MEASURING CONFIDENCE AFTER STROKE

Jane Horne, BSc (Hons)

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‘IF YOU HAVE NO CONFIDENCE IN SELF, YOU ARE TWICE DEFEATED IN THE RACE OF LIFE. WITH CONFIDENCE, YOU HAVE WON EVEN BEFORE YOU HAVE STARTED.’

MARCUS T CICERO
ROMAN PHILOSOPHER (43 BC)

THIS THESIS IS DEDICATED TO MUM AND EVERYONE WHO HAS EVER EXPERIENCED A STROKE

Abstract

Introduction:

Improving confidence following stroke has been cited as a research priority (Pollock et al 2012). It is difficult to measure a change in confidence levels without valid and reliable measures. This research aims to develop and conduct a psychometric evaluation of a self-reported, confidence after stroke measure [CaSM].

Methods:

Items were generated from themes highlighted in the literature review, and from a qualitative interview study, exploring the meaning of confidence. The CaSM was piloted with expert groups to establish face and content validity. The CaSM was administered to a sample of stroke and healthy elderly people recruited from the community. Completed postal questionnaires were analysed for reliability (internal consistency and test-retest), construct validity (factor analysis) and convergent validity. A visual analogue scale, to correlate therapists opinion with CaSM scores was used to assess concurrent validity. Sensitivity to change was assessed by comparing change scores at three time points after a confidence intervention. Case vignettes were used with stroke clinical experts to detect a minimal clinically meaningful change score.

Results:

Stroke (*n*=101) and healthy elderly participants (*n*=101) were recruited. Using item reduction techniques, a 53 item scale was reduced to 27 items. Factor Analysis was used to derive a three factor solution, Self-Confidence, Positive Attitude and Social Confidence, which explained 52% of variance. There was good evidence for internal consistency (α=0.94) and good temporal stability ($r_s=0.85$ $p=0.001$). There was a small positive correlation between the two variables when assessing concurrent validity ($r_s=0.18$, $n=31$, $p<0.34$), and did not demonstrate statistical significance. Four points on the CaSM was recommended by clinical experts as being a clinically important change score.

Conclusion:

The 27 item CaSM [Appendix 1] was shown to be a valid and reliable measure. The CaSM was designed to be used to identify people with low confidence after stroke in order to facilitate appropriate treatment. The CaSM could be used in research, as a patient reported outcome measure to evaluate strategies to improve confidence after a stroke. Assessment of the CaSM’s ability to detect sensitivity to change needs further assessment.

Publications and dissemination

HORNE, J. C., LINCOLN, N. B. & LOGAN, P. A. 2015. *Developing a New, Self-Reported, Confidence after Stroke Measure [CaSM].* 10th UK Stroke Forum Conference, ACC, Liverpool: Accepted Abstract.

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HORNE, J. C., LINCOLN, N. B., PRESTON, J. & LOGAN, P. 2014. What does confidence mean to people who have had a stroke?–A qualitative interview study. *Clinical Rehabilitation*, 28, 1125-1135

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CaSM	Confidence after Stroke Measure
SSEQ	Stroke Self-Efficacy Questionnaire
DLSES	Daily Living Self-Efficacy Scale
VASE	Visual Analogue Self Esteem Scale
TSA	The Stroke Association
PPI	Public and Patient Involvement
NHS	National Health Service
JLA	James Lind Alliance
EPP	Expert Patient Programme
CDSMP	Chronic Disease Self-Management Programme
PCA	Principle Component Analysis
IPA	Interpretive Phenomenology Analysis
RCT	Randomised Controlled Trial
GCP	Good Clinical Practice
WHO	World Health Organisation
JP	External IPA Expert
IR	Internal Qualitative Research Expert
GA	University of Nottingham Administrator
PL	Academic Supervisor
NL	Academic Supervisor
RCAS	Regaining Confidence After Stroke Course
LOCF	Last Observation Carried Forward
VAS	Visual Analogue Scale
NRES	National Research Ethics Service
NIHR	National Institute for Health Research
MDA	Missing Data Analysis
CST	Community Stroke Team
ESD	Early Supported Discharge

Chapter One

1. Introduction

This chapter introduces stroke, the effects stroke survivors commonly experience and the impact stroke has on their daily lives. This includes the loss of confidence after stroke, which is considered to be a significant factor affecting both functional and psychological outcomes, but has received limited attention in the stroke literature. A narrative literature review method was used to explore the definition of confidence and reviews the evidence from the sports literature. Interventions to improve confidence after stroke and their effectiveness are discussed. One of the main barriers to completing robust evaluations of these interventions is the lack of reliable & valid confidence outcome measures. The chapter concludes with presenting the research aims.

1.1 Stroke

Stroke has been defined as one of the most devastating of all neurological diseases (Mukherjee and Patil, 2011) and one of the most common causes of death and disability worldwide (Fisher et al., 2009, Donnan et al., 2008) It is also considered the largest cause of complex disability in adults (Adamson et al., 2004). The Department of Health suggested 33% of all stroke survivors are functionally dependent after one year (2007), and the ‘hidden consequences’ of stroke, such as, psychological and social problems, have been well documented (Daniel et al., 2009, De Wit et al., 2008, Robinson-Smith et al., 2000).

Stroke is defined by the World Health Organisation (WHO) as:

> '*rapidly developed clinical signs of focal (or global) disturbances of cerebral function, with symptoms lasting 24 hours or longer, or leading to death, with no apparent cause other than vascular origin.*' (Aho et al., 1980)

Stroke occurs when there is an interruption to the blood supply to the brain. Pathologically, the two most common types of stroke are ischemic, and haemorrhagic. Ischemic strokes occur, when the blood supply to the brain is interrupted due to a narrowing or blockage of the blood vessels leading to the brain. Brain tissue is damaged due to lack of oxygen (Rosamond et al., 2008). Similar damage is also caused by haemorrhagic strokes when a rupture to the blood vessels, produces bleeding into the brain (Department of Health, 2007).

1.2 Effects of stroke

Stroke is characterised by a sudden onset of weakness to the face, upper and lower limbs, usually affecting one side of the body. Balance and mobility are often compromised (Hellstrom et al., 2003) and functional impairments of the upper and lower limbs are typical (Langhorne et al., 2009).

In addition to physical impairments, mood problems, such as anxiety and depression, are reported as having a profound effect on the daily lives and activities of stroke survivors (Thomas and Lincoln, 2008, Hackett et al., 2008). Dependent on the location and extent of the damage to the brain, cognitive and sensory impairments occur (del Ser et al., 2005, Mercier et al., 2001). Memory, orientation, language, thinking processes, attention and vision are often affected (Loetscher and Lincoln, 2013, Langhorne et al., 2011, Rowe et al., 2009, Ballard et al., 2003).

Stroke often results in survivors needing specialist rehabilitation for up to a year (Aziz et al., 2009). Stroke is considered a lifelong condition (Wolfe et al., 2011). If stroke survivors are to live the rest of their life to their maximum potential, despite their impairments, services need to include support and interventions that are of benefit, well beyond the acute phases of stroke (Jones and Riazi, 2011) and beyond addressing purely the physical impairments. Psychological support after stroke is a recognised unmet rehabilitation need (McKevitt et al., 2011) and it is argued that the often serious and widespread 'invisible' psychological and social consequences following stroke receive less attention than physical factors in the stroke literature (Daniel et al., 2009, Teasdale and Engberg, 2005, Roding et al., 2003). Half of stroke survivors have unmet clinical and social needs up to five years following stroke, and it has been suggested that long term stroke care is undeveloped (McKevitt et al., 2011).

1.3 Impact of stroke

The physical and psychological impairments described above, often prevent stroke survivors doing what they want or need to do (Wood et al., 2010, Hartman-Maeir et al., 2007, Legg et al., 2006). It is common for a stroke survivor to experience difficulties in walking, showering, dressing and participating in home and community activities (Laver et al., 2013). It is argued that the full impact of having a stroke is often not realised until stroke survivors leave hospital and resume their social routines and daily activities (Ellis-Hill et al., 2009, Hellstrom et al., 2003). Stroke survivors are frequently discharged home with unidentified perceptual, cognitive and mood disorders that can restrict participation in daily important activities and roles (Desrosiers et al., 2006). Perceptual problems such as not recognising familiar objects can make simple everyday activities difficult to execute (Brown et al., 2013). In addition, pain and fatigue, may contribute to activity limitation (O'Donnell et al., 2013, Tyrrell and Smithard, 2005). Stroke survivors report social participation being particularly difficult for up to five years after their stroke. Williams and Rudd (2010) suggested that this indicated a need for different models of stroke care that target community based interventions.

The impact of psychological factors stroke survivors face as they attempt to adjust and cope with the their newly acquired stroke impairments is reported to be undeniably difficult (Desrosiers et al., 2006). Resulting in stroke survivors being less competent and confident to perform necessary everyday tasks (Korpershoek et al., 2011, Robinson-Smith and Pizzi, 2003). The way people feel, think and behave may change after experiencing a stroke (Jones et al., 2008). This may be due to lasting physical disabilities, or due to mood changes, such as depression (House et al., 1991, Hackett and Anderson, 2005). Depression is extremely common after a stroke, estimates of prevalence vary, but it is suggested a '*conservative estimate*' of one third of all stroke survivors experience depression at any time following their stroke (Hackett et al., 2005). Even when stroke survivors are not depressed, low mood, anxiety, and feelings or frustration are often evident (Gaete and Bogousslavsky, 2008). The impact of these experiences may result in negative thinking, loss of confidence, as well as developing a low self-worth (Broomfield et al., 2011). These feelings can last from a few months to many years (Åström, 1996).

In addition to the impact that stroke has on a person's physical and psychological status, society places a stigma on the person who has had a stroke, often affecting how they are perceived, treated and communicated with (Stone, 2013, Hare et al., 2006, Hyman, 1971). Robert McCrum, author and associate editor of a national British newspaper, experienced a stroke in 1995 at the age of 42. He articulated '*at first the constraint was physical*' however as his rehabilitation continued '*the reservation became psychological'* (McCrum, 1999). The author cited becoming reunited with work colleagues, as his biggest fear. During his recovery period, McCrum (1999) described this experience as '*the measure of my loss of confidence in myself after the stroke*.'(P97).

In order to design a research study to investigate confidence and stroke, the literature was examined. The result of this process is reported in the literature review that follows.

1.4 Confidence and stroke: A literature review

A literature review was conducted to explore the concept and understanding of confidence and related constructs.

The work of Grant and Booth (2009) was consulted in order to select an appropriate approach to synthesise the literature. Whilst a literature review is a term commonly used to describe a process of gathering published evidence on a particular subject, Grant and Booth (2009) identified 14 approaches to reviewing literature. Alternative cited approaches include; critical, systematic mapping, meta-analysis, overview, scoping, umbrella reviews and systematic search and reviews.

Although a systematic review is internationally recognised as the highest standard in reviewing evidence based healthcare (Higgins and Green, 2008) it is unlikely that, where a gap in the literature has been identified, there will be enough published research to conduct such a review, and it is likely to have limited impact, due to the inclusion of few studies.

A systematic review examining influences of self-efficacy on stroke rehabilitation outcomes, found 22 suitable articles (Jones and Riazi, 2011). The authors suggested the review might have been strengthened by the inclusion of other related constructs, such as, locus of control. In addition, the authors suggested that their review might also have been improved by including interventions that are underpinned by other behaviour change theories, such as, motivational interviewing (Watkins et al., 2011). However, the authors may have found this broad approach detracted from their primary focus, which was to examine the influence of self-efficacy on stroke outcomes (Jones and Riazi, 2011). For the purpose of this thesis, a narrative literature review was conducted to summarise studies on confidence.

Other types of review such as, meta-analysis, umbrella reviews, systematic reviews and mapping reviews were rejected as they are reliant on a large number of studies. Since the topic of confidence did not have a large pool of studies to draw from, alternative approaches were considered. These included an overview review, critical review, scoping review and state of the art review.

The overview approach was rejected on the basis that assessing the rigor and quality of studies was not considered necessary, whereas when reviewing interventions it was felt necessary to assess quality. Inclusion of current papers are the focus of a state of the art review, whereas it was felt current and retrospect papers might add breath to the review. In a 'critical' review, significant items in the field are reviewed, which might omit research that provided a wide ranging and comprehensive understanding of confidence and stroke. Lastly, a scoping review aims to indicate whether a full systematic review is necessary, whereas this had already been identified through the work of Jones and Riazi (2011) and their review was limited, due to a lack of appropriate literature.

The chosen literature review method that aimed to provide consolidation of research from different domains would broaden understanding of confidence after stroke. It aimed to identify gaps in research and develop previous research. This approach seemed logical since the pool of literature on the topic of confidence and stroke, was not vast. As it was predicted that research on confidence and stroke would be minimal, inclusion of literature in other domains, such as sport and education were perceived necessary, in order to capture a full range of literature on confidence. Therefore, a narrative literature review was undertaken.

1.4.1 Search strategy

One of the perceived weaknesses of a literature review, is the approach lacks intent to maximise scope of the subject, and therefore could be open to a particular world viewpoint, which could be a source of bias (Grant and Booth, 2009). In order to reduce potential bias a comprehensive search of the literature was conducted.

Electronic bibliographic databases are a common starting point for healthcare literature reviews. Healthcare interventions, particularly after stroke, are typically delivered by multi-disciplinary teams. In order to explore evidence that might potentially include confidence, self-efficacy and related phenomena, a range of databases were examined, and these are detailed in **Table 1**.

Table 1: Search Strategy

Cochrane Library	Issue 12, 2013
Cochrane Stroke Group Trials Register	January 2013
Allied and Complimentary Medicine Database [AMED]	1995 – October 2013
MEDLINE	1950 – October 2013
Cumulative Index to Nursing and Allied Health Literature [CINAHL]	1982 – October 2013
British Nursing Index [BNI]	1985 – October 2013
PsychINFO	1995 – October 2013
Physiotherapy Evidence Database [PEDro]	1995 - October 2013
EMBASE	1980 – October 2013
OVID	1948 – October 2013
Applied Sciences Index and Abstracts	1987 – October 2013
SPORTdISCUS	1975 - October 2013

Expert librarian advice confirmed these databases were likely to optimise identification of studies in the rehabilitation, neuropsychology, medicine, and sport literature, relevant to the study of confidence after stroke. The initial search was conducted in July 2012 and updated in October 2013, relevant papers were examined and included in the review. MEDLINE, EMBASE, PsycINFO, CINAHL and SPORTdISCUS were used. Duplicates were found and deleted using the software package Endnote (Reuters, 2011) version X7.0.

The core search terms initially focused on exploding free text. The keywords were; stroke, rehabilitation, confidence, self-efficacy, competence, control, adjustment, coping, self-construct, self-esteem, low mood, measurement and volition. To broaden the search, quality of life, well-being, behaviour change, behaviour strategies, life after stroke, self-management, social consequences, worry, locus of control, stigma, self-efficacy scales, emotional state and confidence measures, were added to ensure a comprehensive search of all relevant papers relating to confidence were identified.

The search was extended by hand searching relevant journals and libraries such as the College of Occupational Therapy library, British Library for PhD studies. The National Clinical Guideline for Stroke, 4th Edition, (Intercollegiate Stroke Working Party, 2012) was reviewed to find research that had already been peer reviewed, and considered good enough quality for inclusion. Reference lists in published papers were explored and suitable articles obtained.

Finally, grey literature, such as conference papers and presentations, government documents, third sector sources, dissertations and theses, were reviewed. Professional body websites, such as the College of Occupational Therapy and UK Stroke Forum were searched for references and past papers. Information from the Organisation for Psychological Research in Stroke (OPSYRIS) was accessed for details of past oral presentations and library sources within Nottingham University were used to identify any other appropriate material.

As the literature review developed the papers were organised into themes which are discussed below.

1.4.2 Definition of confidence

The literal definition of confidence is derived from the Italian '*con fede*' simply defined as 'With *faith'* [*belief*] (Con, Fede). Whist there is widespread lay understanding of confidence, the definitions and understanding become more complex in a scientific context.

1.4.3 Confidence & stroke: Models and theories

In order to understand the relationship between confidence and stroke, confidence models were explored within a stroke framework.

Lack of confidence has been identified as an emotional challenge following stroke, and is associated with activity limitation (Intercollegiate Stroke Working Party, 2012) frustration and fear (Ch'Ng et al., 2008) in addition it is a predictor of dependence (Intercollegiate Stroke Working Party, 2012). The way in which stroke survivors approach tasks and challenges, may be attributed to factors such as confidence and self-efficacious beliefs.

In clinical practice, it is argued that stroke rehabilitation clinicians use confidence as a '*benchmark to recovery*' describing low confidence as a barrier to progress, whereas increased confidence is often seen as a positive indicator (Jones et al., 2008). We already know '*finding ways to improve confidence*' is important to stroke survivors (Pollock et al., 2012). In 2012, the James Lind Alliance (JLA) decided to place stroke survivors at the centre of our research agenda, as opposed to research activity and priorities being defined by academics and health professionals. Founder leaders of the Cochrane foundation, an organisation known for trusted healthcare research, joined the James Lind Alliance and set up a collaborative '*unique, comprehensive, rigorous and inclusive*' process to define research priorities for people living with stroke (Pollock et al., 2012). The outcome of this process identified '*finding the best ways to improve confidence after stroke, including stroke clubs or groups, offering support, one to one input and reskilling*' as one of the top ten research priorities.

Stroke survivors told this group:

> '*there was little point in addressing stroke-related impairments in communication or mobility if one did not have the confidence to participate in daily or recreational activities*' (Pollock et al., 2012: P209).

Confidence issues after stroke therefore appear to be important to stroke survivors. To ensure stroke survivors are enabled to be confident to engage in active and fulfilled lives, then finding ways to improve confidence are necessary.

1.4.4 Self–efficacy theory and stroke

Confidence is closely related to self-efficacy, which has been described as task or situation specific confidence (Bandura, 1997). A self-efficacious belief is defined as '*the ability to succeed in a particular situation'* (Bandura, 1997). In essence, self-efficacious beliefs influence all aspects of people's lives whether they think productively, optimistically or are defeatist in their thinking (op. cit.) It is this thought, as opposed to the task itself, that influences motivation, and how much effort is applied to achieving tasks, during adverse periods (Bandura, 1997). Low self-efficacy influences people to believe they 'can't' achieve a task, regardless of whether they are able to or not. They may avoid a difficult task, rather than perceive it as something that can be achieved.

Self-efficacy is also about being confident in a number of skills. Bandura's theory is underpinned by the belief that by mastering each new skill a person's confidence in their ability to learn improves. It is this experience of mastery that increases a person's efficacy. In essence, the theory assumes a person's confidence will improve naturally as their competence increases. Bandura (1986) suggested this process is unconditional, as it relates to an individual's belief, whether or not accurate, in their ability to perform a certain task.

Self-efficacy theory suggests confidence refers to an '*affirmation of capability level*' that is a '*major determinant of intention*' (Poulsen et al., 2014) p64. For example, a person who has successfully mastered the ability to walk ten metres indoors after mobility problems following a stroke may start to believe they can master walking outside. This may be perceived as a more challenging task; however the successful achievement of walking inside, may have altered their thinking, and although they may not have attempted the outdoor task, may now believe they can do it. Bandura (1986) argued that people develop a belief that with someone to teach the skill, investing the time and the necessary resources into learning the new skill, anything is possible, resulting in strong self-efficacy or self-confidence.

Conversely, people with a low self-efficacy may avoid trying a new skill. Avoiding going out of the house, for example, due to lack of confidence was reported by participants in a previous stroke rehabilitation study (Logan et al., 2001). This avoidance is likely to prevent the learning or re-learning of skills. Often personal beliefs about abilities and being able to succeed in everyday tasks and activities may be compromised following stroke. Since one aim of stroke rehabilitation, is to re-learn skills, then an awareness of low confidence levels, in order to enable change is important.

Self-efficacy approaches to self-management interventions after stroke have mainly been driven in the United Kingdom, by Jones et al. (2013) through the development of the 'Bridges' project (McKenna et al., 2013). However, evidence to support the effectiveness and efficacy of self-management interventions remains inconclusive (Korpershoek et al., 2011). The necessary work to evaluate interventions that use self-efficacy approaches, are being developed (McKenna et al., 2013). Jones et al (2011) suggested in a systematic review, collaborative working to further develop and test such interventions, that support self-management skills and confidence, are necessary.

Self-efficacy beliefs may also be associated with stroke survivor's ability to cope and motivate themselves to try certain tasks and activities (Lev and Owen, 1996). It is advocated that self-efficacy beliefs have a major influence on rehabilitation outcomes following stroke (Jones and Riazi, 2011, Korpershoek et al., 2011, Robinson-Smith et al., 2000).

1.4.5 Collective efficacy & stroke

Self-efficacy theory has been developed, to include a 'collective efficacy' component (Bandura, 2000, Myers and Feltz, 2007). The 'collective efficacy' of a group or team for example, may influence a person's behaviour or outcome. A positive interdependent effort from a group or team might enable a person to achieve more than might have been possible on their own, as people are partly products of their own environment (Kielhofner, 2002, Bandura, 2000). Conversely, the 'collective efficacy' of a family or group with a more negative influence, may alter the individual's belief to be more negative or pessimistic about what they think they can achieve.

Bandura's self-efficacy theory initially focused on a personal agency that shapes and influences a person's capability to do whatever it is they want to be able to do. However, this theory is continually developing. The influences of others are currently being discussed within a self-efficacy model. Bandura (2001) suggested a '*proxy agency*' and '*collective agency'* are two components that can also influence self-efficacious beliefs. A '*proxy agency*' is described as the reliance on others to act as an advocate, and this process can influence outcomes. For example, stroke survivor's beliefs may be influenced by an advocacy role adopted by carers, partners, friends and/or family. If this is observed as being positive, then a positive outcome is more likely.

A collective agency is one where a '*socially co-ordinated and interdependent effort influences outcome*' (Bandura, 2000). A stroke survivor making a group contribution, for example, feeling part of a stroke rehabilitation team, or being a member of a stroke survivor peer group, may result in the collective efficacy of the group achieving more than might be achievable on one’s own. A team working towards a shared goal or purpose is likely to lead to more positive outcomes. Examining such influences in relation to confidence levels after a stroke, may be beneficial, as the influences of being in a group or team may contribute to increased/decreased confidence after stroke.

1.4.6 Self-esteem & stroke

Pajares, (Bembenutty, 2007) suggested self-efficacy and self-esteem beliefs are alike and that confidence is a critical component of self-esteem. The key difference between them is that self-esteem includes feelings of self-worth, that is an evaluation of self, whereas self-efficacy is a judgement of capability to engage in a task or activity. It could be argued, that a combination of self-efficacy and self-esteem may be conceptualised into a broader meaning of confidence.

Self-esteem is defined as the way people judge themselves in positive or negative terms (Hilton, 2005). Factors, such as social feedback and family relationships, are thought to influence self-esteem (Mann et al., 2004). Brumfitt and Sheeran (1999) developed a Visual Analogue Self-Esteem Scale (VASES), which is a short measure that includes both judgement statements and pictures to measure self-esteem. The VASES includes two items on ‘confidence’ and ‘optimism’ suggesting they are components of self-esteem. ‘Optimism’ is described by Bandura (1986) as being a trait that is associated with higher levels of self-efficacy. This indicates that confidence, self-esteem and self-efficacy are closely associated.

Self-esteem is developed in adulthood and remains stable over time, but significant life events, such as a stroke, have been found to influence self-esteem levels (Chang and Mackenzie, 1998), and may impact on stroke recovery.

In stroke rehabilitation, studies have found an association with low self-esteem, poor motivation and reluctance to participant in activities (Chau et al., 2012). Poor functional outcome when a low self-esteem has been identified, has been reported (Vickery et al., 2008). As a stroke typically occurs in later life, it may coincide with declining self-esteem levels. The construct of confidence therefore, may have both components of self-efficacy (belief in capability) and self-esteem (values of self-worth) components.

1.4.7 Sport model of confidence and stroke

In elite sport, confidence is considered key to success. Vealy (2009) highlighted that although there are multiple definitions of self-confidence, they are all associated with 'individual beliefs about their abilities or their expectations about achieving success based on these abilities.' (p43). Similar to the self-efficacy construct, belief is an important component.

Vealy (2009) argued that self-confidence in athletes is embedded within a multi layered confidence model illustrated in **Figure 1**:

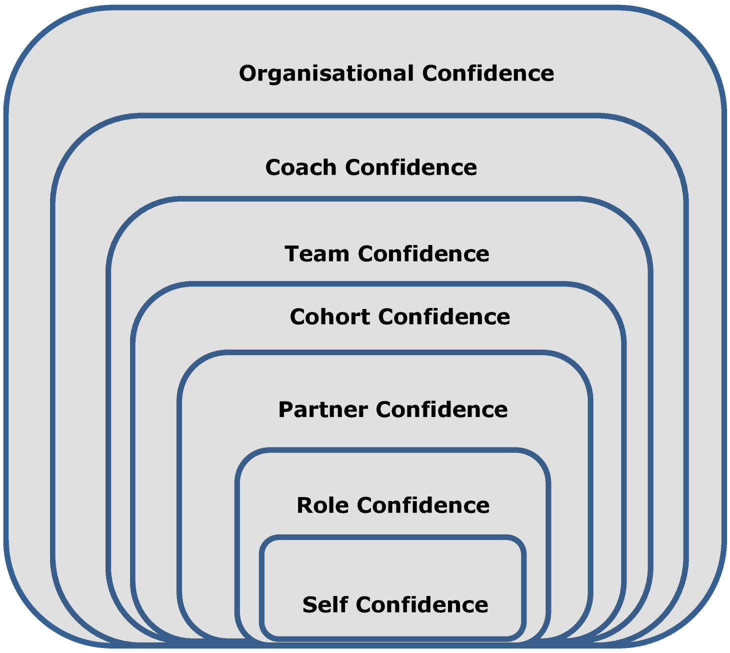

Figure 1: Multi Levels of Confidence in Sport (Vealy, 2009)

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Exploring this model further, may help to draw some parallels between whether models of confidence used in sport, could also be applied to stroke rehabilitation.

Jones et al (2013) expressed similar thinking when discussing self-management approaches after stroke:

> *'Ongoing research focussing on behaviour change should acknowledge individual needs, professional beliefs and values, as well as the organisational context post stroke'* (p257).

This assertion also focusses on broader context to behaviour change and confidence related constructs after stroke.

The literature above highlights the relevance of confidence in recovery after stroke. The literature suggests increased confidence after stroke could be influenced by the behaviours of health professionals, carers and friends, in addition to, stroke survivors themselves. When confidence levels increase, better outcomes after stroke are observed. Clinical interventions that seek to improve confidence are lacking in stroke rehabilitation. Redfern et al. (2006) suggested this might be because stroke care is complex, and developing intervention components to meet complex needs is difficult.

There is evidence to suggest that self-management approaches to treatment in neurological settings are on the increase (Wiesner, 2014), however, the efficacy and effectiveness of such interventions remain inconclusive (Korpershoek et al., 2011). It is nevertheless important to examine what research has already been done clinically, in order to direct future enquiry.

1.5 Clinical relevance of confidence after stroke

The Intercollegiate Stroke Working Party in their national clinical guideline for stroke (Intercollegiate Stroke Working Party, 2012) suggested self-efficacy, self-esteem and self-identity are closely related. The guideline recommends that when stroke survivors are observed as having a lack of motivation and engagement in the rehabilitation process, then an assessment for changes in the above psychological factors should be conducted. If significant changes in self-esteem, self-efficacy and self-identity are identified, the guideline advises psychological intervention such as cognitive behavioural therapy in addition to training in self-management skills.

Cattelani et al., (2010) argued that rehabilitation of emotional, behavioural and social disturbances are not considered to be of primary concern and are considered '*supplementary*' as opposed to a '*core*' component of rehabilitation programmes. As such, the supplementary problems which can have significant consequences, in terms of long term outcome, often remain unidentified and invisible resulting in them being left untreated or ignored. This may significantly impact on a stroke survivor's quality of life after stroke.

1.5.1 Complex interventions

Complex interventions have been defined as '*educational/psychosocial interventions to change knowledge, beliefs or behaviours'* (Redfern et al., 2006). Therefore, an intervention which aims to improve confidence levels would be described as a complex intervention. The multiple components of these interventions can make conducting evaluation studies difficult and often expensive, which may contribute to them not being '*adequately developed or evaluated*' (Redfern et al., 2006). In stroke rehabilitation, randomised controlled trials evaluating complex interventions have been met with challenges, for example, demonstrating a small clinically significant change, that may not be statistically significantly different (Guyatt et al., 2002). Even in trials when the outcomes of an intervention are positive, how and why, is rarely fully understood (Redfern et al., 2006).

There are many reasons cited as to why achieving a statistically significant difference when evaluating complex interventions, may be difficult. A lack of theoretical development before a study is conducted may be one reason. These interventions often involve health professionals, stroke survivors, and carers, as opposed to drugs. This can add complexity and can present a different set of challenges (Campbell et al., 2000). However, it is considered important that researchers continue to find appropriate methods to evidence best practice, in order to improve recovery for stroke survivors.

Two recent large multi-centre stroke trials that have evaluated rehabilitation interventions, found no statistically significant differences on the primary outcomes (Bowen et al., 2012, Forster et al., 2013). The reasons for this could be the treatments were not effective, the methodological approach was flawed, or the outcome measures used were not sensitive enough to detect change. It is important for the recovery of stroke survivors that stroke clinicians and researchers examine the various components of rehabilitation interventions, however difficult this might be, in order to evaluate and test their effectiveness.

1.5.2 Self-Management after stroke

The United Kingdom Department of Health policy for the management of long term conditions aimed to deliver self-management support, through the introduction of the Expert Patients Programme (Rogers et al., 2008) which was piloted in the UK from 2002 to 2006.

This programme (EPP) includes a six week self-management course comprising of weekly 2.5 hourly sessions. The design was based on the Chronic Disease Self-Management Programme (CDSMP) developed at

Stanford University by Lorig et al (2001). The original CDSMP course used Bandura's self-efficacy theory (1997) to underpin the intervention, suggesting it was through this mechanism the intervention worked (Lorig and Holman, 2003). The Expert Patient Programme (EPP) aimed to improve the quality of life of people with chronic conditions by developing self-management skills and improving people's confidence and motivation (Rogers et al., 2008). It was delivered within the NHS, by trained lay volunteers or paid trainers through health care organisations.

Kennedy et al. (2007) conducted a randomised controlled trial to evaluate the outcomes and cost effectiveness of the EPP. It was reported that 10% of the 300 PCT's in the UK advocated the programme (Rogers et al., 2008). A total of 629 patients, with a self-defined long term condition, were recruited into a two armed trial. The control group were recruited from a waiting list of patients expected to receive the intervention. Six months following recruitment, the results showed a statistically significant difference in self-efficacy levels (p=<0.001), demonstrating a moderate effect size (r= 0.44) and a statistically significant change in self-reported energy levels (p=<0.001), demonstrating a small effect size $r = 0.18$. However, the results showed the programme had little impact on routine health services utilisation (Kennedy et al., 2007). In essence, the national evaluation of the programme reported improved health related quality of life that did not add to the total cost of care (Rogers et al., 2008). The numbers of stroke patients in the study were not reported. The impact of the benefits of self-management programmes longer term, particularly after a stroke, still remain unclear (Jones et al., 2013).

Self-management programmes, using a self-efficacy approach, have been introduced to health systems globally over the past decade, and have shown to be of benefit in chronic disease, including stroke (Lorig et al., 2005, Newman et al., 2004, Bourbeau et al., 2003, Barlow et al., 2002). Self-management interventions have been described as adding to the range of services that are effective in treating long term conditions (Rogers et al., 2008). This suggests that learning to modify lifestyles and activities to combat the often devastating physical and psychosocial effects of stroke are necessary. Behaviours that influence reduced participation in daily activities, lack of engagement in social activities and increased dependence need to be avoided (Harwood et al., 2012, Jones et al., 2013).

Whilst we know improvements in self-efficacy have been reported through the implementation of self-management programmes (Lorig et al., 2005), there is still much to be learnt, in terms of the context in which self-management programmes are delivered, particularly after stroke. The timing and the sensitivity of outcomes have also been highlighted as needing further attention (Lennon et al., 2013, McKenna et al., 2013).

A self-management programme, Bridges, has been developed specifically for people with stroke (Jones et al., 2009). It aimed to increase confidence, as people managed their lives after a stroke. The design of the programme continues to evolve and a RCT to test the feasibly of the programme has been conducted by McKenna et al (2013). The self-management programme comprises of structured one to one sessions. Six, hour long sessions facilitated by stroke rehabilitation professionals, focusses on goal setting, recording progress and planned activities. Strategies and progress are recorded in a workbook, retained by the stroke survivor.

McKenna et al (2013) found it was feasible to deliver the intervention to both men and women, with varying levels of stroke severity. Post intervention, differences in self-efficacy, functional activity, and quality of life were demonstrated, with fewer declines in mood and quality of life at 3 months. Although these findings were consistent with past research, as highlighted by de Silva (2011), the sample size was too small to reach any conclusions about effectiveness.

It was however noted that recruitment to the study was low, and due to inadequate treatment fidelity information (McKenna et al., 2013), more research that examines the varying components of the programme is needed. The self-efficacy component to the self-management approach does appear key; self-efficacy appears to be the component that is demonstrating a positive change.

Enabling self-management in clinical practice appears to be of increasing interest, despite a lack of evidence for the effectiveness of these programmes. The drive to improve confidence after a stroke has been initiated by stroke survivors. Interventions aimed at improving self-efficacy have been associated with positive outcomes, but there is more work to be done to examine whether these positive outcomes are sustainable in the longer term (McKenna et al., 2013, Lennon et al., 2013, Jones and Riazi, 2011).

