not applicable*****' to her. ID 11 felt she didn't ask questions as '*****they tell me everything I need to know'*****. ID 10 felt she had no problem in talking things over, and feels confident in any advice given from the doctor ('*****they are the ones with the professional qualification'*****. ID 8 felt that he used to, but his prior experience of vague answers had left him more reluctant to continue doing so.**

41. **I feel confident at discussing any advice I don't understand, with Doctors. (Rounds 1&2 -I feel confident in disagreeing with healthcare professionals, if their advice seems irrelevant to me)**

Notes: ID 9 readily endorsed this item, and gave the example of wanting to know about his medication. ID 10 readily endorsed this and talked about using different doctors (within her practice) for different issues (one GP for brief queries, one for medication reviews). ID 8 felt that '***doctors know best'***** and he would not really discuss anything. ID 11 felt this was hard to endorse, as she's '*****never been in that situation'*****.**

42. I have made changes to my lifestyle since having a stroke to improve my health (round 1 - I take more care with my diet to stay healthy since having a stroke)

Notes: ID 9 talked about changes to his diet and alcohol consumption, but that these were not intentional for health reasons, but rather has been another result of stroke (decreased appetite and alcohol tolerance). ID 11 felt that her lifestyle had changed, but not for the better. ID 10 felt she had made some changes because of stroke '*trying to lose weight' 'drinking wine with my meal*'.ID 8 felt that he was healthy before having his stroke, so had not made deliberate lifestyle changes. Lifestyle changes were interpreted as '*smoking, drinking, exercise*' (ID 8).

43. I try different ways of doing things until I find out what works for my health (round 1 - I generally succeed in the strategies I use to manage my stroke, round 2- I try different ways of doing things, or different strategies until I find out what works for me)

Notes: This item was readily endorsed (all participants).

44. The efforts I take to manage my health have a positive effect (Round 2- The efforts I take to manage my health have a real positive effect, round 1- I feel sure that the efforts I take to manage my condition have a real positive effect)

Notes: ID 9 felt that his efforts were worthwhile ('*otherwise, why do them'*?). ID 11 felt that everything she did was to try and '*make things better'*. ID 10 readily endorsed this item. ID 8 felt that he tried lots of different things, but that they didn't always work out.

45. I am confident that healthcare professionals can answer my questions (rounds 1&2- I feel able to access the information I need to make decisions about my condition

Notes: ID 9 & 11 felt happy with the advice they'd got. ID 10 felt HCPs can answer questions only to '*the best of their ability'* (i.e. they might not always have the answer the person is seeking). (NB ID 10 felt '*really let down'* by her discharge process, perceiving that she missed out on all the stroke therapy available to her (discharged from a cardiac ward). ID 8 did not feel that confident, as he had had conflicting advice in the past.

Format:
Font size 14 fine (ID 9, 10, 11)
Black and white (ID 9) Cream/yellow '*looks classy, professional'* (ID 10)
ID 9 would like important things to be highlighted in red.

Dichotomous scale disliked by all participants.
ID 9 felt the Likert response option was familiar and standard and that this could be 'boring'. He noted that scales were usually 1-10 and this one was 1-6. On probing how he would use the response scale to answer items, ID 9 articulated that he usually polarises his answers and tends to either strongly agree or strongly disagree with something.
ID 10 would like it presented in relevant sections.

Appendix 15 Permissions to advertise Phase III study on websites and newsletters

SRN
South West Stroke Research Network
Part of the
Stroke Research Network

NHS
National Institute for
Health Research

Room 420, Noy Scott House
Royal Devon and Exeter NHS
Foundation Trust
Barrack Road
Exeter
EX2 5DW
Web: http://www.uksrn.ac.uk/
Tel: 01392 406463
Fax: 01392 403012

Email: Leigh.Boxall@nhs.net

09.07.12

Dear Emma,

Please accept this letter as confirmation in principle that we will be happy to advertise your stroke research study in a future edition of our Patient, Carer and Public Newsletter.

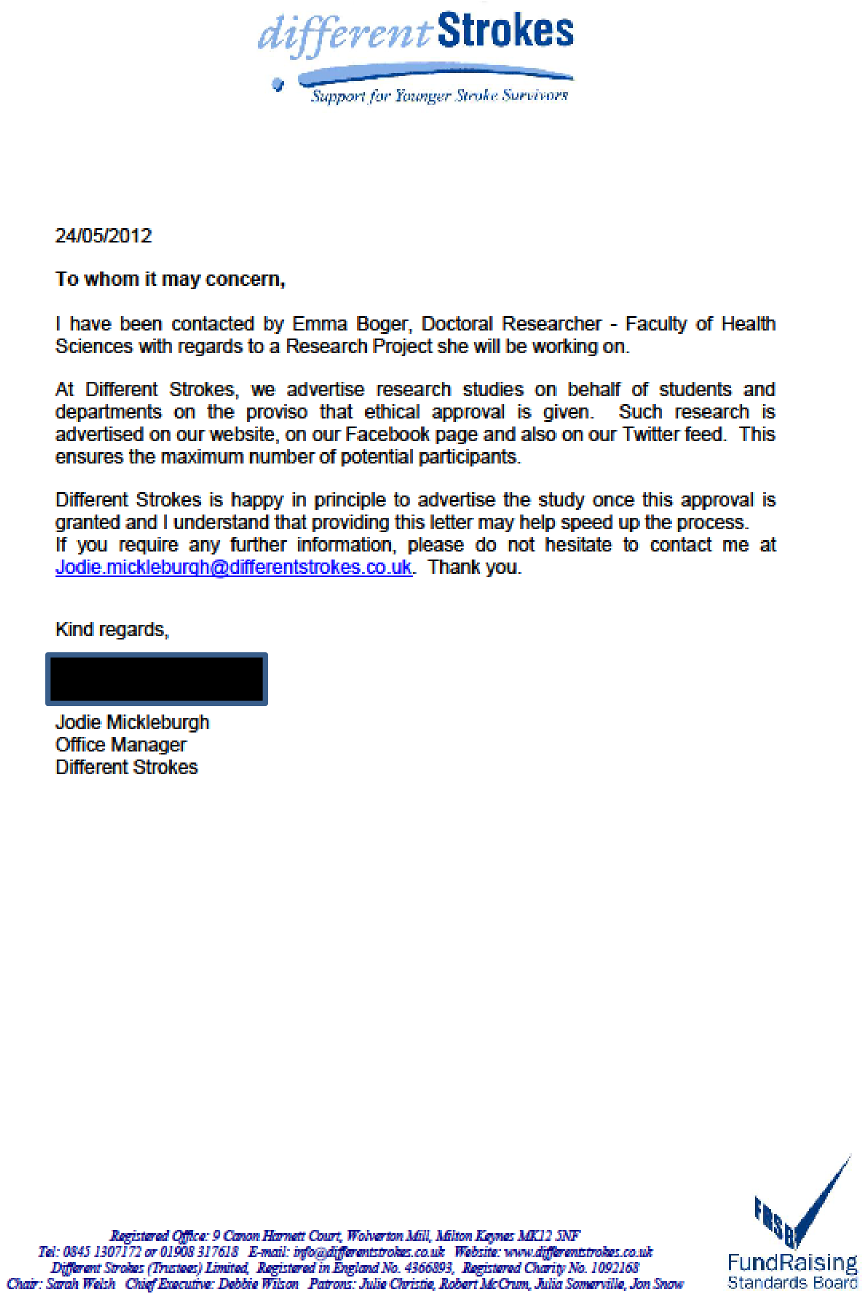
Before proceeding, we will need to received confirmation of your faculty ethics approval and I will need to seek approval from our PCPI lead and working party.

Yours sincerely

Mrs Leigh Boxall

Lead Research Practitioner

South West Stroke Research Network



differentStrokes
Support for Younger Stroke Survivors

24/05/2012

To whom it may concern,

I have been contacted by Emma Boger, Doctoral Researcher - Faculty of Health Sciences with regards to a Research Project she will be working on.

At Different Strokes, we advertise research studies on behalf of students and departments on the proviso that ethical approval is given. Such research is advertised on our website, on our Facebook page and also on our Twitter feed. This ensures the maximum number of potential participants.

Different Strokes is happy in principle to advertise the study once this approval is granted and I understand that providing this letter may help speed up the process.
If you require any further information, please do not hesitate to contact me at Jodie.mickleburgh@differentstrokes.co.uk. Thank you.

Kind regards,

[redacted]

Jodie Mickleburgh
Office Manager
Different Strokes

Registered Office: 9 Canon Harnett Court, Wolverton Mill, Milton Keynes MK12 5NF
Tel: 0845 1307172 or 01908 317618   E-mail: info@differentstrokes.co.uk   Website: www.differentstrokes.co.uk
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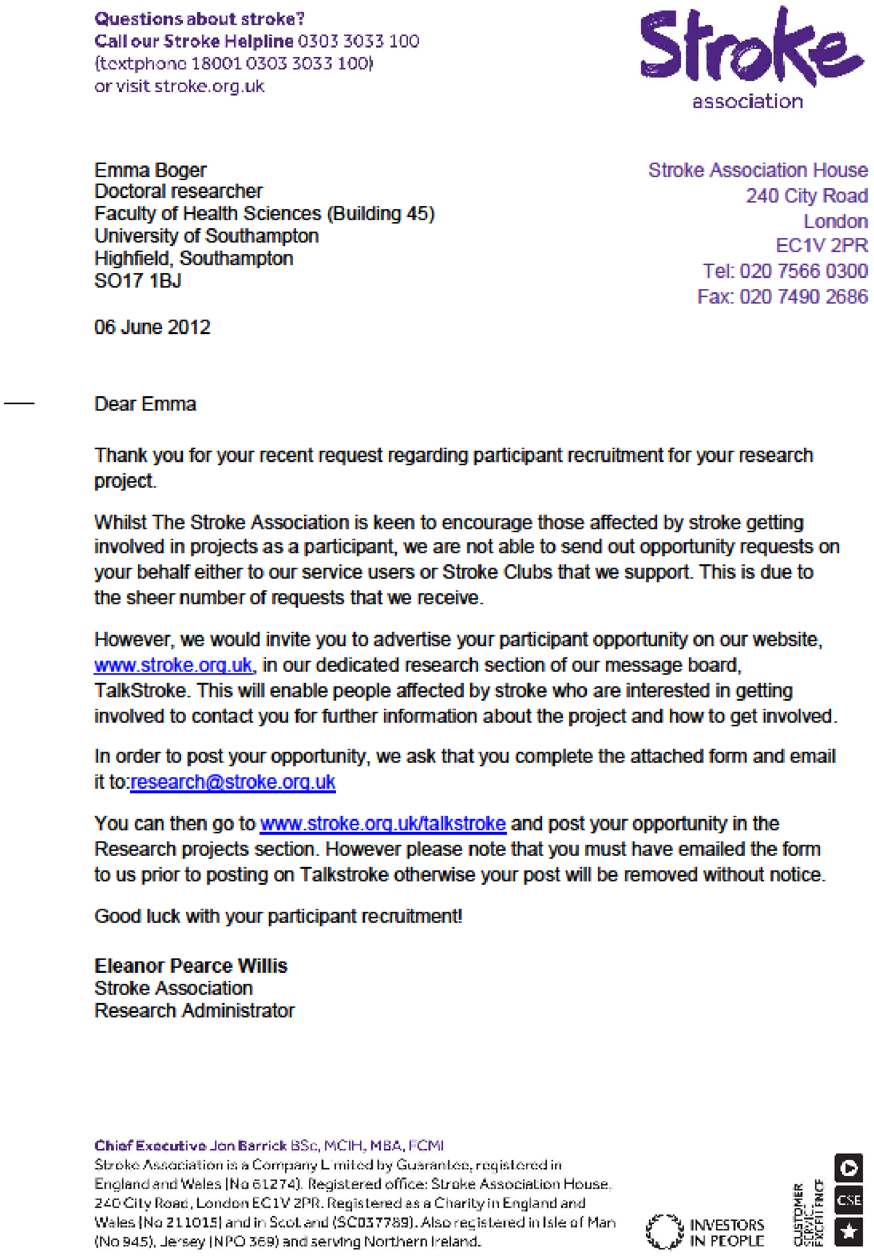


Questions about stroke?
Call our Stroke Helpline 0303 3033 100
(textphone 18001 0303 3033 100)
or visit stroke.org.uk

Stroke association

Stroke Association House
240 City Road
London
EC1V 2PR
Tel: 020 7566 0300
Fax: 020 7490 2686

Emma Boger
Doctoral researcher
Faculty of Health Sciences (Building 45)
University of Southampton
Highfield, Southampton
SO17 1BJ

06 June 2012

Dear Emma

Thank you for your recent request regarding participant recruitment for your research project.

Whilst The Stroke Association is keen to encourage those affected by stroke getting involved in projects as a participant, we are not able to send out opportunity requests on your behalf either to our service users or Stroke Clubs that we support. This is due to the sheer number of requests that we receive.

However, we would invite you to advertise your participant opportunity on our website, www.stroke.org.uk, in our dedicated research section of our message board, TalkStroke. This will enable people affected by stroke who are interested in getting involved to contact you for further information about the project and how to get involved.

In order to post your opportunity, we ask that you complete the attached form and email it to:research@stroke.org.uk

You can then go to www.stroke.org.uk/talkstroke and post your opportunity in the Research projects section. However please note that you must have emailed the form to us prior to posting on Talkstroke otherwise your post will be removed without notice.

Good luck with your participant recruitment!

Eleanor Pearce Willis
Stroke Association
Research Administrator

Appendix 16 – Additional outcome measures

The SSEQ (Jones et al., 2008b)

The Stroke Impact Scale (Duncan et al., 2003)

Stroke Impact Scale

These questions are about the physical problems which may have occurred as a result of your stroke.

1. In the past week, how would you rate the strength of your....	**A lot of strength**	**Quite a bit of strength**	**Some strength**	**A little strength**	**No strength at all**
a. Arm that was most affected by your stroke?	5	4	3	2	1
b. Grip of your hand that was most affected by your stroke?	5	4	3	2	1
c. Leg that was most affected by your stroke?	5	4	3	2	1
d. Foot/ankle that was most affected by your stroke?	5	4	3	2	1

These questions are about your memory and thinking.

2. In the past week, how difficult was it for you to...	**Not difficult at all**	**A little difficult**	**Somewhat difficult**	**Very difficult**	**Extremely difficult**
a. Remember things that people just told you?	5	4	3	2	1
b. Remember things that happened the day before?	5	4	3	2	1
c. Remember to do things (e.g. keep scheduled appointments or take medication)?	5	4	3	2	1
d. Remember the day of the week?	5	4	3	2	1
e. Concentrate?	5	4	3	2	1
f. Think quickly?	5	4	3	2	1
g. Solve everyday problems?	5	4	3	2	1

These questions are about how you feel, about changes in your mood and about your ability to control your emotions since your stroke.

3. In the past week, how often did you...	**None of the time**	**A little of the time**	**Some of the time**	**Most of the time**	**All of the time**
a. Feel sad?	5	4	3	2	1
b. Feel that there is nobody you are close to?	5	4	3	2	1
c. Feel that you are a burden to others?	5	4	3	2	1
d. Feel that you have nothing to look forward to?	5	4	3	2	1
e. Blame yourself for mistakes that you made?	5	4	3	2	1
f. Enjoy things as much as ever?	5	4	3	2	1
g. Feel quite nervous?	5	4	3	2	1
h. Feel that life is worth living?	5	4	3	2	1
i. Smile and laugh at least once a day?	5	4	3	2	1

The following questions are about your ability to communicate with other people, as well as your ability to understand what you read and what you hear in a conversation.

4. In the past week, how difficult was it to...	**Not difficult at all**	**A little difficult**	**Somewhat difficult**	**Very difficult**	**Extremely difficult**
a. Say the name of someone who was in front of you?	5	4	3	2	1
b. Understand what was being said to you in a conversation?	5	4	3	2	1
c. Reply to questions?	5	4	3	2	1
d. Correctly name objects?	5	4	3	2	1
e. Participate in a conversation with a group of people?	5	4	3	2	1
f. Have a conversation on the telephone?	5	4	3	2	1
g. Call another person on the telephone, including selecting the correct phone number and dialing?	5	4	3	2	1

The following questions ask about activities you might do during a typical day.

5. In the past 2 weeks, how difficult was it to...	**Not difficult at all**	**A little difficult**	**Somewhat difficult**	**Very difficult**	**Could not do at all**
a. Cut your food with a knife and fork?	5	4	3	2	1
b. Dress the top part of your body?	5	4	3	2	1
c. Bathe yourself?	5	4	3	2	1
d. Clip your toenails?	5	4	3	2	1
e. Get to the toilet on time?	5	4	3	2	1
f. Control your bladder (not have an accident)?	5	4	3	2	1
g. Control your bowels (not have an accident)?	5	4	3	2	1
h. Do light household tasks/chores (e.g. dust, make a bed, take out garbage, do the dishes)?	5	4	3	2	1
i. Go shopping?	5	4	3	2	1
j. Do heavy household chores (e.g. vacuum, laundry or yard work)?	5	4	3	2	1

The following questions are about your ability to be mobile, at home and in the community.

6. In the past 2 weeks, how difficult was it to...	**Not difficult at all**	**A little difficult**	**Somewhat difficult**	**Very difficult**	**Could not do at all**
a. Stay sitting without losing your balance?	5	4	3	2	1
b. Stay standing without losing your balance?	5	4	3	2	1
c. Walk without losing your balance?	5	4	3	2	1
d. Move from a bed to a chair?	5	4	3	2	1
e. Walk one block?	5	4	3	2	1
f. Walk fast?	5	4	3	2	1
g. Climb one flight of stairs?	5	4	3	2	1
h. Climb several flights of stairs?	5	4	3	2	1
i. Get in and out of a car?	5	4	3	2	1

The following questions are about your ability to use your hand that was MOST AFFECTED by your stroke.

7. In the past 2 weeks, how difficult was it to use your hand that was most affected by your stroke to...	**Not difficult at all**	**A little difficult**	**Somewhat difficult**	**Very difficult**	**Could not do at all**
a. Carry heavy objects (e.g. bag of groceries)?	5	4	3	2	1
b. Turn a doorknob?	5	4	3	2	1
c. Open a can or jar?	5	4	3	2	1
d. Tie a shoe lace?	5	4	3	2	1
e. Pick up a dime?	5	4	3	2	1

The following questions are about how stroke has affected your ability to participate in the activities that you usually do, things that are meaningful to you and help you to find purpose in life.

8. During the past 4 weeks, how much of the time have you been limited in...	**None of the time**	**A little of the time**	**Some of the time**	**Most of the time**	**All of the time**
a. Your work (paid, voluntary or other)	5	4	3	2	1
b. Your social activities?	5	4	3	2	1
c. Quiet recreation (crafts, reading)?	5	4	3	2	1
d. Active recreation (sports, outings, travel)?	5	4	3	2	1
e. Your role as a family member and/or friend?	5	4	3	2	1
f. Your participation in spiritual or religious activities?	5	4	3	2	1
g. Your ability to control your life as you wish?	5	4	3	2	1
h. Your ability to help others?	5	4	3	2	1

9. Stroke Recovery

On a scale of 0 to 100, with 100 representing full recovery and 0 representing no recovery, how much have you recovered from your stroke?

_____ 100 Full Recovery

—

_____ 90

—

_____ 80

—

_____ 70

—

_____ 60

—

_____ 50

—

_____ 40

—

_____ 30

—

_____ 20

—

_____ 10

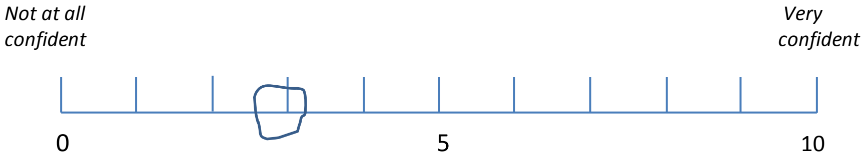
_______ 0 No Recovery

The Stroke self-efficacy questionnaire

These questions are about your confidence that you can do some tasks that may have been difficult for you since your stroke.
For each of the following tasks, please circle a point on the scale that shows how confident you are that you can do the tasks now in spite of your stroke.