Whilst this research continues to build our knowledge of methods to help increase confidence after stroke, more evidence is needed to determine their effectiveness (Lennon et al., 2013, Jones et al., 2013, Jones and Riazi, 2011). Perhaps one of the difficulties with the evaluation of self-management programmes is the multi-faceted nature of such a complex intervention. What is clear from stroke survivors, is that interventions that aim to improve their confidence are important to them (Pollock et al., 2012) and greater confidence plus reduced anxiety are two patient reported benefits of self-management programmes (Challis et al., 2010). Approaches that activate people to feel more confident are likely to change behaviours (de Silva, 2011).

1.5.3 Regaining confidence after stroke course

The ‘Regaining Confidence after Stroke’ (RCAS) course was designed to help stroke patients adjust to life after stroke. It is an eleven session course that teaches strategies to cope with psychological states, such as low mood and feelings of anxiety. It was developed by Townsend (2003), has been used in Shropshire’s community neuro-rehabilitation team since its introduction in 2003 (Holmes, 2013). A retired service manager and lead psychologist updated the programme in 2009, and made the course material and training manual available to clinical services nationally. However, it is not known how widely the programme is used and whether it is effective. An evaluation of one service (Shropshire) was undertaken in 2013. Whilst this evaluation did provide some useful information that could be used to examine the potential benefits of the programme, the numbers included in the evaluation were small. Only one service was evaluated, and this report has yet to be published (Holmes, 2013).

The evaluation of the Shropshire group used a pre-post intervention measurement, the self-rated GHQ-28 (Goldberg and Hillier, 1979). The results indicated significantly lower depression scores at the end of treatment. Improvements were demonstrated in 12 out of 15 group participants on the GHQ-28. For one participant the score got worse and no change was recorded for another two participants (Holmes, 2013).

The Adjustment to Illness Scale AIS (Felton, 1984) was also used as a self-rated outcome of the intervention. Scores were higher at week eleven than week one, suggesting participants showed greater self-rated adjustment post intervention. The scores improved for 60% of the group participants, and the trend was positive. The study did show statistically significant differences, but the study was underpowered. Theoretically this made the study statistically inconclusive as the optimal sample size assures adequate power to detect statistical significance (Suresh and Chandrashekara, 2012).

The acceptability of such a group was reported using qualitative data on a structured feedback form. The feedback indicated that the intervention, had been acceptable to patients and suggested people contributed to group discussion, enjoyed and felt happier having attended the group (Holmes, 2013). A method of data collection, such as interviews, coupled with a qualitative method of analysis, such as thematic analysis or narrative analysis, may have improved the level of depth and meaning of this data.

Nevertheless, these results suggested that examining group interventions that aim to address low confidence in stroke survivors are worth further investigation.

1.5.4 Factors affecting level of confidence

Clinical evidence examining the relationship between self-efficacy self-care, quality of life and depression after stroke is now reported.

Low confidence is associated with thinking pessimistically, which is believed to limit rehabilitation potential after a stroke (Robinson-Smith and Pizzi, 2003), whereas people who think optimistically and have a high level of self-confidence, have increased chances of recovering pre-stroke capabilities (Broomfield et al., 2011, Lenzi et al., 2008).

Robinson-Smith et al., (2000) used a psychological adaptation model to describe the relationship between self-care self-efficacy, quality of life and depression after stroke. Self-care self-efficacy was defined as the '*confidence a person has in their ability to perform relevant self-care activities*' (Lev and Owen, 1996). Sixty three stroke patients were assessed at one and six months after stroke, using four measures, (SUPPH) Strategies Used by People to Promote Health (Lev and Owen, 1996) to measure self-efficacy, Quality of Life Measure, Stroke Version, (Ferrans and Powers, 1992) to measure quality of life, Centre for Epidemiological Studies Depression Scale (Radloff, 1977), to measure depression, and the Functional Independence Measure (Granger et al., 1986) that measured functional independence. The results suggested that self-care self-efficacy scores improved over time, and were strongly correlated with quality of life measures and depression measures at both one and six months after stroke. Functional independence and quality of life increased over time, while depression decreased (Robinson-Smith et al., 2000). The authors argued that self-care self-efficacy, quality of life, and depression were related after stroke, and advocated health care professionals are in a central position to influence the self-efficacy beliefs and self-confidence of stroke patients (Robinson-Smith et al., 2000). This research was conducted in a single rehabilitation facility in the United States, where the delivery of healthcare differs from the United Kingdom and the study sample size was small (n=63). Further research, testing this hypothesis in other geographical areas is needed to confirm these findings.

1.6 Measuring confidence after stroke

It appears from the literature review that there is a need to measure confidence. A number of post stroke interventions have been described. A valid and reliable measure of confidence that can be used to assess whether people change in confidence following such interventions would appear to be of value.

No measures were identified that specifically assess confidence levels after stroke. However, the stroke self-efficacy questionnaire [SSEQ] (Jones et al., 2008) was developed for stroke patients in both acute and community settings to measure self-efficacy judgements in functional performance. This measure was identified as the one that most closely assessed confidence after stroke.

The Stroke Self-Efficacy Questionnaire (SSEQ) was one of the first measures of self-efficacy designed specifically for people with stroke (Jones et al., 2008). This questionnaire was developed to help stroke practitioners examine levels of ‘perceived confidence’ in functional performance. It is a thirteen item questionnaire that includes functional activities, such as getting out of bed, washing and dressing and walking around the house. It goes beyond measuring a purely functional approach to stroke recovery, as it examines levels of confidence a person has to perform such tasks. The SSEQ was designed to identify stroke survivors who need help to improve confidence levels during the recovery process (Jones et al., 2008). Whilst this questionnaire is valuable, it is still in its early development stage, and therefore has its limitations. For example, the functional tasks included in the measure represent basic activities of daily living. More instrumental or complex activities of daily living were not included, which may limit the questionnaire's use as people progress into a longer recovery period.

Principal Component Analysis, was conducted on the SSEQ questionnaire, and suggested a one factor solution, accounting for 44% of the variance. A good factor solution, is one that explains most of the variance with the fewest factors (DeVellis, 2012). Typically, researchers accept 50-75% of the explained variance (DeVellis, 2012), the SSEQ explained variance falls short of this figure. Furthermore, the psychometric literature suggest a sample size of 50 is the minimum (Comery and Lee, 1992), and 200 is considered fair (Nunnally, 1978) for this type of analysis, a sample size of 40 was used when developing the SSEQ (Jones et al., 2008). In a small sample, errors of inference, are often observed with techniques such as PCA (Field, 2009) this is because PCA assumes the sample is large enough to be representative of a population; but with a sample size of 40 this is questionable.

In addition, the SSEQ (V.1) was administered to first time stroke survivors, between two and 24 weeks after stroke. It might then be argued this questionnaire has more relevance in assessing patients in the acute and early rehabilitation stages of stroke, rather than later in their stroke recovery. It might be argued that later in stroke recovery, is the time people are presented with more complex tasks, affecting their confidence to be able to do what they want to do. Therefore, a confidence measure which seeks to include social and psychological components that become more obvious as stroke survivors increase their range of activities was thought to be necessary.

Other scales have included a confidence component. For example, the Stroke Impact Scale (Duncan et al., 2002) measures factors that are related to social confidence, such as, mobility in the community, participation in meaningful activities and engaging with family and friends, but does not include factors relating to self-confidence, such as positive or negative self-beliefs.

The Burden of Stroke Scale (Doyle, 2002) evaluates how stroke has impacted on a person’s health and life. It is a 64 item measure, which covers 12 domains. Three assess physical activity, six psychological distresses and three cognitive limitations. The scale includes one item on how confident one feels since having a stroke and another item on how optimistic one feels about the future, which are part of the psychological distress domain. In the domain labelled social relationships there are five items that require responses pertaining to difficulties with social relationships, which could be suggested is closely associated with social confidence. However, the purpose of this scale was to measure various components of ‘burden’ rather than being a measure of confidence.

This review has provided evidence that highlights that confidence after a stroke is important to stroke survivors. Improving confidence also appears to be central to therapeutic stroke interventions. It is envisaged that a measure of confidence after stroke would identify stoke survivors confidence levels in order to deliver appropriate treatment aimed at improving confidence levels. A valid and reliable measure of confidence could be used to evaluate interventions aimed at improving confidence. The literature review highlights the need for improvements in outcome measures in clinical trials to capture the complexity of stroke rehabilitation interventions. Capturing a confidence component would be a valuable and important step forward.

1.7 Summary

The literature review revealed that there are various theories and models of confidence. Common meanings, suggest confidence comprises of individual beliefs about ability or capability to achieve, based on these beliefs (Vealey, 2009). This interpretation is similar to a self-efficacy definition which is described as situation specific confidence. Bandura's (1997) theory is underpinned by people thinking positivity or negatively about what they can or cannot achieve. A strong self-efficacy results in active behaviour as people believe they are confident to master skills. This belief dictates the amount of effort they are likely to put in to achieve this. Conversely, a low self-efficacy belief is one underpinned by fear and avoidance and therefore the effort and motivation applied to achieve a task is limited. Modelling behaviours, such as, observing other people mastering a skill is also believed to influence thinking and behaviour (op. cit.).

By acting on positive influences of family and friends, for example, people are thought to be more confident about trying to achieve success, than they might if left to their own resources. Collective efficacy, is described by Bandura (2000) as a group or team who collectively can influence the 'I can' attitude or belief. This theory encompasses a broad construct of confidence moving beyond self-confidence to include the influences of others, organisations or society. Vealy's (2009) confidence model, demonstrates a similar interpretation. This suggests that health professionals and multi-disciplinary teams that enable stroke survivors the opportunity to feel part of a team, or are able to connect them to a peer group, for example, may be in a position to increase confidence levels. A confidence construct appears in most models and definitions, to also include the active element of 'doing'.

The literature highlights similarities between self-efficacy and self-esteem. Positive and negative attitudes are known to influence self-efficacy levels and self-esteem levels. Whilst self-esteem is described as being relatively stable throughout a life cycle, age and a major event are two factors that can lead to a decline in self-esteem levels (Chang and Mackenzie, 1998). Self-esteem is defined an individual's feeling of self-worth and is believed to be a critical component of self-efficacy (Bembenutty, 2007). It might be conceptualised therefore that confidence is a combination of self-esteem and self-efficacy beliefs that enable people to do what it is they want to do. Both these constructs can be affected after a stroke.

The literature highlights that confidence is broader than confidence to complete a task, which is a self-efficacy concept. General confidence in self, confidence in others, confidence in life describes confidence from an existential level and from the perspective of people themselves.

Confidence was also described as being central to rehabilitation recovery, suggesting when stroke survivors are more confident they are able to progress in stroke rehabilitation, whereas low confidence often prevents people achieving what they want or are able to do. It is therefore felt that improving confidence is of clinical importance, as the potential for worse long term outcomes, due to lack of confidence, are evident.

This chapter provides the evidence to suggest there is a need to develop a measure of confidence after stroke. These findings will inform item generation on a confidence measure.

1.8 Research question

The hypotheses underpinning this study purports there is a construct of confidence after stroke which can be measured.

The studies that follow were conducted to develop a valid measure of confidence after stroke (CaSM). The process aimed to keep the perspective of stroke survivors, central in all stages of the questionnaire development. The study design was guided by best practice literature for newly developed health questionnaires (Bowling, 2014, DeVellis, 2012, Streiner and Norman, 2008, Terwee et al., 2012). The central research questions that guided this thesis are as follows:

How do stroke survivors describe the meaning of confidence after having a stroke?

Is there a construct of confidence that can be measured in people with a stroke?

If a confidence measure is found to be valid, reliable and responsive to change, is it useful in a clinical setting?

A sequential mixed methods design (Creswell, 2009) was planned. Firstly a qualitative interview study was undertaken for exploratory purposes to help the researcher gain some in-depth understanding of how the meaning of 'confidence' was described after experiencing a stroke.

Chapter Two

2. What does confidence mean to people who have had a stroke?

A qualitative interview method was used to explore with stroke patients what confidence means to them. The chapter describes the design, methods and results of a study to identify the important themes that should be included in a confidence after stroke measure. A discussion including the study limitations follows, leading to a conclusion.

2.1 Background

The aim of this study was to explore the lived experiences of stroke survivors and whether the concepts, definitions and components that emerged from the literature held meaning to them. A comprehensive understanding of the concept of confidence is essential, if it is to be used to inform the development of a measure (Streiner and Norman, 2008).

The research question for this study enquired:

What does confidence mean to people who have had a stroke?

This next section identifies how and why a qualitative methodology was considered the most appropriate to address the research question defined in the previous paragraph. This will be discussed by examining the theoretical underpinnings of a qualitative research approach.

2.1.1 Selecting a qualitative paradigm

The use of qualitative research methods in health continues to grow. (Macdonald, 2009, Mays and Pope, 1995, Britten, 1995). It is argued that qualitative enquiry can often answer challenging questions about a '*national, complex and rapidly changing healthcare system*' (Devers, 1999). In order to develop understanding of the complexity of confidence, a qualitative approach was seen to be appropriate.

According to Creswell (2009) qualitative research is defined as a means for '*exploring and understanding the meaning individuals or groups ascribe to a social or human problem*' (p4). It has previously been defined more simply by Burgess (1984) as '*conversations with a purpose.*' However, the method which is chosen to conduct that conversation will depend on the purpose for having it, and the perspective from which it is undertaken, in other words, your epistemological position. In short, qualitative methodology does not favour the objectivism of positivist epistemology, for example, advocating the application of methods from the natural sciences (Bryman, 2008). It does favour an approach that values subjectivity. Qualitative researchers argue, it is from this subjective experience and meaning the uniqueness of human experience will be revealed (Silverman, 2013, Creswell, 2012, Smith et al., 2009, Mason, 2002).

Prior to embarking on any research project, the researcher should be clear about the purpose. The purpose of this study was to better understand a complex, human and social problem, which focusses on individual meaning, the subjective meaning of 'confidence' to people after experiencing a stroke. An inductive approach to the study appeared logical, as it seeks to develop theory and interpretations from the data, as opposed to a deductive strategy which is designed to test theory (Bryman, 2008). Without a clear understanding and justification of these methodologies at the very start of the enquiry, the outcome and aim of the research may not be realised (Finlay, 2000).

Given the above context, the chosen methodology was selected on the basis of examining common and typical approaches used in qualitative research, and ascertaining an approach which would best answer the research question.

2.1.2 Phenomenology

A variety of qualitative approaches were examined, such as, ethnography, grounded theory, case study and narrative inquiry, prior to deciding on a phenomenology approach to address the research question.

Phenomenology is defined by Creswell (2012) as '*describing a common meaning for several individuals of their lived experience of a concept or phenomenon*' (P78). The aim is to reduce individual experience and describe a collective 'essence' of the concept, '*to grasp the very nature of the thing*' (Van Manen, 1990). The 'what' is experienced and 'how' it is experienced is what is considered important (Moustakas, 1994).

The motivation to understand the lived experience of illness and wellbeing through a phenomenological lens is perhaps the reason for its increased use in rehabilitation research (Finlay, 2009). As well as being a methodology in research, phenomenology is also a philosophy. It seeks to explore patterns and relationships according to Moustakas

(1994) that enable an in-depth understanding of a small number of subjects through extensive engagement (Creswell, 2012). Phenomenology seeks to '*remain as faithful as possible to the phenomenon and to the context in which it appears in the world*' (Giorgi and Giorgi, 2008) (p28). It is concerned with providing deep information and perception through inductive, qualitative methods, such as, interviews, discussion and observation (Creswell, 2009). Phenomenology aims to describe, as opposed to explain. The intention being, to '*make voices heard'* (Lester, 2007). Phenomenologist's epistemological position is based around a paradigm of personal knowledge and subjectivity, and the importance of personal perspective and interpretation (op. cit.), as opposed to the physical worldview of the sciences which is underpinned by a more objective approach (Finlay, 2009).

Laverty (2008) alleged phenomenology and hermeneutic phenomenology are often misunderstood, and asserted that even today, the ideas and theories underpinning this methodology are 'dynamic and evolving.' Edmund Husserl (1900/1970) at the start of the twentieth century proposed that phenomenology should make visible what is hidden and not obvious in ordinary everyday experiences. This strategy of inquiry asks 'what is this experience like?' as it attempts to unfold meaning and as it is lived in every day experiences. In Husserl's view this concept was a way of reaching true meaning, by delving deeper into reality (Laverty, 2008).

In order find the truth from that particular standpoint, Husserl described a process of 'bracketing' the outer world and individual bias, in order to see the phenomenon '*how it really is'* (Osborne, 1994). Phenomenology assumes judgement, beliefs, preconceptions and hypothesis are suspended. This was necessary to see the hidden concepts behind the words, from the participant's standpoint. This approach was perceived as '*powerful*' for understanding subjective experience (Lester, 2007).

However, Heidegger (1927/1962) a former student of Husserl, whilst being influenced by his work, refuted the notion of 'bracketing', suggesting it was not possible to engage in a process without any preconceptions or bias. In Heidegger's opinion, all understanding is connected to prerequisite constructs, such as, personal history, that cannot be 'bracketed' in the way Husserl described (Laverty, 2008).

Heidegger's contrary view suggests that instead of stepping outside ourselves into a purely objective realm, our interpretations have meaning in themselves, and interpretations are needed to help make sense of the experience (Smith et al., 2009). It is assumed therefore, in hermeneutic phenomenology, the researcher is not a neutral individual but an active one, and that according to Smith et al. (2009) '*the interpretation of people's meaning making activities is central to phenomenological enquiry..*' (p18). Thus the beginnings of hermeneutic phenomenology and theory of interpretation started to evolve.

2.1.3 Interpretive phenomenological analysis - Rational for use in a qualitative study on confidence

The previous section described the theoretical and historical underpinnings of phenomenological philosophy and phenomenological methodology, from which interpretive phenomenology analysis has evolved.

This next section will give a more detailed account of this rapidly growing strategy of inquiry within the field of health sciences (Smith et al., 2009). There has been an increasing number of studies in the past few years using IPA to examine health and wellness in the literature (Preston et al., 2014, Wensley and Slade, 2012, Bramley and Eatough, 2005, Carr et al., 2003). A justification for IPA as the favoured approach to explore the meaning of confidence with stroke survivors now follows.

The aim of Interpretive Phenomenology analysis (IPA) is to explore in detail, how participants '*make sense'* of their experiences. It is argued they do this through their own personal and social world by assigning meaning to those experiences and events, from the perspective of the participants (Smith, 2007). This interpretation has evolved from early phenomenological philosophy.

IPA is about believing participants are experts of their own experiences, and can inform researchers about their thoughts, commitments and feelings in their own words (Reid et al., 2005). It also encompasses the researchers' position, as it assumes the researchers' conceptions and interpretations are required in order to make sense of the participants' world (Smith et al., 2009). Whilst IPA acknowledges that researchers cannot gain complete access to the participant's world, it does recognise that the researcher's analysis of this world is a dynamic and interpretive process (Smith et al., 2009). It therefore, engages both the participant and the researcher into a process of talking about and seeking descriptions about, what matters to them.

A two stage data process enables participants to make sense of their own world, whilst the researcher attempts to make sense of the participants' lived experiences (Cronin-Davis et al., 2009). It has been described by Smith et al (2009) as a '*double hermeneutic*' process. IPA seeks to understand participants' stories by critically thinking about meaning behind the ordinary; for example, '*Is something leaking out here that wasn't intended*?' as suggested by Smith el al., (2009).

Successful analysis seeks to be reflexive, which is considered 'obligatory' in an IPA approach (Brocki and Wearden, 2006). The notion of '*looking again, reflecting your thinking back to yourself'* developed from an interpretivist ontological standpoint, seeing people and the world as interrelated (Shaw, 2010) is the objective. A reflexive diary to capture feelings and intuitive thoughts throughout the data collection and analysis period was planned. It is advocated the more detailed the diary, the more interpretative the final analysis becomes (Smith, 2004).
IPA also purports to be transparent, grounded in examples from the data itself, and therefore a trustworthy account (Lincoln, 1995). It aims to give a rich and plausible account to the reader or audience, when disseminating the outcomes (Reid et al., 2005).

Reid (2005) argued that IPA is particularly suited to researching '*unexplored territory*' when, a '*theoretical pretext*' may be lacking. The meaning of 'confidence' in the stroke rehabilitation literature has not been extensively explored. Therefore, an IPA approach may reveal some unexpected findings, which could be fundamental to the development of a confidence questionnaire that seeks to measure confidence.

Semi structured interviews are a common method of data collection in qualitative research. Smith et al (2009) advocated:

> ‘*Participants should have been granted an opportunity to tell their stories, to speak freely and reflectively and to develop their ideas and express concerns at some length.’ (p56)*

Semi structured interviews were considered, in order to have the flexibility to probe a bit more or a bit less in response to varying replies (Bryman, 2008). Smith et al., (2009) argues that this is key to getting a deeper understanding.

As a novice interviewer it is easy to make fundamental mistakes. Therefore a ‘framework of challenges’ developed for use in an interview setting by Bryman (2008), was examined. Kvale and Brinkmann’s (2009) paper *‘learning the craft of qualitative interviewing’* was also examined and the following strategies were applied:

Keeping a reflective diary prior to the interview, and immediately afterwards, enabled the researcher to document feelings and bias’s that had been evident during the interview process, and any surprises about the environment. This was considered useful for being able to park any concerns felt by the researcher and focus on the interview participant, as advocated by Smith et al (2009). Secondly, the diary provided useful data for the interpretative stage and thirdly, the data acted as evidence to check ethically sensitive issues, which Bryman (2008) considered important.

The question of '*How many qualitative interviews is enough*?' is a common question and needed to be examined. According to an expert voices review paper, the answer will almost always be '*it depends*' (Baker and Edwards, 2012). The paper outlines some reasoning on why it depends. In summary, the discussion centres on methodology, research question, and therefore outcome, and researchers' available time. A description as to how these constructs helped the decision making in this study follows.

Typically, as described previously, phenomenological data is collected through in-depth interviews or semi structured interviews, supported by a reflexive account from the researcher (Creswell, 2012). As such, Polkinghorne (1989) argued that five to 25 interviews is the sort of range that is necessary to attach meaning to the phenomenon being studied. In IPA, Smith et al (2009) suggested between three and six is recommended as a reasonable sample, to be able to analyse the similarities and differences between participants. They argue that if the sample size is too large, the vast amount of data becomes overwhelming. Succinctly, Smith (2007) advocated in IPA, one foregoes breadth for depth.

Collaboration with patient groups and public involvement (PPI), was key to the conduct of this study. It is suggested that research agendas can be redefined to ensure they are addressing life after stroke issues that matter, to our stroke population (Pollock et al., 2012).

This introduction provides a background and rational to conduct a qualitative study to develop an understanding of how stroke survivors construct meanings of confidence and their experiences of altered confidence after a stroke. It is envisaged that the findings of the study will inform the development of a measure of confidence questionnaire.

2.2 Methods and methodology

2.2.1 Ethical approval

Ethical approval was obtained from Nottingham Research Ethics Committee 1, for a substantial amendment to the multi-centre randomised controlled trial of rehabilitation aimed at improving outdoor mobility for people after stroke. REC reference number: 09/H0403/55, 13th October 2010 [Appendix 2]. Details submitted to the ethics committee outlined the need to add a semi structured interviews, to broaden our understanding of the meaning of confidence after stroke. The amendment was approved by Nottinghamshire County NHS teaching PCT who granted approval on 13th October 2010 [Appendix 3].

Ethical standards, that span across all areas of the research process, were adhered to by a GCP trained researcher (JH), following the ethical principles that underpin the 'Good Clinical Practice' guidelines (ICH, 1996). See [Appendix 4].

2.2.2 Patient involvement

This study proposal was presented at the Nottingham Stroke Research Consumer Group who provided a favourable response [See Appendix 5].

2.2.3 Piloting

An interview guide was developed and two pilot interviews were conducted with two stroke survivors. They had been excluded from a multi-centred randomised controlled trial of rehabilitation aimed at improving outdoor mobility for people after stroke (Logan et al., 2012), as they were getting out of the house as much as they wanted to. Therefore, they were not eligible for the RCT study. Both consented to being interviewed for the pilot work, following their consent to be invited to participate in future stroke research.

This pilot work informed the main qualitative study, by testing the interview guide, to ensure the questions enabled the flow of conversation and did not hinder the process. The length of the interviews was also timed. In addition, the content of the questions were tested to explore whether they were relevant to answer the main research question. Adjustments were made following feedback from an experienced qualitative interviewer (IR). See [Appendix 6]. Strategies to avoid leading or closed questions and strategies that are likely to aid listening were discussed with the researcher (JH).

2.2.4 Consent and recruitment

Potential participants were identified from a multi-centred randomised controlled trial of rehabilitation aimed at improving outdoor mobility for people after stroke. In this study participants were sent a letter via stroke registers, and GP registers, see [Appendix 7]. Potential participants were screened for eligibility and sent an information sheet, see [Appendix 8].

If a positive reply to the invitation letter was received, potential participants were visited by one of two experienced GCP trained, research associates, employed on the study. In the main RCT, if potential participants gave consent, they were asked to sign a consent form, and a signature from the researcher was also required. A study Identity number was allocated and procedures for the multicentre trial were undertaken.

Where a participant was unable to sign the consent form, and the researcher had assessed the participant as competent and capable of understanding the consent procedure, the form was marked by the participant, and a witness was asked to sign the consent form. All consenting participants were then randomized to either an intervention group or a control group.

2.2.5 Participants in the qualitative study

Potential participants were purposively selected from those who had taken part in a multi-centred randomised controlled trial of rehabilitation aimed at improving outdoor mobility for people after Stroke [the getting out of the house study] (Logan et al., 2012). Two occupational therapy researchers identified potential participants from two geographically convenient sites. The therapists identified stroke survivors lacking in confidence on the basis of their verbal reports at the baseline assessment. The sample selection therefore was deemed to be people with low confidence as not all stroke survivors were included. The interpretation of the findings therefore will be representative of the sample and not generalizable to everyone who has experienced a stroke. Participants were further selected on the basis of their score on the

Modified Rankin Scale (Rankin, 1957), to ensure the sample included people with abilities ranging from '*no significant disability despite symptoms*' score of 1 to '*severe disability'* score of 5. See [Appendix 9]. Ten potential participants were contacted by the qualitative researcher (JH), and invited to participate in the interview study.

2.2.6 Inclusion and exclusion criteria

Participants were identified for inclusion if:

- They were 18 years of age or over
- As least six weeks post stroke
- Wishing to 'get out of the house' more often and had consented to the Multi-Centre Randomised Controlled Trial of rehabilitation aimed at improving outdoor mobility for people after stroke
- Able to take part in an interview for at least 30 minutes (Self-assessment)

Participants were excluded if:

- They were receiving post stroke rehabilitation

2.2.7 Interview procedure

Participants were interviewed in their own homes, to provide a safe and familiar context.

An interview guide was developed and used in the pilot interviews. As a result of feedback from the pilot interviews, slight adjustments were made to the wording prior to using it in the interview study, see [Appendix 10]. As the researcher's competence increased, the guide was put to one side in order to follow the flow of the interviews.

The interview started with an introduction to the researcher and an explanation of the research project. What was expected of them as participants and the expected timing of the interview (an hour) was discussed. Participants were asked if they were willing to continue. In addition, the researcher gave an explanation of the purpose of the study which was to broaden understanding of confidence from the perspective of someone who had experienced a stroke. Participants were given the opportunity to ask questions, and time was given, to enable participants settle into the interview before turning on the recorder. It was envisaged this process would help develop a rapport and enable participants to be able to trust the researcher with their, often sensitive, information.

The interviews were digitally recorded using a small and unobtrusive recorder, the Olympus© professional voice recorder.

Confidentiality was assured and pseudonyms were used to protect participants' identity. Assurance was given that all data would be kept in a lockable, fireproof filing cabinet. Data which was stored on the computer would be password protected, and names would be changed to ensure anonymity. These actions comply with the principles set out in the Caldicott Report (Department of Health, 1997). After completion of the study, the plan for the data to be archived for at least seven years in case of audit, coupled with, using the University of Nottingham's secure procedures, for destroying confidential material responsibly, was also explained to participants.

The majority of the data were elicited from the first question '*Tell me about what happened when you had your stroke*?' Open ended questions attempted to capture data that participants considered important. This approach enabled stroke participants to tell their story, in the context of their daily lives, with some gentle prompts and steering from the researcher. Topics were led by participants as opposed to being led by the interview schedule.

Prompts were used to further explore the participants' experience, for example prompts such as: '*Thinking about the things you were able to do, and the things you were not able to do - talk me through that experience.*' Also embedded in the guide was a direct question about the definition of confidence. '*What does confidence mean to you*?'

The final stage of the interview involved ensuring the participant, had the opportunity to de-brief about any issues or emotions that had arisen during the interview, and that these were resolved to the satisfaction of both the researcher and the participant. The participants were thanked for their contributions and were offered a copy of any outcomes, such as a publication or poster, on the completion of the research.

2.2.8 Reflexivity

The qualitative researcher kept a reflective diary, capturing feelings and thoughts to encompass reflexivity within the study. A self-check was instigated and if it was felt the researcher needed to further explore a situation or issue, the diary was used to facilitate discussion with an experience qualitative researcher (IR), after the interview.

2.2.9 Transcription

The interviews were transcribed verbatim, using digital dictation transcription software.

2.2.10 Data analysis

The data analysis did not start when the data collection was complete. Key questions and ideas were formulated throughout the interview process. Thoughts were captured through supervision sessions, discussions with experienced qualitative researchers (IR & JP) and through transcribing the interviews. A research diary, see [Appendix 11] was invaluable in capturing moments, emotions and ideas. The diary was used as reference throughout the interpretative process.

The data analysis followed IPA principles, using a framework advocated by (Smith et al., 2009). See **Table 2**.

Table 2: Data Analysis Framework

Stage 1	Transcribing, reading and re-reading
Stage 2	Initial noting
Stage 3	Developing emergent themes
Stage 4	Searching for connections across emergent themes
Stage 5	Moving to the next case
Stage 6	Looking for patterns across cases

Stage 1 – Reading and re-reading

In the first stage of the analysis, the researcher read and re-read the transcribed data, to get a general sense of the words, tone and content. Initial notes were recorded in the margins and included thoughts, feelings and ideas stared to emerge from the data, see [Appendix 12].

Stage 2 – Initial noting

Stage two involved analysing the data to seek an understanding of participant's experiences. No rules were applied at this stage, as the researcher's aim was to be as exploratory as possible. The data at this stage increased, as quotes were examined and idea's start to emerge. The opinion of an external experienced researcher in IPA, (JP) was sought to improve the quality and outcome of the data analysis process. Appendix 13, demonstrates an example of this feedback.

The researcher further examined the data, after feedback and the following approach was undertaken. The data were scrutinised for descriptions, including emotional responses, key words and phrases that could hold meaning to each participant. Places and events that were important were identified and noted to the right of the data transcripts. Repetitive comments or words, pauses, laughter and metaphors were observed and recorded in *italics*. Conceptual meanings interpreted from the data were underlined. The data were examined again line by line to develop a deeper understanding. An example of these processes can be found in [Appendix 14]. This stage resulted in a detailed analysis, for each independent participant.

Stage 3- Developing the emergent themes

In stage three the data transcripts and the exploratory notes developed from stage one and two were examined. Interpretation occurred by probing the data for patterns and connections as themes emerged. They were recorded chronologically. Developing ideas were recorded on the right of the transcripts, whilst themes were noted on the left. Concepts emerged, changed and developed, through repeated checking and questioning of the data. The researcher cut interesting quotes into strips. These strips of participant quotes were displayed on flip chart paper positioned around the room and coded accordingly. Time was a factor in digesting the data and continually examining the codes at different time points. This process helped the researcher to develop meanings from each quote, whilst linking the quotes to themes. This rigorous process resulted in the identification of themes with participant quotes at the core.

Stage 4 – patterns and connections across emergent themes

Stage four involved clustering the emerging themes into tables. The process started with identifying some key themes emerging from the data. For example: 'fear' 'influences of significant people' and 'role loss'. These headings were further examined data relating to the theme headings were grouped together. The headings were changed, moved and developed through a further series of re-examination. When the researcher was satisfied with the analysis, the information was synthesised into two tables. One table included words and concepts that underpinned the theme heading. A second table included participant quotes that linked to that interpretation. See, [Appendix 15, 16] as examples. The aim essentially, was to capture what was considered crucial in the data that reflected the meaning of confidence, for each individual participant.

Stage 5 – Moving to the next case

Stage 5 of this analytical process involved repeating stages one to four, as described above, for each participant. Capturing the uniqueness and similarities in each single case ensured each case was analysed in some depth, individually, prior to looking for themes across all the participants. Appendix 15 & Appendix 17 demonstrate that the emerging themes were different for each individual participant. Following the development of themes for each individual participant, patterns and themes were then compared across all ten cases.

Stage 6 – Looking for patterns across cases

The final step of analysis was complete when what was unique to each case was identified and shared experiences between participants evolved.

Appendix 18 demonstrates the data from which the final themes emerged.

An independent researcher (PL), with supervisory responsibility, verified that all six steps of analysis had been followed by randomly selecting two participants, and checking the documentation described above. In addition, an experienced qualitative researcher (IR) checked the first two interviews, examined the content, strengths of the interview and what might be applied to improve subsequent interviews. This information was shared with the researcher (JH). The reflexive diaries also captured this data and impacted on the interpretations. A third independent and external researcher (JP) was sent a sample of interview transcripts; at different stages of the analysis, to identify alternative interpretations adding to the exploration of the meaning of confidence.

Data has been extracted from the transcripts and used to illustrate the emergent themes. Each quotation was followed by a page number and line reference, to enable traceability to the original transcripts and to add transparency to the representation of the individual experiences and meanings.

2.3 Results

The participants included five men and five women, one from a Black Caribbean ethnic origin and nine White British. The interview time ranged from 29 to 75 minutes (mean, 55 minutes). The participants' demographic characteristics are shown in **Table 3**.

Table 3: Characteristics of Participants

STUDY ID	PSEUDONYM	LIVED WITH	AGE	MODIFIED RANKIN SCALE	TIME SINCE STROKE
JH03	Mick	Wife and children	32	Slight disability	2 years 8 months
JH04	Freya	Alone	61	Moderately severe disability	3 years 8 months
JH05	Bob	Wife	69	Moderate disability	2 years 7 months
JH06	June	Alone	59	Moderate disability	9 years 10 months
JH07	Ryan	Wife and children	58	Moderately severe disability	12 years 6 months
JH08	Ted	Alone	77	No significant disability, despite symptoms	3 years 10 months
JH09	Leon	Wife	71	Moderate disability	3 years 3 months
JH10	Helen	Husband	70	Slight disability	1 year 9 months
JH11	Barbara	Alone	70	Slight disability	2 years 9 months
JH12	Alison	Alone	86	Moderate disability	1 year 6 months

2.3.1 Defining confidence

The essence of the meaning of confidence unfolded as the six themes emerged. These themes were loss of identity, fear, social confidence, role confidence, mastering skills, attitude and beliefs.

2.3.2 Identity loss

The notion that having a stroke questions who you are, was articulated by eight participants. Skill loss, decreased competency and lack of engagement in activities were described as contributing to a general feeling of being a lesser person, particularly in the early stages after stroke. Participants linked descriptions of their pre-stroke selves to being confident. Being a worker, a sport activist and a dancer appeared to be associated with confidence. Consequently, when these roles were lost, it reduced confidence. June gave an example by describing herself through what she did in the past, and believes she is no longer capable:

> *'Can't walk far, can't play badminton. I'm just a totally different person.'* (June: 11.9)

Bob described himself as a 'joker' pre stroke. He described his aphasic problems after his stroke has contributed to not being able to re-connect with this identity:

> *'I used to be the life and soul of the party, and erm, when it …it was a speech ther..er difficulty that caused the most problems. I was [pause] I would normally step in with a joke here and a joke there [pause]. Nothing. Now I can't tell jokes at all. NO.'* (Bob: 13.5)

As a young stroke survivor, Mick expressed difficulty in coming to terms with his post stroke self. His active pre-stroke self was as a worker, a father engaged in a variety of family activities and a footballer. His football team had a nickname for him:

> *'I've told people not to call me that anymore 'cos he's gone.'* (Mick: 44.11)

> *'..and I was kinda reborn, in this kinda different person.'* (Mick: 44.36)

> *[My stroke] '..basically turned my life upside down. Everything I used to do, I don't do it anymore, everything. And it's kinda trying to rebuild my life to some kinda normality for me. That's where I want to be, back to work, going out [pause] with the family, socialising. Mmmm.*

> *'But I don't do half the things like that, that I just mentioned.'* (Mick 14.8).

Confidence for Mick, appeared to be associated with engaging in social roles and everyday activities that will re-establish his sense of identity. Doing and being successful at the things he wants to do appear to be linked to feelings of competence. Mick suggests he no longer engages in these activities. This may be because he doesn't believe he is capable.

Participants described a questioning of self-identity, when trying to re-establish routines, in the early stages after stroke. They reported not feeling competent to engage in previous, often familiar, activities and roles, such as '*washing pots, going to the greenhouse or walking the dog* [laughter]' (Ryan 9.17) and this contributed to a loss of confidence. Loss of capability and value as individuals was embedded strongly in the data, perhaps indicating an impact on self-esteem. However, being successful in regaining skills and re-establishing habits and routines helped participants redefine their self-identity.

2.3.3 Fear

Fear of having another stroke, fear of falling, fear of stigma and fear of going outside were commonly experienced. Participants associated fear with avoidance behaviours. Fear of having another stroke, for example, created a barrier to participate in activities outside of the house. Once this fear was established, it was difficult to overcome. Confidence was associated with facing and overcoming fear, in order to participate in everyday activities. Lack of confidence appeared to be related to 'I can't' and avoidance behaviours.

> '…*Every time I had a headache, I feel lightheaded, my leg hurts, there is always that question, erm, maybe [laughs], just kinda maybe*.' (Mick 13.2)

> '.. *you never know what is going to happen tomorrow*.' (June 17.6)

> *'.. am I going to have another stroke? - So that was on my mind.'* (Ted 12.1)

> *'….alert to any changes in my body at all, you know? Anything, because I think now, perhaps this is going to be the big one, you know.'* (Barbara 19.4)

> *'I've never got it [my confidence] back completely. Scared to go out because I thought I was going to make a fool of myself..'* (Alison 14.10)

Participants described '*living with fear*' and how it prevented them from participating in the things they wanted to do. Mick experienced a second stroke, and described this period, as '*cementing the fear in my brain*' (12.14). This second event had a huge impact on his recovery and his confidence to leave the house, resulting in a period of avoiding going out.

> '*I have basically avoided situations, places, people*.' (Mick 50.1)

Gradually overcoming fear led to participants being able to do things that were important to them. Participants reported facing fears and participating in the things they wanted to do. Mick suggests, after a stroke, building confidence has a temporal component. He describes his fear decreasing over time, by participating in different activities.

> *'..gradually, your confidence kinda builds, every time, well like everything now though, like emm, if it's leaving hospital, erm going to the shops, starting a new job, speaking to someone on the phone, the first time is always kinda nervous. Scary, which it is. For me now it is, anyway…*

> (31.4) *The second time it's not too bad, the third time it gradually, gradually, gradually*….(31.12)

> *'Eventually, as your confidence grows, your bubble starts to get bigger, erm, the garden, then the street, then the shops, eventually.'* (Mick: 19.2)

Being active for Mick as each task was successfully achieved, was perhaps changing his beliefs. It suggests he is thinking more positively about the next goal or task and these ingredients are developing his confidence.

Confidence for Barbara was being encouraged by a health professional to achieve something she was unlikely to have tried on her own, initially. Barbara talked about her fears and avoiding a difficult task, but described how her effort and attitude has built on this initial support, to enable her to be more confident in her abilities.

> *' If it was raining, I was frightened of skidding, so he'd [physiotherapist] would say "oh you're not getting away with that, come on" You know, "now come on run." And I'd say I can't run, I can't run. And when he was here, I…when he parked his car, I can tell you how bad I was, because I daren't go out the front door. It was the most horrible feeling, oh God, he's here, you know, and I could open the door from the inside but I wouldn't even go out onto the kerb.* (Barbara15.16)

> *'..I've come a long way, apart from my physiotherapist, without blowing my own trumpet, I think it's due to me. I think it's my attitude because I didn't fancy going into old lady mode… No. And not, you know four walls. ..and I think, don't think of what you can't do think of what you can do.'* (Barbara 17.21)

Participants gave many examples of building up confidence and capability through activity and doing. Relearning skills and mastering a new skill improved confidence. Some participants were slow to start regaining skills and gave examples of how they initially avoided activities that evoked fear and uncertainly. Fear of stigma related closely to the next theme of social confidence.

2.3.4 Social confidence

Social confidence was linked to fear but was a theme in its own right. Fear of going out and being socially active after stroke was commonly perceived as a problem and one that appeared difficult to resolve. Some participants were able to address their fears early in their recovery, whereas others had not been able to achieve this fully and years later avoided going out and accepted a diminished social lifestyle and reduced social confidence.

> *'I wasn't quite happy, after the stroke, being in a crowded place, like the middle of a shopping centre, on my own. Which is when [name of OT] got me out, did me the power of good actually. I mean it was just a small thing, but it turned out*

> *you know, gave me a lot more confidence. I wasn't, I wasn't reclusive, it was just the, you know, it was just that particular thought of being on my own with loads and loads of people, but I'm okay now.'* (Ted: 13.6)

> '…*I'll tell you what it was. And I think, well I know, there's a stigma around strokes, and it was that, I think, which prevented me from being more sociable. The idea of people quizzing me about a stroke and all that, there is a stigma attached to it*.' (Ted 19.4)

For Ted, it was the 'thought' of going to shopping centres and facing crowds and people that created the biggest barrier to going out. Ted, did not have any visible physical impairments, but lacked confidence in social situations. This appeared to relate to perceived negative reinforcement from others. Nevertheless, with support, he was able to face his fear and successfully master an activity he had been avoiding. This successful experience perhaps altered his perceived confidence in engaging in future social activities. The effort required to be able to master a similar activity might have be adjusted based on a successful experience. This concept relates to a self-efficacy model of confidence.

Similar experiences in a social environment, for participants who had experienced aphasia following their stroke, indicated they were less confidence in social situations than they were prior to their stroke. Describing going to a luncheon club twice a week with her son, Alison tells us:

> ‘*And I can’t talk too much because everybody is looking at me, I think. I don’t think they are, but I think they are. Erm, because I can’t talk exactly as they talk. If I talk slowly I think I am boring them, if I talk quickly they can’t understand me. Very upsetting. (Alison 14.13)*

This account suggests Alison’s intrinsic confidence in herself to be able to engage in social interactions, might be lacking. A vulnerability, or lack of value in herself in such situations, appears to be evident. Positive feedback from others might help to prevent feelings of inadequacy in such situations.

Bob described a social experience where negative reinforcement and feedback in a social context resulted in him not having the confidence to go out for a full year after his stroke.

> ‘*..the bar maid at the club we go to. She er, before she knew, what, what my problem was, I was er, and she got very short tempered, you know. “What do you want??” [Aggressive tone of voice]. I got that out [*Aphasia card – I have had a stroke, this means I have difficultly talking*], and she was alright. But, when so many people do it to you, you start to lose your confidence.’* (Bob: 21.13)

Bob’s account suggest this experience, was not a one off situation. Negative judgements from others may undermine stroke survivors’ ability to think positively about themselves, and may impact on self-esteem. Confidence therefore may be a temporal state, over time it could improve or decrease dependent upon positive and negative reinforcement from others.

Ryan described feeling ‘anxious’ and Mick ‘uncomfortable’ in social environments. Ryan described his difficulty with walking into a crowded room:

> *‘I don’t know whether it was that I was self-conscious about the fact that I was struggling in my wheelchair or struggling to walk, people looking at me or not. But that was a worry. In fact at one stage if you had come in, I had coping strategies pinned all over the wall…’* (Ryan: 15.13)

Ryan suggested confidence is a combination of how one feels about one self, and the feedback we receive from others. Whilst participants acknowledged fears about going out and about and engaging in social interactions with others; there was an immense desire to overcome these fears and develop strategies to help them participate in social activities. For some, this process was slow and may never be fully resolved. Confidence appears to develop gradually with experience and success and be affected by the feedback received from others.

Also embedded in the data is the notion of participating in social activities had increased feelings of self-worth and belonging. Participants were able to describe how a social context, enabled them to think more positively about their achievements.

Freya and Bob described their experiences in the context of attending a stroke groups.

> *'Well it was just being with other people that have....you think, you see, that oh nobody knows what I've been through, but everyone else, feels exactly the same thing, and you can tell when they are talking about things, that they are thinking oh she knows exactly how I feel.' (Freya 69.2)*

> *'… I'm thinking about the Thursday stroke club….the stroke society, erm, and I think I can er people there, all know me and everybody, everybody, I've got more confidence there..' (Bob 35.15)*

> *'I'm the only one that has got the problem I've got. [Aphasia]. Erm all the rest have got limbs and arms etc. [physical impairments]…But when they talk to me and they speak to me and they make room for my speech therapy, leave a gap, for me to answer. That's a good thing. And the gaffer that's there, he cracks a joke with me now, and I appreciate that.. and I can words, I can get more words together..' (Bob 37.3)*

Bob is describing a sense of respect and dignity with peers, similar to Freya who describes empathy, support and belonging. In addition to gaining a sense of self value, perhaps there is an element of 'collective efficacy' in this group context.

2.3.5 Role confidence

Participants perceived that loss of roles was linked to decreased confidence. The youngest participant, who described himself as being a father, a husband, a full time worker and a footballer, had difficulty adjusting to life after stroke in the absence of the latter two roles. The most consistent and important roles throughout this participant's recovery period were being a father and a husband. The motivation to engage in tasks and activities, that enabled him to fulfil these roles appeared to have a positive effect on his self-confidence.

> *'I need to push myself, if I don't feel great one morning; I need to go to work for this, for the house, for the kids, for the food, the mortgage. I'm having to push myself, which I guess builds my confidence.'* (Mick: 55.13)

> *'I work for a care company, I don't like the job really [laughs] but it's almost like a stepping stone back into a normal life, a working life..'* (Mick: 18.1)

Confidence therefore appears to relate to successful attainment of former roles and the motivation to attain former roles. Ryan also described how his voluntary roles had replaced his worker role and enabled him to gain a sense of worth. He described being successful in these roles as a '*nice feeling*' and one which '*bucked his confidence*'.

A driving role was considered highly important to Bob. Bob described that his wife was making more decisions, since his stroke, than he had been used to. The ability to drive and take some control was perhaps the motivation to try to get back to this role, Bob hadn't driven for a year.

> *'She [Wife] said are you going to take a lesson to get your confidence back? I said "no" so I went out in the car and it was as though I had never been away.'* (Bob 27.6)

> *'But that really opened up my life to all sorts of other things. We could go out on a Sunday and that. Yeah.* (Bob 27.10)

Bob had a strong belief about his ability to drive; his positive thinking is demonstrated in that he was confident in his ability to achieve this task.

Meaningful roles appeared to be central to having the confidence to resume an active life after stroke. The meaning attached to these roles may influence the amount of effort that participants applied to be successful in these roles. Roles that were considered important pre-stroke or engaging in replacement roles appeared to reinforced beliefs in personal capability.

2.3.6 Doing: Mastering skills

The essence of confidence was commonly described as being associated with a 'doing' component.

> [Confidence is] '*Going out and doing something you want to do.'* (Bob 12.16)

> '*Confidence to me, in relation to this is doing something you want to do, when you want to do it.'* (Ryan 9.13)

> *'It's some way of going back to normal life. Being confident to leave the house, walking again, trying to talk.'* (Mick 26.5)

In addition to a doing component, confidence appears to have deeper meanings to participants after a stroke. '*When you want to do it*' suggests there is an element of control or independence relating to confidence. '*Trying to talk'* suggests the motivation or effort applied to a task or activity could also be a component of confidence.

Helen gave an example of getting up the stairs after her stroke.

> *'..Once the stair rail was up, I mean the family wanted me to have a stair lift. But the [physiotherapist] said: You'd be wasting your money you need to exercise that leg. And so I get up - I go upstairs, well, almost as fast as I did before.* (Helen 5.9)

> '*What made me get going was having the commode downstairs and I hated it.*' [laughs] (Helen 7.5)

> '*Yes I did very well. Everyone kept saying, oh you are doing so well but it wasn't enough for me.'* (Helen 8.2)

Confidence for Helen appeared to be something intrinsic. She described it was her individual belief in her ability that was important, despite describing positive reinforcement from others. This may also link to self-worth.

Once participants were able to believe and demonstrate to themselves that they were successful in a particular task or skill, they went on to believe they could achieve a lot more, suggesting success and motivation increased confidence. This process is best articulated by participants:

> '*Once I could get up and take a step, I knew I could do it, I know it seems daft....*' (Ryan: 10.13)

> '*Eventually, started cooking for myself, I thought, oh I can manage to do different things instead of using the microwave all the time.'* (Freya: 30.2)

Mastering skills was consistently described as difficult initially after the stroke. However, once participants began to succeed and improved by practising small achievable tasks, their belief in themselves improved, enabling them to move on and to attempt other activities. However, when practise did not improve skills, participants described becoming frustrated and found that their confidence decreased.

> *'…and my writing, even my writing gets worse, you can see here. That's me practising, every day I practise....'* (Leon 4.12)

Some participants needed positive affirmation and support when trying things for the first time. Without this reinforcement, it appeared they were less likely to try. Confidence appears to be about motivation, often but not always, reinforced by others.

2.3.7 Attitudes and beliefs

Attitudes towards success and failures pre-stroke, were related to confidence. One participant linked self-esteem and self-efficacy to confidence. She described having very low self-esteem and a history of depression prior to her stroke. She perceived that both her self-esteem, a sense of increased worth, and her self-efficacy beliefs had improved as a result of her stroke journey. She reported '*an inner strength almost that I didn't realise I had*.' (Freya: 35.19). She illustrated this:

> *'..the main barrier is within yourself, I think. The biggest one is within yourself, you think I can't do that and you think about it and you think I'll try. But you don't try very hard because you think you can't do it, you see? So you have to try a bit harder and then you realise you can do it, you know. So often the biggest barrier is within yourself.'* (Freya: 50.11)

In doing and achieving, Freya and others described a process that appears to have increased self-efficacy; further reinforcing the confidence and self-efficacy relationship. A factor that underpinned Freya's success was positive reinforcement from a close friend, who encouraged her to pursue ambitions she would not have considered prior to her stroke:

> *'He [Friend] said "let's go to Cyprus" I said I'm not going to CYPRUS [increased tone: Laughter] – you see I've never flown before, you see, so we flew to Cyprus.'* [laughter] (Freya: 41.7)

Barbara described her rehabilitation as being a very positive experience. She described a fear of falling after her stroke, which she believed was helped by a post stroke intervention to improve mobility. The attributes of the therapist, including empathy, positive reinforcement, humour and encouragement, helped her to build her belief in herself by reinforcing success in her mobility. Keen to feed back her perceived success, she described telephoning her therapist:

> *'..And I said to him, I can walk into town now, I can walk as far as Marks and Spencer's, and he said "I can't believe it, that's wonderful." But I can, and I can now get as far as the shopping centre.'* (Barbara: 24.19)

Confidence could be underpinned by an acknowledgement of ability, as described by Barbara.

Leon described help from stroke rehabilitation clinicians as being part of an equal relationship, perhaps making him think more positively about himself, which is likely to help with his confidence.

> '… *they help you to do things, [get dressed] and they don't speak down to you, you know.'* (Lean 40.5)

Conversely, another participant described her family's 'help' as being restrictive:

> *'They don't let me, well, I can't go out of the back door without someone going with me.* (Helen: 11.13)'

In Helen's case the trust in her own ability was not being reinforced by family, and was more likely to have a negative effect on Helen's confidence than a positive effect.

June also described an absence of positive reinforcement from others and tried to access inner strength.

> *'I know in the back of my head there was something telling me you had to try and do these things, because, if you don't June, you'll just sit and vegetate, and life is too important for that.'* (June: 23.17)

Participants indicated positive and negative attitudes that appeared to influence a number of components that relate to confidence. A positive attitude appears to relate to 'trying' a new task or activity. Respect from others may influence engagement rather than avoidance. Negative attitudes appear to be associated with 'not trying,' avoidance and disengagement. Confidence encompasses an 'active' component and being active, the data suggests, is likely to build belief in capability. Acknowledging successes verbally may also reinforce a belief in what participants 'can' as opposed to 'can't' achieve.

2.4 Discussion

The key findings from this study suggest that confidence held deep and significant meaning for all participants as they continued to live their lives following stroke. Participants, who initially found the concept of confidence difficult to define, were better able to articulate how their self-belief was impacted through experiences such as, avoidance, fear, success and achievement, when the narrative of their stories unfolded.

Participants described how their level of self-efficacy influenced their beliefs to be able to do the things they wanted to. This description is closely related to Bandura's self-efficacy theory (Bandura, 1997), a component of social cognition theory (Bandura, 1986).

Loss of confidence was common despite a stroke survivor's level of impairment. The meaning of confidence was linked to re-engagement in self-defined daily activities and social activities. The successful attainment of former roles or new meaningful roles underpinned the meaning of confidence for stroke survivors, whilst confidence in others, and from others, appeared to heavily influence self-beliefs.

Fear was described as a barrier to achieving this re-engagement in doing the things stroke survivors wanted to be able to do. Fear after stroke has been identified in previous studies. Astrom et al (1996) reported that fear of having another stroke contributed to living a life with caution and not realising full potential, and fear of falling was found to lead to a reduction in being confident outside (Schmid and Rittman, 2007). This is congruent with other stroke studies that also found an association between a lack of confidence and not going out (Alaszewski et al., 2006, Hare et al., 2006, Logan et al., 2004). Regardless of the severity of stroke, fear appeared to be a common experience. Avoidance of tasks and activities that were feared were evident in the early stages of stroke. Fear of participating in social activities appeared to be particularly difficult to resolve. Achievement in everyday activities developed slowly and gradually, suggesting confidence is an insidious process of skill building and reliant on successful experiences.

Participants described how their self-confidence had been challenged since their stroke. Participants associated this with a loss of their former identity. Ellis-Hill and Horn (2000) in a relatively small cross sectional comparison study (n=26), identified a change in confidence levels after stroke. The authors reported that stroke survivors perceived themselves as less interested, capable and independent when compared to a healthy control group, indicating a changed and more negative self-concept after stroke. Confidence has been described as being a '*critical component*' of self-esteem (Bembenutty, 2007). One participant suggested that her stroke recovery journey had improved her self-esteem and this had increased her ability to enjoy who she had become. Another suggested he had feelings of being '*worthless*' since his stroke, and this had negatively affected his ability to engage socially. Confidence and self-esteem appear to be related.

Roles were often described as the motivators to re-engage in daily activities. Being a volunteer, a homemaker, a worker, resulted in positive beliefs of being more capable, and appeared to increase the range of activities stroke survivors participated in. Confidence has been described as a predictor of intention and defined as reinforcing capability levels (Poulsen et al., 2014). If engagement in life roles motivates and helps to attain positive beliefs about abilities, then including a role component when measuring confidence should be considered.

Evidence within the data suggested that the influence of others such as partners, family, friends and health care professionals, contributed to a person's self-belief. Both positive and negative influences from others were described in this study as affecting beliefs to succeed. Being confident to fly abroad for the first time, influenced through positive encouragement and support from others, is one example. Conversely discouragement to go out of the back door independently, a condition reinforced by family members, was another. A confidence measure needs a component that examines the influences of others.

This study captured a perception of a real desire to alter self-efficacy beliefs over time. The perception that 'you can if you try hard enough' evolved when participants were given opportunities to practice skills and experienced successful outcomes. The focus on what they were 'able' to achieve, as opposed to what they were 'not able' to achieve appeared to be a significant factor in this process. If confidence is defined as being developmental and incremental, this would need to be considered when designing a measurement tool.

The study of confidence within a stroke domain is still in its infancy. Vealy's (2009) multi variant confidence model, see [**Figure 1**], encompasses psychosocial factors, which might provide a useful framework to measure confidence. This model may not be sufficient on its own, as other aspects of confidence have been identified. However, a similar model could be incorporated into a self-efficacy approach to measuring confidence and tested with a larger stroke population. Adapting this model for use in stroke rehabilitation is perhaps an area that needs further exploration, but could add value to our knowledge as we attempt to find the best ways to improve confidence for stroke survivors.

A strength of this study is that it has explored a novel phenomenon, which has been identified as a priority by stroke survivors. A coherent definition of confidence is distinctly lacking within the stroke literature and the knowledge from this study will contribute to its development. The reflexive process of having a second opinion (JP) during the analysis phase was fundamental in allowing the researcher to be challenged, adding to the interpretation of the findings.

A range, from 18 months to twelve years since the participants had experienced their stroke was represented in this study. Given there was no upper time limit in the exclusion criteria, a wide range of perspectives were included, adding strength to the study findings.

All ten stroke participants consented to participate in the study without hesitation. This may suggest the meaning of confidence after a stroke was an issue that was of interest to stroke survivors. It is suggested that responses to questionnaires are better when the subject holds the interest of the respondents (Bowling, 2014, McColl et al., 2001), and acceptability of a questionnaire is important in the next phase of the study.

A limitation of this study was the participants were all recruited from a randomised trial of outdoor mobility and may not be representative of all stroke patients in the community. However, it is important to accrue knowledge to better understand confidence after stroke.

This study also included purposefully selected participants who verbally indicated a lack of confidence. A longitudinal study would have characterized the temporal components of confidence. Nonetheless, it was important to start examining whether there was a construct of 'confidence' that was meaningful to stroke survivors.

2.5 Conclusion

To conclude, confidence described by participants in this study, is defined as a combination of self-esteem and self-efficacy and input from the environment that influence individual belief in the ability to do, what a stroke survivor wants to do.

The meaning of confidence to stroke survivors appears to encompass a gradual build-up of skills and activity. The successful engagement in everyday activities to establish a positive self-belief and the influence of others, such as family and friends, to reinforce these beliefs were evident. Participation in life roles provided the motivation to try harder to do whatever it is stroke survivors want to do. Conversely, fear resulted in avoidance of activities, and social activities were perceived to be particularly fearful experiences. Avoidance of social situations was an easier, but less satisfying option, leading to less successful outcomes for some stroke survivor's in the longer term.

It is accepted that the definition of confidence is similar to self-efficacy. However, stroke survivors understand the word confidence as an everyday term, and therefore a preference for using confidence as opposed to self-efficacy is a deliberate choice. Participants in this study suggested there was also a link between self-esteem and confidence.

Previous studies have limited a confidence construct to self-efficacy. Participants in this study broadened the perspective by identifying when their social confidence, role confidence and lack of fear develop; this enhances their stroke recovery journey.

The themes identified in this study provided a framework for item generation for the Confidence after Stroke Measure [CaSM].

Chapter Three

3. Development of a Confidence after Stroke Measure: Design and piloting phase

The previous chapters have examined the literature relating to confidence and explored how confidence was described and experienced after a stroke. In this chapter, the findings from the previous chapters will be synthesised to generate the items for the confidence after stroke measure [CaSM]. The initial design and piloting of the CaSM are presented, and the chapter outlines the methodology that underpins questionnaire design, item generation, designing the response format and piloting the questionnaire. Face and content validity of the CaSM are assessed and the strengths and limitations of this process are identified and discussed. The results of this stage of the study, were intended to inform the development and modification of the CaSM, prior to assessing the measure's psychometric properties.

3.1 Background

The researcher was informed by training on the Questionnaire Design, Application and Data Interpretation course at the University of Bristol, in addition to following guidance in the literature, on developing good quality questions and questionnaires (Bowling, 2014, Terwee et al., 2012, DeVellis, 2012, Streiner and Norman, 2008).

Bowling (2014) suggested the planning phase of questionnaire design should not be overlooked and advocated research ideas should be tested on experts in the field. A plan for the development of the confidence after stroke measure was devised and is illustrated in **Figure 2.**

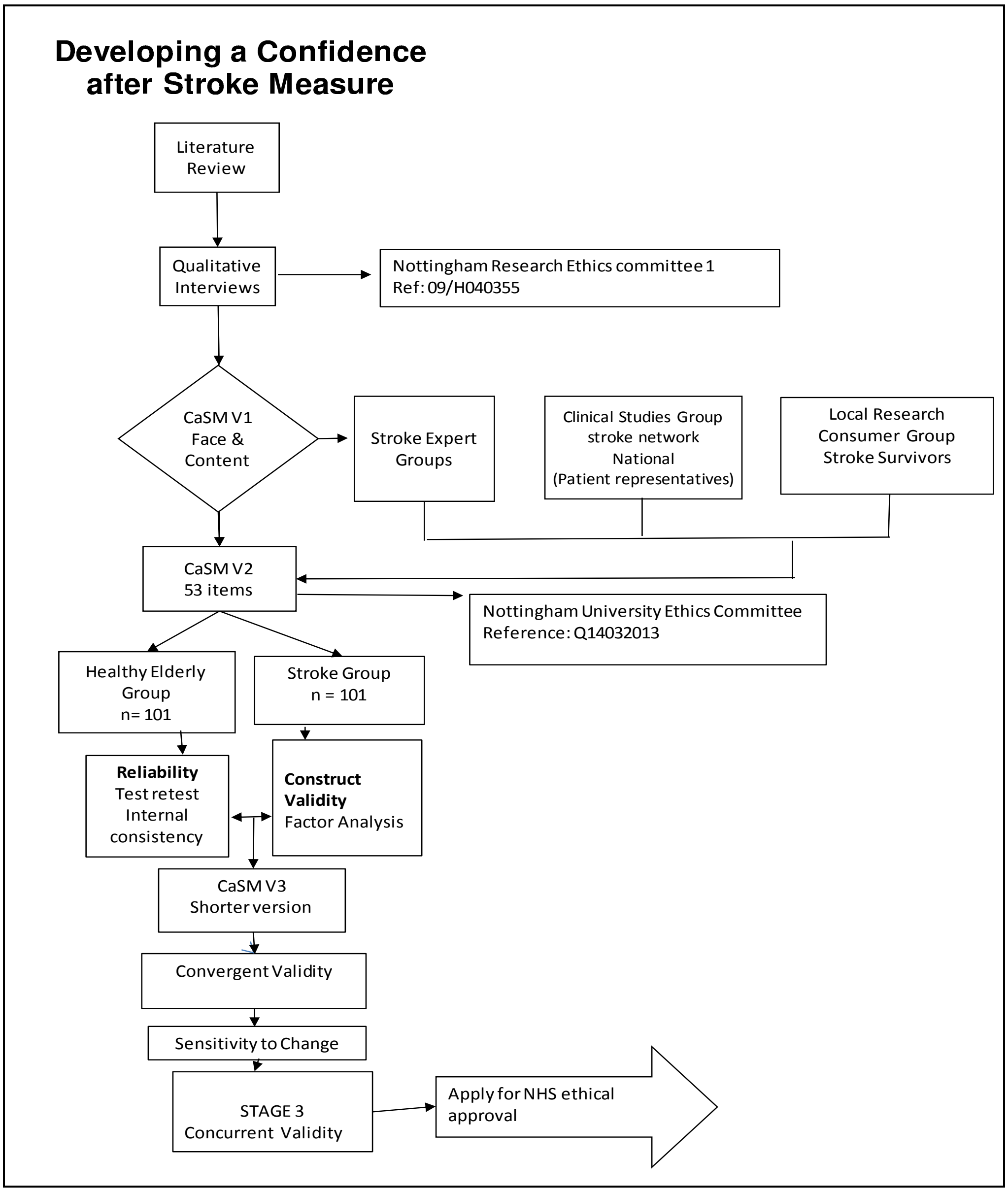


Figure 2: Flow Chart: CaSM Development

Bowling (2014) suggested a mixed method approach, in the initial stages of questionnaire development, is essential. A confidence after stroke questionnaire was designed and piloted with expert groups and key informants using qualitative methods. Quantitative methods, were then undertaken to analyse discrete units on the CaSM that will be compared to other units by using statistical analysis (Maykut and Morehouse, 1994).

Qualitative and quantitative research are based on two different ways of understanding the world, ‘w*ords versus numbers*’ and ‘*discovery versus proof’* (Maykut and Morehouse, 1994). It was felt a qualitative approach would add to the study in the item generation and piloting stage. However, the main component of a measurement study is to assess the validity and reliability of a construct of confidence with a large sample, in order to quantitatively validate its properties.

Creswell and Plano-Clark (2007) described a method of enquiry where qualitative methods inform a quantitative method as a sequential mixed methods approach. The authors suggested the value of using both qualitative and quantitative methods in one study offers more than simply collecting and analysing both kinds of data; the overall strength of the study, when both methods are used in tandem, are seen as being greater than using one single approach (Creswell, 2012).

3.1.1 Face validity

Face validity or appearance validity is described as a subjective assessment of whether a test, in this case the CaSM, measures what it purports to measure (Bowling, 2014). It is a method that superficially examines if on the face of it, the CaSM, for example, ‘looks like’ or appears to be measuring confidence.

3.1.2 Content validity

Content validity is associated with face validity as it is also described as a subjective judgement, typically by experts, that the measure includes all the important and relevant domains that one would expect to see in whatever the measure aims to test (Streiner and Norman, 2008). Items on the CaSM for example, intended to represent a comprehensive assessment of confidence.

3.1.3 Devising the questions

The first step of questionnaire design according to DeVellis (2012) is to generate a large pool of statements that have the potential to be included in a questionnaire. The aim of this process was to get as many ideas relating to confidence that have been highlighted in the literature, and the qualitative study, recorded in statement form. The quality of each statement was not considered important at this stage. DeVellis (2012) suggested, expressing a large number of ideas that is believed to relate to confidence, in preparation for further analysis, is the objective of this process.

It is argued that mild statements extract a lot of agreement, whereas extreme statements may cause offence (DeVellis, 2012). Care was taken to avoid both of these types of statements. Clear wording was a priority during the development of statements (Boynton and Greenhalgh, 2004). Short sentences with key words were more likely to be understood by stroke survivors than complex statements. The aim was also to avoid double-barrelled questions, as recommended by several questionnaire design experts (Bowling, 2014, DeVellis, 2012, Streiner and Norman, 2008).

There appeared to be opposing views in the literature whether or not to include negative statements. Both positive and negative items were included as Devillis (2012) suggested this approach avoids '*acquiescence, affirmation or agreement bias's*' (p83). Babbie (2015) asserted an alternative view, suggesting negative statements should be avoided completely as they can be open to misinterpretation.

Statements were intended to interest stroke survivors, as according to McColl (2001) this is a major factor in response.

3.1.4 Selecting a scale format

Scale and measurement texts were examined prior to selecting a scale format (Babbie, 2015, Bowling, 2014, DeVellis, 2012, Streiner and Norman, 2008). Different scales formats were considered and the advantages and disadvantages of each scale were examined for their use with stroke patients. Consideration, when selecting the scale, was also given to how the collected data would be analysed. Some data, for example, nominal and ordinal, would need the application of a different statistical technique to interval or ratio data (Streiner and Norman, 2008) at the data analysis stage. Statistical tests have different assumptions, and some techniques are more sensitive than others, which needed to be considered as part of the format response selection process.

A Likert response format was chosen because it is reported to be easily understood by respondents. It is argued that a Likert response format takes less time to explain how it should be completed than other response formats, such as a visual analogue format (Hasson and Arnetz, 2005). A Likert response format has been found to be a valid, reliable and responsive measure of attitudes, beliefs and opinion (DeVellis, 2012) in health related research, and is useful in measuring unobservable individual characteristics. The method has been shown to be a quick, efficient and an inexpensive way to collect data by mail, email or when distributing in person.