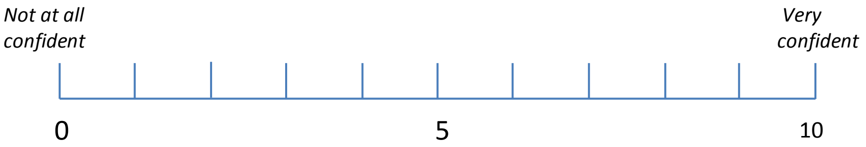
Where 0= *not at all confident* and 10= *very confident*

Example – this response would mean a confidence of about 3 out of 10

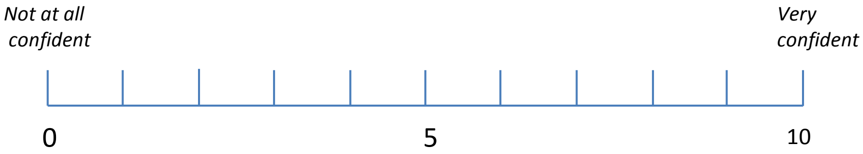


How *confident* are you *now* that you can:

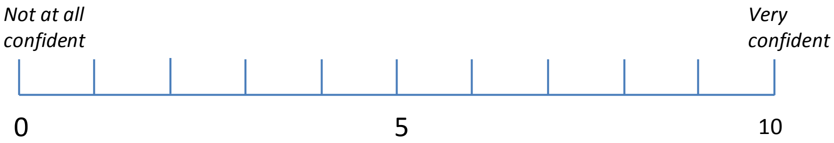
1. Get yourself comfortable in bed every night



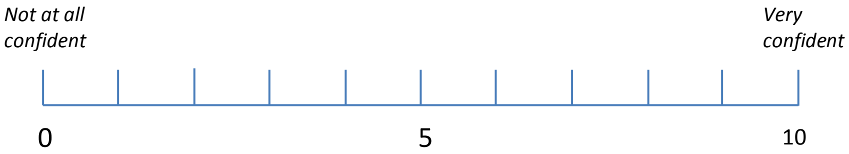
2. Get yourself out of bed on your own even when you feel tired



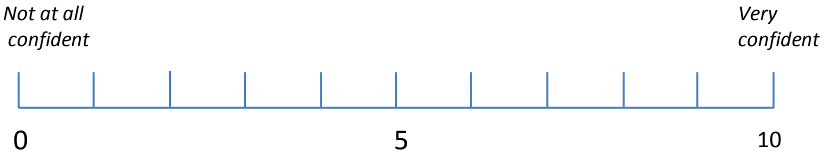
3. Walk a few steps on your own on any surface inside your house



4. Walk about your house to do most things you want



5. Walk safely outside on your own on any surface



6. Use both your hands for eating your food

Not at all confident *Very confident*

0 5 10

7. Dress and undress yourself even when you feel tired

Not at all confident *Very confident*

0 5 10

8. Prepare a meal you would like for yourself

Not at all confident *Very confident*

0 5 10

9. Persevere to make progress from your stroke after discharge from therapy

Not at all confident *Very confident*

0 5 10

10. Do your own exercise programme everyday

Not at all confident *Very confident*

0 5 10

11. Cope with the frustration of not being able to do some things because of your stroke

Not at all confident *Very confident*

0 5 10

12. Continue to do most of the things you liked to do before your stroke

Not at all confident *Very confident*

0 5 10

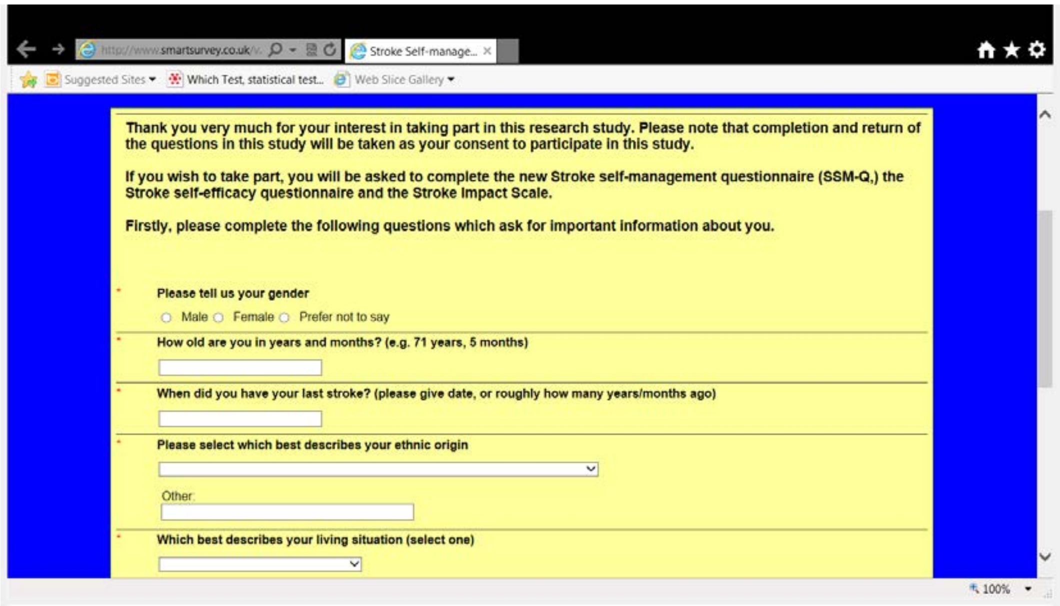
13. Keep getting faster at the tasks that have been slow since your stroke

Not at all confident *Very confident*

0 5 10

Appendix 17 On-line psychometric evaluation study

Example screen-shot for on-line completion of study:



Thank you very much for your interest in taking part in this research study. Please note that completion and return of the questions in this study will be taken as your consent to participate in this study.

If you wish to take part, you will be asked to complete the new Stroke self-management questionnaire (SSM-Q,) the Stroke self-efficacy questionnaire and the Stroke Impact Scale.

Firstly, please complete the following questions which ask for important information about you.

* Please tell us your gender

○ Male ○ Female ○ Prefer not to say

* How old are you in years and months? (e.g. 71 years, 5 months)

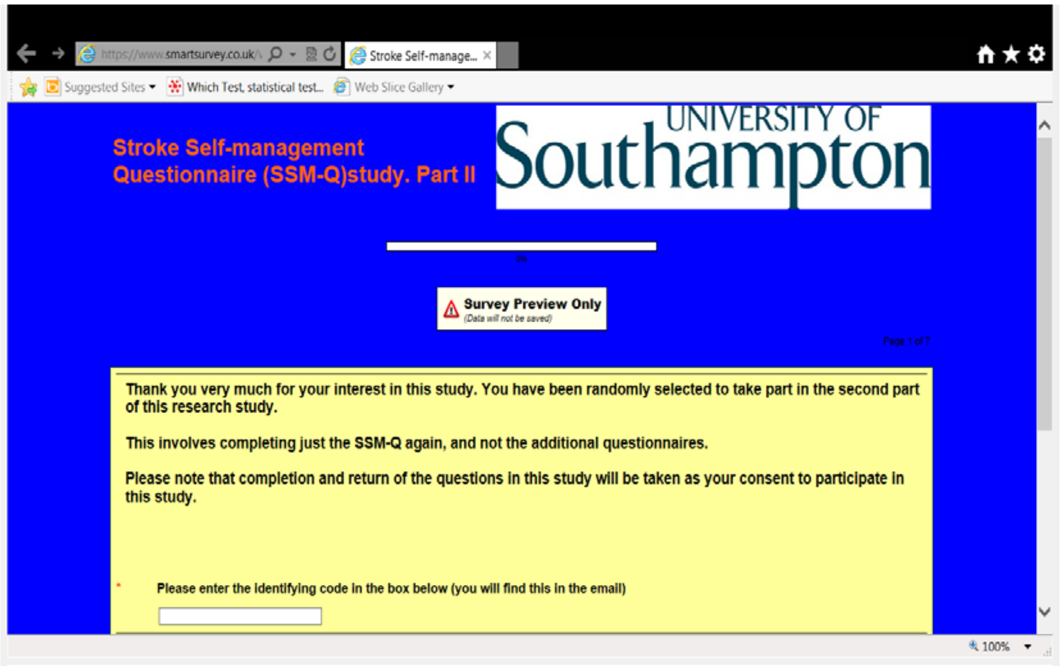
* When did you have your last stroke? (please give date, or roughly how many years/months ago)

* Please select which best describes your ethnic origin

Other:

* Which best describes your living situation (select one)

Example screen shot for test-retest element of evaluation:



Stroke Self-management Questionnaire (SSM-Q)study. Part II

Thank you very much for your interest in this study. You have been randomly selected to take part in the second part of this research study.

This involves completing just the SSM-Q again, and not the additional questionnaires.

Please note that completion and return of the questions in this study will be taken as your consent to participate in this study.

* Please enter the identifying code in the box below (you will find this in the email)

Measuring health and well- being after stroke

Your experience of stroke is unique. Could you help researchers to help other people with stroke by sparing 45 minutes of your time?

'Self- management' means the things that people do to manage their health and well- being.

Little is known about self- management following stroke and how it can be measured. However, in the first stage of this study, 40 people with stroke have told us what it means to them.

Their experiences helped us develop a new questionnaire to assess self-management following a stroke. The questionnaire is called the Stroke Self-Management- Questionnaire (SSM- Q). We hope it will be used to assess self-management for people with stroke.

We would now like your help to test how well the new SSM- Q measures self-management. We would like a large number of people who have had stroke to join in with this research. You can help us by completing the SSM- Q. You can complete it either:

- *via* **the internet**, *or;*
- *using a* **paper version** *(Postage paid return envelope provided).*

For further information, or to receive a questionnaire pack please contact:

Emma Boger

Post- graduate Researcher
Faculty of Health Sciences
University of Southampton
Highfield
Southampton
SO17 1BJ

e.j.boger@soton.ac.uk
Mobile 07596 125575
Landline (0)23 8059 8924

OR follow the link below to access study information and complete the SSM- Q.

http://www.smart- survey.co.uk/v.asp?i= 59347tpkre

Thank you for reading this.

Appendix 18 List of items discarded from item pool (*H* coefficients <0.3)

1. I regularly think about how I might change things to better manage the consequences of stroke (-0.055)
2. I cannot rely solely on others to help me manage the consequences of stroke (0.034)
5. I always follow professional advice about my health, to the letter (0.101)
6. General self-care is important to me to stay as healthy as possible (0.107)
8. I should make most of the decisions about how my stroke is managed (0.115)
14. Treatment or therapy regimes do not take over my life (0.004)
17. I talk about any medication I am prescribed with healthcare professionals (0.024)
18. I find answers to problems about stroke without seeking professional advice (0.091)
21. The lifestyle choices that affect my health (for example, smoking, diet, alcohol, etc) have changed since having a stroke (-0.050)
25. I always ask health care professionals to explain why I should follow their advice (0.097)
28. Following advice from health care professionals is the only way I will manage stroke (0.089)
41. I am reliant upon others to help me do things important to my health and well-being (this might involve attending appointments, shopping for food, social activities, etc) (-0.150)

Appendix 19 Scale '1A' (item number from SSMQ44)

1. Whatever I do, I will not improve my condition (3)
2. When things do not go well with my stroke, it is hard to stay positive (4)
3. It is hard to be motivated to seek out solutions to problems relating to stroke (9)
4. It is difficult to stay motivated to do tasks or strategies important to my recovery (10)
5. My condition would improve if I received more professional help (11)
6. It is not up to me to decide what the best ways to manage my stroke are (12)
7. I find it difficult to tell health care professionals what I want or need (24)
8. The physical effects of stroke mean that I cannot manage my health as I would like (30)
9. My problems with communication mean that I cannot manage my health as I would like (31)
10. The effects of stroke mean that I cannot control any aspect of my recovery and health (32)
11. The effects of stroke mean that I cannot manage my recovery and health (33)
12. I am not sure what signs or symptoms might mean my health is changing (34)
13. My efforts to manage the consequences of stroke turn out how I like (36)
14. I am able to control my general health (37)
15. The efforts I take to manage my health have a positive effect (38)

Appendix 20 Scale '1B' (item number from SSMQ44)

1. Whatever I do, I will not improve my condition (3)
2. When things do not go well with my stroke, it is hard to stay positive (4)
3. It is hard to be motivated to seek out solutions to problems relating to stroke (9)
4. My condition would improve if I received more professional help (11)
5. It is not up to me to decide what the best ways to manage my stroke are (12)
6. I find it difficult to tell health care professionals what I want or need (24)
7. The physical effects of stroke mean that I cannot manage my health as I would like (30)
8. My problems with communication mean that I cannot manage my health as I would like (31)
9. The effects of stroke mean that I cannot manage my recovery and health (33)
10. I am not sure what signs or symptoms might mean my health is changing (34)
11. I am able to control my general health (37)
12. The efforts I take to manage my health have a positive effect (38)

Appendix 21 Self-management capacity scale

1. **Whatever I do, I will not improve my condition**
2. **When things do not go well with my stroke, it is hard to stay positive**
3. **It is hard to be motivated to seek out solutions to problems relating to stroke**
4. **It is not up to me to decide what the best ways to manage my stroke are**
5. **The physical effects of stroke mean that I cannot manage my health as I would like**
6. **My problems with communication mean that I cannot manage my health as I would like**
7. **The effects of stroke mean that I cannot manage my recovery and health**
8. **I am not sure what signs or symptoms might mean my health is changing**
9. **The efforts I take to manage my health have a positive effect**

Appendix 22 SSMQ item list

Items are ordered within each scale from highest to lowest Loevinger's *H* coefficients. Higher *H* values indicate fewer observed Guttman errors, i.e. when a greater number of items are responded to in a manner that corresponds with the 'proper' sequence. Numbers in brackets refer to their original number in the SSMQ44 item pool.

Scale 1 -Capacity

1. **The effects of stroke mean that I cannot manage my recovery and health (8)**
2. **When things do not go well with my stroke, it is hard to stay positive (2)**
3. **It is not up to me to decide what the best ways to manage my stroke are (5)**
4. **The physical effects of stroke mean that I cannot manage my health as I would like (6)**
5. **It is hard to be motivated to seek out solutions to problems relating to stroke (3)**
6. **I am not sure what signs or symptoms might mean my health is changing (9)**
7. **My problems with communication mean that I cannot manage my health as I would like**
8. **Whatever I do, I will not improve my condition (1)**
9. **The efforts I take to manage my health have a positive effect (10)**

Scale 2- Interaction confidence

10. **I find it difficult to tell health care professionals what I want or need (24)**
11. **I work out ways of managing my health following stroke together with health care professionals (29)**
12. **I am confident that health care professionals can answer my questions (27)**
13. **I feel confident at discussing any advice I don't understand with Doctors (23)**

14. I feel confident at getting the information I need from Healthcare professionals (35)
15. I know how to get help if I am concerned about my condition (20)

Scale 3- Strategies

16. I plan my day so I can get things done without being tired (16)
17. I feel confident asking family members to help me do things important to my health (43)
18. I manage things related to stroke as well as other people with stroke (39)
19. I try different ways of doing things, until I find out what works for me (19)
20. Ideas and things that work for other people with stroke are helpful to my recovery (44)
21. I have useful information or advice to give to others regarding managing after stroke (40)
22. I feel comfortable asking friends to help me do things important to my health (42)

Scale 4-Professional guidance

23. I am concerned that the things I do to manage stroke may cause harm if not guided by health care professionals (22)
24. I cannot alter what my health care professionals decide to do about my stroke (13)
25. My condition would improve if I received more professional help (11)
26. Following advice from health care professionals is the only way I will manage stroke (28)
27. I always follow professional advice about my health, to the letter (5)
28. Constant professional advice would help me to manage stroke (26)

Appendix 23 Output summaries for investigation of Monotonicity

R Mokken package **output summaries for investigation of latent monotonicity.**

SSMQ28 (n=78)

```
Item   H   #ac #vi #vi/#ac maxvi sum sum/#ac zmax #zsig crit
V1   0.25  29  0        0      0  0       0    0     0    0
V2   0.33  21  0        0      0  0       0    0     0    0
V3   0.13  18  0        0      0  0       0    0     0    0
V4   0.30  25  0        0      0  0       0    0     0    0
V5   0.36  16  0        0      0  0       0    0     0    0
V6   0.34  23  0        0      0  0       0    0     0    0
V7   0.25  28  0        0      0  0       0    0     0    0
V8   0.10  22  0        0      0  0       0    0     0    0
V9   0.24  18  0        0      0  0       0    0     0    0
V10  0.25  15  0        0      0  0       0    0     0    0
V11  0.21  27  0        0      0  0       0    0     0    0
V12  0.30  19  0        0      0  0       0    0     0    0
V13  0.29  28  0        0      0  0       0    0     0    0
V14  0.29  25  0        0      0  0       0    0     0    0
V15  0.14  26  0        0      0  0       0    0     0    0
V16  0.15  23  0        0      0  0       0    0     0    0
V17  0.11  27  0        0      0  0       0    0     0    0
V18  0.33  23  0        0      0  0       0    0     0    0
V19  0.32  22  0        0      0  0       0    0     0    0
V20  0.36  20  0        0      0  0       0    0     0    0
V21  0.33  24  0        0      0  0       0    0     0    0
V22  0.27  23  0        0      0  0       0    0     0    0
V23  0.27  21  0        0      0  0       0    0     0    0
V24  0.33  15  0        0      0  0       0    0     0    0
V25  0.23  28  0        0      0  0       0    0     0    0
V26  0.23  16  0        0      0  0       0    0     0    0
V27  0.16  27  0        0      0  0       0    0     0    0
V28  0.19  28  0        0      0  0       0    0     0    0
```

Scale 1 ‘Capacity’ (n=82)

```
Item   H  #ac #vi #vi/#ac  maxvi sum sum/#ac zmax #zsig crit
V1   0.41  37  0        0      0  0       0    0     0    0
V2   0.50  29  0        0      0  0       0    0     0    0
V3   0.49  22  0        0      0  0       0    0     0    0
V4   0.44  38  0        0      0  0       0    0     0    0
V5   0.50  30  0        0      0  0       0    0     0    0
V6   0.50  32  0        0      0  0       0    0     0    0
V7   0.47  39  0        0      0  0       0    0     0    0
V8   0.53  26  0        0      0  0       0    0     0    0
V9   0.48  33  0        0      0  0       0    0     0    0
```

Scale 2 ‘Confidence’ (n=84)

```
Item  H   #ac #vi #vi/#ac maxvi sum sum/#ac zmax #zsig
V1  0.42  31   0       0     0  0     0    0     0
```

```
V2  0.51  27   0       0     0   0     0    0     0
V3  0.39  30   0       0     0   0     0    0     0
V4  0.42  42   0       0     0   0     0    0     0
V5  0.41  24   0       0     0   0     0    0     0
V6  0.53  22   0       0     0   0     0    0     0
```

Scale 3 ‘Strategies’ (n=79)

```
ItemH #ac #vi #vi/#ac maxvi sum sum/#ac  zmax #zsig crit
V1  0.33  22   0       0     0   0        0     0    0
V2  0.14  30   0       0     0   0        0     0    0
V3  0.30  20   0       0     0   0        0     0    0
V4  0.27  22   0       0     0   0        0     0    0
V5  0.26  20   0       0     0   0        0     0    0
V6  0.36  26   0       0     0   0        0     0    0
V7  0.32  24   0       0     0   0        0     0    0
```

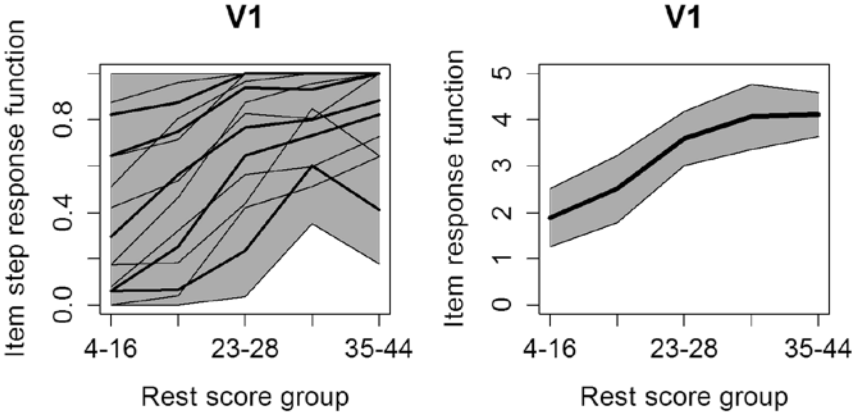
Scale 4 ‘Guidance’ (n=81)

```
Item H   #ac #vi #vi/#ac maxvi sum sum/#ac zmax #zsig crit
V1  0.33  18   0     0     0   0       0    0     0    0
V2  0.41  30   0     0     0   0       0    0     0    0
V3  0.46  24   0     0     0   0       0    0     0    0
V4  0.47  28   0     0     0   0       0    0     0    0
V5  0.29  27   0     0     0   0       0    0     0    0
V6  0.41  25   0     0     0   0       0    0     0    0
```

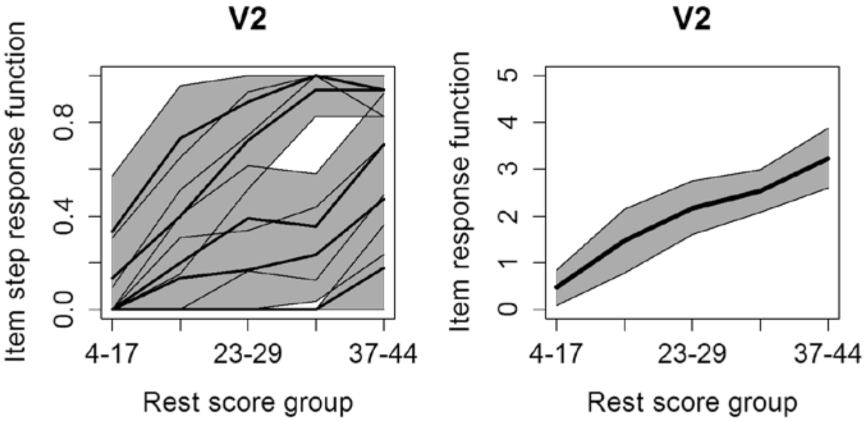
Appendix 24 Item Step Response Function plots for the SSMQ

Item step response function plots of capacity scale items.