One statement is presented and respondents are asked to endorse one of the varying levels of agreement ordered from one extreme to the other, (Streiner and Norman, 2008). For example:

I love writing up my PhD

○	○	○	○	○
Strongly Agree	**Agree**	**Neither Agree or Disagree**	**Disagree**	**Strongly Disagree**

However, using Likert response formats have been criticized for not capturing true attitudes (Bowling, 2014). Likert responses typically have five response points after each statement, but ranges of 3 to 7 are common (Streiner and Norman, 2008). Too few options may lead to limited choice for participants, too many and their choice may become difficult. It has been reported that too few options can also affect sensitivity (Hasson and Arnetz, 2005). Bowling (2014) suggested that the removal of the neutral component of a Likert response, may be useful if the investigator wants to force respondents to answer one way or another.

A visual analog scale was also considered, as an appropriate response format. However, visual analog scales are reportedly more time consuming, when explaining or writing instructions for respondents on how to complete the scale, than a Likert response format (Hasson and Arnetz, 2005). It is also argued that a mark on the line may not mean the same, to each respondent (DeVellis, 2012).

To ensure the views of stroke survivors were central to the scale development, it was felt introducing the design and response format, prior to piloting the Confidence after Stroke Measure would be valuable. The NIHR stroke research network primary care clinical studies group was accessed for this purpose. This group provides the infrastructure that enables high-quality clinical research to take place in the NHS, so that patients can benefit from new and better treatments (NIHR, 2015). The clinical studies group comprised of lay members who had experienced a stroke, lay members who had not experienced a stroke, health professionals and researchers working within a primary care context. The investigator was asked to present the confidence study draft protocol at their group meeting. Expert members were invited to ask questions, make suggestions for design and format improvement. Members were asked for their opinion on the potential of using a confidence questionnaire in an NHS clinical setting.

The need for a confidence measure was endorsed by the group. The group suggested confidence was not limited to stroke survivors with physical disabilities. The group also articulated a measure of confidence might be better administered at a time in stroke survivors' recovery when '*they felt better and more functional*'. Self-administered questionnaires were considered favourable. However, cautionary advice about carers helping with the completion of a questionnaire was given, as it was felt this might influence the responses. One member asked a question about 'over confidence' and whether this might be identified in a measure. Different types of closed question response formats were tabled and the Likert scale response method met with the most favourable response from the group. Moreover, the emphasis on keeping the scale short, and including only the minimum amount of questions was advised.

The above section describes the background to the design planning stages of the CaSM, prior to seeking the opinion of three expert groups. The methods used when designing the first version of the CaSM are described below.

3.2 Ethical approval

The study was granted favourable ethical approval on 21st March 2013 from the University of Nottingham, School of Medicine Ethics committee. Reference: Q14032013 CHS Ageing Rehab. See [Appendix 19].

3.3 Methods

The emergent themes from the confidence qualitative study were used as a framework to develop statements. Using the words and paraphrases from participants derived directly from the interviews, was perceived as being the most relevant source to inform a measure of confidence. For example, fear was a theme that underpinned the meaning of confidence;

Table 4 demonstrates examples of statements developed from that theme.

Table 4: Theme: Fear

I do not feel able to walk into a crowded room
Fear of hurting myself stops me doing certain activities
I fear having another stroke
I feel scared to go out
I feel terrified when I try and do something new
I avoid activities even though they are important to me
Fear makes me stop trying to do things
I have a fear of failure

In addition, the themes and measurement sections of the literature review were examined; components assumed to be related to a construct of confidence were extracted and developed into statements.

A reduction of initial statements was undertaken by the research team (JH) (PL) (NL) to ensure clarity, as advocated by DeVellis (2012). The quality of the statements were examined and covertly complex, long and ambiguous statements were removed. Repetitive statements were examined, and decisions to remove or remain in the item pool were made by the researchers. It was felt necessary for some repetitive statements to remain in the item pool, as different ways to capture similar meanings was considered important.

3.4 Results

The first stage of item development resulted in 95 statements being generated, see [Appendix 20]. Forty seven items were negative, forty seven were positive and one was neutral. The second stage resulted in the statements being refined further; see [Appendix 21]. Sixty seven statements were identified for further testing, by expert groups and key informants. Thirty two of the remaining statements were positive, 34 were negative, and one was neutral. Twenty eight statements were removed and these are presented in **Table 5**.

Table 5: Removed Statements

28 Statements removed	
Negative	**Positive**
Theme: Identity	I do not feel the same person since my stroke
	I struggle to recognise who I am
Theme: Fear	I have a fear of falling
	I fear what the future brings
Theme: Roles	
Voluntary roles have helped to regain confidence	
My partner is my rock	
Theme: Doing	
My partner helps me learn new tasks	I do not do the things I used to
My friends encourage me to try new things	I feel I try to do too much too soon
One-one sessions in rehabilitation gives me confidence	Fear of having another stroke stops me from doing things
Theme: Social confidence	
Going out is very important to me	I feel embarrassed in public places
My friends treat me the same as always	People talk to me as if I am daft
It is exciting meeting people I don't know	
Theme: Attitudes and Beliefs	
I like myself	I am not a confident as I was before my stroke
I feel good about the help I got from my stroke team	
There are people I can go to for support	
The stroke group I attend gave me confidence	
Most days I am able to motivate myself	
I reward myself when I have achieved something good	
Other	
I am confident that my environment is suitable	I feel helpless
	Negative feedback in hospital lowered my confidence
	I have never liked mirrors
n=15	n=13

3.5 Discussion

Although there was opposing opinion in the literature, both positive and negative statements were assessed as being appropriate for the CaSM. The pilot testing phase of the CaSM would be used to determine whether or not a statement remained in the questionnaire for further analysis.

Items were removed because there were considered to be too many repetitive statements. Some items were assessed as not having good characteristics, according to measurement texts (Babbie, 2015, Bowling, 2014, Streiner and Norman, 2008) for example, too wordy and not simple enough to enable stroke patient's to respond, or ambiguous. However, there was a large pool of statements to draw from; therefore a reduction of these statements was felt necessary, to make the psychometric assessment of the items a more manageable process. A collaborative process, such as a focus group, a Delphi method or a cognitive interview approach to reduce the items at this stage, may have been a more robust process to avoid bias, than the pragmatic approach that was undertaken. However, the 95 statements were produced as a creative process, deliberately focussing on ideas and wording items with similar meanings in different ways.

3.6 Conclusion

To conclude, the first stage of the item generation process resulted in sixty seven statements, thirty two positive and thirty four negative items and one neutral being selected for piloting with stroke experts and key informants.

3.7 Establishing face and content validity [Expert opinion]

Expert opinion and key informants were invited to contribute at the very early stages of the development of the CaSM, to help establish face and content validity.

Bowling (2014) suggested the views of experts in the field and group discussions, are required to ensure comprehensive coverage of the topic, in this case, confidence after stroke. It is argued that a group of people, who are knowledgeable about the topic, maximises content validity (DeVellis, 2012). The following groups were identified for this purpose.

1. Therapists and researchers with experience in stroke

2. Psychologists experienced in stroke

3. Stroke survivors with experience in stroke research

3.7.1 Methods: Expert group one

A group of therapists and researchers who were known to the researcher and primary supervisor were recruited as experts. The group were invited to participate in the study by email. Background information about the study was included. An attachment of the 67 statements was sent by email, see [Appendix 22] and the email requested comments.

A reply to the email was accepted as implied consent.

3.7.2 Results: Expert group one

Members of expert group one, are described in **Table 6**.

Table 6: Expert Group One

Profession	**Experience in Stroke**	**Work environment**
Professor of Stroke Rehabilitation (OT)	20 years +	University (UK)
Professor of Healthcare Research (OT)	20 years +	University (UK)
Professor of Rehabilitation Research (OT)	20 years +	University and clinical OT (UK)
Associate Professor of Rehabilitation Research (OT)	20 years +	University (UK)
Research Occupational Therapist	2 years	University (UK)
Research Occupational Therapist	2 years	University (UK)
Practice Development (OT) Band 7	5 years	Acute Service (Australia)
Occupational Therapist- Band 7	10 years+	Acute service (UK)
Occupational Therapist- Band 7	10 years+	Rehabilitation clinical service (UK)
Occupational Therapist-Band 7	10 years +	Rehabilitation clinical service (UK)
Occupational Therapist – Band 7	20 years +	Community clinical service (UK)
Occupational Therapist – Band 7	10 years +	Acute clinical service (UK)
Research Occupational Therapist	5 years	University (UK)

3.7.2.1 Content validity - Expert group one

Thirteen out of seventeen therapists and researchers replied to the invitation to participate. Common issues with the wording were identified. The clarity of some words were questioned, such as, '*stigma*' '*activity*' '*accomplish*' '*role*' '*inclined*' '*feedback*.' One therapist suggested the words '*tasks*' and '*goals*' might be considered jargon.

Opinion was given about statements that were considered vague, too complex and ones that were unclear. The statement '*I have good and bad days*' was perceived by five therapists as ambiguous. One member of the group suggested this was reworded to: '*I have more bad days than good days*.'

The examples below illustrate statements that were questioned in terms of whether they relate to the meaning of confidence. Such as:

'*I feel I've been robbed of life'*

'*I have learnt to* do *things differently*'

Other statements were considered leading, such as:

'*People accept me as I am now*.'

Three members of the group made comments on the close association between self-efficacy and confidence, and also the relationship of confidence to personality traits. One questioned whether social confidence might link to a pre-stroke attitude.

One respondent identified a missing component. Statements relating to '*appearance*' and '*the way people look*' or '*inability to do hair*' had not been included. Experience of working with stroke survivors meant this respondent held the belief that these issues could be a component of a confidence construct.

3.7.2.2 Face validity: Expert group one

There was a positive response to the Likert scale format and the visual photographs of thumbs on the questionnaire. Three therapists suggested that it was better to avoid middle neutral component on the Likert scale and force respondents to strongly agree, agree, disagree or strongly disagree. Another therapist advocated the removal of the neutral component, as the image used '*looked like a punch*.'

It was clear from this initial piloting there was a need to re-phrase and re-word some statements, prior to the next piloting phase. The omission of '*appearance*' as a component of self-confidence was noted.

This first piloting stage resulted in sixty seven statements being refined into items on the first draft version of a CaSM questionnaire. Minor changes were made. Poorly constructed statements were corrected. Words that were observed as unclear were changed. Two statements were added as a result of the feedback:

'*I feel other people judge how I look'*

'*I feel comfortable looking in a mirror*'

Due to the positive response of the Likert scale response format, it was decided to use this format when testing the CaSM with the remaining two expert groups. However, a five point response scale was retained in the questionnaire until the feedback from all the expert groups had been received. Statements were revised and 69 items were inserted into a five point Likert scale format for further testing. The items were ordered under the headings of, Self-Confidence, Self-Efficacy, Doing and Team Confidence. Positive and negative items were ordered intermittently throughout the CaSM questionnaire. As DeVellis (2012) suggests, the order of the questions may influence the way people respond.

3.7.3 Methods: Expert group two

A second expert group were selected on their psychological specialism and experience of working with stroke survivors either clinically or in stroke research. This expert group were known to the second supervisor. This group were contacted mid November 2012. Background information about the study and expectations of their role in the study were outlined, and sent via email. See [Appendix 23]. A response to the email was accepted as implied consent.

3.7.4 Results: Expert group two

Members of expert group two are described in **Table 7**.

Table 7: Expert Group Two

Profession	**Work Environment**
Consultant Clinical Neuropsychologist	University (Midlands)
Lecturer in Rehabilitation Psychology	University (Midlands)
Consultant Clinical Psychologist	University (South)
Consultant Clinical Neuropsychologist	Clinical Services (North)
Clinical Psychologist	Clinical Services (Midlands)
Clinical Psychologist in Neuropsychology	Clinical Stroke Service (South)
Clinical Neuropsychologist	Clinical Service (Midlands)
Clinical Neuropsychologist	Clinical Service (New Zealand)

Thirteen psychologists were invited to participant, however one was unavailable. Out of twelve potential participants, eight responses were received.

Psychologists commented on the wording of the items. '*Stigma*' was considered a problem word to use in a questionnaire. Other words that were questioned were '*significant other*' as respondents expressed this was likely to be an issue if the respondent did not have one.

One respondent felt that stroke survivors might find the CaSM easier to read with a prefix of '*Since my stroke…*' at the top of the questionnaire.

The meaning of the following items was questioned in terms of relating to confidence:

> '*I feel confident I know about my stroke*.'

> '*Looking good is a waste of time*.'

One statement was identified as leading:

> '*I do not feel I have enough support*.'

One respondent commented on the repetitiveness of some of the items. The responses suggested the psychologists felt the CaSM had captured a confidence construct.

One psychologist stated:

'The questionnaire captures confidence, but it also captures other concepts, such as, self-esteem, low mood, self-efficacy. I particularly like the social confidence and team confidence items.'

Another respondent suggested that memory loss after a stroke may affect confidence. Raising the question that stroke survivors may not remember what they have achieved.

3.7.4.1 Face validity: Expert group two

There was conflicting opinion on how many response points should be included on the scale. One group member suggested three points would be easier for self-administration than the five point option. Five was thought to be too difficult for someone with cognitive problems. Another felt stroke survivors would find five points easy to administer, and felt the current format would work.

The sub headings were reported as being confusing by a number of respondents. The majority of comments on the visuals were very positive, although three commented on the perspective, as on the questionnaire some images were smaller than others. One group member liked the scale but not the images.

3.7.4.2 Key informants: Group three

Clinician's opinions are useful in questionnaire development as often they are able to observe and identify a trait, such as, low confidence, through clinical experience. However, Streiner and Norman (2008) suggested:

> '*Only those who have it [the construct or variable being measured] can report on the more subjective elements.' p20*

3.7.4.3 Methods

Members of the Stroke Research Partnership Group were invited to take part. This group meet four times a year. The group is jointly chaired by a professor of stroke rehabilitation and a stroke survivor. The group's philosophy specifies that meaningful research can only be achieved by understanding the actual impact caused by stroke. The group are involved in all stages of research projects, from formulating ideas, through to active participation on steering groups of successfully funded studies. It was this expertise that made this group appropriate to contribute to the piloting of the CaSM questionnaire.

3.7.5 Methods: Key informants

Prior to a group meeting scheduled for 26th November 2013, all group members had been sent an A4 summary of the study [Appendix 24] and a draft copy of the CaSM [69] questionnaire; see [Appendix 25]. The researcher (JH) invited members to consent to the digital recording of the planned session.

Thirty minutes was allocated to the CaSM development at a group meeting. The researcher (JH) gave a brief overview and a reminder of the purpose of the study, and the current development stage of the CaSM questionnaire. Similar to the previous two expert groups, members were asked for views and opinions on content, for example, words, sentence structure and whether the group felt the CaSM captured a comprehensive construct of confidence. They were also asked if they felt anything was missing from the questionnaire items. Finally, the group's opinions were sought on the acceptability of the questionnaire, when administered to stroke survivors.

Consent to record the group session was received, however, the digital recorder was faulty and therefore field notes were hand written by the researcher (JH).

3.7.6 Results: Key informants

Key informants are described in **Table 8**.

Table 8: Key Informants

Participant	**Stroke Research Group Member**	**Gender**
R1	Since 2004	Male
R2	Since 2004	Male
R3	Since 2004	Female
R4	Since 2012	Female
R5	Since 2013	Female

Five members out of five available members of the group consented to participate in the group session. Two group members were aphasic, and all members were over the age of 60. Two members had completed the questionnaire. (R2) and (R4). One male respondent (R1) had made written notes on the questionnaire, but had not completed it. One respondent (R3) stated a preference to give verbal feedback at the group meeting, and not complete the questionnaire. Verbal feedback was given by the to the group administrator from another member who was not able to attend the group, but wanted to contribute to the questionnaire development.

3.7.6.1 Content validity: Key informants

The group articulated that they were strong advocates of short sentences and key words and felt this was demonstrated on the CaSM. One group member was dyslexic and felt short sentences made the CaSM easier to read than complex sentences, as these often confuse people.

Three respondents (R1), (R3) and (R4) felt the questionnaire should be developed in order that aphasic patients could complete it. However, it was also articulated (R2) that questionnaires are not for everybody and some stroke survivors may prefer to speak about their issues, rather than write them down.

Items which included the words '*fear*' and '*I can't*' as well as '*losing control*' were identified by the group identified as relating to a loss of confidence. The link between motivation and confidence was discussed, and the group felt this component was reflected in a few items in the questionnaire, such as:

> '*I achieve more when I enjoy what I am doing*.'

> '*I am able to push myself*.'

Two completed questionnaires were examined for missing items. One was fully complete (R4) and the other had one missing item:

> '*I feel alone*.' Additional comment (R2) [*without family*]

Additional comments were written on 41 of the 69 total statements by (R2). This group member suggested that a section for additional comments would add value, in addition to a scaled response. No comments on the number of preferable responses were noted by the group.

Commenting on the meaning of confidence, (R1) suggested it was ‘common sense’ to lose confidence after a stroke, a ‘personal thing’ that may not be a generalisation. A question about whether pre-stroke confidence affects confidence levels after a stroke also arose.

3.7.6.2 Face validity: Key informants

The group liked the visual images of the thumbs. For example, a photograph of one thumb down supported a ‘disagree’ response and one thumb up photograph supported an ‘agree’ response. The stroke members felt that cartoon pictures were age inappropriate and would not have supported these types of images on a questionnaire. However, they felt comfortable with photographic images used on the CaSM and suggested displaying the images at the top of each page, would improve the questionnaire format.

The tick boxes, on the first version of the CaSM [69] were observed as a potential problem for people with perceptual problems. Although aesthetically pleasing, the group felt a simple tick box would be better than a circle with shadowing.

3.8 Discussion

The pre-piloting phase was conducted to establish content and face validity. The development of the CaSM assumed the expert groups of therapists, researchers, clinical psychologists, and stroke survivors had relevant knowledge and experience of a confidence construct following a stroke. This expertise was utilised to assess the item pool for relevance.

A focus group forum, with the first two expert groups might have facilitated a fuller understanding of the rejected and retained items. Having items confirmed or invalidated in a focus group forum, was also considered good practice by Bowling (2014). This method was used with the stroke survivor group. Whilst the focus group process was of benefit, as it produced some rich data, the analysis was not as rigorous as it could have been. A sound qualitative analysis technique, such as, thematic analysis, might have given more confidence that 'cherry picking' reporting of the data, had not occurred.

The first expert group identified a possible omission in a comprehensive understanding of confidence, relating to '*appearance.*' Although there were limited references to this in the literature, two items that related to physical appearance were added, prior to piloting with the second expert group and key informants.

Pallant (2013), argued there is a real art to designing clear and well-written questionnaire items. There was mutual agreement between the three groups, of potentially problematic items. A matrix to illustrate group opinion as advocated by Streiner and Norman (2008) might have aided the analysis process. However, the process did highlight common thoughts on long, complex or unclear items. Nevertheless, caution was applied, and if the consensus of opinion was small, the items were retained for further analysis.

Expert group two commented on the repetition of some items. However, this was a deliberate strategy, to see whether one item with a similar meaning but different wording performed better that another in the psychometric testing as advocated by Streiner and Norman (2008). Many of the repetitive items had been removed at a previous stage.

Expert group two suggested the wording 'Since my stroke….' should be added to the top of the questionnaire, which may add clarity. This was added to the questionnaire.

The images on the questionnaire received a favourable response if the images were adjusted to ensure they were all a similar size. The size was adjusted in the next version, and all the images were printed at the top of each page, as advocated by the experts.

Plain tick boxes were recommended replacing the current tick boxes, as perceptual problems are common after stroke (Edmans and Lincoln, 1987), and improving the appearance of the questionnaire to make it easier for people with perceptual problem to complete is likely to improve the response rate (McColl et al., 2001).

Having an additional comments section on the questionnaire, as suggested by a key informant was rejected at this stage of development. The challenges of analysing responses to open questions in a newly developing questionnaire is likely to be a time consuming process, for both the researcher and the respondents (Bowling, 2014). The meaning could be lost or distorted if the analysis of qualitative data were not completed to a good standard. Open questions may be more useful on a questionnaire that is measuring a commonly measured and established construct.

This Likert response format was endorsed as appropriate and easy to administer by the majority of experts who commented on the format of the CaSM. However, there was mixed opinion on whether the CaSM's responses to each item should offer a 3 point, 4 point, or 5 point option. A similar debate can be found in the literature (Rattray and Jones, 2007) in relation to whether a neutral point should be offered. The authors cited Burn and Grove (1997) who proposed that if a neutral point is removed, it forces respondents to choose a response leading to irritation resulting in an increased non-response bias. However, Streiner and Norman (2008) suggested that it can be difficult to get this neutral statement right, and could easily be misinterpreted by the respondent. One key informant, answered 17 statements out of 69 at the neutral point, and the information gained from this, was perceived as limiting. It was decided, to force people to answer one way or another, as this opinion was strongly advocated in the expert groups.

The four response categories were scored as 4, 3, 2, 1 for positive items, 4 =Strongly Agree; 3=Agree; 2=Disagree; 1=Strongly Disagree and reversed for negative items. This type of scoring is described in many questionnaire design texts (Bowling, 2014, Babbie, 2015) as appropriate.

The scoring system on the CaSM may be a limitation of the design. In common with other scale designers (Bowling, 2014), the CaSM scale uses a single score, for easy analysis and application. However, this is described (Bowling, 2014) as a 'crude' approach as it assumes all the items on the measure have equal value. They may not, therefore weighting each item or calculating each sub scale are alternative approaches that are likely to be more informative. As the CaSM was in its early development phase, a single score was chosen.

The consensus of the stroke experts suggested that the CaSM should be self-administered. A self-administration structured questionnaire distributed by mail [or electronically, if requested] was planned. Bowling (2014) suggested this mode of administration minimizes interview bias. However the use of pre-coded questions can be a disadvantage, as they force people to answer in a way that may not necessarily represent their views. Nevertheless, self-administered surveys, according to Babbie (2015), make large samples feasible and this can be achieved in a relatively short time-frame. Postal questionnaires are low cost, when compared to other methods (Kelley et al., 2003).

Self-administered questionnaires were thought to be an appropriate way to minimise any influences of carers or family member's when completing a measure of confidence. This would minimise observer bias. However, stroke patients would need to have sufficient cognitive ability that would enable them to self-complete a questionnaire, which may exclude some potential respondents. Nonetheless, although cognitive impairment after stroke is common, severe cognitive impairment is not. It was acknowledged that some stroke respondents would require help to complete the CaSM. This procedure may impact on stroke survivor's responses; however, this was balanced with excluding them from participating.

Response rates have been known to be higher when a researcher delivers or completes a questionnaire (Babbie, 2015). The strengths and weaknesses of a self-administration approach were assessed and, on balance, it was considered to be an appropriate method as the questionnaire would have the potential to be more widely used than if face to face contact was required.

The debate in the literature about the use of expert opinion in research was noted, it is argued that if the experts are 'chosen carefully' they are well place to contribute the latest thinking (Streiner and Norman, 2008). It is suggested, there are no 'hard and fast rules' regarding expert judgement (op. cit.), and the use of three separate groups in this study was believed to be valuable in the development of the CaSM. However, in hindsight, a more structured approach, such as, perhaps a method derived from social and cognitive psychology which explored how people approach answering questions on the CaSM, might have improved the quality of the questions at an earlier stage. Thinking aloud interviews, such as talking to the interviewer whilst answering a question on the CaSM and asking the respondent to re-phase the question in their own words, is a method advocated by Streiner and Norman (2008). As respondents complete each item, probing for further information might have added value at this development stage. Further testing of the CaSM might benefit from this type of cognitive interviewing approach, as recommended by Willis (2004).

A focus group conducted using a narrative approach to analysing the data, for example, may have resulted in the addition or removal of items. A focus group could have been facilitated to gather knowledge about specific statements and the group could have been used to debate their relevance for inclusion or exclusion.

Systematic bias inherent in study design can lead to deviations from the true value (Bowling, 2014). Collecting data that is not subjected to bias is difficult. Bowling (2014) reported on 22 different types of bias in health related research (p179-182) and argued most data collected from humans in research, is subject to some form of error or bias. Therefore, the study design aimed to limit the most common types of bias in questionnaire design. For example, the acceptability of the CaSM was tested with stroke survivors at all stages. The design of the CaSM included consideration as to how the items were presented spatially, for example, not too many questions per page, in order to maximise responses. In addition, any images were selected to be clear and adequately supported what was being asked. Careful choice of questions aimed to increase the quality of responses as according to McColl et al (2001), close attention to this detail at the design stage can reduce bias.

3.9 Conclusion

Key informants supported the development of a confidence questionnaire, as they felt loss of confidence after stroke was a common experience, and each member could describe an example of reduced confidence from their personal experience. The group offered further support in the ongoing development of the CaSM. Generally, experts indicated that a comprehensive construct of confidence had been captured in the draft version of the CaSM.

In summary, stroke participants who were members of the NIHR clinical studies group, contributed to the pre-piloting stage, by making suggestions to improve the study protocol at the design stages. The

Nottingham stroke research group, who are stroke survivors, tested the items and design, prior to the CaSM's evaluation with a large sample of stroke survivors.

Expert groups, key informants and the research team collectively reduced the sixty nine statements perceived to be related to a construct of confidence, to fifty three.

A Likert type format with four responses: Strongly Agree (4 points), Agree (3 points), Disagree (2 points) and Strongly Agree (1 point) for positive items and reversed for negative items, was the selected scale format and scoring structure.

Sub headings were removed, and 'Since my stroke...' was added as a heading to the top of the questionnaire. Plain tick boxes replaced original tick boxes. This pre-piloting stage of the design of the CaSM was now complete. Appendix 26, shows the CaSM [53] version. Face and content validity were established, the next development stage, involved testing the psychometric properties of CaSM [53].

Chapter Four

4. Assessing the psychometric properties of the CaSM

4.1 Background

Chapter four introduces the revised 53 item CaSM. The aim of this next stage of the study was to describe the psychometric characteristics of the CaSM and to establish whether it is demonstrating adequate measurement properties. This chapter will describe the study participants and study procedures, the data collection methods and analysis, prior to reporting the results. An interpretation and discussion of the results are presented and the study's limitations are discussed.

The aim of the study was to assess the validity of the CaSM to ensure it was measuring the construct of confidence that it was designed to measure. The aim was also to test the CaSM's reliability; to test that the scores were consistent over time. The study was specifically designed to generate data from questionnaire respondents to enable an analysis of the psychometric properties.

A validation study of a questionnaire should follow a set of basic principles concerning sample size, reliability and construct validity, including the factor structure of the measure (DeVellis, 2012). The COSMIN checklist was developed as a standardised tool, to help questionnaire developers assess the quality of measurement properties on their newly designed questionnaires (Terwee et al., 2012). This checklist informed the design of this study, to ensure the assessment of the CaSM's measurement properties were conducted to a high standard.

There is no clear consensus for sample size needed to validate patient reported outcome measures in the published literature (Dewberry, 2004). However, a ‘rule of thumb’ is that a sample size of 50 to 100 is adequate for a good validation study (Anthoine et al., 2014, Van Voorhis and Morgan, 2007) and adequate for item analysis. However, this would not be large enough to perform an exploratory factor analysis (Comery and Lee, 1992, Nunnally, 1978), which was planned. Guidance for sample sizes when conducting a factor analysis technique are suggested by Comery and Lee (1992); 100 is considered poor, 200 considered fair, 300 considered good, 500 considered very good and 1000 considered excellent. This guidance informed the sample size for the assessment of the CaSM.

Another consideration for the sample size calculation was a subject to item ratio, four respondents to each questionnaire item are typical (Anthoine et al., 2014).

Item total correlations are considered best practice to assess construct validity of the items (Streiner and Norman, 2008). An item total correlation of <0.3 would be defined as indicating poor construct validity, as these items are assumed not to relate to the construct being measured by the other items (Bowling, 2014). A multivariate factor analysis is considered essential in the design of a new questionnaire to identify items that cluster into a component (Williams et al., 2010). Exploratory factor analysis, such as, a principal component analysis (PCA) is advised when a theoretical construct (Williams et al., 2010), such as confidence, is being tested. Principal component analysis is also considered useful in guiding item reduction. This may help to lessen response bias by reducing the number of items (Babbie, 2015) and prevent response fatigue.

The reliability of a scale is the extent to which the scale (CaSM) measures consistently and is free from random error (Pallant, 2013, Tavakol and Dennick, 2011). In order for the questionnaire to be reliable, it is important to measure the degree to which the items on a questionnaire interrelate, a procedure referred to as internal consistency (Streiner and Norman, 2008). A Cronbach alpha coefficient is recommended to assess internal consistency (DeVellis, 2012, Tavakol and Dennick, 2011, Field, 2009). Expressed as a number between 0 and 1, the higher the value, the greater the extent to which all the items in the test measure the same construct (Tavakol and Dennick, 2011).

The Cronbach alpha coefficient of a scale should be above 0.7 (Kline, 1999), but values above 0.8 are considered preferable (Pallant, 2013). However, values above 0.7 are accepted for psychological constructs, due to the diversity of the constructs being measured (Kline, 1999).

Test-retest reliability was also evaluated to check the temporal stability of the CaSM (Field, 2009). The time interval between assessments is considered key. Too long an interval and participants scores may have changed, as a result of changes in the construct, too short and participants may have remembered what they previously answered (Terwee et al., 2012).

The data analysis procedures were planned for a Likert scale CaSM. A Likert type scale is yields ordinal data, therefore the type of statistical tests that can be used are limited (Pallant, 2013). Non-parametric tests are generally advised for Likert scale responses (Pallant, 2013, Field, 2009), such as Spearman's rank correlation.

DeVellis (2012) suggested items on a Likert scale that have very mild statements, educe a lot of agreement. Since researchers often caution against using offensive statements (DeVellis, 2012), there is a tendency to include more of these mildly worded items. If the majority of respondents, for example >85%, are in agreement (or disagreement) with an individual item, then the value of such information is likely to be limited. Steiner and Norman (2008) suggested such items 'detract' from a scale. Not adding value, whilst making a questionnaire unnecessarily longer, is considered a wasteful use of resources (Tavakol and Dennick, 2011) and such items were observed for removal.

4.2 Methods

4.2.1 Ethical approval

The study was granted favourable ethical approval on 21st March 2013 from the University of Nottingham, School of Medicine, Ethics Committee. Reference: Q14032013. See [Appendix 19].

4.2.2 Participants

To establish the ability of the CaSM to discriminate between stroke related issues and non-stroke related issues the CaSM was administered to a stroke group and a healthy elderly group, described below.

4.2.3 Recruitment: Stroke group

Stroke participants were recruited from a variety of sources. The investigator contacted stroke organisations and obtained permission to recruit from the Stroke Association and Fighting Strokes via their websites. The Stroke Association provided a link to the study. >Home Page>Research>Get involved with research>Project information, see [Appendix 27], and a live tab with a request for potential participants to complete a questionnaire, was displayed on the web pages. A link to this information were also sent to the Stroke Association's Twitter© account. The Stroke Association published the information in Stroke News, which has a national distribution. A similar recruitment strategy was applied to the Fighting Strokes organisation. Details of the study was provided and displayed on the Fighting Strokes Facebook © page. The researcher's contact telephone numbers and email address were included and potential participants were invited to contact the researcher.

The researcher telephoned the lead names of stroke clubs across the East Midlands (including an aphasia conversation group), where the contact information was publically available. Brief information about the study was given, and the researcher asked for an invitation to attend a group meeting to recruit potentially interested participants. Wherever possible the researcher visited groups to discuss the study.

The researcher telephoned a local retirement village, and was invited to the 'village' reception area to recruit to the study. Professional contacts of the research team identified potential participants, who had previously expressed an interest in taking part in future research studies. In addition, the researcher contacted the organisers of two lay stroke conferences, one local and one national, and was invited to talk about the study, to give stroke survivors the opportunity to participate.

4.2.4 Recruitment: Healthy elderly group

A healthy elderly group (60+) was chosen, as it was assumed as people were declining in age, their confidence may also be on the decline. Therefore they were likely to have some of issues regarding reduced confidence levels as stroke survivors. However, the hypothesis assumed this group would demonstrate a difference in confidence levels when compared to a stroke group. Every effort was made to recruit a diverse sample, in terms of geographic distribution and gender, for example. The exclusion criteria, was they had not experienced a stroke, as there was no other exclusion criteria. This group were also recruited from a variety of sources. The investigator used a search engine, to identify potential leisure and social groups around the UK. Social groups, such as, luncheon clubs, sewing groups, photography groups and University of the 3rd Age were identified as potential sources of recruitment. A retirement village was contacted by the researcher, who was invited to potentially recruit to the study in the 'village' reception area. Leisure groups, such as badminton and tennis clubs, bowling clubs and walking groups for the 60+ age group were identified. A walking website 'Go Walking' displayed the study information on their national website. Contacts known to the researcher, such as, parents of friends, were also invited to participate, if they were over the age of 60.

Cluster sampling procedures, were conducted when a face to face contact meeting was not feasible due to geographical distances. Groups were identified, as described above, and the researcher telephoned the lead organiser of the targeted group or organisation and explained the study to them. Typically, these were social and leisure groups for the healthy elderly people.

4.2.5 Procedures

Participants who contacted the researcher for more information, were mailed or emailed a confidence study pack, which included:

- A letter thanking potential participants for their interest as shown in [Appendix 28]
- A demographic information and contact details sheet as shown in [Appendix 29]
- A participant's information sheet providing a brief summary of the study [Appendix 30]
- CaSM (Confidence after Stroke Measure) [Appendix 26]
- Stroke Self-Efficacy Questionnaire (Jones et al., 2008) see, [Appendix 31]
- A briefing sheet of how to complete both questionnaires see, [Appendix 32]
- A stamped addressed return envelope, addressed to the researcher

For those who were recruited from local groups, the research packs described above were taken to each group visited and where a potential participant expressed an interest they were given a pack by the researcher. For participants identified in groups where the researcher could not visit, the lead member of the group was sent an appropriate number of packs relative to the size of the group. In general five to ten packs were sent. The lead for that group invited their members to participant in the study and ‘study packs’ were distributed.

Consent was in accordance with the Good Clinical Practice guidance and the researcher was appropriately GCP trained, see [Appendix 4]. The decision regarding participation in the study was clearly described as entirely voluntary and the participants were informed that they could withdraw from the study at any time. Implied consent was accepted when two questionnaires (CaSM & SSEQ) and a demographic contact sheet were returned to the researcher. Participants were asked to self-complete two questionnaires, with help if required.

Recruitment stopped once the target number of the self-completed questionnaires were returned.

4.2.6 Measures

Demographic Information was collected on a contact sheet. Participant’s name, gender, date of birth, address, telephone number and email address was collected. The question ‘Have you ever experienced a stroke?’ yes/no, was included. If participants answered ‘yes’ this response directed the participant to a further question. ‘Date of last stroke’ and ‘tick if estimated.’ This question determined to which group each participant was allocated. The researcher checked the date of birth on the contact sheet to determine whether participants in the healthy elderly group were over the age of 60 years, and the stroke group were over the age of 18 years.

Stroke Self-Efficacy Questionnaire (SSEQ)

The 13 item Stroke Self-Efficacy Questionnaire (SSEQ) (Jones et al., 2008) was used to assess the convergent validity of the CaSM, [Appendix 31]. Items on the SSEQ are rated 'certainty' on a 10 point scale where 0 represents, 'not at all confident', and 10 represents, 'very confident'. The minimum score is 0 and the maximum score is 130.

CaSM

The 53 item CaSM items were scored 1,2,3,4 for the positive items and 4,3,2,1 for the negative items. The minimum score 53, indicated low confidence and the maximum score of 212 indicated high confidence.

Once returned questionnaires were received, the demographic information with contact details was separated from the questionnaires and stored in a fire proof lockable filing cabinet, separate from the rest of the study data.

A study ID number was issued, and a password protected Microsoft Excel (2010) © database, was designed to monitor recruitment and store study information, such as, date of returned questionnaire, date of birth, group allocation, date of stroke (if applicable). The purpose of this database was intended to reduce administration error by recording pivotal study information. This included recording when questionnaires were returned, when reminders were administered, dates for the test retest procedure, colour coding the text helped with this administration.

Test-retest

Test-retest reliability was assessed. The CaSM's temporal stability was undertaken. The CASM was administered to the same sample at two separate time points. The time when the first questionnaire was received by the investigator was recorded. Four to six weeks later, a second copy of the CASM was mailed to all respondents with a stamped addressed return envelope addressed to the investigator was enclosed. The time frame was selected on the basis that is was likely to be long enough that the respondents would not remember their responses, but short enough that their confidence was unlikely to change.

4.2.7 Statistical procedures

The questionnaire data were stored on a second database, using SPSS © version 22. The researcher input all the data from May 2013 until March 2014. Once this process was undertaken, the data were cleaned and checked first by the researcher, and secondly 10% of all data records were randomly selected by a research administrator employed by the university (GA).

4.2.8 Sample size

The decision on sample size was made on the basis that 'the larger the better' combined with the study's cost and time limitations, an a priori sample size target of *n*=200 was considered adequate.

4.2.9 Missing items

Item redundancy was established by using descriptive statistics, to examine missing values. Items with a high proportion of missing values were identified for potential removal, as this suggests they are not acceptable to respondents. Those with >85 that either endorsed or rejected an item were viewed as having limited value, therefore were removed.

However, when a questionnaire had one or two random items of missing data, replacement values from a previous data collection phase (test retest), were used. These scores were inputted and treated as if the true value had been observed. This is typically referred to as last observation carried forward (LOCF). If items were missing from the initial questionnaire, but were available from the subsequent collection phase (test retest) these values were used as replacements.

4.2.9.1 Item reduction

Item reduction techniques were conducted to identify items deemed appropriate to eliminate.

A Chi squared test for independence was the technique used to compare the responses of two groups, stroke and healthy elderly. Those items which did not differ in the distribution of the responses were considered for removal. Some authors (Pallant, 2013, Hilton, 2005) have suggested that when a Chi squared is used with a two by two table, the Chi squared value is overestimated, therefore a Yates Continuity Correction was used to compensate for any over estimation. A Fisher Exact Test was used on items where the minimum expected cell frequency was <5 and therefore violating the assumptions of the Chi squared, as recommended by Field (2009).

4.2.10 Reliability

Internal consistency, the degree to which the items measured consistently was calculated using Cronbach's Alpha (Cronbach, 1951).

A test-retest procedure for the purpose of establishing the CaSM's temporal stability was undertaken using a Spearman's Rank Order correlation and the Wilcoxon repeated measure test.

4.2.11 Construct validity

Item total correlations were calculated and those >0.3, were considered acceptable CaSM items to indicate homogeneity within the measure. A Mann-Whitney U Test was used to test the differences between the stroke group and the healthy elderly group on the CaSM.

4.2.12 Factor analysis

The underlying factor structure of the CaSM was examined using a five stage framework proposed by Williams et al (2010). The data were screened to ensure it was appropriate to conduct a factor analysis technique. An adequate sample size >200 and the strength of the intercorrelations among the CaSM items were examined. Inspecting the correlation matrix for correlation coefficients of >±0.3 was undertaken to ensure the data were deemed suitable for a principal component analysis.

To help decide how many components to extract an oblique rotation method was conducted and repeated in an attempt to derive the best solution. Kaiser's criteria (eigenvalue >1 rule) (Kaiser, 1970), Scree test (Cattell, 1966), cumulative percent of variance extracted and parallel analysis (Horn, 1965) were considered to inform the component structure.

The final stage of the principal components analysis involved the researcher attributing labels to the final component structure.

4.2.13 Gender and age differences

Differences in responses by age were assessed by correlating age with the total score on the CaSM. Gender difference were be calculated by conducting a Mann-Whitney U Test to detect any different responses between men and women. The CaSM was not designed to be age or gender specific, therefore items which demonstrated significant differences in responses, as a result of age or gender, would need to be considered for exclusion from the CaSM.

4.2.14 Convergent validity

Convergent validity was assessed by correlating the total score of the CaSM with a measure that was assumed to be measuring a similar construct, the Stroke self-efficacy questionnaire [SSEQ] (Jones et al., 2008), using a Spearman's Rank Order Correlation (*r*s).

4.3 Results

4.3.1 Participants

Two hundred and two participants were recruited for this study 92 (45.5%) men and 110 (54.5%) women, with a mean age of 70.07 years (SD = 13.30; range = 22-97 years). The distribution of age, gender, geographical distribution of participants and time since participant's last stroke are shown in **Table 9**.

Table 9: Characteristics of Participants

Stroke Group **n= 101**			**Health Elderly** **n= 101**	
Years			**Years**	
	Mean	**SD**	**Mean**	**SD**
Age	63.6	14.4	76.5	7.9
Time since stroke	5.87	7.98	Not applicable	Not applicable
	Number	**%**	**Number**	**%**
Number of Men	48	47.5	44	43.6
Number of Women	53	52.5	57	56.4
Distribution				
England	97	96	100	99
Scotland	2	2	1	1
Wales	2	2	0	0

Respondents self-reported whether they had experienced a stroke, and on this basis were allocated to either the 'stroke' group or the 'healthy elderly group' **Table 10** and **Table 11** show where participants were recruited from.

4.3.2 Recruitment

Out of the 270 questionnaires sent, 202 were returned between May 2013 and January 2014, none were excluded from the analysis, as all the healthy elderly participants were over the age of 60 years and all stroke participants were over the age of 18 years.

Table 10: Healthy Elderly Respondents

	n	**%**	**Geographical Area**
Luncheon Clubs	18	18	Nottinghamshire, Lincolnshire, Co. Durham
Retirement Village	15	14	Nottinghamshire
Walking Groups	11	11	Leicestershire, Lincolnshire, South Wales, Warwickshire, Cumbria, Yorkshire, Hampshire, Lancashire
University of 3rd Age	11	11	Nottinghamshire, Leicestershire, Buckinghamshire
University Research Contacts	10	10	Nottinghamshire, Yorkshire
Tennis Club 60+ Group	8	8	Nottinghamshire
Bowling Club	8	8	Nottinghamshire
Church Friendship Group	8	8	Nottinghamshire
Personal Contacts	5	5	Yorkshire, Nottinghamshire
Stroke Clubs/Lay Conference	3	3	Nottinghamshire, Derbyshire
Care group	2	2	Nottinghamshire
Dickens Society	1	1	Nottinghamshire
Badminton Group 60 plus	1	1	Cumbria

Table 11: Stroke Respondents

Stroke	***n***	**%**	**Geographical Area**
Stroke Clubs	20	19	Nottinghamshire
Stroke Association Lay Conference	15	15	Cheshire, Lancashire, Shropshire, Dorset, Staffordshire, Lincolnshire, Cumbria, Nottinghamshire, Wiltshire, Co. Durham, Leicestershire, North Shields
Aphasia Conversation Group	13	13	Northamptonshire
University Research Contacts	12	12	Nottinghamshire, Co. Durham
Stroke news	9	9	Gwent, Co. Durham, Lancashire, Derbyshire, Hertfordshire, West Sussex, Nottinghamshire, Lincolnshire
Larkhill Retirement Village	6	6	Nottinghamshire
Fighting Strokes Web Site	5	5	Kent, Lancashire, Cheshire
Stroke Association	4	4	Scotland, Lincolnshire, Wiltshire
Known to Colleagues	3	3	West Yorkshire, Northamptonshire, Nottinghamshire
Care group	4	4	Nottinghamshire
Stroke Clubs	3	3	Derbyshire
Lay Conference	2	2	Nottinghamshire
Patient Representatives	2	2	London
Stroke club	1	1	Cirencester
Poster	1	1	Nottinghamshire
UKSF	1	1	Yorkshire

4.3.3 CASM: Frequency of item endorsement

Frequency tables were produced to show the distribution of responses to each item on the CaSM.

Items with a frequency of respondents endorsing or rejecting any one response category as >85% in both groups was selected as indicating an item for potential elimination from the CaSM, see **Table 12**.

Table 12: Distribution of Responses on Items of the CaSM

		Healthy elderly				**Stroke**						**Chi^2**
Item	**Question**	**SA** *n*	**A** *n*	**D** *n*	**SD** *n*	**SA** *n*	**A** *n*	**D** *n*	**SD** *n*	**>85 H/E**	**>85 Stroke**	***P* Values**
1	Even though I practice tasks, I don't improve	2	15	43	41	9	23	57	11			.02
2	I think positively about myself	47	42	6	6	26	41	27	6	89		.01
3	I feel robbed of my identity	2	5	21	72	16	30	30	24	93		.01
4	I feel alone	4	7	31	59	14	26	38	22	90		.01
5	I am afraid of having another stroke	0	0	0	0	27	34	30	9			n/a
6	Other people would say I was confident	40	53	6	0	31	48	17	4			.01
7	I feel less capable	1	25	31	43	34	39	18	9			.01
8	I feel I can push myself to achieve	37	52	8	4	23	48	25	4	89		.01
9	**I am confident in my own home**	**74**	**25**	**2**	**0**	**41**	**51**	**7**	**1**	**99**	**92**	**.10 cc**
10	I feel comfortable looking in a mirror	50	45	5	1	30	49	15	6	95		.01

		Healthy elderly				Stroke						Chi^2
Item	**Question**	**SA** *n*	**A** *n*	**D** *n*	**SD** *n*	**SA** *n*	**A** *n*	**D** *n*	**SD** *n*	**>85** **H/E**	**>85** **Stroke**	***P*** **Values**
11	I can usually handle what comes my way	48	50	3	0	19	46	28	7	98		.01
12	I do not have much to be proud of	0	8	36	57	5	28	40	27	93		.01
13	I believe I am a failure	2	1	24	74	3	16	45	36	98		.01
14	It’s hard for me to achieve my goals	2	22	40	37	18	46	26	10			.01
15	It is difficult to handle situations that are unplanned	0	23	38	40	17	39	32	12			.01
16	My attitude helps me to be confident	44	48	3	6	25	53	19	3			.02
17	I avoid important everyday tasks	2	11	32	56	6	27	47	20			.01
18	I believe I can achieve what I want to	36	56	7	2	17	43	35	5			.01
19	I am able to do things as well as most people	40	50	10	1	7	37	38	18	90		.01
20	I worry I am not safe to use electrical equipment	2	8	32	59	7	21	42	30	91		.01

		Healthy elderly				**Stroke**						**Chi^2**
Item	**Question**	**SA** *n*	**A** *n*	**D** *n*	**SD** *n*	**SA** *n*	**A** *n*	**D** *n*	**SD** *n*	**>85 H/E**	**>85 Stroke**	***P* Values**
21	I have a fear of failure	2	17	34	48	15	28	40	17			.01
22	I achieve more when I enjoy what I am doing	58	38	5	0	17	40	28	15	96		.055
23	I am able to push myself	48	50	2	1	23	61	16	0	98		.01
24	I believe you can do anything if you try hard enough	29	56	13	3	26	44	26	5	85		.03
25	I believe I have inner strength	35	61	4	1	29	55	14	2	96		.03
26	I manage to solve problems if I try hard enough	38	58	5	0	23	56	17	4	96		.01
27	I do not feel comfortable in public places	3	10	39	49	16	29	40	15	88		.01
28	I feel home is the only place where I am safe	3	9	35	54	11	26	44	19	89		.01
29	**I am confident enough to leave the house**	**74**	**24**	**2**	**1**	**47**	**46**	**6**	**1**	**98**	**93**	**.32 cc**
30	I am confident enough to leave the house	2	10	43	46	16	24	38	22	89		.01

		Healthy elderly				Stroke						Chi^2
Item	**Question**	**SA** *n*	**A** *n*	**D** *n*	**SD** *n*	**SA** *n*	**A** *n*	**D** *n*	**SD** *n*	**>85** **H/E**	**>85** **Stroke**	***P*** **Values**
31	I feel terrified meeting people I don't know	1	1	41	58	4	21	47	28	99		.01
32	I do not feel able to attend social events	1	2	37	61	7	18	49	26	98		.01
33	Other people's comments knock my confidence	0	22	41	38	14	38	30	18			.01
34	I worry I will fall and hurt myself when I am out	7	18	33	43	20	28	32	20			.01
35	I feel I am not very good company	1	16	47	36	14	30	44	12			.01
36	I feel other people overprotect me	3	12	37	49	13	36	36	15	86		.01
37	I don't like other people seeing me using aids, such as, walking aids	3	10	31	57	14	22	31	33	88		.01
38	I feel other people judge how I look	1	27	34	38	13	24	43	20			.21
39	It bothers me that I can't do things like I used to	8	40	35	18	48	29	16	7			.01

		Healthy elderly				**Stroke**						**Chi^2**
Item	**Question**	**SA** *n*	**A** *n*	**D** *n*	**SD** *n*	**SA** *n*	**A** *n*	**D** *n*	**SD** *n*	**>85 H/E**	**>85 Stroke**	***P* Values**
40	I have learnt to do things differently since my stroke	0	0	0	0	34	61	3	2		95	N/A
41	I do well when I do a bit at a time	24	57	13	7	35	61	4	0		96	.01
42	I feel scared to go out	2	2	24	73	3	14	45	38	97		.01
43	**I am able to do things at my own pace**	**44**	**50**	**2**	**5**	**27**	**69**	**3**	**1**	**94**	**96**	.55
44	It's hard to find a hobby that I value	2	11	33	55	19	28	35	18	88		.01
45	I feel terrified when I try to do something new	2	7	42	50	8	32	39	20	92		.01
46	I get frustrated when I can't do as much as I want to	11	57	22	11	55	37	6	1		92	.01
47	I get excited about learning new things	29	55	14	3	20	50	24	6			.04
48	My family/friends encourage me to do things	34	58	7	2	25	59	13	3	92		.19
49	Other people push me to achieve more than I think I can	4	15	57	25	14	38	38	10			.01

		Healthy elderly				**Stroke**						**Chi^2**
Item	**Question**	**SA** *n*	**A** *n*	**D** *n*	**SD** *n*	**SA** *n*	**A** *n*	**D** *n*	**SD** *n*	**>85** **H/E**	**>85** **Stroke**	***P*** **Values**
50	**I get a lot of positive encouragement from my family/friends/neighbours**	**35**	**53**	**10**	**3**	**35**	**53**	**8**	**4**	**88**	**88**	.01
51	I am encouraged by my health professionals	15	52	21	5	20	55	15	7			**.23 cc**
52	I feel people speak down to me	1	8	32	60	10	22	52	16	92		.01
53	**When people tell me I've done well it makes me feel more confident**	**30**	**63**	**7**	**1**	**35**	**51**	**12**	**1**	**96**	**86**	.25

SA = Strongly Agree A = Agree D = Disagree SD = Strongly Disagree

CC = Continuity Correction: Yates Continuity Correction is identified in bold, with the letters CC in the last column

The items where the frequency of agreement/disagreement were greater than 85% in both groups and were therefore identified for removal were 9, 29, 43, 50 and 53 see **Table 12**.

The response distribution on item 40 was high for the stroke group, but the item was missed by the entire healthy elderly group, and was also considered for removal. Level of endorsement for the stroke group was also high in items 41 and 46 but not for the healthy elderly. See **Table 12.**

The frequency of responses was compared between the two groups. A Chi squared test for independence was used. **Table 12** shows the Chi^2 results and where the Yates Continuity Correction was used, this is identified in bold and with the letters CC, in the last column. Refer to **Table 12**.

Items which demonstrated a statistically significant difference were considered appropriate to remain in the CaSM. Items that were not demonstrating a statistically significant difference needed to be further evaluated.

As the 'minimum expected cell frequency' was <5, in items 9, 29, 51, and 53, a Fisher Exact Test was computed. Comparisons of the frequency of responses between groups, that were not found to be significantly significant, are shown in **Table 13**.

Table 13: Stroke Group Vs Healthy Elderly Group

Item		Ch2 >.05	Fishers Exact p =>.05	Yates Continuity Correction p =>.05
9	I am confident in my own home	N/A	.06	.10
22	I achieve more when I enjoy what I am doing	.38	.41	.55
29	I am confident enough to leave the house	N/A	.21	.32
38	I feel other people judge how I look	.16	.18	.21
43	I am able to do things at my own pace	.36	.55	.54
48	My family/friends encourage me to do things	.13	.14	.19
51	I am encouraged by my health professionals	N/A	.22	.23
53	When people tell me I've done well it makes me feel more confident	N/A	.18	.25

On the basis of this analysis, 12 items were considered for removal. These are 9, 22, 29, 38, 40, 41, 43, 46, 48, 50, 51, and 53.

Items 9, 29, 43, 50, 53 demonstrated high frequency responses in one response category from respondents in both groups, as illustrated in **Table 12**. In addition, items 9, 29, 43 and 53 did not show a statistically significant difference between stroke participants and healthy controls when the Ch^2/Fisher exact tests were computed. Items 43 and 53 were removed. Items 9 and 29 however, appeared to relate to the meaning of confidence of stroke survivors in the interview study (Horne et al., 2014) and going outside was linked to confidence in the literature review. These items remained in for further analysis.

Item 50 demonstrated a high distribution of responses in one category in both groups. Item 48 had a similar meaning in the questionnaire and demonstrated a more balanced frequency of responses, therefore item 50 was considered redundant. The Ch^2 result suggested a minimal difference between the stroke group and healthy elderly responses for item 22. This item detracted from the core construct of confidence and was removed.

At the end of this process items 22, 43, 50 and 53 were removed. Items 9, 29, 38, 40, 41, 46, 48 and 51, were considered for further analysis at this stage.

4.3.4 Missing values

The number of missing values on each item of the questionnaire was recorded. Results are shown in **Table 14**.

	n	Mean	Std Deviation	Missing		No. of Extremes	
				Count	Percent	Low	High
Item1	201	2.96	.82	0	.0	11	0
Item2	201	3.08	.87	0	.0	12	0
Item3	200	3.13	1.00	1	.5	0	0
Item4	201	3.06	.96	0	.0	0	0
Item5	100	2.21	.95	101	50.2	0	0
Item6	200	3.20	.72	1	.5	4	0
Item7	198	2.60	1.06	3	1.5	0	0
Item8	200	3.05	.79	1	.5	8	0
Item9	201	3.52	.61	0	.0	1	0
Item10	201	3.23	.77	0	.0	7	0
Item11	201	3.11	.79	0	.0	7	0
Item12	201	3.19	.81	0	.0	5	0
Item13	201	3.41	.75	0	.0	5	0
Item14	201	2.70	.94	0	.0	0	0
Item15	201	2.78	.93	0	.0	0	0
Item16	201	3.14	.78	0	.0	9	0
Item17	201	3.11	.85	0	.0	8	0
Item18	201	2.99	.78	0	.0	7	0
Item19	201	2.81	.90	0	.0	0	0
Item20	201	3.21	.85	0	.0	9	0
Item21	201	2.93	.94	0	.0	0	0
Item22	201	3.40	.66	0	.0	3	0
Item23	201	3.25	.63	0	.0	1	0
Item24	201	3.00	.80	0	.0	9	0
Item25	200	3.21	.65	1	.5	3	0
Item26	201	3.15	.69	0	.0	4	0
Item27	201	2.94	.94	0	.0	0	0
Item28	201	3.05	.90	0	.0	14	0
Item29	201	3.54	.62	0	.0	2	0
Item30	201	2.99	.93	0	.0	0	0
Item31	200	3.27	.75	1	.5	5	0
Item32	201	3.25	.79	0	.0	8	0
Item33	200	2.83	.91	1	.5	0	0
Item34	201	2.82	1.02	0	.0	0	0
Item35	200	2.86	.87	1	.5	0	0
Item36	201	2.92	.93	0	.0	0	0
Item37	182	3.03	.97	19	9.5	0	0
Item38	199	2.89	.91	2	1.0	0	0
Item39	201	2.22	.99	0	.0	0	0
Item40	100	3.27	.62	101	50.2	2	0
Item41	201	3.14	.71	0	.0	7	0
Item42	201	3.42	.74	0	.0	5	0
Item43	201	3.27	.65	0	.0	6	0
Item44	201	2.96	.99	0	.0	0	0
Item45	200	3.06	.87	1	.5	10	0
Item46	201	2.41	6.90	0	.0	0	13
Item47	201	2.97	.78	0	.0	0	0
Item48	201	3.14	.69	0	.0	5	0
Item49	201	2.27	.85	0	.0	0	0
Item50	201	3.19	.74	0	.0	7	0
Item51	190	2.87	.78	11	5.5	0	0
Item52	201	3.12	.86	0	.0	11	0
Item53	200	3.21	.65	1	.5	2	0

Table 14: Missing Values

The frequency of missing values on the CaSM was low (2.29%). Items 5 and 40 had high levels of missing data, ie >50%. Both questions referred to stroke, and respondents who had not had a stroke did not complete these items. Therefore, items 5 and 40 were removed.

Item 51: '*I am encouraged by my health professionals*' had 11 (5%) missing values, eight (8%) from the healthy elderly group and three (3%) from the stroke group. As item 51 also showed no significance difference of frequency of responses between groups, this item was also removed.

Item 37, '*I don't like other people seeing me using aids, such as, walking aids'* had missing values for 13 (13%) in the healthy elderly group and 6 (6%) of stroke group and was removed.

Once items 5, 40, 51, 37 were removed, there were (.012%) of missing responses.

The removal of items 5, 22, 37, 40, 43, 50, 51 and 53 reduced the questionnaire from 53 items to 45 items. Further psychometric testing was undertaken on the 45 items.

4.3.5 Reliability of the CaSM [45 items]

4.3.5.1 Internal consistency

The Cronbach Alpha score of the 45 item CaSM are shown in **Table 15**.

Table 15: Cronbach alpha by Group

Group		**Cronbach's Alpha**
Stroke	*n*=101	.93
Heathy Elderly	*n*=101	.93
All respondents	*n*=202	.95

The results indicate very good internal consistency, for the healthy elderly and stroke groups as the values are greater than 0.9 (0-1). However there may be some item redundancy.

4.3.5.2 Item total correlations

The item total-correlation coefficient values were calculated and are shown in **Table 16**. Items with values less than ±0.3 were examined for potential removal.

Table 16: Item-total Correlations

		Item-total correlations	
	Item	**Healthy Elderly**	**Stroke**
1	Even though I practice tasks, I don't improve	.48	.38
2	I think positively about myself	.33	.62
3	I feel robbed of my identity	.39	.47
4	I feel alone	.52	.56
6	Other people would say I was confident	.45	.29
7	I feel less capable	.58	.42
8	I feel I can push myself to achieve	.34	.49
9	I am confident in my own home	.66	.43
10	I feel comfortable looking in a mirror	.50	.44
11	I can usually handle what comes my way	.68	.61
12	I do not have much to be proud of	.69	.59
13	I believe I am a failure	.56	.60
14	It is hard for me to achieve my goals	.44	.53
15	It is difficult to handle situations that are unplanned	.65	.46
16	My attitude helps me to be more confident	.30	.46
17	I avoid important everyday tasks	.49	.53
18	I believe I can achieve what I want to	.65	.53
19	I am able to do things as well as most people	.65	.54
20	I worry I am not safe to use electrical equipment or appliances	.56	.39
21	I have a fear of failure	.55	.64
23	I am able to push myself	.41	.50
24	I believe you can do anything if you try hard enough	.33	.41
25	I believe I have inner strength	.49	.48
26	I manage to solve problems if I try hard enough	.57	.46

		Item-total correlations	
	Item	**Healthy Elderly**	**Stroke**
27	I do not feel comfortable in public places	.46	.47
28	I feel home is the only place where I am safe	.64	.55
29	I am confident enough to leave the house	.63	.50
30	I am worried about how others see me	.53	.63
31	I feel terrified meeting people I don't know	.49	.63
32	I do not feel able to attend social events	.48	.55
33	Other people knock my confidence	.44	.53
34	I worry I will fall and hurt myself when I am out	.55	.52
35	I feel I am not very good company	.50	.60
36	I feel other people overprotect me	.42	.14
38	I feel other people judge how I look	.27	.50
39	It bothers me that I can't do thinks like I use to	.56	.59
41	I do well when I do a bit at a time	-.17	-.03
42	I feel scared to go out	.63	.56
44	It is hard to find a hobby I value	.62	.59
45	I feel terrified when I try to do something new	.61	.62
46	I get frustrated when I can't do as much as I want to	.40	.47
47	I get excited about learning new things	.46	.26
48	My family/friends encourage me to do things	.38	.25
49	Other people push me to achieve more than I think I can	-.30	-.14
52	I feel people speak down to me	.54	.48

The majority of values i.e. 51 were shown to be >±0.3 in the healthy elderly group. In the stroke group, items 6, 36, 41, 47, 48 and 49 had low correlations with the other items, and were removed, see **Table 16.** Items 41 and 49 demonstrated negative correlations in both the stroke and healthy elderly group. Item 38 was <0.3 only in the healthy elderly group, see **Table 16**. However, as the questionnaire was designed for people who have experienced a stroke, item 38 was retained in the questionnaire.

The CaSM was reduced from 45 to 39 items.

The Cronbach alpha was repeated on the 39 item CASM and is shown in **Table 17**.

Table 17: Cronbach alpha by Group

Group	**Cronbach's Alpha**
Stroke	.94
Healthy Elderly	.94
All respondents	.96

The 39 item CaSM retained high internal consistency; therefore the construct validity was examined in the reduced, 39 item version.

4.3.6 Construct validity of the scale [39 Items]

The construct validity of the scale was tested by comparing the two groups using a Mann Whitney U Test, see **Table 18**.

Table 18: Comparison of the CaSM, 39 Item

	Stroke ***n* = 101**	**Healthy Elderly** ***n* = 101**
Mean	68.31	134.69
SD	18.64	15.28
Range	65-150	87-156
Percentiles		
25th	91.5	117.5
50th	106	132
75th	118	140.5

SD = Standard Deviation

The CaSM score in the healthy elderly group was statistically significantly different from in the stroke group. (U = 1748.5, p=<0.001) with higher scores in the healthy elderly group.

The effect size was calculated by dividing the Z value by the square root of n. This was *r* = .57 representing a large effect.

The effects of age and gender on the CASM were also investigated.

4.3.7 Age

The relationship between age and CaSM score is displayed in **Figure 3**.

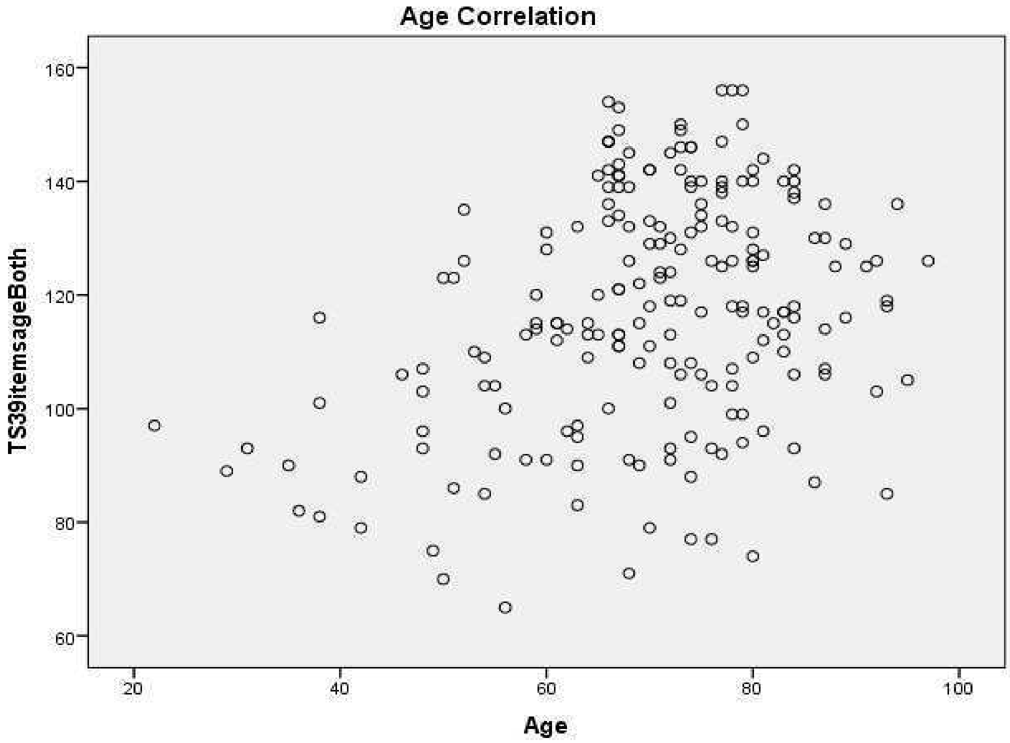


Figure 3: Age and CaSM Total Score

There was weak significant correlation (*rs* =0.25, *n=101 p*=0.001) in the healthy elderly group and a weak significant correlation in the stroke group (*rs* =0.21, *n*=101 *p*=0.028).

4.3.8 Gender difference

Responses of men and women were compared using the Mann-Whitney U Test (u = 4403, p=0.11). The results did not show a significant difference between confidence scores of men and women. A small effect size was calculated (*r* =0.11).

Each item was also examined for gender differences. Results are shown in **Table 19**.

Table 19: Comparison of Men and Women on Individual Items

		Chi^2
No	**Item**	***P* value**
1	Even though I practice tasks, I don't improve	.77
2	I think positively about myself	.06
3	I feel robbed of my identity	.25
4	I feel alone	.09
7	I feel less capable	.28
8	I feel I can push myself to achieve	.30
9	I am confident in my own home	.04
10	I feel comfortable looking in a mirror	.49
11	I can usually handle what comes my way	.72
12	I do not have much to be proud of	.86
13	I believe I am a failure	.59
14	It is hard for me to achieve my goals	.72
15	It is difficult to handle situations that are unplanned	.90
16	My attitude helps me to be confident	.77
17	I avoid important everyday tasks	.52
18	I believe I can achieve what I want to	.57
19	I am able to do things as well as most people	.12
20	I worry I am not safe to use electrical equipment or appliances	.31

21	I have a fear of failure	.49
23	I am able to push myself	.54
24	I believe you can do anything if you try hard enough	.56
25	I believe I have inner strength	.90
26	I manage to solve problems if I try hard enough	.62
27	I do not feel comfortable in public places	.95
28	I feel home is the only place where I am safe	.75
29	I am confident enough to leave the house	.24
30	I am worried about how others see me	.10
31	I feel terrified meeting people I don't know	.27
32	I do not feel able to attend social events	.66
33	Other people's comments knock my confidence	.29
34	I worry I will fall and hurt myself when I am out	.01
35	I feel I am not very good company	.87
38	I feel other people judge how I look	.58
39	It bothers me that I can't do thinks like I use to	.20
42	I feel scared to go out	.06
44	It is hard to find a hobby I value	.45
45	I feel terrified when I try to do something new	.04
46	I get frustrated when I can't do as much as I want to	.83
52	I feel people speak down to me	.30

Item nine '*I am confident in my own home*' showed statistically significant differences between men and women, and was removed.

Items 34 and 45 also showed significant differences according to gender. An observation of the frequency of responses was conducted for both of these items and the differences were considered not large enough for item removal. See **Table 20**.

Table 20: Gender Difference, Items <*p*=0.05

Item No	Item	Frequency				Ch2
		Men *n*=92		Women *n*=110		*P* Value
		SA/ Agree	SD/ Disagree	SA/ Agree	SD/ Disagree	
9	I am confident in my own home	92	0	101	9	.04
34	I worry I will fall and hurt myself when I am out	22	70	52	58	.01
45	I feel terrified when I try to do something new	16	76	33	77	.04

The removal of item 9 resulted in 38 item questionnaire.