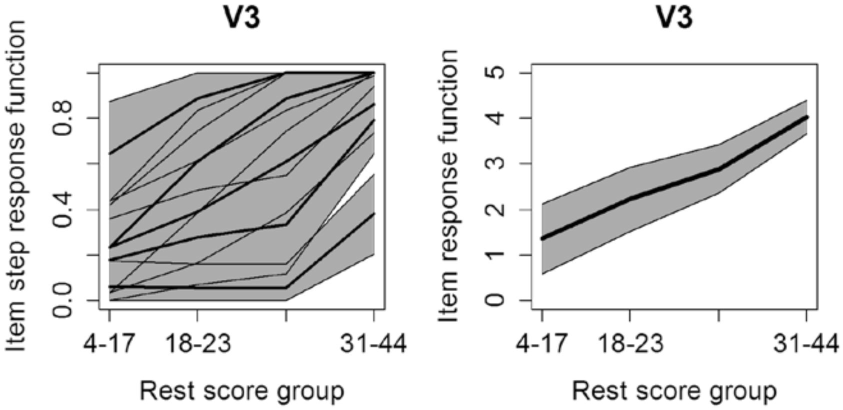
V1: Whatever I do, I will not improve my condition



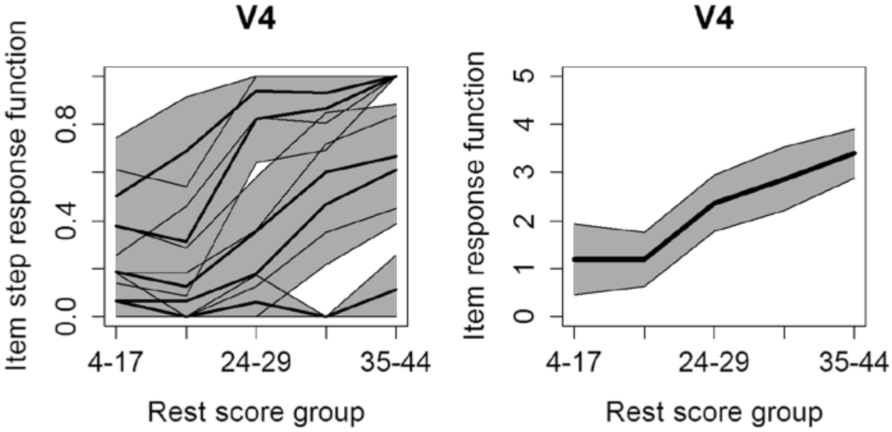
V2: When things do not go well with my stroke, it is hard to stay positive



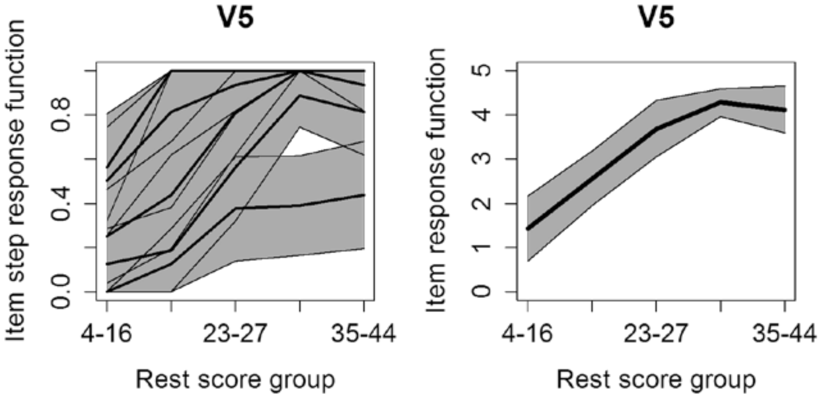
V3: It is hard to be motivated to seek out solutions to problems relating to stroke



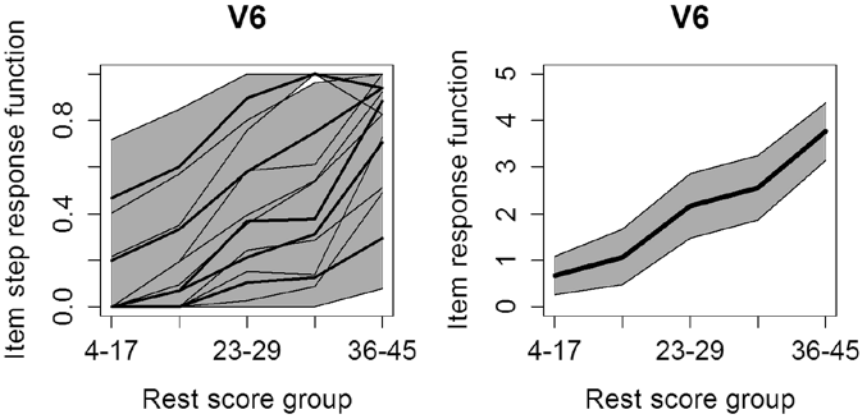
V4: It is not up to me to decide what the best ways to manage my stroke are



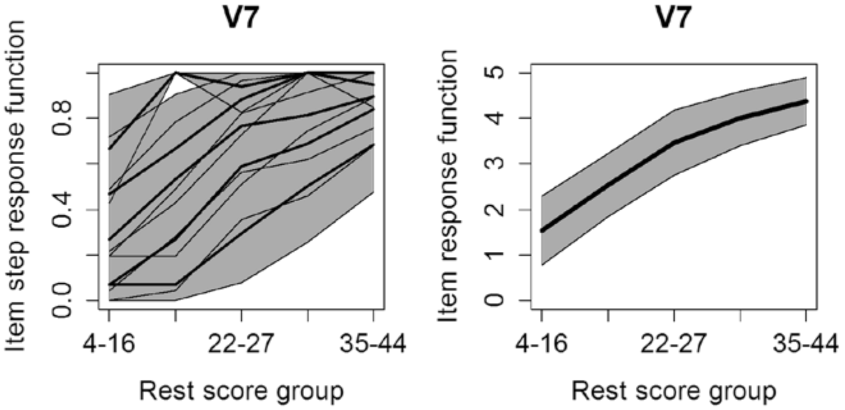
V5: The physical effects of stroke mean that I cannot manage my health as I would like



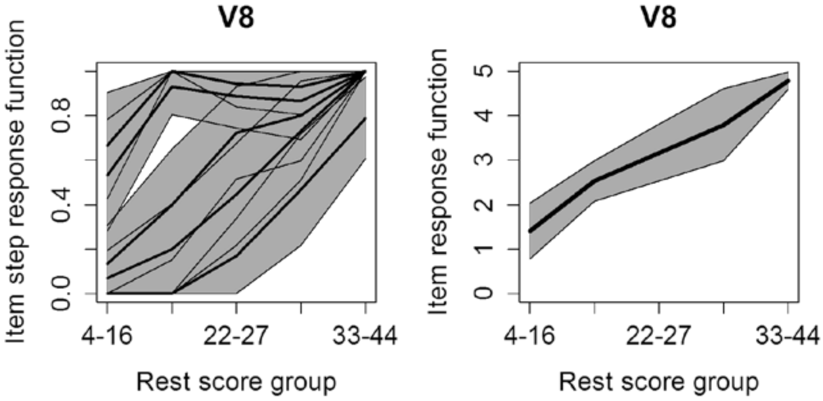
V6: My problems with communication mean that I cannot manage my health as I would like



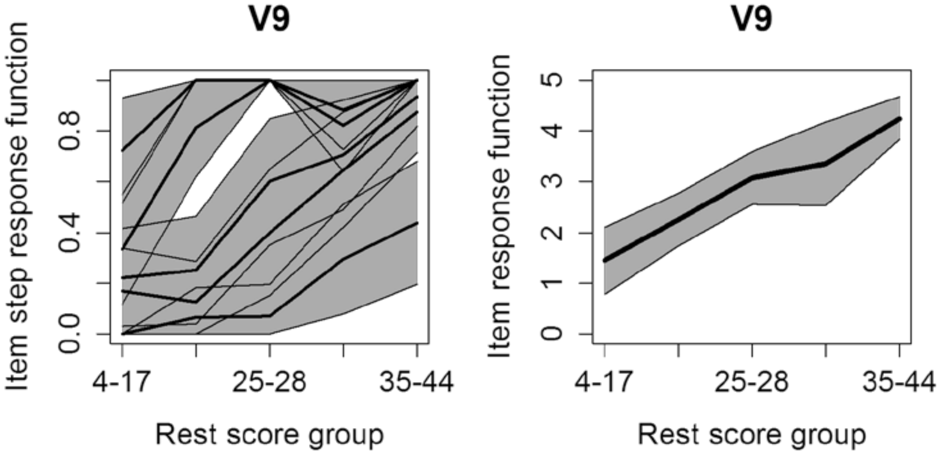
V7: The effects of stroke mean that I cannot manage my recovery and health



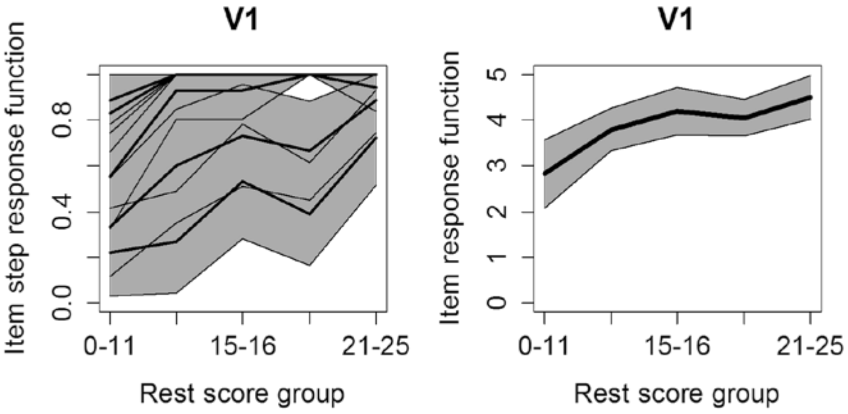
V8: I am not sure what signs or symptoms might mean my health is changing



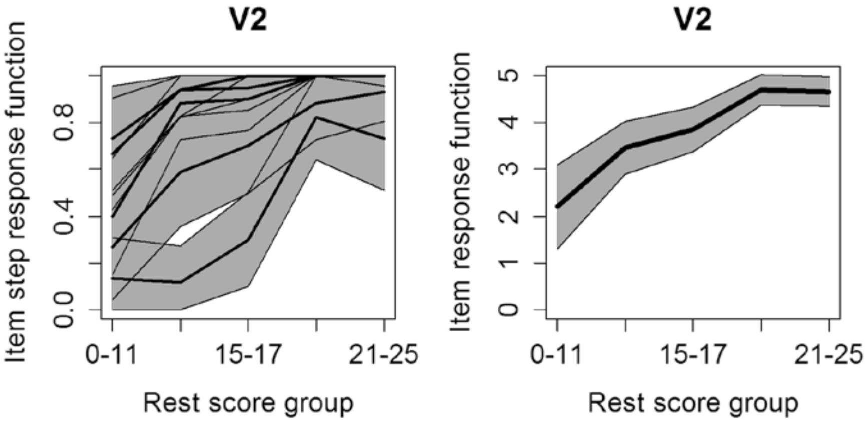
V9: The efforts I take to manage my health have a positive effect



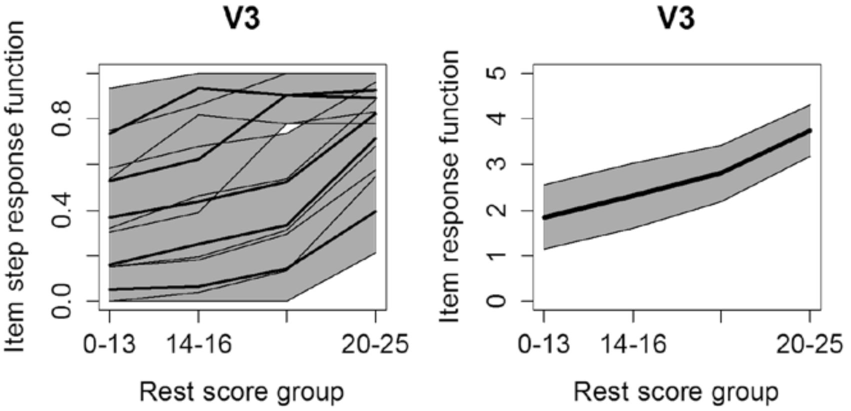
ISRF plots of Interaction confidence scale.



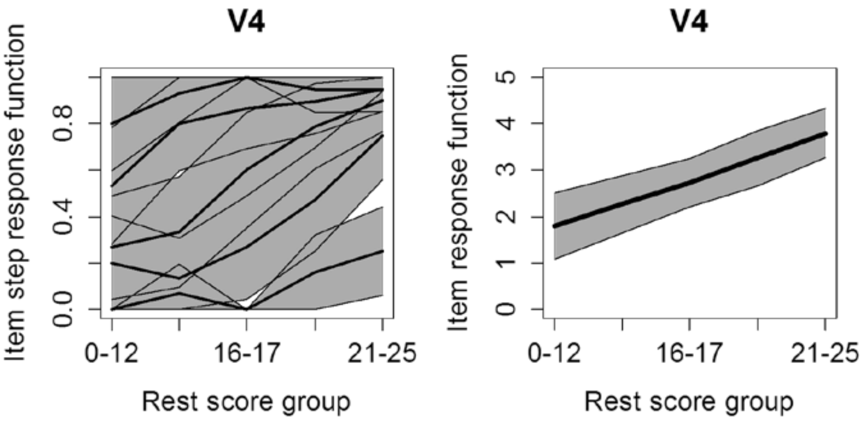
V1: I am confident that health care professionals can answer my questions



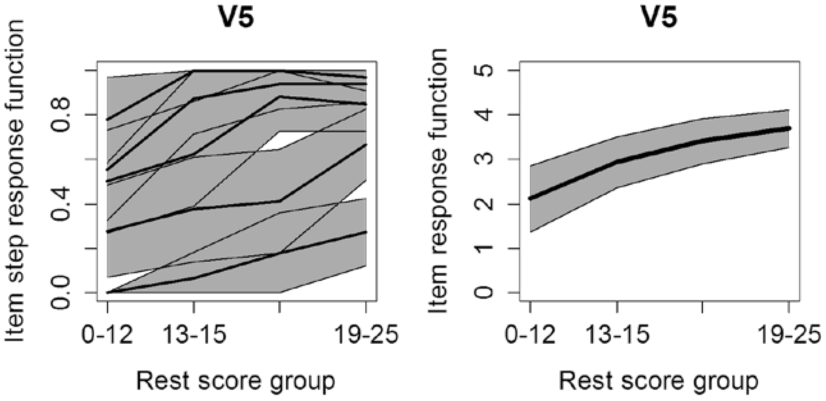
V2: I work out ways of managing my health following stroke together with health care professionals



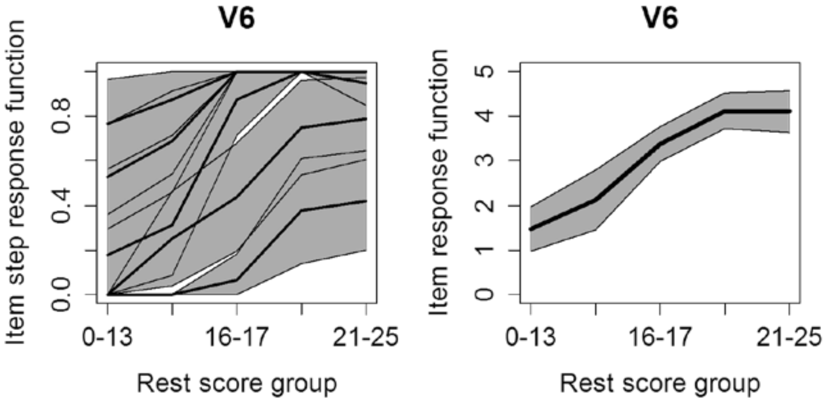
V3: I know how to get help if I am concerned about my condition



V4: I feel confident at discussing any advice I don't understand with Doctors



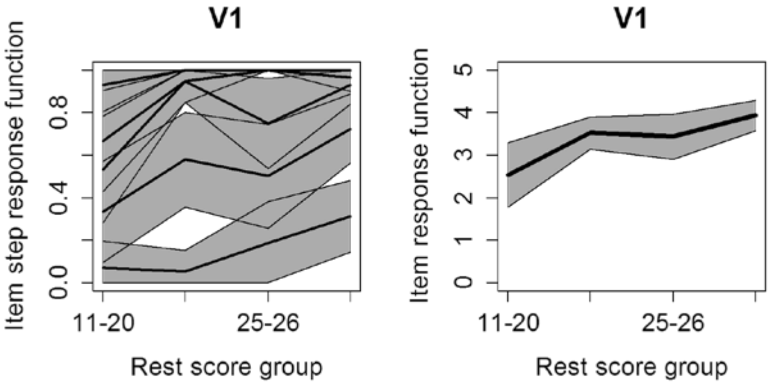
V5: I feel confident at getting the information I need from Healthcare professionals



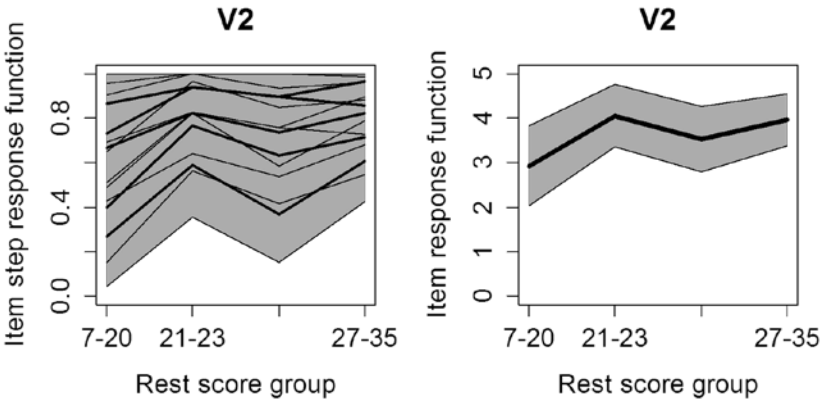
V6: I find it difficult to tell health care professionals what I want or need

ISRF plots of the strategies scale.

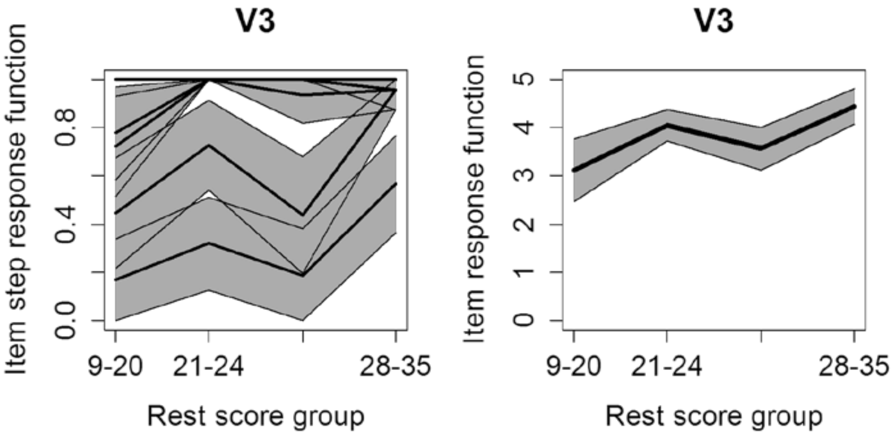
V1: I feel confident asking family members to help me do things important to my health



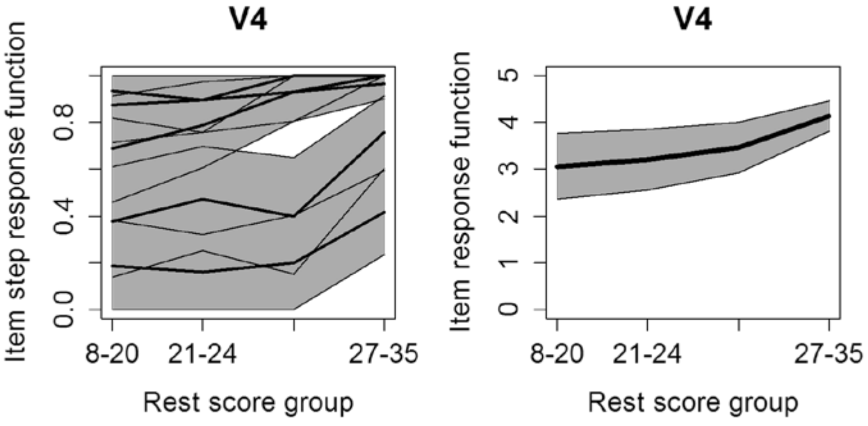
V2: I feel comfortable asking friends to help me do things important to my health



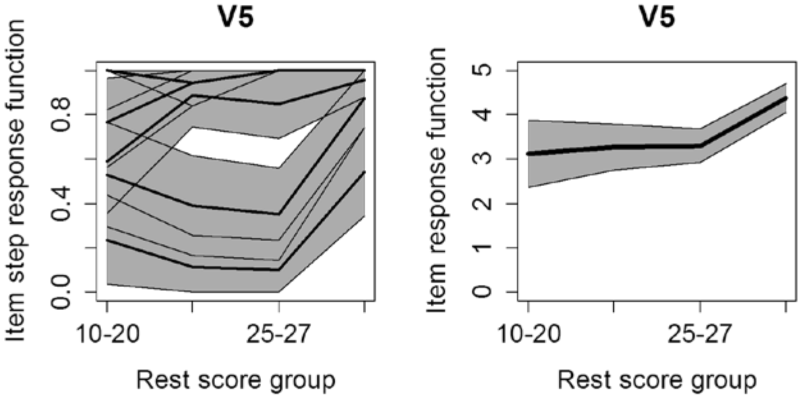
V3: I try different ways of doing things, until I find out what works for my health



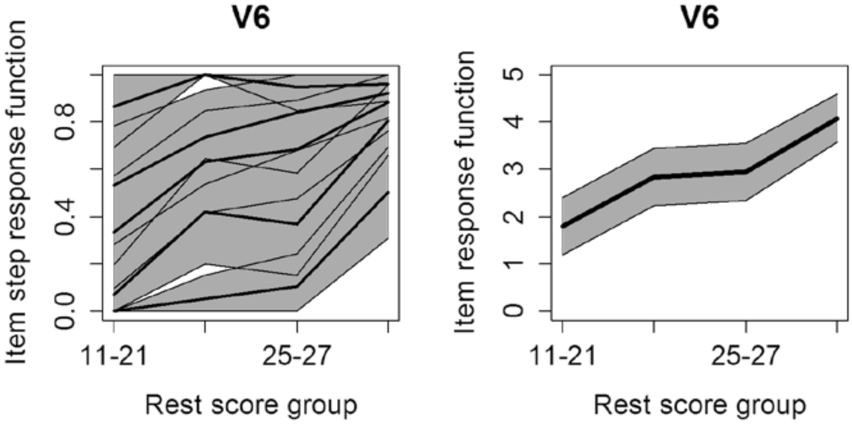
V4: Ideas and things that work for other people with stroke are helpful to my recovery



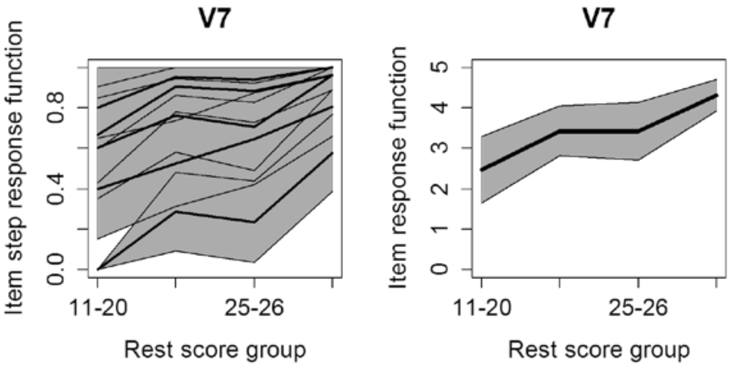
V5: I have useful information or advice to give to others regarding managing stroke



V6: I plan my day so I can get things done without being tired

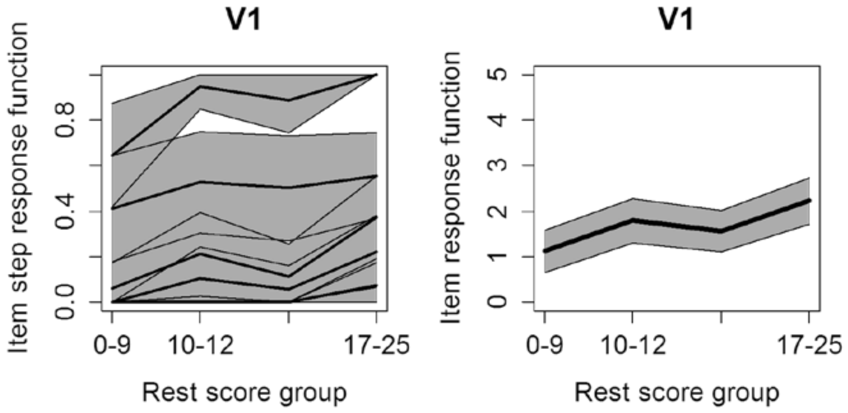


V7: I manage things related to stroke as well as other people with stroke

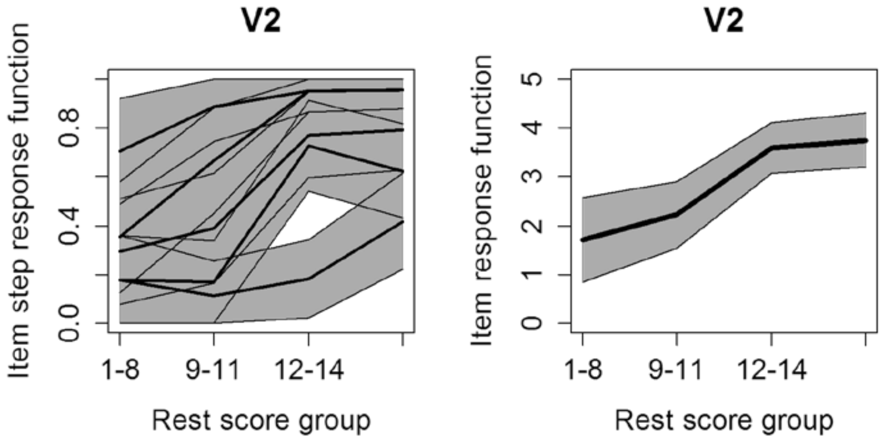


ISRF plots of guidance scale

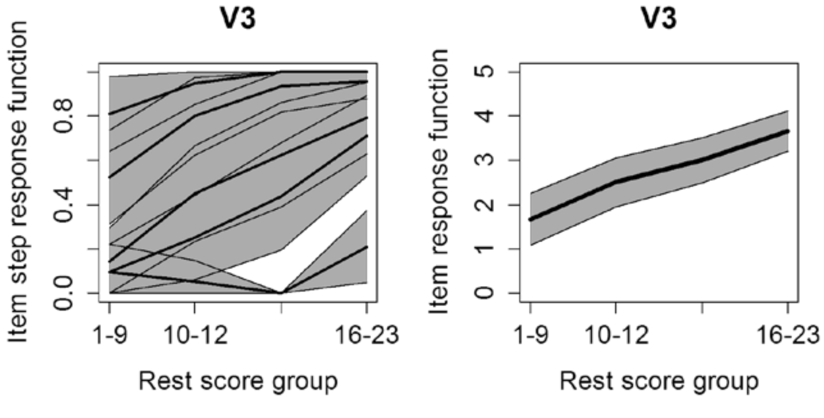
V1: I always follow professional advice about my health, to the letter



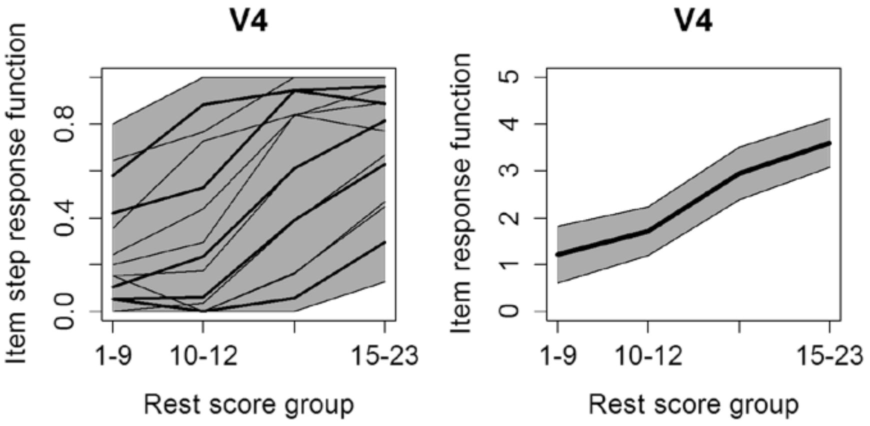
V2: My condition would improve if I received more professional help



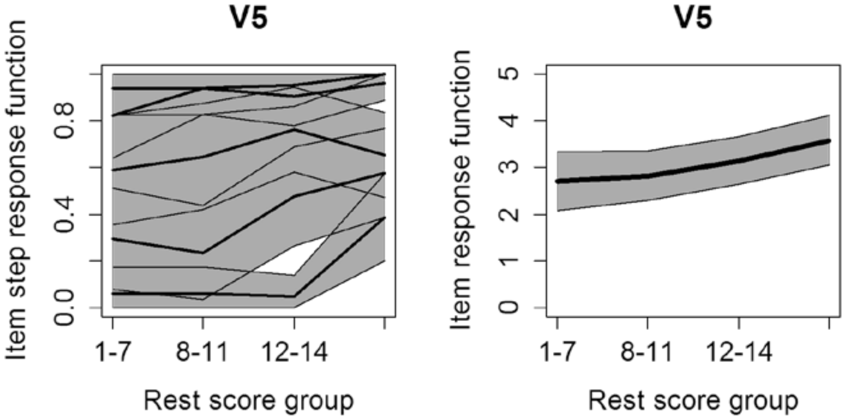
V3: I cannot alter what my health care professionals decide to do about my stroke



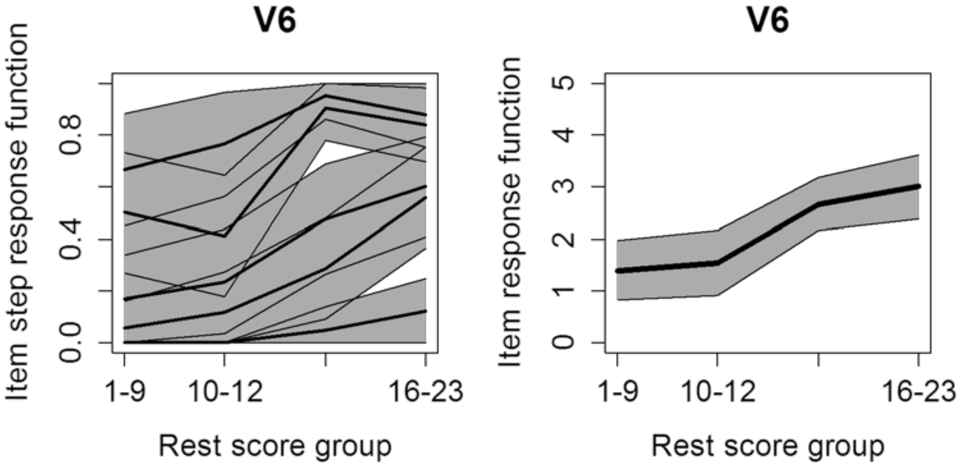
V4: I am concerned that the things I do to manage stroke may cause harm if not guided by health care professionals



V5: Constant professional advice would help me to manage stroke



V6: Following advice from health care professionals is the only way I will manage stroke



Appendix 25 - The Stroke Self-Management Questionnaire (SSMQ)

The statements below ask you about managing your health after stroke. Take a break between sections if needed. You may ask someone to help you complete the questionnaire. There are no 'right' or 'wrong' answers.

Please read the following statements carefully. Thinking about the last month, indicate how true or false statements 1-9 are for you. Tick or cross in the box which most closely represents your view.

	Always true	Mostly true	Somewhat true	Somewhat false	Mostly false	Always false
1. The effects of stroke mean that I cannot manage my recovery and health						
2. When things do not go well with my stroke, it is hard to stay positive						
3. It is not up to me to decide what the best ways to manage my stroke are						

	Always true	Mostly true	Somewhat true	Somewhat false	Mostly false	Always false
4. The physical effects of stroke mean that I cannot manage my health as I would like						
5. It is hard to be motivated to seek out solutions to problems relating to stroke						
6. I am not sure what signs or symptoms might mean my health is changing						
7. My problems with communication mean that I cannot manage my health as I would like						
8. Whatever I do, I will not improve my condition						
9. The efforts I take to manage my health have a positive effect						

This section asks you to think about communicating with health care professionals. Thinking about the last month, indicate how true or false these statements are for you

	Always true	Mostly true	Somewhat true	Somewhat false	Mostly false	Always False
10. I find it difficult to tell health care professionals what I want or need						
11. I work out ways of managing my health following stroke together with health care professionals						
12. I am confident that health care professionals can answer my questions						
13. I feel confident at discussing any advice I don't understand with Doctors						
14. I feel confident at getting the information I need from Health care professionals						
15. I know how to get help if I am concerned about my condition						

This section asks you about some of the things you might do to manage your health. Thinking about the last month, indicate how true or false these statements are for you.

	Always true	Mostly true	Somewhat	Somewhat	Mostly false	Always False

			true	false		
16. I plan my day so I can get things done without being tired						
17. I feel confident asking family members to help me do things important to my health						
18. I manage things related to stroke as well as other people with stroke						
19. I try different ways of doing things, until I find out what works for me						
20. Ideas and things that work for other people with stroke are helpful to my recovery						
21. I have useful information or advice to give to others regarding managing after stroke						
22. I feel comfortable asking friends to help me do things important to my health						

The last section, asks you to think about how health professionals might assist you to manage your health. Thinking about the last month, please indicate how true or false these statements are for you.

	Always true	Mostly true	Somewhat true	Somewhat false	Mostly false	Always False
23. I am concerned that the things I do to manage stroke may cause harm if not guided by health care professionals						
24. I cannot alter what my health care professionals decide to do about my stroke						
25. My condition would improve if I received more professional help						
26. Following advice from health care professionals is the only way I will manage stroke						
27. I always follow professional advice about my health, to the letter						
28. Constant professional advice would help me to manage stroke						

Did you complete this questionnaire: yourself? YES/NO

with help from someone else? YES/NO

If yes, please state the relationship of the person who assisted you:

Glossary

Arterial embolism Sudden interruption of blood flow due to an embolus adhering to the wall of an artery.

Construct The theoretical characteristic that is measured in a questionnaire. Constructs may have different facets, represented by domains.

Domain An aspect that contributes to the overall construct measured in a questionnaire.

Dysphasia Communication impairment, affecting the ability to use and understand spoken and written language. Aphasia and dysphasia are often used inter-changeably.

Embolus Any detached, travelling intravascular mass (solid, liquid, or gaseous) carried by blood circulation, capable of impeding circulation.

Hypertension Elevated blood pressure (BP) in the arteries. BP involves two measurements, systolic (top reading) and diastolic (bottom reading), each relate to contraction (systole) or relaxation (diastole) of cardiac muscle. Normal BP is conventionally stated as at or below 120/80 mmHg. High BP is present if readings persist at or above 140/90 mmHg.

Monotonicity Increasing probability of an item score increasing as the level of the latent trait increases.

Ordinal Data where values/observations belonging to it can be ranked or put in order. Intervals between each value are not necessarily equal.

Reliability Extent to which an outcome measure is consistent and reduces random error.

Stochastic Item score is dependent on the level of the trait under measurement. Item score is independent of other item scores.

Stroke - the term given to the rapid loss of brain function(s) due to disturbance in the blood supply to the brain. This can be due to ischaemia (lack of blood flow) caused by a blockage (thrombosis, arterial embolism), or a haemorrhage (leakage of blood).

Unidimensional Set of items that measure one construct or domain.

Validity Extent to which an outcome measure really measures what it intends to measure.

References

ABEN, L., BUSSCHBACH, J., PONDS, R. & RIBBERS, G. 2008. Memory self-efficacy and psychosocial factors in stroke. J Rehabil Med, 40, 681-3.

AJZEN, I. 1985. The theory of planned behavior. *Organizational Behavior and Human Decision Processes,* 50, 179-211

AJZEN, I. & FISHBEIN, M. 2005. The influence of attitude on behaviour. In: ALBARRACÍN, D., JOHNSON, B. & ZANNA, M. (eds.) Handbook of Attitudes. New Jersey: Lawrence Erlbaum Ltd.

ALLEN, K., HAZELETT, S., JARJOURA, D., WRIGHT, K., CLOUGH, L. & WEINHARDT, J. 2004. Improving stroke outcomes: implementation of a post-discharge care management model. Journal of Clinical Outcomes Management, 11, 707-714.

ANDERSON, C., NI MHURCHU, C., BROWN, P. M. & CARTER, K. 2002. Stroke rehabilitation services to accelerate hospital discharge and provide home-based care: an overview and cost analysis. Pharmacoeconomics, 20, 537-52.

ANDERSON, C., RUBENACH, S., MHURCHU, C., CLARK, M., SPENCER, C. & WINSOR, A. 2000. Home or Hospital for stroke rehabilitation? Results of a randomized controlled trial I: Health outcomes at 6 months. Stroke, 31 (5), 1024-1031.

ANDRESEN, E. 2000. Criteria for assessing the tools of disability outcomes research. Arch Phys Med Rehabil, 81, S15-20.

ANGUS, J. & CLARK, A. 2012. Using critical realism in nursing and health research: promise and challenges. Nursing Inquiry, 19, 1-3.

APPELROS, P. 2006. Prevalence and predictors of pain and fatigue after stroke: a population-based study. Int J Rehabil Res, 29, 329-33.

ARMITAGE, C. & CHRISTIAN, J. 2003. From attitudes to behaviour: Basic and applied research on the theory of planned behaviour. Current Psychology, 22, 187-195.

ARTHUR, A., KOPEC, J., KLINKHOFF, A., ADAM, P., CARR, S., PRINCE, J., DUMONT, K. & NIGG, C. 2009. Readiness to manage arthritis: a pilot study using a stages-of-change measure for arthritis rehabilitation. Rehabilitation Nursing, 34, 64.

ASAYAMA, K., OHKUBO, T., KIKUYA, M., METOKI, H., OBARA, T., HOSHI, H., HASHIMOTO, J., TOTSUNE, K., SATOH, H. & IMAI, Y. 2005. Use of 2003 European Society of Hypertension-European Society of Cardiology guidelines for predicting stroke using self-measured blood pressure at home: the Ohasama study. Eur Heart J, 26, 2026-31.

AUDULV, A., ASPLUND, K. & NORBERGH, K. 2010. Who's in charge? The role of responsibility attribution in self-management among people with chronic illness. Patient Education and Counseling, 81, 94-100.

AUDULV, A. 2011. BEING CREATIVE AND RESOURCEFUL. Individuals' abilities and possibilities for self-management of chronic illness. Thesis: Doctor of Philosophy, Mid Sweden University (Mittuniversitetet).

BAKER, D., WOLF, M., FEINGLASS, J., THOMPSON, J., GAZMARARIAN, J. & HUANG, J. 2007. Health literacy and mortality among elderly persons. Arch Intern Med, 167, 1503-9.

BANDURA, A. 1989. Human agency in social cognitive theory. Am Psychol, 44, 1175-84.

BANDURA, A. 2005. The Primacy of Self-Regulation in Health Promotion. Applied Psychology, 54, 245-254.

BANDURA, A. 2011. The Social and Policy impact of Social Cognitive Theory. In: MARK, M., DONALDSON, S. & CAMPBELL, B. (eds.) Social Psychology and Evaluation. New York: Guildford Press.

BARBOUR, R. 2007. Doing Focus Groups, London, SAGE.

BARKER, R. & BRAUER, S. 2005. Upper limb recovery after stroke: The stroke survivors' perspective. Disability and Rehabilitation, 27, 1213-1223.

BARLOW, J., STURT, J. & HEARNSHAW, H. 2002a. Self-management interventions for people with chronic conditions in primary care: Examples from arthritis, asthma and diabetes. Health Education Journal, 61, 365-378.

BARLOW, J., WRIGHT, C., SHEASBY, J., TURNER, A. & HAINSWORTH, J. 2002b. Self-management approaches for people with chronic conditions: a review. Patient Educ Couns, 48, 177-87.

BARRETT, J. & KIRK, S. 2000. Running focus groups with elderly and disabled elderly participants. Applied Ergonomics, 31, 621-629.

BASEMAN, S., FISHER, K., WARD, L. & BHATTACHARYA, A. 2010. The relationship of physical function to social integration after stroke. J Neurosci Nurs, 42, 237-44.

BATTERSBY, M., LAWN, S. & POLS, R. 2010a. Conceptualisation of self-management. In: KRALIK, D., PATERSON, B. & COATES, V. (eds.) Translating Chronic Illness Research into Practice. Chichester: John Wiley and Sons Ltd.

BATTERSBY, M., VON KORFF, M., SCHAEFER, J., DAVIS, C., LUDMAN, E., S., PARKERTON, M. & WAGNER, E. 2010b. Twelve evidence-based principles for implementing self-management support in primary care. Joint Commission Journal on Quality & Patient Safety, 36, 561-570.

BAYLISS, E., ELLIS, J. & STEINER, J. 2007. Barriers to self-management and quality-of-life outcomes in seniors with multimorbidities. Annals of Family Medicine, 5, 395-402.

BAYLISS, E., ELLIS, J., STEINER, J. & MAIN, D. 2005. Initial validation of an instrument to identify barriers to self-management for persons with co-morbidities. Chronic Illness, 1, 315-320.

BAYLISS, E., STEINER, J., FERNALD, D., CRANE, L. & MAIN, D. 2003. Descriptions of barriers to self-care by persons with comorbid chronic diseases. Ann Fam Med, 1, 15-21.

BEATON, D., BOMBARDIER, C., KATZ, J. & WRIGHT, J. 2001. A taxonomy for responsiveness. J Clin Epidemiol, 54, 1204-17.

BEATTY, P. & WILLIS, G. 2007. Research Synthesis: The Practice of Cognitive Interviewing. Public Opinion Quarterly, 71, 287-311.

BECK, A., RUSH, J., SHAW, B. & EMERY, G. 1979. Cognitive Therapy of Depression, New York, Guildford Press.

BECKER, M. 1974. The Health Belief Model and personal health behaviour. Health Education Monographs, 2, 324-508.

BENNETT, H. & LINCOLN, N. 2006. Potential screening measures for depression and anxiety after stroke International Journal of Therapy and Rehabilitation, 13, 401-406.

BENTON, T. & CRAIB, I. 2001. Philosophy of Social Science: The Philosophical Foundations of Social Thought, Basingstoke, Palgrave.

BERG, A., LONNQVIST, J., PALOMAKI, H. & KASTE, M. 2009. Assessment of depression after stroke: a comparison of different screening instruments. Stroke, 40, 523-9.

BERNHARDT, J., DEWEY, H., THRIFT, A. & DONNAN, G. 2004. Inactive and Alone. Stroke, 35, 1005-1009.

BHATNAGAR, P., SCARBOROUGH, P., SMEETON, N. & ALLENDER, S. 2010. The incidence of all stroke and stroke subtype in the United Kingdom, 1985 to 2008: a systematic review. BMC Public Health, 10, 539.

BLAKEMAN, T., BOWER, P., REEVES, D. & CHEW-GRAHAM, C. 2010. Bringing self-management into clinical view: a qualitative study of long-term condition management in primary care consultations. Chronic Illn, 6, 136-50.

BLOOR, M., FRANKLAND, J., THOMAS, M. & ROBSON, K. 2001. Focus groups in social research, London, Sage.

BODENHEIMER, T., LORIG, K., HOLMAN, H. & GRUMBACH, K. 2002a. Patient self-management of chronic disease in primary care. Journal of the American Medical Association, 288, 2469-2475.

BODENHEIMER, T., WAGNER, E. & GRUMBACH, K. 2002b. Improving primary care for patients with chronic illness: the chronic care model, Part 2. *JAMA,* 288, 1909-14.

BOGER, E., DEMAIN, S. & LATTER, S. 2013. Self-management: A systematic review of outcome measures adopted in self-management interventions for Stroke. Disabil Rehabil, 35 (17), 1415-28.

BOLLEN, K. 1984. Multiple indicators: Internal consistency or no necessary relationship? Quality and Quantity, 18, 377-385.

BOLLEN, K. & LENNOX, R. 1991. Conventional wisdom on measurement: A structural equation perspective. Psychological Bulletin, 110, 305-314.

BOND, T. & FOX, C. 2001. Basic Principles of the Rasch Model. In: BOND, T. & FOX, C. (eds.) Applying the Rasch Model: fundamental measurement in the human sciences. New Jersey, USA: Lawrence Erlbaum Associates, Inc.

BONETTI, D. & JOHNSTON, M. 2008. Perceived control predicting the recovery of individual-specific walking behaviours following stroke: testing psychological models and constructs. British Journal of Health Psychology, 13, 463-478.

BOURDIEU, P. 1984. Distinction: A social critique of the judgement of taste, London, Routledge.

BOWLING, A. 1995. What things are important in people's lives? A survey of the public's judgements to inform scales of health related quality of life. Soc Sci Med, 41, 1447-62.

BOWLING, A. 2005. Mode of questionnaire administration can have serious effects on data quality. Journal of Public Health, 27, 281-291.

BOWLING, A. 2007. Health status assessment. In: AYERS, S., BAUM, A., MCMANUS, C., NEWMAN, S., WALLSTON, K., WEINMAN, J. & WEST, R. (eds.) Cambridge Handbook of Psychology, Health and Medicine. Cambridge, UK: Cambridge University Press.

BOWLING, A. 2009. Research Methods in Health, Maidenhead, UK, Open University Press.

BRADBURN, N., SUDMAN, S. & WANSINK, B. 2004. Asking Questions: The Definitive Guide to Questionnaire Design - For Market Research, Political Polls, and Social and Health Questionnaires, California, USA, Jossey-Bass.

BRADEN, C. 1993. Research program on learned response to chronic illness experience: Self-help model. Holistic Nursing Practice, 8, 38-44.

BRADY, T., MURPHY, L., O'COLMAIN, B., BEAUCHESNE, D., DANIELS, B. & GREENBERG, M. 2013. A Meta-Analysis of Health Status, Health Behaviors, and Health Care Utilization Outcomes of the Chronic Disease Self-Management Program. Prev Chronic Dis, 10, E07.

BRANTE, T. 2001. Consequences of realism for sociological theory – building. J Theory of Soc Behav, 31, 167-195.

BRAUN, V. & CLARKE, V. 2006. Using thematic analysis in Psychology. Qualitative Research in Psychology, 3, 77-101.