4.3.9 Principal component analysis

The 38 items of the CaSM were subjected to a principal component analysis (PCA), with an oblique rotation. Prior to conducting a PCA, the suitability of the CaSM data were assessed. Inspection of the correlation matrix revealed many coefficients >±0.3 and the sample size was adequate >200. The Kaiser Meyer-Olkin value was (0.94) exceeding the recommended value of 0.6 and the Bartlett's Test of Sphericity reached statistical significance (*p*=0.01) supporting the factorability of the correlation matrix.

Principal components analysis revealed the presence of eight components, with eigenvalues exceeding 1, explaining 39.2%, 5.77%, 4.5%, 3.3%, 3%,2.9%,2.8%,2.6% of the variance respectively.

A scree test was used to help decide how many components to extract. The results of a scree plot are illustrated in **Figure 4** below:

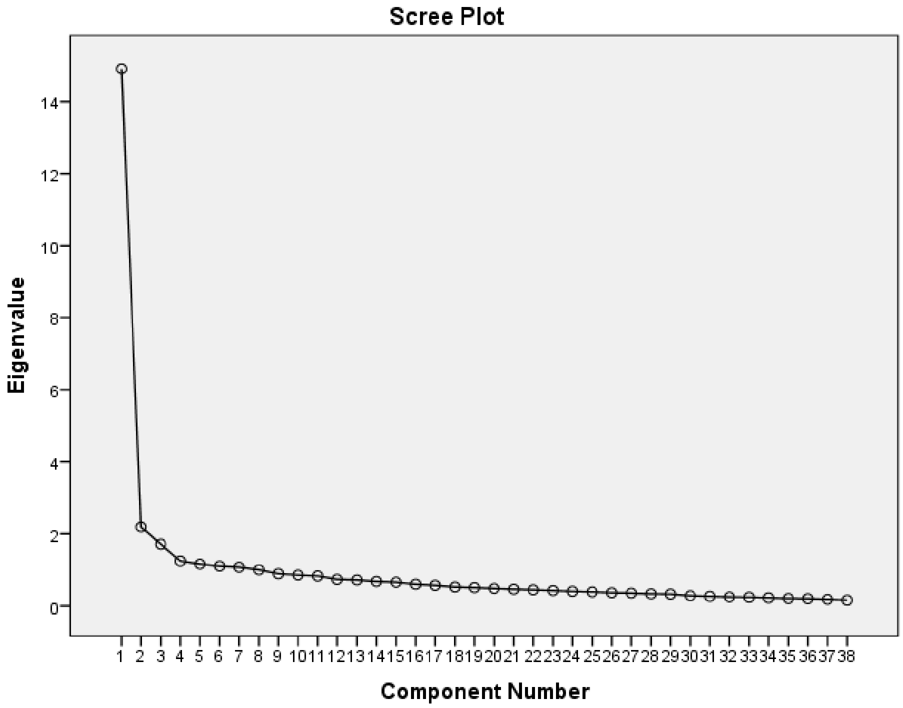


Figure 4: Scree Plot, 38 Item CaSM

The scree plot was examined for points of inflection; a clear break is seen after the fourth component.

A parallel analysis technique was conducted and the results are reported in **Table 21**, and indicated retaining two components.

Table 21: Parallel Analysis, 38 Item CaSM

COMPONENT	ACTUAL EIGENVALUE FROM PCA	RANDOM ORDER PARALLEL ANALYSIS	DECISION
1	14.91	1.92	Retain
2	2.19	1.82	Retain
3	1.71	1.73	Reject
4	1.25	1.66	Reject
5	1.16	1.59	Reject
6	1.10	1.53	Reject
7	1.07	1.47	Reject
8	1.00	1.41	Reject
9	.89	1.36	Reject
10	.85	1.32	Reject

The factor matrix is divided into a pattern matrix, **Table 22** and the structure matrix **Table 23**.

.

Table 22: Pattern Matrix

	Components							
Item	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
I feel robbed of my identity	**.733**							
It is hard for me to achieve my goals	**.613**							
I feel alone	**.609**							
I believe I am a failure	**.470**						-.315	
I do not have much to be proud of	**.437**							
I feel home is the only place where I am safe	**.384**		-.312		-.305			
It's hard to find a hobby that I value	**.378**							
I feel I am not very good company	**.374**		-.367					
I believe you can do anything if you try hard enough		**.825**						
I believe I have inner strength		**.752**						
I am able to push myself		**.732**						
I manage to solve problems if I try hard enough		**.487**						
I feel other people judge how I look			**-.770**					
I am worried about how others see me			**-.714**					
I have a fear of failure			**-.568**					
I feel terrified meeting people I don't know			**-.518**					
Other people's comments knock my confidence			**-.482**					
I do not feel comfortable in public places	.435		**-.435**					
I feel people speak down to me			**-.424**			-.304		
I feel terrified when I try something new			**-.418**	.315				
I do not feel able to attend social events			-**.351**					

I am confident enough to leave the house				**.817**				
I feel scared to go out				**.669**				
I worry I will fall and hurt myself when I am out				**.495**				-.475
I worry I am not safe to use electrical equipment or appliances					**.590**			
I avoid important everyday tasks					**.579**			
Even though I practice tasks I don’t improve	.353				**.373**			
I feel I can push myself to achieve						**-.784**		
I think positively about myself						**-.669**	-.376	
It is difficult to handle situations that are unplanned					.323	**-.331**		-.304
I feel comfortable looking in a mirror							**-.684**	
My attitude helps me to be confident							**-.636**	
I believe I can achieve what I want to							**-.499**	
I can usually handle what comes my way							**-.396**	-.344
I get frustrated when I can’t do as much as I want to								**-.610**
It bothers me that I can’t do things like I used to								**-.591**
I feel less capable								**-.489**
I am able to do things as well as most people								**-.460**

Table 23: Factor Structure Matrix

	Components							
Item	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
I feel robbed of my identity	**.805**			.399		-.333		-.466
I feel alone	**.751**		-.383	.381	-.364			-.478
It is hard for me to achieve my goals	**.716**	.313			.382		-.391	-.368
I do not have much to be proud of	**.647**	.339	-.518	.431	.332	-.508		
I believe I am a failure	**.631**	.375	-.517	.356		-.368	-.503	
It is hard to find a hobby that I value	**.628**	.304	-.408	.497		-.492		-.495
I feel home is the only place where I am safe	**.605**	.412	-.577	.500				-.381
I feel I am not very good company	**.593**	.315	-.563			-.461		-.347
Even though I practice tasks I don't improve	**.511**	.333			.495			-.418
I believe I have inner strength		**.804**					-.417	
I believe you can do anything if you try hard enough		**.799**					-.341	
I am able to push myself		**.767**	-.313	.316		-.405		
I manage to solve problems if I try hard enough	.309	**.633**		.545			-.408	-.345
I am worried about how others see me	.406		**-.820**	.464			-.314	
I feel other people judge how I look			**-.738**					
I have a fear of failure	.415	.349	**-.716**	.340		-.466	-.395	
I feel terrified meeting people I don't know	.453	.354	**-.698**	.523				-.343
I feel terrified when I try something new	.466	.334	**-.645**	.578		-.307		-.481
Other people's comments knock my confidence	.367	.377	**-.611**			-.305	-.395	-.353

I do not feel comfortable in public places	.606	.310	**-.610**	.352				-.333
I feel people speak down to me	.400		**-.600**	.363	.369	-.489		-.447
I do not feel able to attend social events	.480	.380	**-.561**	.396		-.397		-.383
I am confident enough to leave the house	.302	.331	-.317	**-.858**		-.360		
I feel scared to go out	.434		-.500	**.792**			-.346	
I worry I will fall and hurt myself when I am out			-.353	**.650**	.370			-.636
I worry I am not safe to use electrical equipment or appliances	.311		-.322	**.427**	.687	-.311		-.387
I avoid important everyday tasks	.472	.409	-.454	**.334**	.666			
I feel I can push myself to achieve		.380		.306		**-.811**		
I think positively about myself	.316					**-.746**	-.524	
I feel comfortable looking in a mirror		.308	-.383	.364			**-.752**	
My attitude helps me to be confident		.362					**-.691**	
I believe I can achieve what I want to	.319	.510	-.357	.332		-.354	**-.661**	-.455
I can usually handle what comes my way	.386	.430	-.358	.439		-.480	**-.584**	-.556
It bothers me that I can’t do things like I used to	.452		-.469	.364		-.445		**-.746**
I get frustrated when I can’t do as much as I want to	.479		-.423					**-.714**
I feel less capable	.572	.307		.376	.386		-.355	**-.678**
I am able to do things as well as most people	.537	.421	-.343	-.334	.352	-.333	-.470	**-.655**
It is difficult to handle situations that are unplanned	.394	.331	-.467	.315	.484	-.525		**-.538**

An examination of **Table 22** and **Table 23** identified items that were cross loading onto more than one factor, or loading poorly <±0.3. These items were considered for removal.

The pattern matrix showed item one '*Even though I practice tasks I don't improve'* was not substantively loading onto any component <.40. The structure matrix showed this item had the lowest loading on component one (.51) and was removed.

Item eight, '*I feel I can push myself to achieve'* was similar to Item 23 '*I am able to push myself*'. Item 23 clustered better with other items on the structure matrix, it was retained and item eight was removed.

Item 11, '*I can usually handle what comes my way'* was not substantively loading across any component of the pattern matrix. Component 7 (0.39) and (-0.34) on component 8. A check on the structure matrix revealed it was loading across seven components and not substantively. It was therefore removed.

Item 15, '*It is difficult to handle situations that are unplanned'* demonstrated low loadings <0.40, on the pattern matrix; component four (0.32), component five (0.33) and component seven (-0.30). It was cross loading across all components other than component six of the structure matrix. It was therefore removed.

Item 20 '*I worry I am not safe to use electrical equipment'* was demonstrating a relationship with only one item on the pattern matrix, and also cross loading across all components except two and seven on the structure matrix, and was removed.

Item 21 '*I have a fear of failure'* was similar to another item 13 on the questionnaire, '*I believe I am a failure*' and this item was clustering well with other items on component one, this item was retained and item 21 removed.

Item 34 '*I worry I will fall and hurt myself when I am out'* was clustering almost equally on two components 4 and 8 (.049), (-0.47) on the pattern matrix. The structure matrix showed this item loading across four components, it was therefore removed.

Item *45 'I feel terrified when I try something new'* was loading highly onto all components other than five and seven on the structure matrix and was removed.

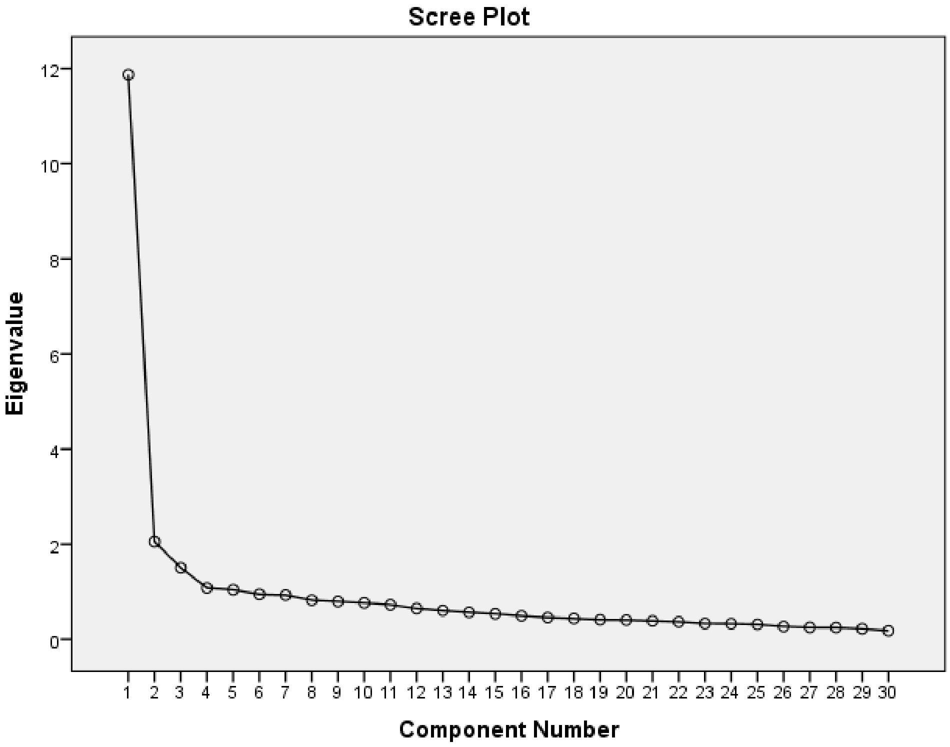
Item 27 '*I do not feel comfortable in public places* 'was retained for further analysis.

The relevant stages of the PCA were repeated on a 30 item CaSM, items 1, 8, 11, 15, 20, 21, 34, 45 were removed.

The data were re-checked for suitability. The Kaiser-Meyer-Olin Measure of Sampling Adequacy was high (0.932) and Bartlett's Test of Sphericity demonstrated statistical significance (p=.001). An inspection of the correlation matrix for loadings <±0.30 was reviewed. The correlation matrix showed 79.5% of the variables were ≥ 0.3. These results demonstrated suitability for repeating the PCA on the 30 item CaSM.

The PCA revealed a five component solution, with eigenvalues above one, accounting for 58.51% of the total variance. A scree plot was also inspected see **Figure 5.**

Figure 5: Scree Plot, 30 Item



The scree plot was examined for points of inflection; a break is seen after the fourth component.

The parallel analysis indicated retaining a two component structure, see **Table 24**.

Table 24: Parallel Analysis, 30 Item

Component	**Actual Eigenvalue from PCA**	**Random order Parallel Analysis**	**Decision**
1	11.87	1.80	Retain
2	2.05	1.68	Retain
3	1.50	1.60	Reject
4	1.08	1.52	Reject
5	1.04	1.45	Reject
6	.95	1.39	Reject
7	.93	1.33	Reject
8	.82	1.28	Reject
9	.80	1.23	Reject
10	.77	1.19	Reject

The pattern matrix revealed, items 12 and 17 were demonstrating poor loadings ≤0.4 on component one (0.37); (0.32). Item 35 was loading on two components (0.45; 0.41). Item 13 showed the lowest loading on component four (.30), and on examination of the structure matrix, this item was cross loading across all five components. Items 12, 13 and 35 were removed. Item 17 was retained.

This multi model principal component analysis was run for a third time on the 27 item CaSM.

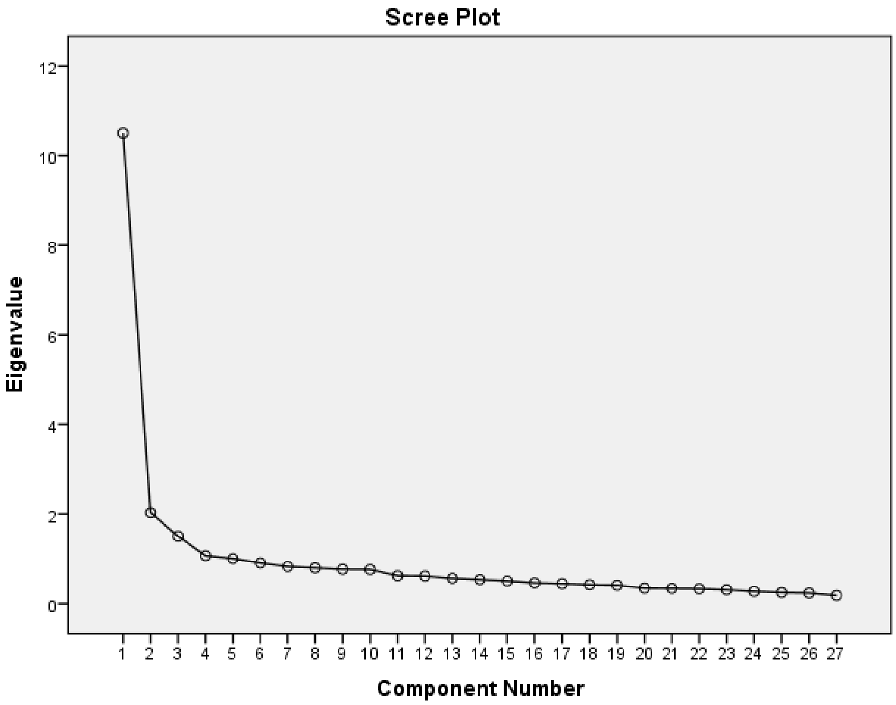


Figure 6: Scree Plot, 27 Item

The scree plot point of inflection showed a break after the fourth component.

The parallel analysis indicated retaining two components, refer to **Table 25.**

Table 25: Parallel Analysis, 27 Items

Component	Actual Eigenvalue from PCA	Random order parallel analysis	Decision
1	10.50	1.74	Retain
2	2.03	1.63	Retain
3	1.50	1.53	Reject
4	1.07	1.46	Reject

The pattern and structure coefficients were computed for the 27 item CaSM and examined further, see **Table 26**.

Table 26: Pattern and Structure Coefficients

Item	**Pattern coefficients**			**Structure coefficients**		
	C1	C2	C3	C1	C2	C3
I feel robbed of my identity	.885			.811		.413
I feel less capable	.776			.785	.405	.394
I feel alone	.728			.774	.300	.494
It is hard for me to achieve my goals	.704			.726	.409	.366
I am able to do things as well as most people	.657			.754	.536	.436
I get frustrated when I can’t do as much as I want to	.640			.690		.456
It bothers me that I can’t do things like I used to	.628			.728		.542
It’s hard to find a hobby that I value	.599			.732	.373	.557
I avoid important everyday tasks	.287			.513	.423	.504
I believe I have inner strength		.849			.801	.328
I believe you can try anything if you try hard enough		.786			.721	
My attitude helps me to be confidence		.621		.305	.620	
I manage to solve problems if I		.587		.324	.560	.477

try hard enough						
I am able to push myself		.570		.361	.649	.404
I believe I can achieve what I want to		.567		.518	.694	.423
I feel comfortable looking in a mirror		.444	.309	.324	.560	.477
I think positively about myself		.419		.428	.537	.360
I feel other people judge how I look			.837			.712
I am worried about how others see me			.830			
I feel terrified meeting people I don't know			.698			
I feel home is the only place where I am safe			.549	.563	.404	.709
I feel scared to go out			.540	.523	.405	.685
I do not feel comfortable in public places			.518	.523		.646
I feel people speak down to me	.337		.508	.573		.652
I do not feel able to attend social events			.506	.521	.380	.652
I am confident enough to leave the house			.472	.437	.428	.607
Other peoples comments knock my confidence			.416	.459	.463	.587

A three component solution on the 27 item questionnaire (CaSM) explained a total of 51.98% of the variance. Component one contributed 38.9% of the explained variance, component two contributed 7.51% and component three 5.56%. See, **Table 27.**

Table 27: Explained Variance

	Initial Eigenvalues			**Extraction Sums of Squared loadings**		
Component	**Total**	**% of Variance**	**Cumulative %**	**Total**	**% of Variance**	**Cumulative %**
1	**10.204**	**38.905**	**38.905**	**10.504**	**38.905**	**38.905**
2	**2.029**	**7.514**	**46.419**	**2.029**	**7.514**	**46.419**
3	**1.502**	**5.564**	**51.983**	**1.502**	**5.564**	**51.983**
4	1.068	3.956	55.939			
5	1.002	3.712	59.651			
6	.906	3.355	63.006			
7	.827	3.064	66.071			
8	.799	2.959	69.029			
9	.767	2.842	71.871			
10	.760	2.814	74.685			

Items clustering on each component were represented as component 1 self-confidence, component 2 positive attitudes and component 3 social confidence, see **Table 28**.

Table 28: Component Structure

Component 1	Self Confidence
Component 2	Positive Attitude
Component 3	Social Confidence

The principal component analysis resulted in the removal of the following items: Item 1, item 8, item 11, item 12, item 13, item 15, item 20, item 21, item 34, item 35 and item 45. The CaSM has retained 27 items.

4.3.10 Reliability and validity of 27 item CaSM

4.3.11 Internal consistency

The Cronbach Alpha coefficient measure was repeated, on the reduced 27 item CaSM and the results are shown in **Table 29**.

Table 29: Cronbach alpha, 27 Item

Group		Cronbach's Alpha
Stroke	*n*=101	.92
Heathy Elderly	*n*=101	.90
All respondents	*n*=202	.94

The CaSM 27 demonstrated good internal consistency.

4.3.12 Test retest reliability

Of the 202 participants who agreed to be contacted, 189 returned questionnaires (94%).

The demographic characteristics of participants who completed the retest are shown in **Table 30**.

Table 30: Test Re-test Demographics

Stroke Group ***n*= 97**				**Health Elderly** ***n*= 92**		
	Mean	**SD**	**Range**	**Mean**	**SD**	**Range**
Age	64.15	14.0	29-95	76.41	7.8	65-97
	n	%		n	%	
Number of Men	46	50		44	45.4	
Number of Women	46	50		53	54.6	

Preliminary analyses indicated there was a high positive correlation, between of the test and retest data, as illustrated in **Figure 7.**

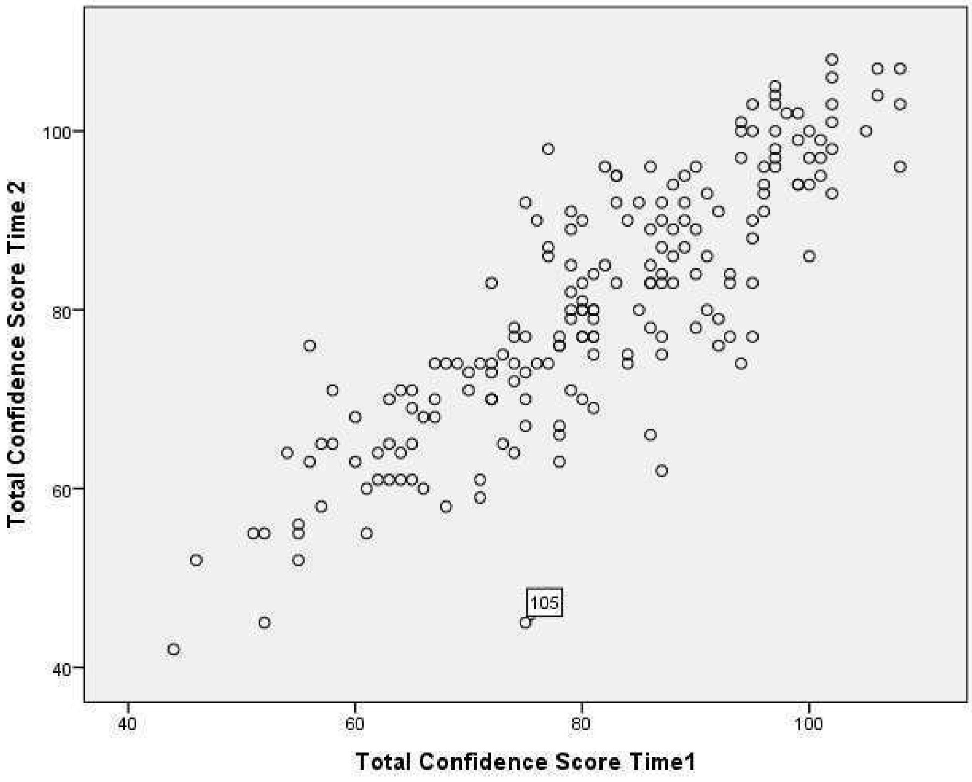


Figure 7: Test Retest

The results of a Spearman's correlation confirm the results of the scatter plot, revealing a strong correlation (r_s = 0.85 n=189 p=0.001). The confidence scores at time one demonstrated a statistically significant association with confidence scores at time two.

The Wilcoxon Signed Ranks Test, was also used to compare the confidence scores at two time points. See **Table 31**.

Table 31: Confidence Scores Test Retest

	n	**Percentiles**		
		25th	**50th**	**75th**
CASM27 Test	189	72	81	93
CASM 27 Retest	189	70	80	93

The Wilcoxon Signed Rank Test revealed the confidence score at time one, did not show a statistically significant difference from the score at time two (p=0.35), demonstrating a small effect size (r=0.05).

4.3.13 Convergent validity

A Spearman's correlation was used to assess convergent validity. The scores on the CaSM were correlated with the scores on the SSEQ. The results showed a high correlation (r_s =0.77. n=202, p=0.001) demonstrating a statistically significant relationship between the CaSM and the SSEQ.

4.3.14 Construct validity of 27 item CaSM

4.3.14.1 Age

A weak significant correlation was shown between the CaSM scores with age (r_s = 0.26, *n*=202, *P*=0.001), indicating that those who were older had lower levels of confidence, see **Figure 8**.

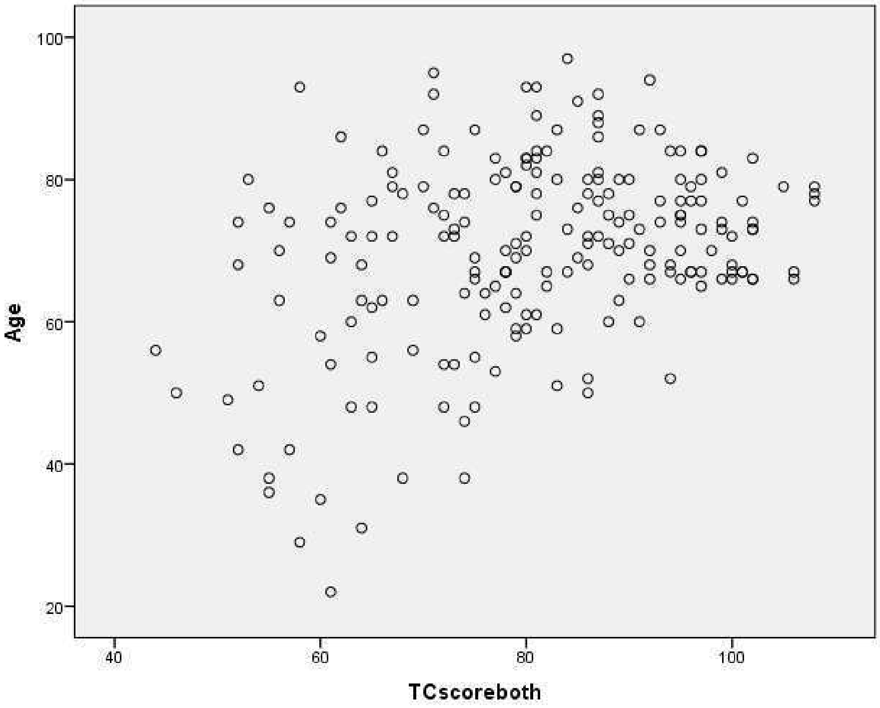


Figure 8: Correlation with Age

The correlation between age and CaSM score was also investigated for each group individually. The stroke group showed a weak significant negative correlation (r_s =-0.29, *n*=101, *p*=0.003) whereas, the healthy elderly group showed a weak non-significant positive correlation (rs=0.22, n=101, P=0.26). The healthy elderly group demonstrated a statistically significant correlation, the stroke group showed no significant relationship.

4.3.14.2 Gender, 27 item

A Mann Whitney U Test was conducted to compare the responses of men (*md* 83, *n*=202) and women (*md* 80, *n*=202) and did not show a statistically significant difference between men and women on the 27 item CaSM (*u*=4395.5, *z*=-1.61, *p*=.11, *r*=0.11) and demonstrated a small effect size.

Individual item responses were computed using a Chi^2. When the assumptions of the Chi^2 were violated, these items were re-examined using the frequency of responses, refer to **Table 12**. This demonstrated no items in the stroke group showed significant differences in the distribution of responses (*p*=<0.05) between men and women; therefore all 27 items remained in the questionnaire for further analysis.

4.4 Discussion

The design and development of the CaSM followed the stages that are considered essential elements in newly developed questionnaires (Rattray and Jones, 2007). The comprehensive testing to assess validity and reliability used a wide variety of data analysis methods with 202 participants.

Participants were recruited over a nine month period. The recruitment strategy was reliant on potential participants contacting the researcher with an expression of interest. Despite advertising the research through large national stroke organisations web sites, the majority of respondents were recruited by face to face visits from the researcher to local stroke groups, lay conferences and a retirement village. Personal contact and invitation improved response rate which supports previous research (Babbie, 2015, Edwards, 2009).

The expected response rate for postal healthcare questionnaires is approximately 60% (Cook et al., 2009) which was achieved in this study. When five questionnaires were posted to activity and social clubs, typically two or three were returned. A small number, 15 (5%) people contacted the researcher for a questionnaire, but no completed questionnaire was returned, the reasons were unknown. However, previous stroke studies have shown a low response in the completion of questionnaires (Maujean et al., 2014, Das et al., 2007, Parker and Dewey, 2000) these authors have suggested that cognitive impairments and symptoms of depression may contribute to lack of participation. The CaSM is now a shorter questionnaire and this is likely to increase response rates according to Edwards (2009). Assessing the potential of non-respondents is important to avoid a response bias. The response rate of the CaSM was comparable to other studies suggesting it is acceptable questionnaire. High test retest response rate (94%) may further indicate acceptability of the CaSM, in addition to a low missing item count. Careful monitoring of non-responses would be recommended in any future assessment of the CaSM.

Individual items assessed as having limited value, were examined for redundancy, in an attempt to reduce the burden on respondents. Items which demonstrated high frequency of responses in one category indicate poor discriminatory power (Rattray and Jones, 2007) and these items were the first to be identified for potential removal. Eight items in the stroke group and 32 in the healthy elderly group, but some items were retained in order not to remove too early, as advocated by DeVellis (2012).

Throughout the duration of the study, there were eight occasions, where a whole sheet of the questionnaire was left blank. The 53 item questionnaire consisted of seven A4 sheets. If a page was left blank, the researcher made one off telephone call to ask for the missing data over the phone. This was acceptable to all of the respondents. The questionnaire is currently reduced to 27 items on three pages; therefore the risk of missing pages, to the same extent, is likely to be reduced. Overall, the amount of missing data were low, as previously reported, which suggests self-administration was an acceptable procedure in this study.

The CaSM’s reliability was examined (internal and test retest). Assuming that a high Cronbach’s alpha always demonstrates good internal consistency, was challenged by Tavakol and Dennick (2011) who suggested it may just reflect the length of the questionnaire. The CaSM’s Cronbach alpha was calculated at various stages of item reduction, and a high Cronbach alpha was attained consistently. This indicates that the CaSM is likely to be demonstrating good internal consistency. However, there may still be some item redundancy.

The test retest results demonstrated a high correlation between two time points (r_s =.85), and the confidence scores at the two time points were not significantly different. These results showed a small effect, using Cohen's criteria (1988). This confirmed the items on the CaSM were demonstrating good temporal stability, suggesting there is likely to be a construct of confidence that is measureable.

Although the sample size was deemed adequate for the purpose of conducting a principal component analysis in this study 202 was still only considered a '*fair*' sample for this technique (Nunnally, 1978). However, a combination of examining the statistical information gathered from the principal component analysis and professional judgement by the researcher was the basis that resulted in items being removed. According to Field (2009), the researcher's conceptual knowledge in any factor analysis process is key. This was demonstrated in this study when the first observation of the scree plot (Cattell, 1966) and the parallel analysis (Horn, 1965) suggested high loadings on component one. However, on inspection these items appeared to have an emphasis on self-esteem, whereas the items thought to strongly reflect the construct of confidence, were demonstrating lower loadings, such as, 'I *do not feel able to attend social events*' and 'I *avoid important everyday tasks.*' The researcher took the decision to retain these items even though they may be demonstrating poor psychometric properties. Findings from the interview study (Horne et al., 2014) and the literature (McKevitt et al., 2011) suggested the former items reflected social confidence and the latter item was felt to reflect the theoretical unpinning of self-efficacy theory (Bandura, 1997). Eight items were however removed, guided by advice by Williams et al.,

(2010) suggesting poor loadings on a single component <0.40 should be considered for removal, and items cross loading onto more than one component <0.40 may also be redundant. The PCA was used as a guide to enable the researcher to make some decisions on ensuring the final factor solution captured a confidence construct.

This process resulted in a three factor solution representing self-confidence, positive attitude and social confidence explaining 51.98% of the variance. Henson et al., (2001) found 52% was the average amount of explained variance when examining 60 studies that had conducted an exploratory factor analysis. All studies were reported in four psychological journals. The authors challenged previous research that suggested 75% of explained variance should be the aim, suggesting this may not be reasonable in applied psychological research. The amount of variance accounted for, supported the three factor solution and was comparable to other psychological studies (Henson et al., 2001).

The PCA undertaken in this study indicates the CaSM has the potential to be used as three separate measures. The evaluation of the CaSM to date, has been assessed using the total score. However, the reliability of each component has been evaluated separately using Cronbach alpha, and demonstrated each component has a high alpha (C1, *a*=0.89, C2, *a*= 0.82, C3, a=.88) suggesting good interrelatedness between items and indicates each component is unidimensional (Tavakol and Dennick, 2011). This is considered useful as stroke survivors, who may have self confidence in their daily activities for example, may lack social confidence. Measuring these separate components of confidence, is likely to help stroke clinicians target specific domains of confidence.

Further investigation, by conducting a confirmatory factor analysis, is needed to confirm these findings.

Support for convergent validity was provided by a high correlation, with a scale measuring a similar construct, the stroke self-efficacy questionnaire (Jones et al., 2008). It may be debated that if there is a high correlation between the CaSM and the SSEQ, why a new measure is needed. The SSEQ was developed using a sample that was two to twenty four weeks post stroke, whereas it is envisaged that the CaSM would target people later on in stroke recovery. It has been identified by the developers of the SSEQ, that the 13 item questionnaire which was used to assess the convergent validity of the CaSM, had its limitations. Further analysis to improve the SSEQ has since been conducted (Riazi et al., 2014). The SSEQ has been redesigned following a Rasch analysis (Rasch, 1960), resulting in a two factor structured scale, representing activity, self-efficacy and self-management self-efficacy. The new version of the SSEQ was tested on a larger sample (*n* =118), and the response format has changed from a VAS 11 point scale to a 4 point scale. Whist it is acknowledged that the SSEQ has been further developed and improved, it does not measure social or psychological components of confidence, suggesting there is need for a measure that encompasses these components of a confidence construct. Validation against this new measure would provide additional support for the CaSM's evaluation.