BREWER, L. & WILLIAMS, D. 2010. A review of early supported discharge after stroke. Reviews in Clinical Gerontology, 20, 327-337.

BROD, M., TESLER, L. & CHRISTENSEN, T. 2009. Qualitative research and content validity: developing best practices based on science and experience. Qual Life Res, 18, 1263-78.

BROOM, A. & WILLIS, E. 2007. Competing Paradigms and Health Research. In: SAKS, M. & ALLSOP, J. (eds.) Researching Health: Qualitative, Quantitative and Mixed Methods. London: Sage.

BROOMFIELD, N., LAIDLAW, K., HICKABOTTOM, E., MURRAY, M., PENDREY, R., WHITTICK, J. & GILLESPIE, D. 2011. Post-stroke depression: the case for augmented, individually tailored cognitive behavioural therapy. Clin Psychol Psychother, 18, 202-17.

BRUCE, N., POPE, D. & STANISTREET, D. 2008. Quantitative Research Methods for Health Professionals: A Practical Interactive Course, Chichester, John Wiley & Sons Ltd.

BRUNIER, G. & GRAYDON, J. 1996. A comparison of two methods of measuring fatigue in patients on chronic haemodialysis: visual analogue vs Likert scale. *International Journal of Nursing Studies,* 33, 338-348.

BRYMAN, A. 2004. Social Research Methods, New York, Oxford University Press.

BURKS, K. 1999. A nursing practice model for chronic illness. Rehabilitation Nursing, 24, 197-200.

BURROWS, D. & KENDALL, S. 1997. Focus Groups: What are they and how can they be used in nursing and health care research? Social Sciences in Health, 3, 244-253.

BURY, M. 2001. Illness narratives. Fact or fiction? Sociol Health Illn, 23, 263-85.

BURY, M. 2004. Researching patient-professional interactions. J Health Serv Res Policy, 9 Suppl 1, 48-54.

BURY, M., NEWBOULD, J. & TAYLOR, D. 2005. A rapid review of the current state of knowledge regarding lay-led self-management of chronic illness. London: National Institute for Health and Care Excellence.

BURY, M. & PINK, D. 2005. The HSJ debate. Self-management of chronic disease doesn't work. Health Service Journal, 115, 18-9, 1.

BUTLER, C. 2008. The American Academy for Cerebral Palsy and Developmental Medicine Methodology to Develop Systematic Reviews of Treatment Interventions. [Online]. Available: http://www.aacpdm.org/membership/members/committees/treatment_outcomes_methodology.pdf 2008, revision 1.2].

CADILHAC, D., HOFFMANN, S., KILKENNY, M., LINDLEY, R., LALOR, E., OSBORNE, R. & BATTERBSY, M. 2011. A Phase II Multicentered, Single-Blind, Randomized, Controlled Trial of the Stroke Self-Management Program. Stroke, 42, 1673-9.

CAMERON, I. 2010. Models of rehabilitation: commonalities of interventions that work and of those that do not. Disability & Rehabilitation, 32, 1051-1058.

CAMPBELL, M. & MACHIN, D. 1993. Medical statistics. A commonsense approach, Chichester, Wiley & Sons Ltd.

CAMPBELL, N., MURRAY, E., DARBYSHIRE, J., EMERY, J., FARMER, A., GRIFFITHS, F., GUTHRIE, B., LESTER, H., WILSON, P. & KINMONTH, A. 2007. Designing and evaluating complex interventions to improve health care. BMJ, 334, 455-9.

CANO, S. & HOBART, J. 2011. The problem with health measurement. Patient Preference and Adherence, 5, 279-290.

CANTER, R. 2001. Patients and Medical Power. British Medical Journal, 323, 414.

CARBONE, E., CAMPBELL, M. & HONESS-MORREALE, L. 2002. Use of cognitive interview techniques in the development of nutrition surveys and interactive nutrition messages for low-income populations. Journal of the American Dietetic Association, 102, 690-696.

CARE QUALITY COMMISSION 2011. Supporting life after stroke. A review of services for people who have had a stroke and their carers in England. Care Quality Commission review. London: Care Quality Commission.

CARLSSON, G., MOLLER, A. & BLOMSTRAND, C. 2009. Managing an everyday life of uncertainty: a qualitative study of coping in persons with mild stroke. Disabil Rehabil, 31, 773-82.

CASEBEER, A. & VERHOEF, M. 1997. Combining qualitative and quantitative research methods: Considering the possibilities for enhancing the study of chronic diseases. Chronic Diseases in Canada, 18, 130-135.

CARO, J., HUYBRECHTS, K. & DUCHESNE, I. 2000. Management patterns and costs of acute ischemic stroke: an international study. For the Stroke Economic Analysis Group. Stroke, 31, 582-90.

CATALANO, T., DICKSON, P., KENDALL, E., KUIPERS, P. & POSNER, T. 2003. The perceived benefits of the chronic disease self-management program among participants with stroke: A qualitative study. Australian Journal of Primary Health, 9, 80-89.

CENTRE FOR EVIDENCE-BASED MEDICINE. 2010. Asking Focused Questions [Online]. Oxford: Centre for Evidenced Based Medicine, University of Oxford. Available: http://www.cebm.net/EBMtools/ [Accessed 2nd November 2010 2010].

CHABOYER, W., RINGDAL, M., AITKEN, L. & KENDALL, E. 2012. Self-care after traumatic injury and the use of the therapeutic self care scale in trauma populations. Journal of Advanced Nursing, 69, 2, 286–294.

CHARMAZ, K. 2000. Experiencing chronic illness. In: ALBRECHT, G., FITZPATRICK, R. & SCRIMSHAW, S. (eds.) The handbook of social studies in health and medicine. London: Sage.

CHAU, J., THOMPSON, D., TWINN, S., CHANG, A. & WOO, J. 2009. Determinants of participation restriction among community dwelling stroke survivors: A path analysis. BMC Neurology, 9, 49, 1-7.

CHODOSH, J., MORTON, S., MOJICA, W., MAGLIONE, M., SUTTORP, M., HILTON, L., RHODES, S. & SHEKELLE, P. 2005. Meta-analysis: chronic disease self-management programs for older adults. Ann Intern Med, 143, 427-38.

CHRISTODOULOU, C., JUNGHAENEL, D. U., DEWALT, D. A., ROTHROCK, N. & STONE, A. A. 2008. Cognitive interviewing in the evaluation of fatigue items: results from the patient-reported outcomes measurement information system (PROMIS). Qual Life Res, 17, 1239-46.

CLARK, N., GONG, M. & KACIROTI, N. 2001. A model of self-regulation for control of chronic disease. Health Educ Behav, 28, 769-82.

CLARKE, A., SOHANPAL, R., WILSON, G. & TAYLOR, S. 2010. Patients' perceptions of early supported discharge for chronic obstructive pulmonary disease: a qualitative study. Quality & Safety in Health Care, 19, 95-98.

COCHRANE STROKE GROUP 2005. Cochrane Database Systematic Review: Organised inpatient (stroke unit) care for stroke. Issue 2.

COCKERHAM, W. 2007. Social causes of health and disease, Cambridge, Polity Press.

COHEN, J. 1997. Statistical power for the behavioural sciences, New York, Academic Press.

COLLINS, D. 2003. Pretesting survey instruments: an overview of cognitive methods. Qual Life Res, 12, 229-38.

CORSER, W. & DONTJE, K. 2011. Self-management perspectives of heavily comorbid primary care adults. Professional Case Management, 16, 6-17.

COSCO, T., DOYLE, F., WATSON, R., WARD, M. & MCGEE, H. 2012. Mokken scaling analysis of the Hospital Anxiety and Depression Scale in individuals with cardiovascular disease. Gen Hosp Psychiatry, 34, 167-72.

COSTER, S. & NORMAN, I. 2009. Cochrane reviews of educational and self-management interventions to guide nursing practice: a review. International Journal of Nursing Studies, 46, 508-528.

COTT, C., WILES, R. & DEVITT, R. 2007. Continuity, transition and participation: preparing clients for life in the community post-stroke. Disability and Rehabilitation, 29, 1566-1574.

COULTAS, D., FREDERICK, J., BARNETT, B., SINGH, G. & WLUDYKA, P. 2005. A randomized trial of two types of nurse-assisted home care for patients with COPD. Chest, 128, 2017-2024.

COULTER, A., PARSONS, S. & ASKHAM, J. 2008. Policy brief: Where are the patients in decision-making about their own care? Copenhagen, Denmark: Picker Institute.

CRESWELL, J. 2011. Controversies in mixed methods research. In: DENZIN, N. & LINCOLN, Y. (eds.) The SAGE handbook of qualitative research. 4th edition ed. Thousand Oaks, CA: Sage.

CRESWELL, J. & PLANO CLARK, V. 2011. Designing and Conducting Mixed Methods Research, London: Sage.

CRITICAL APPRAISAL SKILLS PROGRAMME. 2010. Solutions for Public Health-CASP Tools [Online]. London: Dept. of Health. Available: http://www.sph.nhs.uk/what-we-do/public-health-workforce/resources/critical-appraisals-skills-programme [Accessed November 23rd 2010].

CRONBACH, L. 1951. Coefficient alpha and the internal structure of tests. Psychometrika, 16, 297-334.

CURTIS, S., GESLER, W., SMITH, G. & WASHBURN, S. 2000. Approaches to sampling and case selection in qualitative research: examples in the geography of health. Soc Sci Med, 50, 1001-14.

DALEY, L., FISH, A., FRID, D. & MITCHELL, G. 2009. Stage-specific education/counseling intervention in women with elevated blood pressure. Prog Cardiovasc Nurs, 24, 45-52.

DAMUSH, T., OFNER, S., YU, Z., PLUE, L., NICHOLAS, G. & WILLIAMS, L. 2011. Implementation of a stroke self-management program. Translational Behavioral Medicine, 1, 561-572.

DARRIGRAND, B., DUTHEIL, S., MICHELET, V., REREAU, S., ROUSSEAUX, M. & MAZAUX, J. 2010. Communication impairment and activity limitation in stroke patients with severe aphasia. Disabil Rehabil.

DAVEY SMITH, G., DORLING, D., MITCHELL, R. & SHAW, M. 2002. Health inequalities in Britain: continuing increases up to the end of the 20th century. Journal of Epidemiology and Community Health, 56, 434-435.

DE SILVA, D. 2011. Helping people help themselves: A review of the evidence considering whether it is worthwhile to support self-management. Evidence review. London: The Health Foundation.

DE VET, H., TERWEE, C., MOKKINK, L. & KNOL, D. 2011. Measurement in Medicine, Cambridge, University Press.

DEL SER, T., BARBA, R., MORIN, M., DOMINGO, J., CEMILLAN, C., PONDAL, M. & VIVANCOS, J. 2005. Evolution of Cognitive Impairment after Stroke and Risk Factors for Delayed Progression. Stroke, 36, 2670-2675.

DEMAIN, S., WILES, R., ROBERTS, L. & MCPHERSON, K. 2006. Recovery plateau following stroke: fact or fiction? Disabil Rehabil, 28, 815-21.

DEMURO, C., LEWIS, S., DIBENEDETTI, D., PRICE, M. & FEHNEL, S. 2012. Successful implementation of cognitive interviews in special populations. Expert Review of Pharmacoeconomics & Outcomes Research, 12, 181-187.

DEVELLIS, R. 2003. Scale development. Theory and Applications, Thousand Oaks: Sage Publications.

DEVLIN, N. & APPLEBY, J. 2010a. Getting the most out of PROMS. Putting health outcomes at the heart of NHS decision-making. London: The King's Fund.

DEVLIN, N. & APPLEBY, J. 2010b. Putting health outcomes at the heart of NHS decision making. London: King's Fund.

DIXON, A., HIBBARD, J. & TUSLER, M. 2009. How do People with Different Levels of Activation Self-Manage their Chronic Conditions? Patient, 2, 257-268.

DIXON, G., THORNTON, E. & YOUNG, C. 2007. Perceptions of self-efficacy and rehabilitation among neurologically disabled adults. Clin Rehabil, 21, 230-40.

DOH 1999. Saving lives: our healthier nation. London: Department of Healthy.

DOH 2001. The expert patients programme. A new approach to chronic disease management for the 21st century. London: Department of Health.

DOH 2004. The NHS Improvement plan. Putting people at the heart of public services. London: Department of Health.

DOH 2005a. Self care—a real choice: self care support—a practical option. London: Department of Health.

DOH 2005b. Supporting people with long-term conditions. An NHS and Social care model to support local innovation and integration London: Department of Health.

DOH 2006. White Paper. Our Health, Our Care, Our Say: A New Direction for Community Services. London: Department of Health.

DOH 2007a. National Stroke Strategy. London: Department of Health.

DOH 2007b. Research evidence on the effectiveness of self care support. London: Department of Health.

DOH 2008. Common core principles to support self care: a guide to support implementation London: Department of Health.

DOH 2010a. Healthy Lives, Healthy People: Our strategy for public health in England. London: Department of Health.

DOH 2010b. Equity and excellence: liberating the NHS. London: Department of Health.

DOH 2011. The Operating Framework for the NHS in England 2012/13. London: Department of Health.

DOH 2012. The Health and Social Care Act. London: Department of Health

DORAN, D., HARRISON, M., LASCHINGER, H., HIRDES, J., RUKHOLM, E., SIDANI, S., HALL, L., TOURANGEAU, A. & CRANLEY, L. 2006. Relationship between nursing interventions and outcome achievement in acute care settings. Res Nurs Health, 29, 61-70.

DORAN, D., SIDANI, S., KEATINGS, M. & DOIDGE, D. 2002. An empirical test of the Nursing Role Effectiveness Model. J Adv Nurs, 38, 29-39.

DORMAN, P., SLATTERY, J., FARRELL, B., DENNIS, M. & SANDERCOCK, P. 1998. Qualitative Comparison of the Reliability of Health Status Assessments with the EuroQol and SF-36 Questionnaires after Stroke. Stroke, 29, 63-68.

DOWSWELL, G., LAWLER, J., DOWSWELL, T., YOUNG, J., FORSTER, A. & HEARN, J. 2000. Investigating recovery from stroke: a qualitative study. Journal of Clinical Nursing, 9, 507-515.

DOYLE, P., MCNEIL, M., MIKOLIC, J., PRIETO, L., HULA, W., LUSTIG, A., ROSS, K., WAMBAUGH, J., GONZALEZ-ROTHI, L. & ELMAN, R. 2004. The Burden of Stroke Scale (BOSS) provides valid and reliable score estimates of functioning and well-being in stroke survivors with and without communication disorders. J Clin Epidemiol, 57, 997-1007.

DRENNAN, J. 2003. Cognitive interviewing: verbal data in the design and pretesting of questionnaires. Journal of Advanced Nursing, 42, 57-63.

DRENTH, J. & SIJTSMA, K. 1990. Introduction into the theory of psychological tests and their applications, Houten, Netherlands, Bohn, Stafleu & Van Loghum.

DUNCAN, P., BODE, R., MIN LAI, S. & PERERA, S. 2003b. Rasch analysis of a new stroke-specific outcome scale: the Stroke Impact Scale. Arch Phys Med Rehabil, 84, 950-63.

DUNCAN, P., JORGENSEN, H. & WADE, D. 2000. Outcome measures in acute stroke trials: a systematic review and some recommendations to improve practice. Stroke, 31, 1429-38.

DUNCAN, P., STUDENSKI, S., RICHARDS, L., GOLLUB, S., LAI, S., REKER, D., PERERA, S., YATES, J., KOCH, V., RIGLER, S. & JOHNSON, D. 2003a. Randomised clinical trial of therapeutic exercise in subacute stroke. Stroke, 34, 2173-2180.

DUNCAN, P., WALLACE, D., MIN LAI, S., JOHNSON, D., EMBRETSON, S. & JACOBS LASTER, L. 1999. The Stroke Impact Scale Version 2.0: Evaluation of Reliability, Validity, and Sensitivity to Change Stroke, 30, 2131-2140.

DUNCAN, P., WALLACE, D., STUDENSKI, S., LAI, S. & JOHNSON, D. 2001. Conceptualization of a new stroke-specific outcome measure: the stroke impact scale. Top Stroke Rehabil, 8, 19-33.

EDWARDS, J. & BAGOZZI, R. 2000. On the nature and direction of relationships between constructs and measures. Psychological Reviews, 5, 155-74.

ELLIS-HILL, C., PAYNE, S. & WARD, C. 2008. Using stroke to explore the Life Thread Model: An alternative approach to understanding rehabilitation following an acquired disability. Disabil Rehabil, 30, 150-159.

ENGEL, G. 1980. The clinical application of the biopsychosocial model. Am J Psychiatry, 137, 535-44.

ESCR. 2011. The research ethics guidebook [Online]. London: Institute of Education, University of London. Available: http://www.ethicsguidebook.ac.uk/Reporting-to-the-people-who-provided-your-data-179 [Accessed 04/03/2013 2013].

FARNSWORTH, J. & BOON, B. 2010. Analysing group dynamics within the focus group. Qualitative Research, 10, 605-624.

FARQUHAR, C. & DAS, R. 1999. Are focus groups suitable for ‘sensitive’ topics? In: BARBOUR, R. & KITZINGER, J. (eds.) Developing Focus Group Research: Politics, Theory and Practice. London: Sage.

FAZIO, R. & OLSON, M. 2003. Implicit measures in social cognition research: their meaning and use. Ann Rev Psychol, 54, 297-327.

FEIGIN, V., LAWES, C., BENNETT, D., BARKER-COLLO, S. & PARAG, V. 2009. Worldwide stroke incidence and early case fatality reported in 56 population-based studies: a systematic review. Lancet Neurol, 8, 355-69.

FEIL, D., ZHU, C. & SULTZER, D. 2012. The relationship between cognitive impairment and diabetes self-management in a population-based community sample of older adults with Type 2 diabetes. Journal of Behavioral Medicine, 35, 190-199.

FINCH, H. & LEWIS, J. 2003. Focus Group Research. In: RITCHIE, J. & LEWIS, J. (eds.) Qualitative research in practice: a guide for social science students. London: Sage.

FITZPATRICK, R., DAVEY, C., BUXTON, M. & JONES, D. 1998. Evaluating patient-based outcome measures for use in clinical trials. Health Technol Assess, 2, i-iv, 1-74.

FLEISS, J. & COHEN, J. 1973. The equivalence of weighted kappa and the intraclass correlation coefficient as measures of reliability. *Educational and Psychological Measurement,* 33, 613-619.

FLESCH, R. 1948. A new readability yardstick. Journal of Applied Psychology, 32, 221-233.

FODDY, W. 1993. Constructing Questions for Interviews and Questionnaires: Theory and Practice in Social Research, Cambridge: University Press.

FOSS, C. & ELLESFENS, B. 2002. The value of combining qualitative and quantitative approaches in nursing research by means of triangulation. Methodological Issues in Nursing Research, 40, 242-248.

FRANK, G., JOHNSTON, M., MORRISON, V., POLLARD, B. & MACWALTER, R. 2000. Perceived control and recovery from functional limitations: Preliminary evaluation of a workbook-based intervention for discharged stroke patients. British Journal of Health Psychology, 5, 413-420.

FRANKLAND, J. & BLOOR, M. 1999. Some issues arising in the systematic analysis of focus group materials In: BARBOUR, R. & KITZINGER, J. (eds.) Developing Focus Group Research: Politics, Theory and Practice. London: Sage.

FREDRICKSON, B. 2003. The value of positive emotions—the emerging science of positive psychology in coming to understand why it's good to feel good. Am Sci, 91, 330-5.

FRIES, J., ROSE, M. & KRISHNAN, E. 2011. The PROMIS of better Outcome Assessment: Responsiveness, Floor and Ceiling Effects, and Internet Administration. The Journal of Rheumatology, 38, 1759-1764.

FROST, M., REEVE, B., LIEPA, A., STAUFFER, J. & HAYS, R. 2007. What Is Sufficient Evidence for the Reliability and Validity of Patient-Reported Outcome Measures? Value in Health, 10, Supplement 2, S94-S105.

FULTZ, N., OFSTEDAL, M., HERZOG, A. & WALLACE, R. 2003. Additive and interactive effects of comorbid physical and mental conditions on functional health. J Aging Health, 15, 465-81.

GALLANT, M. 2003. The influence of social support on chronic illness self-management: a review and directions for research. Health Education & Behavior, 30, 170.

GAMBLE, G., BARBERAN, E., BOWSHER, D., TYRRELL, P. & JONES, A. 2000. Post stroke shoulder pain: more common than previously realized. Eur J Pain, 4, 313-5.

GAO, W. & YUAN, C. 2011. Self-management programme for cancer patients: a literature review. International Nursing Review, 58, 288-295.

GARGANO, J. & REEVES, M. 2007. Sex Differences in Stroke Recovery and Stroke-Specific Quality of Life: Results From a Statewide Stroke Registry Paul Coverdell National Acute Stroke Registry Michigan Prototype Investigators. Stroke, 38, 2541-2548.

GERBER, L., BARRON, Y., MONGOVEN, J., MCDONALD, M., HENRIQUEZ, E., ANDREOPOULOS, E. & FELDMAN, P. 2011. Activation among chronically ill older adults with complex medical needs: challenges to supporting effective self-management. J Ambul Care Manage, 34, 292-303.

GERRISH, K. & LACEY, A. (eds.) 2010. The Research Process in Nursing, Chichester, UK: Wiley Blackwell.

GEYH, S., CIEZA, A., KOLLERITS, B., GRIMBY, G. & STUCKI, G. 2007. Content comparison of health-related quality of life measures used in stroke based on the international classification of functioning, disability and health (ICF): a systematic review. Qual Life Res, 16, 833-51.

GIBBS, G. 2007. Analyzing Qualitative Data, London: Sage.

GLASER, B. & STRAUSS, A. 1967. The discovery of grounded theory, New York: Aldine.

GLASSON, J., CHANG, E., CHENOWETH, L., HANCOCK, K., HALL, T., HILL-MURRAY, F. & COLLIER, L. 2006. Evaluation of a model of nursing care for older patients using participatory action research in an acute medical ward. Journal of Clinical Nursing, 15, 588-598.

GOLDACRE, M., DUNCAN, M., GRIFFITH, M. & ROTHWELL, P. 2008. Mortality rates for Stroke in England from 1979-2004 Stroke, 39, 2197-2203.

GOLDSMITH, M., BANKHEAD, C. & AUSTOKER, J. 2007. Synthesising quantitative and qualitative research in evidence-based patient information. J Epidemiol Community Health, 61, 262-70.

GRAVES, N., WEINHOLD, D., TONG, E., BIRRELL, F., DOIDGE, S., RAMRITU, P., HALTON, K., LAIRSON, D. & WHITBY, M. 2007. Effect of healthcare-acquired infection on length of hospital stay and cost. Infect Control Hosp Epidemiol, 28, 280-92.

GREAVES, C. & CAMPBELL, J. 2007. Supporting self-care in general practice. British Journal of General Practice, 57, 814-21.

GREEN, J. & THOROGOOD, N. 2009. Qualitative Methods for Health Research, London: Sage.

GREENE, J. 2007. Mixed Methods in Social Inquiry, San Francisco: Wiley press.

GREENHALGH, J., LONG, A., BRETTLE, A. & GRANT, M. 1998. Reviewing and selecting outcome measures for use in routine practice. J Eval Clin Pract, 4, 339-50.

GREENHALGH, T. 2009. Patient and public involvement in chronic illness: beyond the expert patient. BMJ (Clinical Research Ed.), 338, b49-b49.

GREENWOOD, N. & MACKENZIE, A. 2010. Informal caring for stroke survivors: Meta-ethnographic review of qualitative literature. Maturitas, 66, 268-276.

GROLEAU, D., ZELKOWITZ, P. & CABRAL, I. 2009. Enhancing generalizability: moving from an intimate to a political voice. Qual Health Res, 19, 416-26.

GROSS, R. 2010. Psychology. The science of mind and behaviour, Abingdon: Hodder education.

GUADAGNOLI, E., CLEARY, P. & MCNEIL, B. 1995. The influence of socioeconomic status on change in health status after hospitalization. Social Science & Medicine, 40, 1399-1406.

GUBA, E. & LINCOLN, Y. 1994. Competing paradigms in qualitative research. In: DENZIN, N. & LINCOLN, Y. (eds.) Handbook of qualitative research. London: Sage.

GUIDETTI, S. & YTTERBERG, C. 2011. A randomised controlled trial of a client-centred self-care intervention after stroke: a longitudinal pilot study. Disabil Rehabil, 33, 494-503.

GUTTMAN, L., STOUFFER, S., SUCHMAN, E., LAZARSFIELD, P., STAR, S. & CLAUSEN, J. 1950. The basis for Scalogram analysis, New York: Wiley.

GUYATT, G., FEENY, D. & PATRICK, D. 1993. Measuring health-related quality of life. Ann Intern Med, 118, 622-629.

HACKETT, M., VANDAL, A., ANDERSON, C. & RUBENACH, S. 2002. Long-term outcome in stroke patients and caregivers following accelerated hospital discharge and home-based rehabilitation. Stroke, 33, 643-5.

HAFSTEINSDOTTIR, T., VERGUNST, M., LINDEMAN, E. & SCHUURMANS, M. 2010. Educational needs of patients with a stroke and their caregivers: A systematic review of the literature. Patient Educ Couns.

HÄGGSTRÖM, T., AXELSSON, K. & NORBERG, A. 1994. The experience of living with stroke sequelae illuminated by means of stories and metaphors. Qualitative Health Research, 4, 321-337.

HAJAT, C., DUNDAS, R., STEWART, J., LAWRENCE, E., RUDD, A., HOWARD, R. & WOLFE, C. 2001. Cerebrovascular Risk Factors and Stroke subtypes : Differences between Ethnic Groups. Stroke, 32, 37-42.

HAMMOND, A. & FREEMAN, K. 2001. One-year outcomes of a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis Rhuematology, 40, 1044-51.

HARDEMAN, W., JOHNSTON, M., JOHNSTON, D., BONETTI, D., WAREHAM, N. & KINMONTH, A. 2002. Application of the Theory of Planned Behaviour in Behaviour Change Interventions: A Systematic Review. Psychology & Health, 17, 123 - 158.

HARRISON, M., FULLWOOD, C., BOWER, P., KENNEDY, A., ROGERS, A. & REEVES, D. 2010. Exploring the mechanisms of change in the chronic disease self-management programme: Secondary analysis of data from a randomised controlled trial. Patient Educ Couns. 85 (2) 39-47.

HARRISON, M., REEVES, D., HARKNESS, E., VALDERAS, J., KENNEDY, A., ROGERS, A., HANN, M. & BOWER, P. 2011. A secondary analysis of the moderating effects of depression and multimorbidity on the effectiveness of a chronic disease self-management programme. Patient Educ Couns. 87 (1) 67-73.

HART, E. 2001. System induced setbacks in stroke recovery. Sociology of Health & Illness, 23, 101-123.

HARWOOD, M., WEATHERALL, M., TALEMAITOGA, A., BARBER, P., GOMMANS, J., TAYLOR, W., MCPHERSON, K. & MCNAUGHTON, H. 2012. Taking charge after stroke: promoting self-directed rehabilitation to improve quality of life: a randomized controlled trial. Clin Rehabil, 26, 493-501.

HAWTHORNE, G., RICHARDSON, J. & OSBORNE, R. 1999. The Assessment of Quality of Life (AQoL) instrument: a psychometric measure of health-related quality of life. Qual Life Res, 8, 209-24.

HELLSTRÖM, K., LINDMARK, B., WAHLBERG, B. & FUGL-MEYER, A. 2003. Self-efficacy in relation to impairments and activities of daily living disability in elderly patients with stroke: a prospective investigation. Journal of Rehabilitation Medicine, 35, 202-207.

HIBBARD, J., STOCKARD, J., MAHONEY, E. & TUSLER, M. 2004. Development of the Patient Activation Measure (PAM): Conceptualizing and Measuring Activation in Patients and Consumers. Health Services Research, 39, 1005-1026.

HIRSCHE, R., WILLIAMS, B., JONES, A. & MANNS, P. 2011. Chronic disease self-management for individuals with stroke, multiple sclerosis and spinal cord injury. Disabil Rehabil, 33, 1136-1146.

HOBART, J. 2007. Measuring outcomes in clinical trials of stroke: time for state-of-the-art clinical trials to reject state-of-the-ark rating scales. J Neurol, 254, 1119.

HOFFMAN, A., VON EYE, A., GIFT, A., GIVEN, B., GIVEN, C. & ROTHERT, M. 2011. The development and testing of an instrument for perceived self-efficacy for fatigue self-management. Cancer Nurs, 34, 167-75.

HOLSTEIN, J. & GUBRIUM, J. (eds.) 2003. Inside interviewing: new lenses, new concerns, Thousand Oaks, CA: Sage.

HORGAN, N., O'REGAN, M., CUNNINGHAM, C. & FINN, A. 2009. Recovery after stroke: a 1-year profile. Disabil Rehabil, 31, 831-9.

HOWELL, E., DUNCKLEY, M. & REEVES, R. 2004. Development and pilot testing of the questionnaire for use in NHS trust-based stroke survey. Oxford, UK: Picker Institute Europe.

HSIEH, H.-F. & SHANNON, S. 2005. Three Approaches to Qualitative Content Analysis. Qualitative Health Research, 15, 1277-1288.

HUCK, S. & CORMER, W. 1996. Reading Statistics and Research, New York: Harper Collins.

HUIJBREGTS, M., MCEWEN, S. & TAYLOR, D. 2009. Exploring the Feasibility and Efficacy of a Telehealth Stroke Self-Management Programme: A Pilot Study. Physiotherapy Canada, 61, 210-220.

HUIJBREGTS, M., MYERS, A., STREINER, D. & TEASELL, R. 2008. Implementation, process, and preliminary outcome evaluation of two community programs for persons with stroke and their care partners. Topics in Stroke Rehabilitation, 15, 503-520.

HUNG, S., PICKARD, A., WITT, W. & LAMBERT, B. 2007. Pain and depression in caregivers affected their perception of pain in stroke patients. J Clin Epidemiol, 60, 963-70.

HYDE, M., WIGGINS, R., HIGGS, P. & BLANE, D. 2003. A measure of quality of life in early old age: The theory, development and properties of a needs satisfaction model (CASP-19). Aging & Mental Health, 7, 186 - 194.

IBM CORP 2011. IBM SPSS Statistics for Windows, Version 20.0. Armonk, New York: IBM corp.

IMISON, C., NAYLOR, C., GOODWIN, N., BUCK, D., CURRY, N., ADICOTT, R. & ZOLLINGER-READ, P. 2011. Transforming our health care system: Top ten priorities for commissioners. London: The king's Fund.

INTERCOLLEGIATE STROKE WORKING PARTY 2012a. National clinical guidelines for stroke. London: Royal College of Physicians.

INTERCOLLEGIATE STROKE WORKING PARTY 2012b. Concise guide for stroke 2012 London: Royal College of Physicians.

IVEY, J. & MEW, M. 2010. Theoretical Basis. In: EDMANS, J. (ed.) Occupational Therapy and Stroke. 2nd edition. Chichester: Wiley-Blackwell.

JANSON, S., MCGRATH, K., COVINGTON, J., CHENG, S. & BOUSHEY, H. 2009. Individualized asthma self-management improves medication adherence and markers of asthma control. J Allergy Clin Immunol, 123, 840-6.

JERANT, A., VON FRIEDERICHS-FITZWATER, M. & MOORE, M. 2005. Patients' percieved barriers to active self-management of chronic conditions. Patient Education and Counseling, 57, 300-307.

JOHNS, R. 2010. Likert items and scales. Survey Bank Methods Fact Sheets. University of Strathclyde.

JOHNSON, E., BAKAS, T. & LYON, B. 2008. Cognitive Appraisal of Health Scale: early instrument development in stroke. Clin Nurse Spec, 22, 12-8.

JOHNSON, R., ONWUEGBUZIE, A. & TURNER, L. 2007. Toward a definition of mixed methods research. Journal of Mixed Methods Research, 1, 112-133.

JOHNSTON, M., BONETTI, D., JOICE, S., POLLARD, B., MORRISON, V., FRANCIS, J. & MACWALTER, R. 2007. Recovery from disability after stroke as a target for a behavioural intervention: results of a randomized controlled trial. Disabil Rehabil, 29, 1117-1127.

JOHNSTON, M., MORRISON, V., MACWALTER, R. & PARTRIDGE, C. 1999. Perceived control, coping and recovery from disability following stroke. Psychology & Health, 14, 181-192.

JONES, F. 2006. Strategies to enhance chronic disease self-management: how can we apply this to stroke? Disabil Rehabil, 28, 841-847.

JONES, F., MANDY, A. & PARTRIDGE, C. 2008a. Reasons for recovery after stroke: a perspective based on personal experience. Disabil Rehabil, 30, 507-516.

JONES, F., MANDY, A. & PARTRIDGE, C. 2009. Changing self-efficacy in individuals following a first time stroke: preliminary study of a novel self-management intervention. Clinical Rehabilitation, 23, 522-533.

JONES, F., PARTRIDGE, C. & REID, F. 2008b. The Stroke Self-Efficacy Questionnaire: measuring individual confidence in functional performance after stroke. Journal of Clinical Nursing, 17, 244-252.

JONES, F. & RIAZI, A. 2011. Self-efficacy and self-management after stroke: a systematic review. Disabil Rehabil, 33, 797-810.

JONES, F., RIAZI, A. & NORRIS, M. 2013. Self-management after stroke: time for some more questions? Disabil Rehabil, 35, 257-264.

JONSDOTTIR, H. 2013. Self-management programmes for people living with chronic obstructive pulmonary disease: a call for a reconceptualisation. J Clin Nurs, 22, 621-37.

JORDAN, J., BRIGGS, A., BRAND, C. & OSBORNE, R. 2008. Enhancing patient engagement in chronic disease self-management support initiatives in Australia: the need for an integrated approach. Med J Aust, 189, S9-S13.

JUNGA, K., MERLO, J., GULLBERG, B., BOG-HANSEN, E., RASTAM, L. & LINDBLAD, U. 2006. Residual risk for acute stroke in patients with type 2 diabetes and hypertension in primary care: Skaraborg Hypertension and Diabetes Project. Diabetes Obes Metab, 8, 492-500.

KABIR, T. & WYKES, T. 2010. Measures of outcomes that are valued by service users. In: THORNICROFT, G. & TANSELLA, M. (eds.) Mental Health Outcome Measures. 3rd edition London: Royal College of Psychiatrists.

KALRA, L. & LANGHORNE, P. 2007. Facilitating recovery: evidence for organized stroke care. J Rehabil Med, 39, 97-102.

KALRA, L. & WALKER, M. 2009. Stroke rehabilitation in the United Kingdom. Top Stroke Rehabil, 16, 27-33.

KAPTEIN, A., KLOK, T., MOSS-MORRIS, R. & BRAND, P. 2010. Illness perceptions: impact on self-management and control in asthma. Curr Opin Allergy Clin Immunol, 10, 194-9.

KARNER, A., TINGSTROM, P., ABRANDT-DAHLGREN, M. & BERGDAHL, B. 2005. Incentives for lifestyle changes in patients with coronary heart disease. J Adv Nurs, 51, 261-75.

KEARNEY, B. & FLEISCHER, B. 1979. Development of an Instrument to measure Exercise of Self-care Agency. Research in Nursing & Health, 2, 25-34.

KELLY, M. & FIELD, D. 1996. Medical sociology, chronic illness and the body. Sociology of Health & Illness, 18, 241-257.

KENDALL, E., CATALANOA, T., KUIPERSA, P., POSNERB, N., BUYSA, N. & CHARKERA, J. 2007. Recovery following stroke: The role of self-management education. Social Science and Medicine, 64, 735-746.

KENDALL, E. & ROGERS, A. 2007. Extinguishing the social?: state sponsored self-care policy and the Chronic Disease Self-management programme. Disability & Society, 22, 129-143.

KENNEDY, A., REEVES, D., BOWER, P., LEE, V., MIDDLETON, E., RICHARDSON, G., GARDNER, C., GATELY, C. & ROGERS, A. 2007. The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with long-term conditions: a pragmatic randomised controlled trial. J Epidemiol Community Health, 61, 254-261.

KENNEDY, A., ROGERS, A. & BOWER, P. 2007. Support for self care for patients with chronic disease. BMJ, 335, 968-70.

KERSTEN, P., ASHBURN, A., GEORGE, S. & LOW, J. 2010. The subjective index for physical and social outcome (SIPSO) in stroke: investigation of its subscale structure. BMC Neurol, 10, 26.

KIDD, P. & PARSHALL, M. 2000. Getting the focus and the group: enhancing analytical rigor in focus group research. Qualitative Health Research, 10, 293-308.

KIELMANN, T., HUBY, G., POWELL, A., SHEIKH, A., PRICE, D., WILLIAMS, S. & PINNOCK, H. 2010. From support to boundary: a qualitative study of the border between self-care and professional care. Patient Educ Couns, 79, 55-61.

KIM, H., CRAIK, F., LUO, L. & WEEN, J. 2009. Impairments in prospective and retrospective memory following stroke. Neurocase, 15, 145-56.

KING, N. 2010. Interviews in Qualitative research, London, Sage.

KING, R., LLOYD, C. & MEEHAN, T. (eds.) 2007. Handbook of Psychosocial Rehabilitation, Oxford: Blackwell Publishing.

KITZINGER, J. 1996. Introducing Focus Groups. In: MAYS, N. & MAYS, C. (eds.) Qualitative Research in Health Care. London: British Medical Journal Publishing Group.

KITZINGER, J. & BARBOUR, R. 1999. Introduction: the challenge and promise of focus groups. In: KITZINGER, J. & BARBOUR, R. (eds.) Developing focus group research: Politics, Theory and Practice. London: Sage.

KLINE, P. 2000. Handbook of psychological testing, London: Routledge.

KNAFL, K., DEATRICK, J., GALLO, HOLCOMBE, G., BAKITAS, M., DIXON, J. & GREY, M. 2007. The analysis and interpretation of cognitive interviews for instrument development. Res Nurs Health, 30, 224-34.

KORPERSHOEK, C., VAN DER BIJL, J. & HAFSTEINSDOTTIR, T. 2011. Self-efficacy and its influence on recovery of patients with stroke: a systematic review. J Adv Nurs, 67, 1876-94.

KOSMALA-ANDERSON, J., WALLACE, L. & TURNER, A. 2010. Confidence matters: a Self-Determination Theory study of factors determining engagement in self-management support practices of UK clinicians. Psychology, Health & Medicine, 15, 478-491.

KOTHARI, C. 2004. Research Methodology: Methods and Techniques, New Delhi: New Age International.

KRALIK, D., KOCH, T., PRICE, K. & HOWARD, N. 2004. Chronic illness self-management: taking action to create order. J Clin Nurs, 13, 259-67.

KREUGER, R. & CASEY, M. 2009. Focus groups: a practical guide for applied research, London: Sage.

KURTAIS, Y., KÜÇÜKDEVECI, A., ELHAN, A., YILMAZ, A., KALLI, T., TUR, B. & TENNANT, A. 2009. Psychometric properties of the Rivermead Motor Assessment: its utility in stroke. Journal of Rehabilitation Medicine, 41, 1055-1061.

KVALE, S. 1996. Interviews: An introduction to Qualitative Research Interviewing, Thousand Oaks: Sage.

LAKHANI, M., MAUREEN BAKER, M. & FIELD, S. (eds.) 2007. The future direction of General Practice: A roadmap, London: Royal College of General Practitioners.

LANGHORNE, P., TAYLOR, G., MURRAY, G., DENNIS, M., ANDERSON, C., BAUTZ-HOLTER, E., DEY, P., INDREDAVIK, B., MAYO, N., POWER, M., RODGERS, H., RONNING, O., RUDD, A., SUUWANWELA, N., WIDEN-HOLMQVIST, L. & WOLFE, C. 2005. Early supported discharge services for stroke patients: a meta-analysis of individual patients' data. Lancet, 365, 501-506.

LANGHORNE, P. & WIDEN-HOLMQVIST, L. 2007. Early supported discharge after stroke. Journal of Rehabilitation Medicine, 39, 103-108.

LARSEN, T., OLSEN, T. & SORENSEN, J. 2006. Early home-supported discharge of stroke patients: a health technology assessment. Int J Technol Assess Health Care, 22, 313-20.

LASCH, K., MARQUIS, P., VIGNEUX, M., ABETZ, L., ARNOULD, B., BAYLISS, M., CRAWFORD, B. & ROSA, K. 2010. PRO development: rigorous qualitative research as the crucial foundation. Qual Life Res, 19, 1087-96.

LAVER-FAWCET, A. 2007. Principles of Assessment and Outcome Measurement for Occupational Therapists and Physiotherapists: Theory, Skills and Application, Chichester: Wiley Blackwell.

LAWN, S., MCMILLAN, J. & PULVIRENTI, M. 2011. Chronic condition self-management: expectations of responsibility. Patient Educ Couns, 84, e5-8.

LAWRENCE, M., KERR, S., WATSON, H., PATON, G. & ELLIS, G. 2010. An exploration of lifestyle beliefs and lifestyle behaviour following stroke: findings from a focus group study of patients and family members. BMC Fam Pract, 11, 97.

LAZARUS, R. & FOLKMAN, S. 1984. Stress appraisal and coping, New York: Springer.

LE BRASSEUR, N., SAYERS, S., OUELLETTE, M. & FIELDING, R. 2006. Muscle impairments and behavioral factors mediate functional limitations and disability following stroke. Physical Therapy, 86, 1342-1350.

LEE, S., SHAFE, A. & COWIE, M. 2011. UK stroke incidence, mortality and cardiovascular risk management 1999–2008: time-trend analysis from the General Practice Research Database. BMJ Open, 1, 1-8.

LÉGARÉ, F., TURCOTTE, S., STACEY, D., RATTÉ, S., KRYWORUCHKO, J. & GRAHAM, I. 2012. Patients' Perceptions of Sharing in Decisions: A Systematic Review of Interventions to Enhance Shared Decision Making in Routine Clinical Practice. The Patient: Patient-Centered Outcomes Research, 5, 1-19.

LEIDY, N. & VERNON, M. 2008. Perspectives on patient-reported outcomes: content validity and qualitative research in a changing clinical trial environment. Pharmacoeconomics, 26, 363-70.

LENKER, S., LORIG, K. & GALLAGHER, D. 1984. Reasons for the lack of association between changes in health behavior and improved health status: An explanatory study. Patient Education and Counseling, 69-72.

LENNON, S. & JOHNSON, L. 2000. The modified rivermead mobility index: validity and reliability. Disabil Rehabil, 22, 833-9.

LENNON, S., MCKENNA, S. & JONES, F. 2013. Self-management programmes for people post stroke: a systematic review. Clinical Rehabilitation 27, 867-878.

LEV, E., MUNRO, B. & MCCORKLE, R. 1993. A shortened version of an instrument measuring bereavement. Int J Nurs Stud, 30, 213-26.

LEV, E. & OWEN, S. 1996. A measure of Self-Care Self-efficacy. Research in Nursing and Health, 19, 421-429.

LEWIS, S., DENNIS, M., O'ROURKE, S. & SHARPE, M. 2001. Negative attitudes among short-term stroke survivors predict worse long-term survival. Stroke, 32, 1640-5.

LIKERT, R. 1932. A technique for the measurement of attitudes. Archives of Psychology, 22, 55.

LIN, C.-C., ANDERSON, R., CHANG, C.-S., HAGERTY, B. & LOVELAND-CHERRY, C. 2008a. Development and testing of the diabetes self-management instrument: A confirmatory analysis. Research in Nursing & Health, 31, 370-380.

LIN, C., ANDERSON, R., HAGERTY, B. & LEE, B. 2008b. Diabetes self-management experience: a focus group study of Taiwanese patients with type 2 diabetes. Journal of Clinical Nursing, 17, 34-42.

LINCOLN, N. & FLANNAGHAN, T. 2003. Cognitive behavioral psychotherapy for depression following stroke: a randomized controlled trial. Stroke, 34, 111-5.

LINCOLN, N., NICHOLL, C., FLANNAGHAN, T., LEONARD, M. & VAN DER GUCHT, E. 2003. The validity of questionnaire measures for assessing depression after stroke. Clinical Rehabilitation, 17, 840-846.

LINDSAY, S. 2008. How and why the motivation and skill to self-manage coronary heart disease are socially unequal. Research in the Sociology of Health Care, 26, 17-39.

LINDSAY, S. 2009. The influence of childhood poverty on the self-management of chronic disease in later life Research in the Sociology of Health Care, 27, 161-183.