4.4.1 Study limitations

The study had a number of limitations. Firstly, little information was known about the non-respondents. Therefore a potential response bias could have been introduced (Bowling, 2014). It is likely during the data collection phase of the CaSM, some sub-groups related to stroke may have been under represented, such as people with more severe levels of cognitive or physical impairment, and therefore not representative of stroke survivors across the pathway. Nevertheless, due to the severity of stroke impairment not all stroke survivors would be willing or able to complete a questionnaire; therefore other strategies would need to be developed to assess confidence.

The only exclusion criteria for the healthy elderly group was that they had not experienced a stroke, it was therefore plausible that older people with comorbidities or other neurological conditions, such has a head injury, for example, completed some questionnaires representing the healthy elderly sample, which may have had implications on the results, as they may also experience low confidence. Many of the recruitment sites however, such as walking groups and social clubs are not typically populated by people with restrictive function. Therefore, it was assumed the majority of respondents in the healthy elderly group were representative, although this cannot be assured.

It is also highly likely that the study lacked cross culture representation as the CaSM was a written measure, in English. The contact sheet failed to include a question about ethnicity, limiting information about the study sample. These factors are important as they can limit the generalisability of the study. However, even if the generalisability cannot be assured, the methods used are common in the initial stages of questionnaire development and the results do highlight important information relating to the measurement of confidence that is at an appropriate level for the initial development stages.

Aphasic participants were underrepresented in the stroke sample. A third of stroke survivors experience long term difficulties with written or spoken language, as a result of their stroke (Brady et al., 2012). Although 13% of the study sample was aphasic after stroke, these respondents were all attending a conversational group; their data therefore, may differ from other aphasic stroke survivors who may not have the social confidence to attend such groups. It is not known what percentage of the other participants in the stroke sample had aphasia, and completed the questionnaire, as the question was not asked. Further development of the CaSM, focussing on making the questionnaire more aphasia friendly has always been the plan. However, it was decided to design and test the measure one step at a time was the best approach.

A potential limitation was identified in the test retest procedure. The time between completing the CaSM at time one and again at time two, was four to six weeks, some measurement texts recommend a shorter time period, such as two weeks (Babbie, 2015, Streiner and Norman, 2008) as it gives less time for people to change. However there is then the risk of participants remembering the answers they gave initially. As there was little change this does not seem to be a problem.

Further research on whether item order on the CaSM makes a difference to how people respond, as suggested by Bowling (2014) and Devellis (2012) is recommended. Component one and three include both positive and negative items, whereas components two include all positive items. There is a potential for an acquiesce bias to occur now the positive items are pooled together. Further testing to monitor for this bias is suggested.

4.5 Conclusion

The initial 53 item CaSM was reduced to 27 items. Three items were removed on the basis of high endorsement or rejection, by the majority of participants (85%). One item was removed on the basis of a lack of differences between responses from the stroke participants and the healthy elderly. Four Items with a high proportion of missing values were also eliminated.

The 45 items were reduced to 39 by removing six items which demonstrated item total correlations of ±<0.3. A further item was removed due to gender difference.

The 38 item CaSM underwent a factor analysis and eight items were removed at the first stage. A further three were removed when 30 items were examined with a PCA for a second time. Twenty seven items remain in the CaSM.

The CaSM was assessed as being highly correlated with a measure of a related construct. The CaSM demonstrated good reliability when assessed for temporal stability and internal consistency.

The CaSM [27] was found to be both valid and reliable. The next chapter examines whether the CaSM detects change in response to changing circumstances, such as an intervention.

Chapter Five

5. Sensitivity of the CaSM

5.1 Introduction

The CaSM has the potential to be used both clinically and in research as a patient reported outcome measure. It is therefore important to assess whether the CaSM it is able to detect change, as a result of an intervention.

Sensitivity and responsiveness to change are terms that have evolved in the psychometric literature over the past decade, they are often used interchangeably in texts, yet the distinction between the two are often misunderstood (Streiner and Norman, 2008).

Liang (2000) offers clarification by suggesting:

> '*Sensitivity to change is the ability of an instrument to measure change in a state regardless of whether it is relevant or meaningful to the decision maker*' (p85).

Whereas, responsiveness to change the author describes as:

> 'T*he ability of an instrument to measure a meaningful or clinically important change in a clinical state*' (p85).

This current study aims to investigate the sensitivity of the CaSM to detect change as a result of an intervention designed to improve confidence.

Methodology texts suggest there are different ways to assess sensitivity to change, but a global consensus has yet to be reached (Bowling, 2014, Streiner and Norman, 2008). Typically, researchers report statistically significant differences, yet it is argued that whilst these methods are necessary for assessing one measured outcome over another (Todd et al., 1996), they have been criticised for having little clinical relevance (Wise, 2004). Methods that aim to assess an effect size are the most common, and using the raw score of the measure is another approach.

The 53 item version of the CaSM had been developed and was undergoing psychometric assessment with participants living in the community. Concurrently, a randomised controlled trial to test the feasibility of a ‘Regaining Confidence After Stroke Course’ intervention was also being conducted, at the University of Nottingham (April 2013-August 2015). A component of this trial aimed to assess the feasibility of outcomes; therefore, it was an opportunity to further evaluate the CaSM with an independent sample. The CaSM was being tested along with the COPE (Carver et al., 1989) to assess adjustment and coping which may also be suitable for detecting a change, post intervention. Two other measures were needed for a power calculation. These were the GHQ-28 (Goldberg and Williams, 1988) and the NEADL (Nouri and Lincoln, 1987). The results were likely to indicate whether the items on the CaSM had adequate sensitivity to change properties.

The detail of the RCAS study will be reported elsewhere (Hooban et al., in progress). However, a brief description of the study aim, design and procedures now follows (Hooban et al., 2015).

The Regaining Confidence after Stroke (RCAS) course is a group therapy designed for community stroke patients to help them adjust to the effects of stroke and to teach strategies to cope with low mood and confidence. The purpose of the study was to determine the feasibility of the proposed study design for a randomised controlled trial and to gather data for sample size estimation.

A feasibility single centre randomised controlled trial was conducted. Participants were randomly allocated into two groups. Group A received the RCAS course, and group B did not receive the intervention. Data were collected from participants and their carers' in both groups at baseline, three months and six months, through the battery of questionnaires described above, and interviews. The CaSM [53] item questionnaire was part of this battery of outcome measures.

The CaSM scores pre and post intervention were collected as part of the RCAS procedures. However, the CaSM data were analysed independently for the purpose of this study.

5.2 Methods

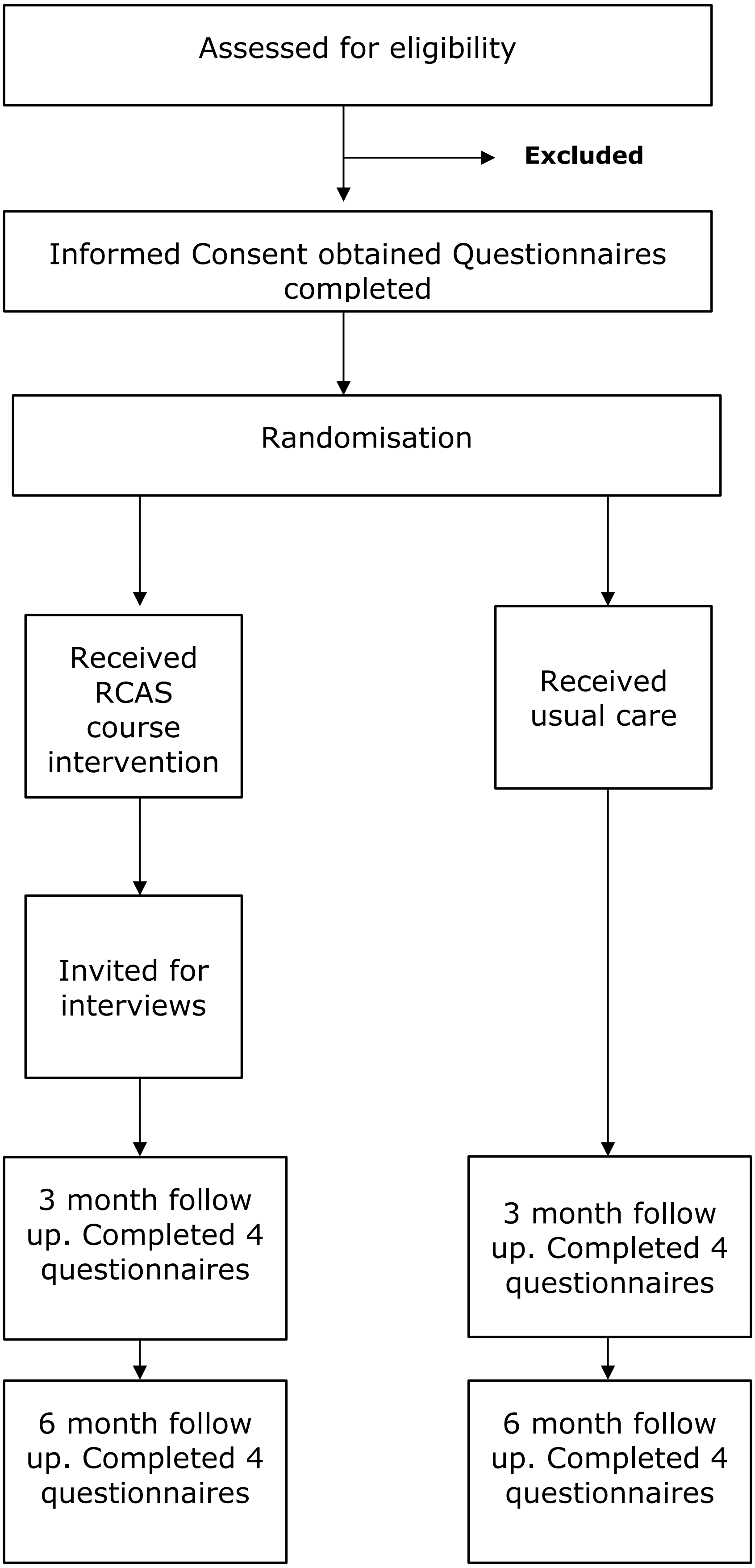
5.2.1 Ethical approval

The RCAS randomised controlled trial received favourable ethical approval from Nottingham 1 Ethics Committee in March 2013. Reference: REC 12061 RCAS.

5.2.2 Participants

Participants were invited to take part in the study if they had a clinical diagnosis of stroke and were less than two years after stroke onset. They were eligible if they were resident in the community, had been discharged from other rehabilitation therapies, not involved in other trials of psychological interventions and able to give informed consent. They were excluded from the study if they had a Barthel score <10 (Mahoney, 1965), as they needed the mobility to attend a group in the community, or if they scored < 8 on the Sheffield Screening Test (Syder, 1993) for acquired language disorder, as they would not have the language abilities to fully participate in a group intervention, with verbal interaction and written materials. Participants were interviewed at baseline, 3 months and 6 months, after randomisation. See, flow chart in **Figure 9**.

Figure 9: Flow Chart of RCAS Study



5.2.3 Procedure

All participants who consented to the RCAS trial were assessed in their own home by a research assistant, with experience of working in stroke rehabilitation. Participants completed four measures in the same order.

Three months after randomisation all participants in the study were posted the above outcome measures a second time. Participants were asked to self-report, unless they needed help to complete the measures. In this instance, a member of the research team visited the participants at home to help complete the measures. Participants were asked to return the measures in a pre-paid envelope to the University of Nottingham. Participants were reminded by a single telephone call from a research assistant, if a questionnaire had not been returned within one month of administering.

Six months after the randomisation, another set of outcome measures were posted to all study participants. The follow up at six months adhered to procedures as described at the three month follow up.

In order to assess sensitivity of the CaSM only participants allocated to intervention were included.

5.2.4 Data management

SPSS © version 22 was used for all data collection and analysis procedures.

5.2.5 Statistical procedures

To examine the pre-test and post test scores of the CaSM, a Friedman's ANOVA technique was considered as the non-parametric alternative to the one-way repeated measures analysis of variance. A Friedman's technique is considered useful when the assumptions of a parametric test, such as the commonly used ANOVA, are violated (Field, 2009). The sample size was considered too small to be able to justify a normal distribution of the data. Therefore, a Friedman's technique to test the CaSM scores at three different time points, with the same sample was viewed as a more appropriate option.

Missing data were dealt with in the following ways. A missing data analysis (MDA) was conducted. When more than 10% of the items on the CaSM were missing, the case was excluded from the analysis. However, where less than 10% of the data were missing, the missing value was replaced with the mean of all other items on that questionnaire.

5.3 Results

Twenty two participants in the intervention group completed the CaSM at baseline (Time 1) prior to the confidence intervention. Sixteen completed the CaSM at 3 months (Time 2), at six months eleven completed the CaSM.

Three cases were excluded from the analysis due to <10% of missing data. See **Table 32.**

Table 32: Missing Values RCAS

ID	Missing Items (Count)	%	Exclude	Items
Baseline				
1032	5	18	Y	38,39,42,44,46
3 Months				
1023	14	52	Y	17,18,19,23,24,25,26,27,28,29,30,31,32,33
1026	1	4	N	16
6 Months				
1013	5	18	Y	38,39,42,44,46
1023	1	4	N	30
1029	2	7	N	18,33

A Friedman's ANOVA was conducted on the CaSM scores at pre intervention, post intervention (3 month follow up) and follow up (6 months) are reported.

The results of the Friedman Test showed there was no significant difference in scores at the three time points (x^2 [2, n=8] = 2.77, *p*=0.25). Inspection of the medium values showed a decrease in confidence levels from pre-intervention (*Md*=72) to post intervention at 3 months (Md = 71) and a further follow up at 6 months *(Md=65*) shown in **Table 33.**

Table 33: Descriptive Statistics for the CaSM Scores of Participants in the Intervention Group

Descriptive Statistics				
		Percentiles		
	n	25th	50th (Median)	75th
TS Baseline	8	66.75	72.00	81.00
TS 3 Month FU	8	62.25	71.00	74.75
TS 6 month FU	8	61.75	65.00	75.00
Group = intervention				

5.4 Discussion

Outcome measures used in stroke rehabilitation interventions that have the sensitivity to adequately detect change are limited (Wolf et al., 2015). It was disappointing that the CaSM did not demonstrate a statistically significant difference in the CaSM score over time, but perhaps not surprizing. The study lacked rigor in terms of sample size, a sample of eight was not a large enough sample to be confident in these results.

Three cases were excluded because of missing data <10%. This made a difference to the analysis as the study already had a small sample. Two incomplete data sets missed the penultimate page. The questionnaire was double sided; it was therefore likely participants missed these questions as opposed to any complex reasons for not completing the CaSM. Missing pages were identified as a problem in the validation study. A follow up call to the participant from the researcher, resolved this issue, which was acceptable to participants. Missing data on a questionnaire is more likely to occur when the questionnaire is lengthy (Edwards, 2009). Although the analysis in this study was conducted on 27 items, the CaSM administered in the RCAS study was the 53 item questionnaire. The third case excluded from the analysis had completed the first two pages and the last page, whereas the middle pages were incomplete, suggesting the participant may have got bored, which has been identified as a common reason for incomplete questionnaire data (Boynton and Greenhalgh, 2004). Incomplete data is less likely to happen in a shorter questionnaire (Edwards, 2009).

The participants' base line scores appeared to be high. Participants may have had higher confidence scores by chance, or the intervention group might have had higher confidence levels than would be expected for people targeted to participate in an intervention designed to improve confidence. For example, one participant had a score of 68, the score on the CaSM ranged from 0 to 81. Given the CaSM is a developing measure, it is hard to know if a high score may be more difficult to change than a lower score, but would benefit from further examination.

The data collection methods were different at baseline, than they were at the three and six month follow up period. In the RCAS study, a member of the research team typically completed the measures at baseline, whereas at the 3 month and 6 month follow up the measures were self-completed and returned by post. The difference in score may have been due different data collection methods. Careful monitoring of these methods to understand if they had an effect on change scores or to ensure administration was the same at each time point, should be considered at the design stage of any research to further test the CaSM's sensitivity.

As a newly developed measure, the CaSM perhaps needs further refinement to have the ability to detect change after an intervention. A confidence construct has not been measured after stroke previously and the construct of confidence is a particularly difficult construct to capture in a measure, given its multi complex components. In sport research confidence is found to fluctuate at different times in an event calendar (Vealey, 2009) which makes capturing change after an intervention challenging. However, finding ways to improve confidence after stroke is a research priory and therefore finding ways that enable stroke clinicians to capture improvement is important.

If a statistically significant difference was detected in this study then it would have been necessary to conduct a post hoc test, to compare the three time points to examine at which point the most change was occurring (Pallant, 2013). This would be also necessary to calculate an effect size. The Wilcoxon tests for post hoc comparisons is considered an appropriate test for this purpose (Field, 2009). If a post hoc test was conducted with a large sample size, the advice is to use Bonferroni adjusted alpha to control for a type I error (Pallant, 2013). It was felt that a post hoc test would show no statistically significant differences, as the main analysis demonstrated non-significant results; there was little point in conducting this analysis in this current study. However, this would have been conducted in the event of a significant result.

The RCAS was a feasibility study. There was no existing evidence that this intervention was effective. It could therefore be the intervention or any components of the intervention that was not effective. Further research to examine whether any of the other measures used in the RCAS trial demonstrated a positive change is likely to give some indication if it was the CaSM performing poorly in the measurement of change, or the intervention that was not effective.

5.4.1 Strengths and limitations

A strength of this study was that sensitivity of the measure was examined in the early stages of instrument development. It was fortunate that a confidence intervention study was running concurrently with the development of the CaSM, and an opportunity to conduct this research was taken by the researcher.

The main limitation in this study, as previously reported, was the small sample size. However, it is envisaged further examination to assess the CaSM's sensitively with a larger sample will be undertaken.

5.5 Conclusion

To conclude, in terms of detecting a change score after a confidence intervention the results did not reveal statistically significant difference between the CaSM score before and after intervention. This could have occurred due to chance. The participants scores decreased from pre intervention to post intervention at three months, and decreased further at six month follow up. However, evidence that the confidence intervention is effective is currently inconclusive. The randomised control trial used to assess the sensitivity scores of the CaSM, was a feasibility study. Therefore, further research is needed to assess whether it was the properties on the CaSM are sensitive to measuring change, or whether the intervention, or components of the intervention, were not effective. As Steiner and Norman (2008) suggested '..*it is hard to disentangle characteristics of the instrument from characteristics of the treatment*' (P284). A further examination of the CaSM's properties, in relation to change is needed.

The next stage of development was to assess the concurrent validly of the CaSM in a clinical environment. This correlation study is defined and described in chapter six.

Chapter Six

6. Concurrent validity

A confidence measure is considered important, as it is likely to enable researchers and clinicians to target treatment and evaluate the clinical effectiveness of stroke rehabilitation interventions. If the CaSM is to be used as intended, it is necessary to demonstrate it is a valid measure. The previous chapters have reported that the CaSM has demonstrated face and content validity, tested during the piloting phases. The CaSM has also demonstrated good construct validity, evaluated by examining the item-total correlation, and a factor analysis technique. It has shown to have good convergent validity, by correlating significantly with the SSEQ (Jones et al., 2008).

When a new measure has been developed, it is considered best practice to test that the measure is directly related to another well-established measure for the same construct, referred to as criterion validity (Fayers, 2005). When assessing two different measures at the same time it is described as concurrent validity, a type of construct validity. Concurrent validity is important to establish as it is an indicator that there is a consistent relationship between the scores on the two measures (Streiner and Norman, 2008). Correlation methods are commonly used, as it is the strength of the relationship that is of interest (DeVellis, 2012). The higher the correlation the more confidence we can be that the same construct is being measured.

The issue in this correlation study was that there were no known established measures that could be used. It has already been identified that the only similar measure available for stroke participants was the 13 item SSEQ (Jones et al., 2008). This measure has also been newly developed; therefore to describe it as an established measure may be questionable. It has also been reported that this measure did not include social and psychological components of confidence that are included in the CaSM. The best available alternative assessment of confidence was considered to be therapists' opinion.

One of the core skills of occupational therapists has been defined as the ability to build and improve the confidence of their patients. NHS Choices, the UK's biggest health website, describes occupational therapy rehabilitation as helping to get the most out of life. '*It (*Occupational Therapy*) is used to help gradually build your confidence and establish meaningful roles, that you may have otherwise avoided*' (NHS, 2014). The Canadian Association of Occupational Therapists' described occupational therapists' role as being able to use activity to help improve confidence and self-belief (CAOT, 2014). This literature suggested that occupational therapists' opinion could be used as a well-established method of assessing a stroke survivors' level of confidence.

To gather therapists' opinion, a visual analogue scale was considered an appropriate measurement method that was likely to easily, quickly and accurately capture an occupational therapists' opinion on a continuum, to assess a stroke patient's level of confidence. Visual analogue scales are believed to capture an underlying continuum that is not easily directly measurable (Crichton, 2001), such as confidence. The continuum was chosen as it was likely to capture a snapshot opinion from the occupational therapist, without having to consider an interval response, such as ‘do you think this person is confident’ ‘all of the time’ or ‘some of the time’. Bandura (2006) suggested the 0-100 scale method is more sensitive and more reliable than a five point interval data response. Although, Hasson and Arnetz (2005), suggested the Likert scale and the VAS have been shown to be equal in terms of statistical performance, the authors suggested a VAS is thought to more closely represent respondents experience. Pragmatically, a VAS, where a single line on a continuum was required from the therapist, was considered an appropriate method to administer in a clinical setting.

The study hypothesis was that the CaSM would demonstrate a high correlation (>0.7) with the well-established criterion of therapists’ opinion.

6.1 Methods

6.1.1 Ethical approval

The Confidence after Stroke Measure – Stage 3 protocol, consent forms and participant information sheets received favourable opinion from the NRES Committee, South Central Hampshire on 23rd July 2014, REC reference number 14/SC/1154, protocol number 14068 and IRAS project ID 158459, see [Appendix 33].

The National Health Service (NHS) Research & Development (R&D) approvals were also granted by the following.

- Nottingham City Care Partnerships, research and development approval letter dated 12th January 2015.

- Derbyshire Community Health Services, research and development approval letter, reference DCHS/2015/001, dated 22nd January 2015.
- Derby Hospitals NHS Foundation Trust, research and development approval letter, reference DHRD/2014/083, dated 29th January 2015.

The study was adopted by the comprehensive local research network (CLRN) and monthly recruitment data, was required and monitored.

6.1.2 Study design

A correlation study to test the relationship between the CaSM score completed by stroke rehabilitation patients in the community and a VAS rating scale [Appendix 34], completed by occupational therapists, was conducted to ascertain the concurrent validity of the CaSM.

6.1.3 Inclusion

Inclusion criteria for the stroke participants were that they were over the age of 18 years and they had experienced a stroke.

Therapists were required to have at least one assessment visit with the participant to be eligible to complete the rating scale.

6.1.4 Recruitment

Three NHS sites were identified in the East Midlands, and were geographically convenient. Site one a community stroke team (CST), sites two and three, were early supported discharge teams (ESD). Sites one and two were city teams and site three was based in a rural community.

6.1.5 Clinicians

Three clinical stroke rehabilitation teams that were geographically convenient, Nottingham City, Derby City and Derbyshire County consented to participate. Clinically experienced occupational therapists located in these services, were visited by the researcher, and were given written and verbal information about the study. They were given the opportunity to ask questions, and time to consider participating. A signed consent form indicated a willingness to participate in the study.

6.1.6 Stroke survivors

Potential stroke participants receiving stroke rehabilitation in the community were informed about the study by their usual care occupational therapist, who had been briefed by the researcher.

Occupational therapists located in the above clinical teams identified patients who were potentially willing to complete the CaSM. The therapists handed the potential participants a study pack, and they were invited to read the study information. Completion and subsequent return of the CaSM questionnaire was taken as implied consent. If any additional help or clarification was required by the participant, the clinical team and the researcher were available for help. The contact numbers were given.

Any stroke participants who did not return questionnaires were not followed up, on the assumption they did not chose to participate.

6.1.7 Study procedures

The study pack for stroke participants included a 27 item CaSM [Appendix 1], patient information sheet [Appendix 35], a contact sheet, and a stamped addressed envelope. Principal investigators at each site were given a site folder, which included background information, study procedures, blank copies of the VAS (OT) rating scale, see [Appendix 34], blank copies of the MRS see [Appendix 9], and stamped addressed envelopes. The sites were asked to contact the researcher if further packs were needed.

Once the therapist had left a study pack with the potential participant, the therapists independently completed the VAS (OT) rating scale and MRS (Rankin, 1957). They were asked to place the VAS and MRS in a sealed envelope and post them to the researcher. A study log which included ID number and contact information (including the location of the clinical service) was stored on an Excel and SPSS databases, both were password protected. The data were checked monthly for accuracy.

Participants completing the CaSM sent the contact sheet and the questionnaire to the University of Nottingham in a stamped addressed envelope. The researcher inputted the contact sheet information onto the study database, and allocated a study number. The contact sheet was separated from the CaSM and stored separately in order to protect participant's identity. The site number and participant's initials were used to match the participants' CaSM to the OT rating scale. In the event of more than one participant with the same initials from the same site, it was agreed the researcher would contact the clinical team to clarify details, as a contingency. No further involvement in the study was required by the participant, and the participant continued to receive usual care.

Missing rating scales were followed up with a single telephone call or email from researcher to the therapist, to collect any missing data.

6.1.8 Measures

The VAS [Appendix 34] was used for therapists to rate participants' level of confidence. The VAS was numbered 0-100 and each 'block' measured 10mm, therefore each mm represented a point from 1-10. A line was drawn by the therapist to represent the level of confidence of the participant between 0 (no confidence at all) to 100 (could not get any more confident).

The CaSM's 27 individual items were scored. The previous version of the CaSM scored each item, 4,3,2,1, from strongly agree to strongly disagree, and reversed for negative responses 1,2,3,4. Therefore, on a 27 item scale the total score ranged from 27-108. As a total score range of 0-81 was more appropriate, positive items were recoded to

3,2,1,0 representing, strongly agree to strongly disagree, and reversed for negative items 0,1,2,3. The CaSM total score ranged from 0–81.

The Modified Rankin Scale was completed by the therapists, to assess stroke severity, in order to describe participants' characteristics.

6.1.9 Sample size

A minimum sample size of 13 was calculated using a computer programme, ©G power (Faul et al., 2007). Significant levels were set at *p*=0.5, and probability of a type II error at 80%, and a strong association r=>0.7 (Cohen, 1988) was assumed. However, this sample size was calculated as the minimum. A sample size of 40 was deemed a reasonable target sample size for correlation research, on the basis that you cannot over sample, yet small enough for the data to be manageable and not over burden clinicians.

6.1.10 Data analysis

The study findings were analysed using IBM© SPSS statistics version 22 software. Correlation analysis was used to describe the strength and direction of the relationship between scores on the CaSM, completed by stroke participants, and a confidence rating score completed by occupational therapists. A Spearman Rank Order correlation (rho) was used because a histogram to show the distribution of the data revealed the data were not normally distributed and the sample size of 31 also makes such an assumption questionable.

6.1.11 Missing items

Missing values were dealt with on a case by case basis. If there was evidence of less than 10% of missing item on the CaSM, a mean score on each of the items was used to replace the missing items. If there were more than 10% of missing values the case was excluded from the analysis.

6.2 Results

The data were checked for missing values and outliers. One page of one CaSM questionnaire was missing, and was later retrieved, by telephoning the participant. Out of the remaining possible 841 responses (100%), six (0.7%) items were missing, the missing items were analysed for patterns, such as, the same item demonstrating a non-response. No pattern was observed. Mean values of each item was calculated for these small number of missing items. No cases were excluded. No outliers were observed. No rating scales were missing.

Occupational therapists who participated in the study are described in **Table 34.**

Table 34: Occupational Therapists Characteristics

SITE	BAND	GENDER	Data Collected *n*	%
Site 1	5	Female	1	3
Site 1	6	Female	2	6
Site 1	7	Female	7	23
Site 2	7	Female	3	10
Site 2	6	Female	12	39
Site 2	7	Female	1	3
Site 3	7	Male	5	16

The characteristics of stroke participants are described in **Table 35.**

Table 35: Characteristics of Participants

Participants n = 31			
Years			
	Mean	**SD**	**Range**
Age in years	69.71	17	35-95
Time since stroke (Weeks)	7.06	5.73	0.3-26
Score CaSM [0-81]	47.32	10.14	17-67
Score Therapists Rating Scale [1 -100]	59.61	17.64	20-92
	n	**%**	
Men	12	39	
Women	19	61	
Stroke Service			
Site 1 (CST)	10	32	
Site 2 (ESD)	16	52	
Site 3 (ESD)	5	16	

Modified Rankin Scale (MRS)	***n***	**%**
No significant disability	1	3
Slight disability	6	19
Moderate disability	21	68
Moderately severe	3	10

A scatter plot was computed to illustrate the correlation results, see **Figure 10**.

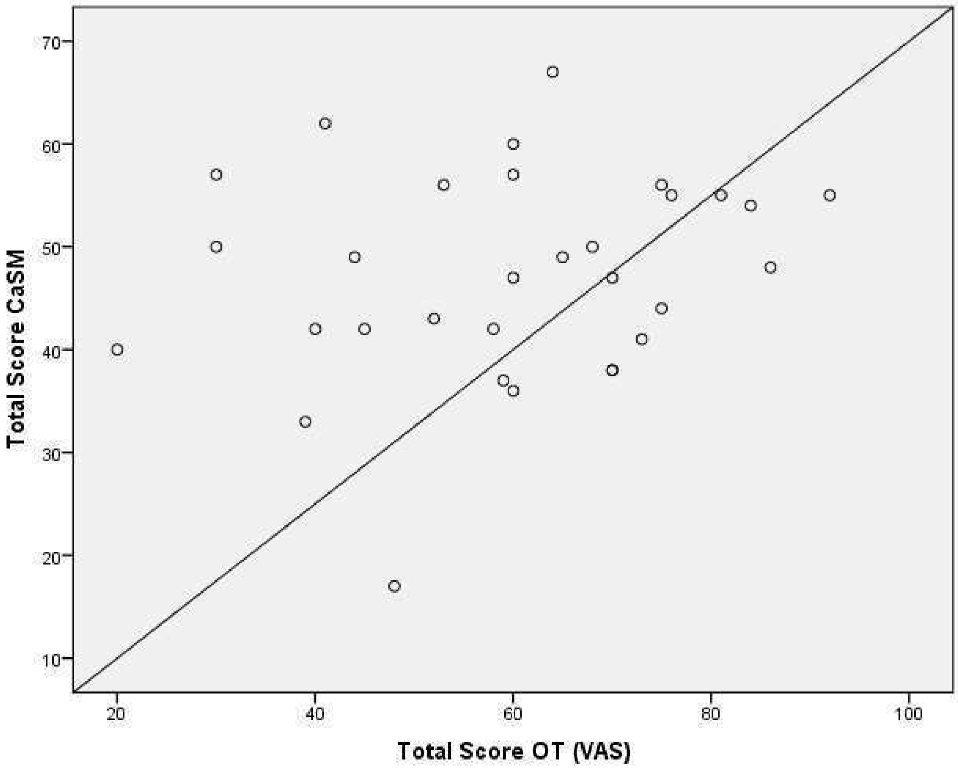


Figure 10: Confidence Score Correlation

There was a small positive correlation between the scores on the CaSM and the scores on the VAS (OT) rating scale, r_s=0.18, *n*=31, *P*<0.338, which was not statistically significant.

6.3 Discussion

The results of this correlation study did not support the hypothesis. A high correlation between the two measures was not demonstrated, and the concurrent validity of the CaSM not established using this method. Whilst a low correlation when using therapist's opinion is perhaps not surprising, such a low correlation was not expected. There are various reasons why this might be the case.

Firstly the study may have lacked statistical power. This study under recruited, and the final sample size was n=31 therefore the results may not have had the statistical power to detect a relationship. However, ©G power (Faul et al., 2007) suggested a minimal sample of 13 would be adequate, but such a small sample is not likely to be enough to capture adequate data. Nevertheless, the scatter plot did not suggest there was a relationship and failed to reach statistical significance.

The theory of using well established measures to assess concurrent validity, is typically based on selecting a measure that has had extensive use in clinical practice, and has demonstrated good measurement properties (Streiner and Norman, 2008). Using therapist's opinion as the gold standard is not as robust as using a known, valid and reliable measure. Nevertheless, it was expected that the therapists' would be aware of participants' level of confidence. It may be that one treatment session prior to completing a rating scale did not enable the therapists to assess their patients' confidence levels as they might if they had longer to establish a therapeutic relationship. A measure of confidence may be the objective measure needed to help with assessment of confidence after a stroke.

Another explanation for the low correlation could be the properties of the CaSM are not adequate. Confidence is not a construct that can be observed in the same way that physical impairments can be observed, and therefore it can be more difficult to measure (DeVellis, 2012). However, given the rigorous development based on qualitative interviews this would seem unlikely.

It is also possible, that occupational therapists' may not be expert at assessing confidence. Although their professional philosophical underpinning teaches a holistic approach and is assumed that enabling a person to build up their confidence is a core skill, there is no known published evidence to support their ability to assess levels of confidence. The range of the scores on the VAS (OT) was broad 20-92, suggesting they were able to recognise differences between participants. Previous research has found discrepancies in patient views and clinicians views when measuring outcome, in many areas of healthcare (Lamping et al., 2002). It would appear this was a possibility in this study. There may be some justification for conducting a sub analysis on the different sites, or individual therapists, to determine whether these results are general, or site or therapist specific. Although, the sample size was too small; but may warrant some further research in the future.