LIPSCOMB, M. 2008. Mixed method nursing studies: a critical realist critique. Nursing Philosophy, 9, 32-45.

LJUNGBERG, C., HANSON, E. & LOVGREN, M. 2001. A home rehabilitation program for stroke patients: a pilot study. Scandinavian Journal of Caring Sciences, 15, 44-53.

LORIG, K. 1993. Self-management of chronic illness: a model for the future. Generations, 17, 11-14.

LORIG, K. 1996. Outcome measures for health education and other health interventions, Thousand Oaks: Sage.

LORIG, K. & HOLMAN, H. 2003. Self-management education: history, definition, outcomes, and mechanisms. Annals of Behavioral Medicine, 26, 1-7.

LORIG, K., HOLMAN, H., SOBEL, D., LAURENT, D., GONZÁLEZ, V. & MINOR, M. 2006a. Living a Healthy Life with Chronic Conditions. Self-Management of Heart Diseases, Arthritis, Diabetes, Asthma Bronchitis, Emphysema and others, Boulder, CO: Bull Publishing.

LORIG, K., LUBECK, D., KRAINES, R. G., SELEZNICK, M. & HOLMAN, H. R. 1985. Outcomes of self-help education for patients with arthritis. Arthritis Rheum, 28, 680-5.

LORIG, K., RITTER, P., LAURENT, D. & PLANT, K. 2006b. Internet-based chronic disease self-management: a randomized trial. Medical Care, 44, 964-71.

LORIG, K., RITTER, P., PIFER, C. & WERNER, P. 2013. Effectiveness of the Chronic Disease Self-Management Program for Persons with a Serious Mental Illness: A Translation Study. Community Ment Health J. [epub ahead of print].

LORIG, K., RITTER, P. & PLANT, K. 2005. A disease-specific self-help program compared with a generalized chronic disease self-help program for arthritis patients. Arthritis Rheum, 53, 950-7.

LORIG, K., RITTER, P., STEWART, A., SOBEL, D., BROWN, B. J., BANDURA, A., GONZALEZ, V., LAURENT, D. & HOLMAN, H. 2001. Chronic disease self-management program, 2 year health status and healthcare utilization outcomes. Medical Care, 39, 1217-23.

LORIG, K., SELEZNICK, M., LUBECK, D., UNG, E., RL, C. & HR, H. 1989. The beneficial outcomes of the arthritis self-management course are not adequately explained by behaviour change. Arthtiris Rheumatism, 32, 91-95.

LORIG, K., SOBEL, D., STEWART, A., BROWN, B., JR., BANDURA, A., RITTER, P., GONZALEZ, V., LAURENT, D. & HOLMAN, H. 1999. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. Medical Care, 37, 5-14.

LUTZ, B., KNEIPP, S. & MEANS, D. 2009. Developing a health screening questionnaire for women in welfare transition programs in the United States. Qualitative Health Research, 19, 105-115.

MAGASI, S., RYAN, G., REVICKI, D., LENDERKING, W., HAYS, R., BROD, M., SNYDER, C., BOERS, M. & CELLA, D. 2011. Content validity of patient-reported outcome measures: perspectives from a PROMIS meeting. Qual Life Res.

MAHONEY, F. & BARTHEL, D. 1965. Functional evaluation: the Barthel Index. Maryland Medical Journal, 14, 61-65.

MARKS, R., ALLEGRANTE, J. & LORIG, K. 2005. A Review and Synthesis of Research Evidence for Self-Efficacy-Enhancing Interventions for Reducing Chronic Disability: Implications for Health Education Practice (Part I). Health Promotion Practice, 6, 37-43.

MARSDEN, D., QUINN, R., POND, N., GOLLEDGE, R., NEILSON, C., WHITE, J., MCELDUFF, P. & POLLACK, M. 2010. A multidisciplinary group programme in rural settings for community-dwelling chronic stroke survivors and their carers: a pilot randomized controlled trial. Clinical Rehabilitation, 24, 328-41.

MARSHALL, S., HAYWOOD, K. & FITZPATRICK, R. 2006. Impact of patient-reported outcome measures on routine practice: a structured review. Journal of Evaluation in Clinical Practice, 12, 559-568.

MARTINO, R., FOLEY, N., BHOGAL, S., DIAMANT, N., SPEECHLEY, M. & TEASELL, R. 2005. Dysphagia after stroke: incidence, diagnosis, and pulmonary complications. Stroke, 36, 2756-63.

MASON, J. 2002. Qualitative Researching, London: Sage.

MAUTHNER, N. & DOUCET, A. 2003. Reflexive Accounts and Accounts of Reflexivity in Qualitative Data Analysis. Sociology, 37, 413-431.

MAWSON, S. & MOUNTAIN, G. 2011. The SMART rehabilitation system for stroke self-management: issues and challenges for evidence-based health technology research. Journal of Physical Therapy Education, 25, 48-53.

MAYS, N. & POPE, C. 1995. Rigour and qualitative research. BMJ, 311, 109-12.

MAYS, N. & POPE, C. 2000. Qualitative research in health care. Assessing quality in qualitative research. BMJ, 320, 50-2.

MCDONALD, R., MEAD, N., CHERAGHI-SOHI, S., BOWER, P., WHALLEY, D. & ROLAND, M. 2007. Governing the ethical consumer: identity, choice and the primary care medical encounter. Sociol Health Illn, 29, 430-56.

MCDOWELL, I. & NEWELL, C. 1996. Measuring Health: a guide to rating scales and questionnaires, New York: Oxford University Press.

MCEVOY, P. & RICHARDS, D. 2003. Critical realism: a way forward for evaluation research in nursing? Journal of Advanced Nursing, 43, 411-420.

MCKEVITT, C., FUDGE, N., REDFERN, J., SHELDENKAR, A., CRICHTON, S., RUDD, A., FORSTER, A., YOUNG, J., NAZARETH, I., SILVER, L., ROTHWELL, P. & WOLFE, C. 2011. Self-reported long-term needs after stroke. Stroke, 42, 1398-403.

MEADOWS, K. 2011. Patient-reported outcome measures: an overview. British Journal of Community Nursing, 16, 146-151.

MEDI, C., HANKEY, G. & FREEDMAN, S. 2010. Stroke risk and antithrombotic strategies in atrial fibrillation. Stroke, 41, 2705-13.

MEDICAL RESEARCH COUNCIL 2000. A framework for development and evaluation of RCTs for complex interventions to improve health. London: Medical Research Council.

MEIJER, R. & BANEKE, J. 2004. Analyzing psychopathology items: a case for nonparametric item response theory modeling. Psychol Methods, 9, 354-68.

MEYER, S. & LUNNAY, B. 2013. The Application of Abductive and Retroductive Inference for the Design and Analysis of Theory-Driven Sociological Research. Sociological Research Online, 18, 12.

MICHIE, S., JOHNSTON, M., FRANCIS, J., HARDEMAN, W. & ECCLES, M. 2008. From Theory to Intervention: Mapping Theoretically Derived Behavioural Determinants to Behaviour Change Techniques. Applied Psychology: an international review, 57, 660-680.

MICHIE, S., MILES, J. & WEINMAN, J. 2003. Patient-centredness in chronic illness: what is it and does it matter? Patient Educ Couns, 51, 197-206.

MILES, M. & HUBERMAN, A. 1984. Drawing valid meaning from qualitative data: Toward a shared craft. Educational Researcher, 13, 20-30.

MILES, M. & HUBERMAN, M. 1994. Qualitative data analysis: An expanded sourcebook, Thousand Oaks: Sage.

MIRBAGHERI, M., ALIBIGLOU, L., THAJCHAYAPONG, M. & RYMER, W. 2008. Muscle and reflex changes with varying joint angle in hemiparetic stroke. J Neuroeng Rehabil, 5, 6-22.

MISHRA, G., GALE, C., SAYER, A., COOPER, C., DENNISON, E., WHALLEY, L., CRAIG, L., KUH, D. & DEARY, I. 2011. How useful are the SF-36 sub-scales in older people? Mokken scaling of data from the HALCyon programme. Quality of Life Research, 20, 1005-1010.

MOFFATT, S., WHITE, M., MACKINTOSH, J. & HOWEL, D. 2006. Using quantitative and qualitative data in health services research - what happens when mixed method findings conflict? BMC Health Serv Res, 6, 28-38.

MOKKAN, R. & LEWIS, C. 1982. A Nonparametric approach to the Analysis of Dichotomous Item Responses. Applied Psychological Measurement, 6, 417-430.

MOKKEN, R. 1971. The theory and procedure of scale analysis with applications in political research, New York: Walter de Gruyter Mouton.

MOKKINK, L., TERWEE, C., GIBBONS, E., STRATFORD, P., ALONSO, J., PATRICK, D., KNOL, D., BOUTER, L. & DE VET, H. 2010a. Inter-rater agreement and reliability of the COSMIN (COnsensus-based Standards for the selection of health status Measurement Instruments) Checklist. BMC Med Res Methodol, 10, 82, 1-11.

MOKKINK, L., TERWEE, C., PATRICK, D., ALONSO, J., STRATFORD, P., KNOL, D., BOUTER, L. & DE VET, H. 2010b. The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. Qual Life Res, 19, 539-49.

MOKKINK, L., TERWEE, C., STRATFORD, P., ALONSO, J., PATRICK, D., RIPHAGEN, I., KNOL, D., BOUTER, L. & DE VET, H. 2009. Evaluation of the methodological quality of systematic reviews of health status measurement instruments. Quality of Life Research, 18, 313-333.

MOLENAAR, I. 1982. Mokken scaling revisited. Kwantitatieve Methoden, 3, 145-164.

MORGAN, D. 1997. Focus groups as qualitative research, London: Sage.

MORGAN, D. 2007. Paradigms lost and pragmatism regained: Methodological implications of combining qualitative and quantitative methods. Journal of Mixed Methods Research, 1, 48-76.

MORSE, J. (ed.) 1994. Critical Issues in Qualitative Research Methods, Thousand Oaks: Sage.

MORSE, J., BARRETT, M., MAYAN, M., OLSON, K. & SPIERS, J. 2002. Verification strategies for establishing reliability and validity in qualitative research. International Journal of Qualitative Methods, 1, 1-19.

MUKHERJEE, D., LEVIN, R. & HELLER, W. 2006. The cognitive, emotional, and social sequelae of stroke: psychological and ethical concerns in post-stroke adaptation. Top Stroke Rehabil, 13, 26-35.

MUKHERJEE, D. & PATIL, C. 2011. Epidemiology and the Global Burden of Stroke. World Neurosurgery, 76, S85-S90.

MYINT, P., WELCH, A., BINGHAM, S., LUBEN, R., WAREHAM, N., DAY, N. & KHAW, K. 2006. Smoking predicts long-term mortality in stroke: The European Prospective Investigation into Cancer (EPIC)-Norfolk prospective population study. Prev Med, 42, 128-31.

NATIONAL AUDIT OFFICE 2010. Progress in improving stroke care. London: National Audit Office.

NEWBOULD, J., TAYLOR, D. & BURY, M. 2006. Lay-led self-management in chronic illness: A review of the evidence. Chronic Illness, 2, 249-261.

NHS CHOICES. 2010. FAST [Online]. London: Department of Health. Available: http://www.nhs.uk/actfast/pages/stroke.aspx [Accessed 29/03/2011 2011].

NHS IMPROVEMENT. 2011. NHS Improvement- Stroke. Rehabilitation service models [Online]. London: Department of Health. Available: http://www.improvement.nhs.uk/stroke/CommunityStrokeResource/CSRRehabilitationservicemodels [Accessed February 2011 2011].

NICE 2007. Behaviour change at populations, community and individual levels. London: National Institute for Health and Care Excellence.

NICKLIN, J., CRAMP, F., KIRWAN, J., URBAN, M. & HEWLETT, S. 2010. Collaboration with Patients in the Design of Patient-Reported Outcome Measures: Capturing the Experience of Fatigue in Rheumatoid Arthritis. Arthritis Care and Research, 62, 1552-58.

NOLTE, S., ELSWORTH, G., NEWMAN, S. & OSBORNE, R. 2012. Measurement issues in the evaluation of chronic disease self-management programs. Qual Life Res. 22, 1655-64.

NORRIS, M. & KILBRIDE, C. 2013. From dictatorship to a reluctant democracy: stroke therapists talking about self-management. Disabil Rehabil, [epub ahead of print].

NOUR, K., LAFOREST, S., GAUVIN, L. & GIGNAC, M. 2006. Behavior change following a self-management intervention for housebound older adults with arthritis: an experimental study. Int J Behav Nutr Phys Act, 3, 4-22.

NUNNALLY, J. & BERNSTEIN, I. 1994. Psychometric theory, New York: McGraw-Hill.

NVIVO 2010. NVivo qualitative data analysis software. 9 ed. Stockport, UK: QSR International Ltd.

O'CONNELL, B., HANNA, B., PENNEY, W., PEARCE, J., OWEN, M. & WARELOW, P. 2001. Recovery after stroke: a qualitative perspective. Journal of Quality in Clinical Practice, 21, 120-125.

OGDEN, J. 2007. Health Psychology: a text book, Maidenhead: Open University Press.

OGDEN, J. & LO, J. 2011. How meaningful are data from Likert scales? An evaluation of how ratings are made and the role of the response shift in the socially disadvantaged. J Health Psychol, 3, 350-61.

OLIVER, M. 1996. Understanding disability: from theory to practice. Basingstoke: Palgrave Press.

OPPENHEIM, A. 2000. Questionnaire Design, Interviewing and Attitude Measurement. London: Pinter.

OREM, D. 1995. Nursing: concepts of practice, 4th edition, St Louis, USA: Mosby.

OREM, D. 2001. Nursing: concepts of practice, 6th edition, St Louis, USA: Mosby.

OSBORNE, R., ELSWORTH, G. & WHITFIELD, K. 2007. The Health Education Impact Questionnaire (heiQ): An outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions. Patient Education and Counseling, 66, 192-201.

OSGOOD, C., SUCI, G. & TANNENBAUM, P. 1957. The Measurement of Meaning, Urbana, Illinois: University of Illinois Press.

OSTIR, G., BERGES, I.-M., OTTENBACHER, M., CLOW, A. & OTTENBACHER, K. 2008. Associations between Positive Emotion and Recovery of Functional Status Following Stroke. Psychosomatic Medicine, 70, 404-409.

OWEN, S., SHORTRIDGE, L. & MARCHELLO, M. 1990. Using self-efficacy in evaluating a personal health management program. Conference Paper. Annual Instrumentation conference in Nursing. Tuscon, Arizona, USA.

PAASCHE-ORLOW, M., RIEKERT, K., BILDERBACK, CHANMUGAM, A., HILL, P., RAND, C., BRANCATI, F. & KRISHNAN, J. 2005. Tailored education may reduce health literacy disparities in asthma self-management. Am J Respir Crit Care Med, 172, 980-6.

PALEY, J. 2010. Qualitative interviewing as measurement. Nurs Philos, 11, 112-26.

PANG, M., ENG, J. & MILLER, W. 2007. Determinants of satisfaction with community reintegration in older adults with chronic stroke: role of balance self-efficacy. Phys Ther, 87, 282-91.

PARCHMAN, M., ARAMBULA-SOLOMAN, T., NOEL, P., LARME, A. & PUGH, J. 2010. Stage of change advancement for diabetes self-management behaviors and glucose control. Diabetes Educ, 29, 128-134.

PARK, C. & GAFFEY, A. 2007. Relationships between psychosocial factors and health behavior change in cancer survivors: an integrative review. Ann Behav Med, 34, 115-34.

PATEL, M., COSHALL, C., RUDD, A. & WOLFE, C. 2002. Cognitive Impairment after Stroke: Clinical Determinants and Its Associations with Long-Term Stroke Outcomes. Journal of the American Geriatrics Society, 50, 700-706.

PATERSON, B. & HOPWOOD, M. 2010. The relevance of self-management programmes for people with chronic disease at risk for disease-related complications. In: KRALIK, D., PATERSON, B. & COATES, V. (eds.) Translating Chronic Illness Research into Practice. Chichester: Wiley-Blackwell.

PATERSON, B., RUSSELL, C. & THORNE, S. 2001. Critical analysis of everyday self-care decision making in chronic illness. J Adv Nurs, 35, 335-41.

PATERSON, B., THORNE, S. & RUSSELL, C. 2002. Disease-specific influences on meaning and significance in self-care decision-making in chronic illness. Can J Nurs Res, 34, 61-74.

PAWSON, R. & TILLEY, N. 1997. Realistic evaluation, London: Sage.

PINCUS, T., ESTHER, R., DEWALT, D. & CALLAHAN, L. 1998. Social Conditions and Self-Management are more powerful determinants of health than Access to Care. Annals of Internal Medicine, 129, 406-411.

POLIT, D. & BECK, C. 2010. Generalization in quantitative and qualitative research: Myths and strategies. International Journal of Nursing Studies, 47, 1451-1458.

POLLOCK, A., ST GEORGE, B., FENTON, M. & FIRKINS, L. 2012. Top 10 research priorities relating to life after stroke - consensus from stroke survivors, caregivers, and health professionals. Int J Stroke, 1747-4949.

POPE, C. & MAYS, N. 1995. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. BMJ (Clinical Research Ed.), 311, 42-45.

POWELL, R. & SINGLE, H. 1996. Methodology Matters V- Focus Group Methodology. International Journal for Quality in Health Care, 8, 499-504.

PROCHASKA, J., DICLEMENTE, C. & NORCROSS, J. 1992. In search of how people change. Applications to addictive behaviours. Am Psychol, 47,1102-14.

PROTHEROE, J., ROGERS, A., KENNEDY, A., MACDONALD, W. & LEE, V. 2008. Promoting patient engagement with self-management support information: a qualitative meta-synthesis of processes influencing uptake. Implement Sci, 3, 44.

PROTHEROE, J., BROOKS, H., CHEW-GRAHAM, C., GARDNER, C. & ROGERS, A. 2012. 'Permission to participate?': A qualitative study of participation in patients from differing socio-economic backgrounds. J Health Psychol. 8, 1046-55.

PUCHTA, C. & POTTER, J. 2004. Focus Group Practice, London: Sage.

QUINN, T., LANGHORNE, P. & STOTT, D. 2011. Barthel index for stroke trials: development, properties, and application. Stroke, 42, 1146-1151.

R DEVELOPMENT CORE TEAM. 2010. R: A language and environment for statistical computing [Online]. Vienna, Austria: R Foundation for statistical computing. Available: http://www.R-project.org.

RABIEE, F. 2004. Focus-group interview and data analysis. Proceedings of the Nutrition Society, 63, 655-60.

RAT, A., POUCHOT, J., GUILLEMIN, F., BAUMANN, M., RETEL-RUDE, N., SPITZ, E. & COSTE, J. 2007. Content of quality-of-life instruments is affected by item-generation methods. Int J Qual Health Care, 19, 390-8.

REDMAN, B. 2007. Accountability for patient self-management of chronic conditions; ethical analysis and a proposal. Chronic Illn, 3, 88-95.

REEVES, S., ALBERT, M., KUPER, A. & HODGES, B. 2008. Why use theories in qualitative research? BMJ, 337, a949.

RICHARD, A. & SHEA, K. 2011. Delineation of Self-Care and Associated Concepts. Journal of Nursing Scholarship, 43, 255-264.

RICHARDS, T. 2012. Experts urge commissioners to invest in self management courses for patients with chronic disease. BMJ, 345, e7857.

RIJKEN, M., JONES, M., HEIJMANS, M. & DIXON, A. 2008. Supporting self-management In: NOLTE, E. & MCKEE, M. (eds.) Caring for People with Chronic Conditions. A Health System Perspective. Berkshire: Open University press.

RITCHIE, J. & LEWIS, J. (eds.) 2003. Qualitative Research Practice, London: Sage.

ROBERTS, L. & COUNSELL, C. 1998. Assessment of clinical outcomes in acute stroke trials. Stroke, 29, 986-91.

ROBINSON-SMITH, G. 2002. Self-efficacy and quality of life after stroke. Journal of Neuroscience Nursing, 34, 91-98.

ROBINSON-SMITH, G., JOHNSTON, M. V. & ALLEN, J. 2000. Self-care self-efficacy, quality of life, and depression after stroke. Archives of Physical Medicine & Rehabilitation, 81, 460-464.

ROBINSON-SMITH, G. & PIZZI, E. 2003. Maximizing stroke recovery using patient self-care self-efficacy. Rehabil Nurs, 28, 48-51.

ROBISON, J., WILES, R., ELLIS-HILL, C., MCPHERSON, K., HYNDMAN, D. & ASHBURN, A. 2009. Resuming previously valued activities post-stroke: who or what helps? Disabil Rehabil, 31, 1555-1566.

ROCHETTE, A., DESROSIERS, J., BRAVO, G., ST-CYR-TRIBBLE, D. & BOURGET, A. 2007. Changes in Participation after a Mild Stroke: Quantitative and Qualitative Perspectives. Topics in Stroke Rehabilitation, 14, 59-68.

ROGERS, A., BURY, M. & KENNEDY, A. 2009. Rationality, rhetoric, and religiosity in health care: the case of England's Expert Patients Programme. Int J Health Serv, 39, 725-47.

ROGERS, A., KENNEDY, A., NELSON, E. & ROBINSON, A. 2005. Uncovering the limits of patient-centeredness: implementing a self-management trial for chronic illness. Qual Health Res, 15, 224-39.

ROGERS, A., KENNEDY, A., BOWER, P., GARDNER, C., GATELY, C., LEE, V., REEVES, D. & RICHARDSON, G. 2008. The United Kingdom Expert Patients Programme: results and implications from a national evaluation. MJA, 189, S21-22.

RONNING, O. & STAVEM, K. 2010. Predictors of Mortality following Acute Stroke: A Cohort Study with 12 years of follow-up. J Stroke Cerebrovasc Dis, 5, 369-72.

ROSAL, M., CARBONE, E. & GOINS, K. 2003. Use of cognitive interviewing to adapt measurement instruments for low-literate Hispanics. Diabetes Educ, 29, 1006-17.

ROSE, D., EVANS, J., SWEENEY, A. & WYKES, T. 2011. A model for developing outcome measures from the perspectives of mental health service users. International Review of Psychiatry, 23, 41-46.

ROSE, D. & KASNER, S. 2011. Informed Consent: The Rate-Limiting Step in Acute Stroke Trials. Front Neurol [eCollection 2011], 2, 65.

ROSENSTOCK, I., STRECHER, V. & BECKER, M. 1988. Social learning theory and the health belief model. Health Education Quarterly, 15, 175-183.

ROTHMAN, R., MALONE, R., BRYANT, B., DEWALT, D. & PIGNONE, M. 2002. Health literacy and diabetic control. JAMA, 288, 2687-8.

ROTTER, J. 1966. Generalized expectancies for internal vs. external control of reinforcement. Psychological Monographs, 80, 1-28.

ROWE, F., BRAND, D., JACKSON, C., PRICE, A., WALKER, L., HARRISON, S., ECCLESTON, C., SCOTT, C., AKERMAN, N., DODRIDGE, C., HOWARD, C., SHIPMAN, T., SPERRING, U., MACDIARMID, S. & FREEMAN, C. 2009. Visual impairment following stroke: do stroke patients require vision assessment? Age Ageing, 38, 188-93.

ROYAL COLLEGE PHYSICIANS 2012. Sentinel Stroke National Audit Programme (SSNAP). Acute organisational audit report. London: Royal College of Physicians.

RUDD, P., MILLER, N., KAUFMAN, J., KRAEMER, H., BANDURA, A., GREENWALD, G. & DEBUSK, R. 2004. Nurse management for hypertension. A systems approach. Am J Hypertens, 17, 921-7.

RUNDEK, T. & SACCO, R. 2008. Risk factor management to prevent first stroke. Neurology Clinician, 26, 1007-45.

SABARI, J., MEISLER, J. & SILVER, E. 2000. Reflections upon rehabilitation by members of a community based stroke club. Disabil Rehabil, 22, 330-6.

SACKLEY, C., WADE, D., MANT, D., ATKINSON, J., YUDKIN, P., CARDOSO, K., LEVIN, S., LEE, V. & REEL, K. 2006. Cluster randomized pilot controlled trial of an occupational therapy intervention for residents with stroke in UK care homes. Stroke, 37, 2336-41.

SAKRAIDA, T. & ROBINSON, M. 2009. Health literacy self-management by patients with type 2 diabetes and stage 3 chronic kidney disease. Western Journal of Nursing Research, 31, 627-647.

SALE, J., LOHFELD, L. & BRAZIL, K. 2002. Revisiting the Quantitative-Qualitative Debate: Implications for Mixed-Methods Research. Quality & Quantity, 36, 43-53.

SALTER, K., HELLINGS, C., FOLEY, N. & TEASELL, R. 2008. The experience of living with stroke: a qualitative meta-synthesis. J Rehabil Med, 40, 595-602.

SALTER, K., MOSES, M., FOLEY, N. & TEASELL, R. 2008. Health-related quality of life after stroke: what are we measuring? Int J Rehabil Res, 31, 111-7.

SAMSA, G., MATCHAR, D., GOLDSTEIN, L., BONITO, A., DUNCAN, P., LIPSCOMB, J., ENARSON, C., WITTER, D., VENUS, P., PAUL, J. & WEINBERGER, M. 1998. Utilities for major stroke: results from a survey of preferences among persons at increased risk for stroke. American Heart Journal, 136, 703-13.

SANDELOWSKI, M., VOILS, C. & KNAFL, G. 2009. On quantitizing. Journal of Mixed Methods Research, 3, 208-222.

SARKIN, J., JOHNSON, S., PROCHASKA, J. & PROCHASKA, J. 2001. Applying the Transtheoretical Model to regular moderate exercise in an overweight population: Validation of a Stages of Change Measure. Preventive Medicine, 33, 462-469.

SAXENA, S., NG, T., KOH, G., YONG, D. & FONG, N. 2007. Is improvement in impaired cognition and depressive symptoms in post-stroke patients associated with recovery in activities of daily living? Acta Neurologica Scandinavica, 115, 339-346.

SCHERMER, T., THOONEN, B., AKKERMANS, R., GROL, R., FOLGERING, H., VAN WEEL, C. & VAN SCHAYCK, C. 2002. Randomized controlled economic evaluation of asthma self-management in primary health care. American Journal of Respiratory & Critical Care Medicine, 166, 1062-1072.

SCHOLTES, V., TERWEE, C. & POOLMAN, R. 2011. What makes a measurement instrument valid and reliable? Injury, 42, 236-240.

SCHUURMANS, H., STEVERINK, N., FRIESWIJK, N., BUUNK, B., SLAETS, J. & LINDENBERG, S. 2005. How to measure self-management abilities in older people by self-report. The development of the SMAS-30. Qual Life Res, 14, 2215-28.

SECREST, J. & ZELLER, R. 2007. The relationship of continuity and discontinuity, functional ability, depression, and quality of life over time in stroke survivors. Rehabil Nurs, 32, 158-64.

SEENAN, P., LONG, M. & LANGHORNE, P. 2007. Stroke units in their natural habitat: systematic review of observational studies. Stroke, 38, 1886-92.

SHIPPEE, N., SHAH, N., MAY, C., MAIR, F. & MONTORI, V. 2012. Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. J Clin Epidemiol, 65, 1041-51.

SIDANI, S. 2003. Self-care. In: DORAN, D. (ed.) Nursing-sensitive outcomes: State of the science. Sudbury, USA: Jones and Bartlett.

SIJTSMA, K., MEIJER, R. & VAN DER ARK, A. 2011. Mokken scale analysis as time goes by: An update for scaling practitioners. Personality and Individual Differences, 50, 31-37.

SIJTSMA, K. & MOLENAAR, I. 2002. Introduction to nonparametric item response theory, London: Sage.

SIJTSMA, K. & VAN DER ARK, L. 2003. Investigation and treatment of missing item scores in test and questionnaire data. Multivariate Behavioral Research, 38, 505-528.

SILVERMAN, D. 2001. Interpreting Qualitative Data, London: Sage.

SINGH, K. 2007. Quantitative social research methods, New Delhi: Sage.

SIT, J., YIP, V., KO, S., GUN, A. & LEE, J. 2007. A quasi-experimental study on a community-based stroke prevention programme for clients with minor stroke. Journal of Clinical Nursing, 16, 272-281.

SKANER, Y., NILSSON, G., SUNDQUIST, K., HASSLER, E. & KRAKAU, I. 2007. Self-rated health, symptoms of depression and general symptoms at 3 and 12 months after a first-ever stroke: a municipality-based study in Sweden. BMC Fam Pract, 8, 61.

SLOAN, J., DUECK, A., ERICKSON, P., GUESS, H., REVICKI, D. & SANTANELLO, N. 2007. Analysis and interpretation of results based on patient-reported outcomes. Value Health, 10 Suppl 2, S106-15.

STANGE, K., CRABTREE, B. & MILLER, W. 2006. Publishing multi-method research. Annals of Family Medicine, 4, 292-294.

STEED, L., COOKE, D. & NEWMAN, S. 2003. A systematic review of psychosocial outcomes following education, self-management and psychological interventions in diabetes mellitus. Patient Educ Couns, 51, 5-15.

STOCHL, J., JONES, P. & CROUDACE, T. 2012. Mokken scale analysis of mental health and well-being questionnaire item responses: a non-parametric IRT method in empirical research for applied health researchers. BMC Med Res Methodol, 12, 74.

STRAUSS, M. & SMITH, G. 2009. Construct validity: advances in theory and methodology. Annu Rev Clin Psychol, 5, 1-25.

STREINER, D. 2003. Starting at the beginning: an introduction to coefficient alpha and internal consistency. J Personality Assessment, 80, 99-103.

STREINER, D. & NORMAN, G. 2008. Health Measurement Scales, a practical guide to their development and use. Oxford: University Press.

STROKE ASSOCIATION. 2009. Facts and figures about stroke [Online]. United Kingdom: The Stroke Association. Available: http://www.stroke.org.uk/media_centre/facts_and_figures/index.html [Accessed 1st February 2011 2011].

SUDORE, R., YAFFE, K., SATTERFIELD, S., HARRIS, T., MEHTA, K., SIMONSICK, E., NEWMAN, A., ROSANO, C., ROOKS, R., RUBIN, S., AYONAYON, H. & SCHILLINGER, D. 2006. Limited literacy and mortality in the elderly: the health, aging, and body composition study. J Gen Intern Med, 21, 806-12.

SWITZER, G., WISNIEWSKI, S., BELLE, S., DEW, M. & SCHULTZ, R. 1999. Selecting, developing and evaluating research instruments. Social Psychiatry Epidemiology, 34, 399-409.

TASHAKKORI, A. & CRESWELL, J. 2007. Editorial: The New Era of Mixed Methods. Journal of Mixed Methods Research, 1, 3-7.

TAVAKOL, M. & DENNICK, R. 2011. Making sense of Cronbach's alpha. Int J of Medical Education, 2, 53-55.

TAYLOR, D. & BURY, M. 2007. Chronic illness, expert patients and care transition. Sociol Health Illn, 29, 27-45.

TEDDLIE, C. & TASHAKKORI, A. 2008. Foundations of Mixed Methods Research: Integrating Quantitative and Qualitative Approaches in the Social and Behavioral Sciences, Thousand Oaks: Sage.

TENG, J., MAYO, N., LATIMER, E., HANLEY, J., WOOD-DAUPHINEE, S., COTE, R. & SCOTT, S. 2003. Costs and caregiver consequences of early supported discharge for stroke patients. Stroke, 34, 528-536.

TERWEE, C., BOT, S., DE BOER, M., VAN DER WINDT, D., KNOL, D., DEKKER, J., BOUTER, L. & DE VET, H. 2007. Quality criteria were proposed for measurement properties of health status questionnaires. Journal of Clinical Epidemiology, 60, 34-42.

THOMAS, S. & LINCOLN, N. 2008. Predictors of Emotional Distress after Stroke. Stroke, 39, 1240-1245.

THOOLEN, B., DE RIDDER, D., BENSING, J., GORTER, K. & RUTTEN, G. 2007. Who participates in diabetes self-management interventions?: Issues of recruitment and retainment. Diabetes Educ, 33, 465-74.

THORNE, S., PATERSON, B. & RUSSELL, C. 2003. The structure of everyday self-care decision making in chronic illness. Qualitative Health Research, 13, 1337-52.

THURSTONE, L. 1928. Attitudes can be measured. American Journal of Sociology, 33, 529-54.

TIMMINS, F. & HORAN, P. 2007. A critical analysis of the potential contribution of Orem's (2001) self-care deficit nursing theory to contemporary coronary care nursing practice. European Journal of Cardiovascular Nursing, 6, 32-39.

TOD, A. 2010. Interviewing. In: GERRISH, K. & LACEY, A. (eds.) The research process in Nursing. Oxford: Blackwell Publishing.

TONES, K. 1981. Affective education and health. In: COWLEY, J., DAVID, K. & WILLIAMS, T. (eds.) Health education in schools. London: Harper and Row.

TONES, K. 1997. Health education as empowerment. In: SIDELL, M., JONES, L., KATZ, J. & PEBERDY, A. (eds.) Debates and Dilemmas in Promoting Health. A Reader. Basingstoke: Macmillan Press.

TONG, A., SAINSBURY, P. & CRAIG, J. 2007. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care, 19, 349-57.

TOURANGEAU, R., RIPS, L. & RASINSKI, K. 2000. The Psychology of survey response, Cambridge: University Press.

TOWNSEND, A., WYKE, S. & HUNT, K. 2006. Self-managing and managing self: practical and moral dilemmas in accounts of living with chronic illness. Chronic Illn, 2, 185-94.

TRIGG, R. & WOOD, V. 2000. The Subjective Index of Physical and Social Outcome (SIPSO): a new measure for use with stroke patients. Clin Rehabil, 14, 288-99.

TULSKY, D., KISALA, P., VICTORSON, D., TATE, D., HEINEMANN, A., AMTMANN, D. & CELLA, D. 2011. Developing a contemporary patient-reported outcomes measure for spinal cord injury. Arch Phys Med Rehabil, 92, S44-51.

US DEPARTMENT OF HEALTH AND HUMAN SERVICES 2010. Healthy People 2010: understanding and improving health. Washington, USA.

UNRUH, M., YAN, G., RADEVA, M., HAYS, R., BENZ, R., ATHIENITES, N., KUSEK, J., LEVEY, A. & MEYER, K. 2003. Bias in assessment of Health-Related Quality of Life in a Hemodialysis population: A comparison of Self-administered and Interviewer-Administered surveys in the HEMO Study. Journal of the American Society of Nephrology, 14, 2132-2141.

VALLIS, M., RUGGIERO, L., GREENE, G., JONES, H., ZINMAN, B. & ROSSI, S. 2003. Stages of change for healthy eating in diabetes: Relation to demographic, eating-related, health care utilization, and psychosocial factors. Diabetes Care, 26, 1468-1474.

VAN ABSWOUDE, A., VERMUNT, J., HEMKER, B. & VAN DER ARK, L. 2004. Mokken Scale Analysis using Hierarchical Clustering Procedures. Applied Psychological Measurement, 28, 332-354.

VAN DE LAAR, K. & VAN DER BIJL, J. 2001. Strategies enhancing self-efficacy in diabetes education: a review. Sch Inq Nurs Pract, 15, 235-248.

VAN DER ARK, A. 2011. Getting started with Mokken Scale Analysis in R. Tilberg: University of Tilburg, Netherlands.

VAN DER ARK, L. 2007. Mokken Scale Analysis in R. Journal of Statistical Software, 20, 11.

VAN DER ARK, L. 2012. New Developments in Mokken Scale Analysis in R. Journal of Statistical Software, 48, 1-27.

VAN DER GAAG, A., SMITH, L., DAVIS, S., MOSS, CORNELIUS, V., LAING, S. & MOWLES, C. 2005. Therapy and support services for people with long-term stroke and aphasia and their relatives: a six-month follow-up study. Clin Rehabil, 19, 372-380.

VAN HARTINGSVELD, F., LUCAS, C., KWAKKEL, G. & LINDEBOOM, R. 2006. Improved interpretation of stroke trial results using empirical Barthel item weights. Stroke, 37, 162-6.

VAN SCHUUR, W. 2003. Mokken Scale Analysis: Between the Guttman Scale and Parametric Item Response Theory. Political Analysis, 11, 139-163.

VAN SCHUUR, W. 2011. Ordinal Item Response Theory. Mokken Scale Analysis, London: Sage.

VAN STRATEN, A., DE HAAN, R., LIMBURG, M., SCHULING, J., BOSSUYT, P. & VAN DEN BOS, G. 1997. A Stroke-Adapted 30-Item version of the Sickness Impact Profile to assess Quality of Life (SA-SIP30). Stroke, 28, 2155-2161.

VASSILEV, I., ROGERS, A., SANDERS, C., KENNEDY, A., BLICKEM, C., PROTHEROE, J., BOWER, P., KIRK, S., CHEW-GRAHAM, C. & MORRIS, R. 2011. Social networks, social capital and chronic illness self-management: a realist review. Chronic Illn, 7, 60-86.

VICKERY, C., SEPEHRI, A., EVANS, C. & JABEEN, L. 2009. Self-esteem level and stability, admission functional status, and depressive symptoms in acute inpatient stroke rehabilitation. Rehabilitation Psychology, 54, 432-439.

VOGT, D., KING, D. & KING, L. 2004. Focus groups in psychological assessment: enhancing content validity by consulting members of the target population. Psychol Assess, 16, 231-43.

VOGT, P. 2008. Quantitative versus qualitative is a distraction: Variations on a theme by Brewer & Hunter (2006). Methodological Innovations Online, 3, 1-10.

WACHERBARTH, S., STREAMS, M. & SMITH, M. 2002. Capturing the insights of family caregivers: survey item generation with a couples interview/focus group process. Qualitative Health Research, 12, 1141-54.

WAGNER, E. 1998. Chronic disease management: what will it take to improve care for chronic illness? Effective Clinical Practice, 1, 2-4.

WAGNER, E. 1999. Care of older people with chronic illness. In: CALKINS, E., COULT, C., WAGNER, E. & PACALA, J. (eds.) New ways to care for older people: building systems based on evidence. New York: Springer.

WALLSTON, K. 1989. Assessment of control in healthcare settings. In: STEPTOE, A. & APPELS, A. (eds.) Stress, personal control and health. Chichester: Wiley.

WALLSTON, K., ROTHMAN, R. & CHERRINGTON, A. 2007. Psychometric properties of the Perceived Diabetes Self-Management Scale (PDSMS). Journal of Behavioral Medicine, 30, 395-401.

WALLSTON, K., WALLSTON, B., SMITH, S. & DOBBINS, C. 1987. Perceived control and health. Current Psychological Research and Reviews, 6, 5-25.

WANLESS, D. 2002. Securing our future health: taking a long-term view. Final Report. London: HM Treasury.

WARE, J., SNOW, K., KOSINSKI, M. & GANDEK, B. 1993. SF-36 Health Survey: Manual and Interpretation Guide. The Health Institute. Boston: New England Medical Center.

WARR, D. 2005. "It was fun. But we don't usually talk about these things": Analyzing Sociable Interaction in Focus Groups. Qualitative Inquiry, 11, 200-225.

WATSON, R., VAN DER ARK, L., LIN, L., FIEO, R., DEARY, I. & MEIJER, R. 2012. Item response theory: how Mokken scaling can be used in clinical practice. J Clin Nurs, 21, 2736-46.

WEBB, C. & KEVERN, J. 2001. Focus groups as a research method: a critique of some aspects of their use in nursing research. J Adv Nurs, 33, 798-805.

WEBB, T. & SHEERAN, P. 2006. Does changing behavioral intentions engender behavior change? A meta-analysis of the experimental evidence. Psychology Bulletin, 132, 249-68.

WEINGARTEN, S., HENNING, J., BADAMGARAV, E., KNIGHT, K., HASSELBLAD, V., GANO, A. & OFMAN, J. 2002. Interventions used in disease management programmes for patients with chronic illness-which ones work? Meta-analysis of published reports. BMJ, 325, 925.

WHITE, J., MAGIN, P., ATTIA, J., POLLACK, M., STURM, J. & LEVI, C. 2008. Exploring poststroke mood changes in community-dwelling stroke survivors: a qualitative study. Archives of Physical Medicine & Rehabilitation, 89, 1701-1707.

WHYTE, E., MULSANT, B., VANDERBILT, J., DODGE, H. & GANGULI, M. 2004. Depression after Stroke: A prospective epidemiological study. Journal of the American Geriatrics Society, 52, 774-778.

WIDAR, M., AHLSTROM, G. & EK, A. 2004. Health-related quality of life in persons with long-term pain after a stroke. J Clin Nurs, 13, 497-505.

WIEBE, S., GUYATT, G., WEAVER, B., MATIJEVIC, S. & SIDWELL, C. 2003. Comparative responsiveness of generic and specific quality-of-life instruments. Journal of Clinical Epidemiology, 56, 52-60.

WIEBERS, D., FEIGEN, V. & BROWN, R. (eds.) 2006. Handbook of Stroke, Philadelphia, USA: Lippincott Williams and Wilkins.

WILD, S., FISCHBACHER, C., BROCK, A., GRIFFITHS, C. & BHOPAL, R. 2007. Mortality from all causes and circulatory disease by country of birth in England and Wales 2001–2003. Journal of Public Health, 29, 191-198.

WILKINSON, A. & WHITEHEAD, L. 2009. Evolution of the concept of self-care and implications for nurses: A literature review. International Journal of Nursing Studies, 46, 1143-1147.

WILLEY, C., REDDING, C., STAFFORD, J., GARFIELD, F., GELETKO, S., FLANIGAN, T., MELBOURNE, K., MITTY, J. & JAIME CARO, J. 2000. Stages of change for adherence with medication regimens for chronic disease: Development and validation of a measure. Clin Ther, 22, 858-871.

WILLGERODT, M. 2003. Using focus groups to develop culturally relevant instruments. Western Journal of Nursing Research, 25, 798-814.

WILLIAMS, A. 2003. How to...write and analyse a questionnaire. J Orthod, 30, 245-52.

WILLIAMS, M., BAKER, D., PARKER, R. & NURSS, J. 1998. Relationship of functional health literacy to patients' knowledge of their chronic disease. Arch Intern Med, 158, 166-72.

WILLIAMS, C. & GARLAND, A. 2002. A cognitive–behavioural therapy assessment model for use in everyday clinical practice. Advances in Psychiatric Treatment, 8, 172-179.

WILLIAMS, L., WEINBERGER, M., HARRIS, L., CLARK, D. & BILLER, J. 1999. Development of a stroke-specific quality of life scale. Stroke, 30, 1361-1369.

WILLIS, G. 2005. Cognitive interviewing: A tool for improving questionnaire design, Thousand Oaks: Sage.

WILSON, D., LOWE, D., HOFFMAN, A., RUDD, A. & WAGG, A. 2008. Urinary incontinence in stroke: results from the UK National Sentinel Audits of Stroke 1998-2004. Age Ageing, 37, 542-6.

WILSON, M. 2005. Constructing Measures. An item response modelling approach, New Jersey: Lawrence Erlbaum Associates.

WILSON, P., KENDALL, S. & BROOKS, F. 2006. Nurses' responses to expert patients: the rhetoric and reality of self-management in long-term conditions: a grounded theory study. International Journal of Nursing Studies, 43, 803-818.

WIMPENNY, P. & GASS, J. 2000. Interviewing in phenomenology and grounded theory: is there a difference? Journal of Advanced Nursing, 31, 1485-92.

WOLLIN, J., FULCHER, G., MCDONALD, E., SPENCER, N., MORTLOCK, M., BOURNE, M. & SIMMONS, R. 2010. Psychosocial Factors That Influence Quality of Life and Potential for Self-Management in Multiple Sclerosis. International Journal MS Care, 12, 133-141.

WHO. 2001. World Health Organization. International Classification of Functioning, Disability and Health [Online]. Geneva: World Health

Organisation. Available: http://www.who.int/classifications/icf/en [Accessed January 2011].

WRIGHT, C., BARLOW, J., TURNER, A. & BANCROFT, G. 2003. Self-management training for people with chronic disease: An exploratory study. British Journal of Health Psychology, 8, 465-476.

WU, H.-S. & MCSWEENEY, M. 2004. Assessing fatigue in persons with cancer. Cancer, 101, 1685-1695.

YEN, M. & LO, L. 2002. Examining test-retest reliability: an intra-class correlation approach. Nursing Research, 51, 59-62.

ZIGMOND, A. & SNAITH, R. 1983. The hospital anxiety and depression scale. Acta Psychiatr Scand, 67, 361-70.

ZNANIECKI, F. 1934. The method of sociology, New York: Farrar & Rinehart.