Stroke patients are typically treated by Multi-disciplinary teams, based on best evidence (Intercollegiate Stroke Working Party, 2012), it may be useful therefore, to examine how other members of the team assess the confidence of stroke patients, to investigate whether low confidence has being highlighted and therefore treated by any of the MDT after stroke.

An alternative approach to assess the CaSM's concurrent validity would be to measure it against a gold standard measure. A measure was not available for this purpose, when this study was designed. A new confidence measure, the 'Daily Living Self-Efficacy Scale' [DLSES] has been recently developed in Australia. Maujean et al., (2014) developed this measure in parallel with the CaSM design and development. Although this measure is described as a '*daily living self-efficacy scale*' the items in this scale appear to have some commonality with the CaSM. Whilst the CaSM has three components the DLSES has two. The DLSES domains are described as '*activities of daily living' and* '*psychosocial*'. The CaSM's self-confidence component includes items relating to '*doing*' and '*everyday tasks*' and takes a more generic approach to activities of daily living, whereas the DLSES, uses more specific descriptions, such as, '*Either do or arrange to have the shopping done.*'

The positive attitude component of the CaSM has items, such as, '*I believe I can achieve what I want to*' compared with the DLSES '*Not allow feelings of discouragement to stop me from doing the things I want to*.' Finally the third component on the CaSM, social confidence, includes an item '*I do not feel able to attend a social event*' which appears to be comparable to '*Attend an event or go places on my own*' on the DLSES. The DLSES, as with the CaSM is in its development stages. However, it is reassuring that the need and development of a confidence after stroke measure has being identified in another country.

The interest and importance of research relating to confidence and stroke appears to be gaining momentum (Jones et al., 2013).

As the sample was not randomly selected, it does pose the question as to whether the sample in this study was a representative sample. Two out of the three sites were early supported discharge services. People with severe strokes were not eligible for these services, the results of the Modified Rankin Scale indicates that the majority of people (68%) in this study had a moderate disability (Rankin, 1957). Including people with severe strokes may have altered the results. However, the results do appear to indicate that lack of confidence is common, regardless of level of impairment, which was a finding in the interview study reported in chapter two (Horne et al., 2014). Approximately two thirds of participants in this study reported mid to low confidence. Although this may not be related to concurrent validity, it does broaden our knowledge about confidence and stroke.

The study limitations are as follows. The inclusion criteria in the current study required occupational therapists to assess a stroke participant's level of confidence after a minimum of one intervention. This may not have been enough clinical time to develop a therapeutic relationship with the stroke participant. It may have been useful to record the proportion of therapists' that saw a participant once prior to making a judgment about their confidence, but this was not done. Assessing a person's beliefs in their abilities to do want it is they want to do, may need more time, in order to be able to make an accurate assessment. Confidence, as a psychological construct is not directly measurable (Babbie, 2015, Streiner and Norman, 2008) and may not be as easy to assess as putting on a jumper, for example. Therefore, if the therapists conducted more than one intervention, their rating scale assessment may have shown different outcomes. Future research could look at sub-dividing participants between those who were assessed after one session and those that were assessed after more. Secondly, a sub-analysis by sites may have given some indication whether the correlation differed between services or therapists.

The recruitment was poor. One of the reasons may be limited time allocated for this purpose. Although ethical approval was received in July 2014, there was a delay of six months getting NHS Research and Development approval, which delayed the start of recruitment. The process of getting NHS Research and Development approval has been identified previously, as being time consuming and complex (Whitehead et al., 2011). It is difficult within time constraints of a PhD study, to ensure adequate time for recruitment procedures are planned, and contingency measures are in place. Nevertheless, it is part of any research procedure and must be given adequate thought and time.

Confidence, as measured on the CaSM, has three components, Stroke participants may have demonstrated high levels of social confidence, for example, but might be less confident doing everyday tasks, whilst the CaSM aims to capture this scenario, the VAS (OT) rating scale captured a generic confidence score. An analysis of the subscales would have been useful to check this. Therapists may have had a dilemma, in terms of how to interpret a participant’s confidence with one score.

Another limitation in this study was using a visual analogue type scale for the collection of therapists' opinion. The 'mark' may not mean the same to all people (DeVellis, 2012). Therefore, one therapist may have scored '60' whereas other may have scored the same person '50' despite observing the same scenario. However, Bandura (2006) suggested a 1-100 scale is more reliable than using units of intervals. It has to be acknowledged that no measure is going to capture everything you want it to (Bowling, 2014), therefore, making informed choices, with the best available evidence, was the basis on which this study was conducted.

The study avoided a single centre bias. However the sample was small and the study would need to be repeated on a larger sample, with stroke patients demonstrating a broader range of impairment, to be confident in the results.

In hindsight, the subjective opinion of therapists should not have been used as the 'gold standard' criteria, to evaluate a measure, as we cannot be assured that this was a valid or a reliable measurement. Finding a measurement property that is able to test concurrent validity in order to persuade the potential users of the measure that it captured confidence, was difficult and is a common problem in measurement development (Polit and Yang, 2016). Many patient reported scales involve asking patient to report on conditions or statues through other means. These 'other means' suggest (Polit and Yang, 2016) could be a suitable criteria. If this study was to be repeated, an alternative approach could be to ask patients themselves to indicate their level of confidence on a VAS similar to the one completed by the Occupational Therapists, and correlate the scores. An increased sample size to 100 is recommended for the study to be grated as excellent on the COSMIN checklist (Terwee et al., 2012).

6.4 Conclusion

The concurrent validly of the CaSM, was not established in relation to therapists scores on a VAS rating scale of confidence. The results demonstrated a small positive correlation that was not statistically significant. Future testing of the CaSM concurrent validity could use other measures, such as the Daily Living Self-Efficacy Scale (Maujean et al., 2014) or the refined SSEQ (Riazi et al., 2014), which have recently been published. The CaSM demonstrated good reliability and validity in the previous study, suggesting that a discrepancy between patient and clinicians rating may reflect factors other than lack of concurrent validity.

Chapter Seven

7. Responsiveness of the CaSM

7.1 Background

The previous chapters have described the systematic development of the CaSM. This final chapter, prior to summing up and concluding this thesis, aims to investigate the potential ability of the CaSM to '…*measure a meaningful or clinically important change in clinical state*' p85 (Liang, 2000), defined as responsiveness to change.

In clinical trials it is suggested that measures, specifically quality of life measures, do not perform well at detecting small but clinically meaningful changes (Fayers, 2005). Despite many years of attempting to find the best methods to detect clinically important changes in outcome measures, no one method is found to be ideal, and a standard that is universally accepted is yet to be determined (Copay et al., 2007, Streiner and Norman, 2008, Gatchel and Mayer, 2010). Despite, hundreds of articles and texts written on clinical significance, the '*thorny*' issue of interpreting change scores are still being discussed (Polit and Yang, 2016).

It is considered important to assess the responsiveness to change of a measure, such as the CaSM, because it enables clinicians to inform patients about what might have changed after their treatments or interventions (Jacobson and Truax, 1991). Quality of life instruments are used increasingly in clinical trials, and determining the statistical significance of change is considered relatively simple. However, Juniper et al., (1994) argued that interpreting statistically significant results so that they have a relevance for health professionals, has not been easy. Patients themselves need and want to be able to understand the impact that interventions have on their recovery (Copay et al., 2007), a meaningful change score on a measure may be a way of informing them.

An expert panel of stroke clinicians was one approach considered to ascertain views and opinions of clinicians and researchers, on what may represent a clinically meaningful change score of the CaSM. A consensus panel is a method used to bring together a group of experts to discuss a specific topic, with the aim of developing a consensus (Bowling, 2014). A group approach, such as a consensus panel, is useful to capture views on whether evidence based practice is adequately captured in the questionnaire (Rubin and Babbie, 2009) and to establish how and why clinicians think in a particular way (Kitzinger, 1995). Opinion informed by years of clinical experience may be valuable, and Streiner and Norman (2008) argued, experts often represent the most recent thinking. A disadvantage of expert groups is that they can be biased, and therefore may not reflect a range of opinion (Streiner and Norman, 2008), this could be overcome by careful selection of the experts.

The views of researchers with experience of measurement in clinical trials, for example, coupled with expertise in working with stroke patients may be different from clinicians who are not as experienced in research methods. Their views, however, are likely to add value in terms of their clinical everyday experience, as to what is considered clinically important. Rubin and Babbie (2009) recommended testing a newly developed scale with practitioners, some who have research experience and other who do not, because it is an additional test of a scale’s validity.

The size of the group is also important, too large and it might have been difficult to manage (Earl-Slater, 2004), larger groups may also result in some participants not contributing to the discussion. However, a small sample may limit the statistical procedures that may be appropriate for establishing a change score. Steiner and Norman (2008) suggested there are no clear rules, but recommended three to ten is appropriate number for an expert panel.

Case vignettes were used as they are likely to give clinicians, a basis to help them understand what represents a clinically important change. As there is no recognised standard for establishing a measure’s responsiveness, this method to test the CaSM’s clinical relevance and important change score may be appropriate.

Statistical procedures to determine a clinically important change are commonly established by calculating the mean difference in item or total score (Juniper et al., 1994). Calculating the effect size is another common method (Streiner and Norman, 2008). However, the former was considered as the preferred option because it is suitable for smaller samples.

The study aim was to determine a clinically meaningful change score on the CaSM. The research question was:

- How many points on the CaSM would a stroke patient need to change, to make a minimal clinically important difference?

7.2 Methods

Ethical Approval from the NHS Research Ethics Committee, Hampshire South was granted, REC reference number 14/SC/1154.

7.2.1 Expert group recruitment

An invitation email was sent to three, geographically convenient, NHS clinical services in the NHS and research departments at the University of Nottingham. Potential participants were sent brief details of the study and asked to express an interest in taking part, by sending their name to the researcher. Interested clinicians were later contacted by email and asked to send the researcher their availability, if they were willing to participate in an expert group.

7.2.2 Expert group procedure

Prior to the start of the expert group session, a participant information sheet outlining details of the study was given to the clinical expert panel. If they were willing to participate they were invited to sign a consent form.

A meeting room in a hospital building, which was familiar to participants, was the chosen setting for this study. A context for the session was set by the researcher who presented the development of the CaSM to date.

The session was scheduled for two hours, and was digitally recorded using an Olympus© voice recorder.

7.2.3 Measures

Case studies

Three case study vignettes were developed informed by stroke survivors. Each case study was based on a stroke survivor who had been involved in this programme of study. The case study information was collated through interview, observation and personal correspondence. Where further information was required, the researcher added information based on her own clinical experience of being a stroke rehabilitation occupational therapist. The case studies were verified as representative of stroke survivors demonstrating low confidence by a research supervisor (PL) who is also a clinical therapist. See, [Appendix 36, 37 & 38] for copies of the case studies.

Background information, pre-stroke activities, impact of stroke and context were included in the case studies to illustrate what may have impacted on a person's confidence levels, such as, being conscious of other people's comments, being easily discouraged, role and skill loss and the importance, or not, of goal related activity.

The purpose of the session was explained to the group. Firstly participants read the case study vignettes. They were asked to imagine how each stroke survivor portrayed on the case studies, would complete the CaSM. Clinicians independently completed the CaSM for each of the three case studies, and a total score for each one was calculated.

Participants were asked to repeat the exercise, imagining they had delivered an intervention that focussed on improving confidence. Participants were asked to assume the intervention had gone well, and to complete the CaSM again, for each of the three case studies. Once the exercise was complete, participants were encouraged to discuss any reasoning that might have underpinned their scores.

7.2.4 Consensus Panel of stroke experts

After the experts had rated the vignettes they were asked to reach a consensus by debating what they felt would represent a suitable minimal clinical change score, when using the CaSM with a stroke patient. The researcher facilitating the group session (JH) suggested they consider the clinically important items on the CaSM to help to decide what they considered constitutes a minimal important clinical change.

At the end of the expert group session, clinicians were thanked for their contribution to this research.

7.2.5 Data management

Two copies of the CaSM were collected from each clinician, for each case study. A study ID was issued and the data were analysed using IBM ©SPSS statistics software package version 22.

7.2.6 Data analysis

The data were analysed using descriptive statistics. The total CaSM raw scores derived from using the vignettes which represented pre-intervention (time 1), and post-intervention (time 2), were input onto the SPSS database. The experts' raw change scores were calculated and totalled for each vignette. The final analysis involved calculating a total mean change score, standard deviation and range from the three vignettes. The minimum and maximum ranges were examined to check for errors. The data were also examined for missing values.

7.3 Results

7.3.1 Participants

Seven stroke clinicians agreed to participate in the study and their demographic information is described in **Table 36.**

Table 36: Expert Group Characteristics

	Gender	**Profession**	**Role**
R01	Female	Occupational Therapist	Researcher/Clinician
R02	Female	Occupational Therapist	Clinician
R03	Female	Occupational Therapist	Clinician
R04	Female	Physiotherapist	Stroke Service Manager/Clinician
R05	Female	Occupational Therapist	Researcher/Clinician
R06	Female	Occupational Therapist	Researcher/Clinician
R07	Female	Occupational Therapist	Researcher/Clinician

7.3.2 Change scores

The scores on the CaSM after reading the case study vignettes are shown in **Table 37.**

Table 37: Total Change Scores

All participants **=7**	**MR M**		**Change Score**	**MRS C**		Change **Score**	**MS F**		**Change Score**	**Total**
	Time1	Time2		Time1	Time2		Time1	Time2		
R01	28	40	12	33	42	9	21	36	15	
R02	40	55	15	25	47	22	27	42	15	
R03	44	62	18	36	47	11	52	51	1	
R04	37	54	17	28	51	23	35	50	15	
R05	24	35	1	13	23	10	46	39	-7	
R06	32	40	8	42	47	5	35	37	2	
R07	28	37	9	32	39	7	21	32	11	
Mean	34.71	46.16	11.43	19.86	42.29	12.43	33.86	41.11	7.43	10.43
SD	6.02	10.60	5.52	9.23	9.36	6.63	11.95	7.16	8.16	2.65
Range	28-44	35-62	1-18	13-42	23-51	5-23	21-52	32-51	-7-15	-7-23

The average change score deemed to be clinically significant was ten points.

7.4 Discussion

The results indicate a difference of ten points. However, there was a consensus within the group that the case study method used was difficult to undertake and deemed as *‘a bit abstract.’*

The experts identified items on the CaSM that were deemed as clinically important, to enable them ascertain how many minimal change points they would recommend.

Items which had the most support for being clinically important were described as:

- I avoid important everyday tasks
- It is hard for me to achieve my goals
- I am confident to leave the house
- I am able to attend social events

The outcome from the vignettes exercise, showed a mean change score of ten points (n=7, *sd* =2.65) on the CaSM. It is important in clinical trials to find the *minimal* important change score in a measure (Fayers, 2005, Perera et al., 2006, Juniper et al., 1994), researchers are likely to have such knowledge through conducting clinical trials. However, clinicians focussing on making a difference though their clinical interventions may not.

It may be noteworthy that there was a wide range of scores shown in both groups. The difference in the groups however, perhaps justified the need for integrated discussion to capture a range of clinical opinion when attempting to establish a minimal change score.

Despite differences in change scores, shown in the quantitative data, the consensus panel demonstrated high levels of agreement, through discussion as opposed to big differences in opinion. The group was a manageable size and contributions from each group member were observed.

The consensus of the expert panel suggested that four points would represent an acceptable change score on the CaSM questionnaire. In arriving at this conclusion it is acknowledged that this study had a number of both strengths and limitations.

It is thought that the outcome of this study has provided a useful indication of what is considered to be a minimal clinically important difference by the consensus panel. A strength of this study therefore, was that a minimally significant change score was established with stroke clinicians. This can be used to inform future research, especially power calculations for intervention studies.

7.5 Limitations

The main limitation of this study was the sample size; using larger groups of clinicians may have given more confidence in these results.

Using a mix of clinicians, stroke survivors and researchers may have yielded different results collating a broader range of opinion.

The methods of recruitment could have introduced bias into the study, as the recruitment selection was through personal contact and involved experts who were geographically convenient. Random sampling may have limited any bias, and improved the generalisability of the findings; however, random sampling is rarely used to recruit experts. Other methods may be worth considering, when seeking a consensus, is to recruit using the databases of health professional membership bodies, such as, the College of Occupational Therapists' or the Royal College of Physicians. The content of the vignettes could be developed and the number of vignettes could be increased. This method could reduce bias and increase the sample size.

Using narrative in the case study vignettes to make a clinical assessment was challenging for the clinicians. The CaSM was designed to be a self-reported measure; therefore completing the measures as clinicians, having to predict how a stroke survivor might answer, was perceived as difficult. It was recommended the study design may have been improved by using video footage or by including stroke survivors themselves.

An alternative method would be to use the CaSM in clinical practice, and ask stroke survivors about what is a meaningful change score. This score could be compared to health profession opinion.

Despite the limitations in the methodology, this study resulted in a consensus, through change scores and opinion and provides a starting point from which further research could be conducted.

7.6 Conclusion

To conclude, the CaSM has potential to detect a clinically significant change. Clinicians' likely to be administering the CaSM in a clinical context, need to be able to interpret the results so they are meaningful to themselves and their patients. Using the CaSM in clinical practice to evidence a change in confidence, in order to share improved outcomes with stroke patients, stroke clinicians and commissioners of stroke services, for example, was the primary reason for conducting this research.

Chapter Eight

8. Summary of Results

This thesis presents a number of studies that collectively report the design, development and evaluation of a Confidence after Stroke Measure [CaSM]. The studies are related and follow a logical sequence. The strengths and limitations of each study have already been presented, along with an interpretation of the results. This final chapter therefore, aims to provide a summary of this programme of research. The chapter reviews and reports the study's strengths and limitations. It makes recommendations for the development of research related to confidence after stroke, and a main conclusion is drawn.

8.1 Overall findings

The aim of this thesis was to contribute to the evidence that improves life after having a stroke. A measure of confidence [CaSM] is the first known measure of confidence that incorporates social confidence, in the UK. The development of a measure, found to be valid and reliable in our study population, has been achieved.

In order to accomplish this, it was necessary to determine what confidence meant to stroke survivors, to further understand the construct. The key findings in the interview study, conducted to explore this phenomenon, indicated that low confidence was common, regardless of level of impairment. Social interactions were particularly fearful experiences for stroke survivors, which was not surprising as this has been identified in a number of other stroke related studies

(Maujean, 2013, Boden-Albala et al., 2005). Successful engagement in meaningful roles provided the motivation to try harder to do whatever it was stroke survivors wanted to do. The active ingredient of 'doing' helped build up positive self-beliefs, and reinforcement from family and friends contributed to enabling a gradual rebuilding of confidence and competence. This meaning was created from the study's developed themes and underpinned what was felt important to capture in a confidence questionnaire. This study also enabled the development of a definition of confidence that was used to underpin the questionnaire. Confidence after stroke is defined as:

> *'A combination of self-efficacy, self-esteem and input from the environment that influence individual belief in the ability to do, what a stroke survivor wants to do.'*

Whilst this is closely associated with a self-efficacy construct, it differs from other work that is been conducted in stroke rehabilitation. The CaSM is underpinned by a broader definition of confidence that is not a pure self-efficacy approach. It encompasses, self-esteem, and some items in the CaSM use the word 'feel' in an attempt to capture low mood associated with low confidence and low self-esteem.

The primary goal of this research was to systematically develop a valid and reliable confidence measure that was clinically useful. The collaboration with stroke survivors at each stage of development was thought to contribute to the CaSM being acceptable to stroke survivors.

8.2 Strengths of this programme of study

8.2.1 Systematic development

The CaSM was designed using a systematic approach. A conceptual framework was developed using the COSMIN checklist (Mokkink et al., 2010) in addition to quality health measurement texts (Bowling, 2014, Streiner and Norman, 2008). These gold standard procedures guided the development and evaluation of the CaSM, and provided a format for reporting the study's findings. The strength of using these methods was to demonstrate the scientific merit of the CaSM.

This systematic process carefully pre-tested the items with stroke survivors and stroke experts, ensuring the questions and response scales were easy for stroke survivors to understand and self-report.

The assessment of internal consistency, construct validity, convergent validity, concurrent validity, sensitivity and responsiveness of the CaSM followed a methodological framework, defined by international experts, inferring the evaluation of the CaSM was conducted to a good quality.

8.2.2 Large sample

The CaSM was developed and psychometrically assessed using a large sample of stroke and healthy elderly participants living in the community. Ensuring the sample size was adequate suggests that we can be confident of the statistically significant results in this study. A large sample size also enabled a factor analysis to be conducted, deemed as a quality maker in questionnaire design. Many authors develop their questionnaires with an inadequate sample size for performing a factor analysis, resulting in flawed measures.

Attention to personalising letters, saying thank you, giving adequate information about how the results planned to be used, and providing a SAE for returning the CaSM, contributed to the target sample of 202 participants being achieved in the required timeframe. Postal questionnaires were found to be cheap and easy to administer, in addition to reducing bias by using a self-reported design, and therefore no direct involvement from researchers were required during the completion stage.

Acceptability was assumed by the small amounts of missing data, the test-retest response rate (94%) and the returned responses from an aphasia conversation group (13%). Stroke survivors are interested in the study of confidence after stroke. This was demonstrated by letters of support, for investigating confidence issues, attached to completed questionnaires.

8.2.3 Thorough psychometric evaluation

Many psychometric properties were accessed using the same sample. The reliability of the CaSM was repeatedly tested as the CaSM got shorter. A large sample and a large dataset has been known to artificially inflate alpha (Tavakol and Dennick, 2011), and as a Cronbach alpha result was one of two main tests of reliability, the CaSM maintained good internal consistency when the items were reduced. Systematic item reduction techniques were used throughout the study, resulting in reducing respondent's burden, whilst still retaining the psychometric properties of the CaSM. Each of the three components of the CaSM were also found to have high internal consistency, suggesting the items on each component, were measuring a similar construct, indicating the CaSM has the potential to be used as three separate measures.

The psychometric evaluation of the CaSM confirmed the hypothesis that stroke participant's confidence scores measured by the CaSM, demonstrated lower scores than the healthy elderly group, and the results were statistically significant. Similar methods to detect differences between gender and age were also conducted, adding to the scientific rigour of the CaSM. Hypothesis testing to evaluate construct validity is considered a good quality method, however, it is suggested the results are used with caution given this is one of the first measures of confidence developed after stroke. A further evaluation of the items to confirm they represent a confidence construct would be appropriate.

A factor analysis resulted in three component solution and conceptually reflected a construct of confidence which were thought to mirror the findings in the literature review and interview study. Care was taken to keep the research question at the forefront of the analysis, to avoid the plausible result of developing another self-esteem measure. This process could be viewed as strength or a weakness of the study. The process did not purely rely on the statistical information to define the best factor solution; the researcher's familiarity with the literature contributed to the removal of items. However, as this is a partially subjective process, there could be debate on as to whether each item that was removed was justified. Nevertheless, this is almost the point of an exploratory factor analysis. A confirmatory factor analysis is recommended to confirm these findings. A definite strength was a factor analysis was conducted on the CaSM with an appropriate sample size, and a three factor solution was derived.

8.2.4 Evaluation of sensitivity and minimal clinically meaningful change score

A further strength of this study was that the sensitivity to change as a result of a confidence intervention was evaluated. Assessing the responsiveness and sensitivity of a measure are listed in the COSMIN checklist, as indicators of methodological quality. Sensitivity to detect change is essential if the measure is to be used to evaluate a confidence intervention. However, partly due to the small sample size used when assessing the CaSM's sensitivity, this needs further attention and assessment.

A study to determine a minimally important change score was also undertaken. Responsiveness is important to assess, as clinician's often make decisions about effective healthcare on the basis of a change score (Polit and Yang, 2016). It is clinically important that the correct conclusions are drawn. Clinical experts assessed the responsiveness of the CaSM, suggesting a minimal important clinical change score of four as the benchmark from which to build. This clinically minimum important change score, would benefit from further evaluation. Interpreting a change score to ensure it is meaningful to patients, and clinician's, holds increasing interest for health measurement developers. To have a measure that is able to demonstrate a change, as a result of an intervention that is deemed important to patients themselves, is perhaps the ultimate goal of any measure and the goal of stroke rehabilitation.

8.3 Limitations of this programme of study

Limitations of each study have been reported in individual chapters. However, there are some limitations that are relevant to this programme of research.

8.3.1 Recruitment

Recruitment was primarily from one geographical area (Nottinghamshire). Every attempt was made to broaden the distribution of responses. However, the most successful recruitment strategy was when the questionnaires were delivered in person to a specific group. Recruitment from stroke conferences yielded the most diverse distribution of responses. Nevertheless, generally, the overall distribution was limited to the Midlands area, which has implications for the generalisability of the results.

The ethnic origin of the participants were not recorded, therefore this group may have been unrepresented. Future research should record and include this group in the future evaluation of the CaSM.

8.3.2 Response rate

Although the response rate was comparable to other stroke questionnaire studies, a moderate response rate was achieved. The

CaSM was a 53 item questionnaire and shorter questionnaires have been known to get a better response rate than longer questionnaires (Edwards, 2009). The reduced 27 item CaSM, would be expected to achieve a greater response rate in any follow up studies.

8.3.3 'Gold Standard' criteria

Criterion validity of the CaSM could not be fully assessed as there was no 'gold standard' to test the measure against. Predictive and concurrent validity are typically assessed using an established gold standard measures, deemed to measure a similar construct. In the absence of a suitable measure to assess the CaSM's concurrent validity, therapists' opinion was used. Stroke patients completed the CaSM at the same time as the therapist rated a patients' level of confidence, and the scores were correlated. No statistically significant relationship between the two measures was found. A weakness of this study was defining 'therapists' opinion' as the gold standard, as there was no prior evidence to suggest their opinion represented a gold standard. There are currently, two published confidence scales in the stroke literature, the SSEQ (Riazi et al., 2014) and the DLSES (Maujean et al., 2014) that may be suitable for evaluating predictive criterion validity in further study's. However, these measures are also newly developed therefore defining these measures as gold standard for future research, may be questionable. It may be the criterion validity of a confidence measure is not possible until there are more stringent 'gold standards' to measure against.

8.3.4 Lack of confidence interventions

The CaSM's sensitivity to change was assessed using a confidence course that was been delivered as a RCT feasibility study [RCAS] at the University of Nottingham. As the RCAS was a feasibility study, it was not known if the non-statistically significant result, on the CaSM's change scores pre-intervention, post intervention, and six month follow up, was an indication of the CaSM's measurement properties or an indication of the intervention not being effective. The sample size in this study was small, therefore, the study would benefit from being repeated on a known effective confidence intervention, with an increased sample size. However, there are no known confidence interventions that have been found to be effective, in stroke rehabilitation, making the assessment of sensitivity to change, difficult.

In summary, the findings highlight that the measure of confidence is an emerging development in the stroke rehabilitation literature. However, targeted interventions and gold standards that may enable the CaSM's properties to be further assessed, are still in their infancy. This indicates that broadening the knowledge relating to confidence after stroke is important and necessary.

8.4 Further research

Recommendations for further research have been reported following each chapter and have been summarised above. However, further evaluation of the psychometric properties of any newly developed measure is essential and is recommended. Four priority areas have been identified, and warrant a specific mention. These are, further evaluation of the psychometric properties of the CaSM, further evaluation of the sensitivity and responsiveness of the CaSM, developing the measure in order that it is valid and reliable for people with aphasia and developing population norms for the CaSM.

8.4.1 Further evaluation of the CaSM

Test-retest in a larger sample is likely to confirm the temporal stability of the CaSM, in order to confirm that the findings in this study were not due to chance.

8.4.1.1 Confirmatory factor analysis

A confirmatory factor analysis is recommended to confirm whether the current model of a three component structure is supported. Once a factor structure is confirmed, a modern statistical technique such as Rasch analysis (Rasch, 1960), which uses item response theory as opposed to classical test theory, to examine any further item redundancy, and to confirm the overall fit of the model is advisable.

8.4.1.2 Evaluation of sensitivity and responsiveness to change

The ability of the CaSM's sensitivity to detect change by examining the change score before and after a confidence intervention, did not detect a statistically significant result (p=0.13). Detecting a clinical change is notoriously difficult, as patients and clinicians are often evaluating different outcomes, with the same measure. However, it is important that a measure developed to detect a change in confidence has the properties to achieve this. One of the problems, as previously indicated, is the lack of effective interventions that target confidence levels after a stroke. It is suggested that the CaSM is used in stroke rehabilitation trials as a secondary outcome measure, when an improvement in confidence underpins the primary outcome such as, in the getting out of the house RCT (Logan et al., 2012). Evaluating the CaSM to investigate the measure's sensitivity to detect change pre and post intervention, is recommended. The more the measure is used both in research and clinically, the more likely it is that the true measurement properties of the CaSM will be determined.

Further investigation into the clinically important items is also recommended. A study design using a cognitive interviewing methods (Willis, 2004) may be appropriate to investigate the clinical meaning of the items. A small sample of stroke survivors, and another small sample of clinicians, five to ten is recommended, could be asked to complete the CaSM using a thinking aloud technique as they answer each question. Probing questions by a researcher, elicits further understanding of why participants are responding to items in a certain way.

Once this data has been collected and analysed, a Delphi study of stroke rehabilitation clinicians and stroke survivors could be undertaken to provide a consensus of clinically important items and ranked in order of importance. The top clinically important items could be weighted to score higher on the CaSM than other items.

8.4.1.3 Aphasia

The CaSM was not developed specifically for stroke survivors who are aphasic. Since one third of all people who experience a stroke have aphasia, in the acute stages of stroke, in order for the outcomes of our research to be generalizable, people with aphasia need to be represented. Designing measures that are appropriate for people with aphasia are considered essential. It is also important to enable people with aphasia to collaborate in research studies. Further assessment of the CaSM properties with stroke survivors who have aphasia is recommended. In order to achieve this, a mixed methods programme of research would need to be designed. A similar framework to this current programme of study is proposed.

Stage 1: A literature search for measures that are used in stroke and have been developed for people who have aphasia should be conducted. Strategies that have been successful in previous studies could be used to guide the development of an aphasia version of the CaSM.

Stage 2: A focus group design that is facilitated by trained interviewers could be considered. Seeking the views from people with aphasia on how the CaSM could be improved if it were to be adapted to be aphasia friendly, drawing from successful strategies in the literature, could be undertaken.

Stage 3: Piloting the aphasia friendly version of the measure, with small samples could then be undertaken.

Stage 4: The final stage would need to assess the psychometric properties of the aphasia CaSM, using robust scientific methodology, similar to the framework used in this programme of study.

It is often articulated, if you get it right for people with communication problems, you get it right for everyone.

8.4.2 Implications for clinical practice

The CaSM was designed to correctly identify stroke survivors with low confidence and is considered a useful tool in a clinical setting. The experts suggested that having a tool that enables stroke clinicians to overtly discuss confidence issues with their patients, and identify items that were important to them, is likely to help clinicians target stroke rehabilitation interventions and patient goals, to specifically address improving confidence. The invisible consequences of stroke, such as, low confidence, can be hidden from stroke clinicians; therefore having a quality measure that has been scientifically evaluated and systematically developed is deemed as valuable.

Prior the CaSM being used in clinical practice or research, it is useful to have an interpretation of the score. This is a quality marker on the COSMIN checklist (Mokkink et al., 2010) and by having scores that are interpretable in a clinical setting the usefulness of the measure is likely to be enhanced. The 27 item CaSM total score ranges from 0-81. The raw scores of the CaSM have been converted into percentiles, to indicate what might represent a low confidence score. It is suggested that a mean score of 36 (-1 *SD*) would indicate possible concern and a mean score of 28 (-2 *SD*) would indicate a probable problem. These benchmarks, were defined by using a commonly used test scores reference cited in (Lezak, 1995):p155. In order to evaluate this guidance, the development of population norms for the CaSM are needed. Comparisons by age, gender, stroke severity in large samples of people who have experienced a stroke should be undertaken to determine what is likely to represent low and mid confidence levels on the CaSM.

In addition to predicting confidence levels in stroke patients, the CaSM was designed to evaluate the benefits and outcomes of stroke rehabilitation interventions and research trials. Monitoring improvements in confidence, as well as deterioration in confidence is an important resource. However, as previously stated further evaluation of the CaSM's sensitivity to change properties are needed. By using the CaSM in clinical trials and in clinical practice and evaluating the outcomes is recommended.

The evaluation of the concurrent validity of the CaSM suggested there was not a statically significant relationship between the confidence scores on the CaSM, rated by stroke survivors, and a confidence rating scale completed by occupational therapists, which is an important finding. Clinicians make decisions about effective healthcare on a daily basis; therefore if a stroke survivor's low confidence has not been identified by a clinician then stroke patients' treatment is not likely to include an intervention that improves confidence. Conversely, if the measure lacks scientific rigor then clinicians may not be confident about using measurement, as it may not be deemed trustworthy. Either way, the findings support the clinical need for a high quality measure of confidence.

8.5 Conclusion

Measuring and improving confidence to optimise a stroke survivor's performance through rehabilitation interventions is likely to change how stroke survivors feel about themselves and their future. Leaving people who are physically capable, unable to leave their home; unable to return to important roles and being unable to engage in social activities, through lack of confidence, is a real challenge that we seek to address in stroke rehabilitation.

In conclusion, the CaSM is the first known comprehensive measure of confidence to be developed after a stroke. It has demonstrated good psychometric properties and has the potential to measure self-confidence, positive attitude and social confidence as three separate scales. The CaSM was found to be clinically important and is an appropriate measure to use in clinical practice, as well as in research. It is a practical self-reporting measure that is acceptable to stroke survivors. This programme of study makes an important contribution to the emerging stroke rehabilitation literature which examines the social, emotional and mood related difficulties experienced everyday by stroke survivors. Evaluating confidence levels in order to facilitate and target appropriate rehabilitation is necessary to enable people to be optimistic about leading meaningful and active lives after their stroke.

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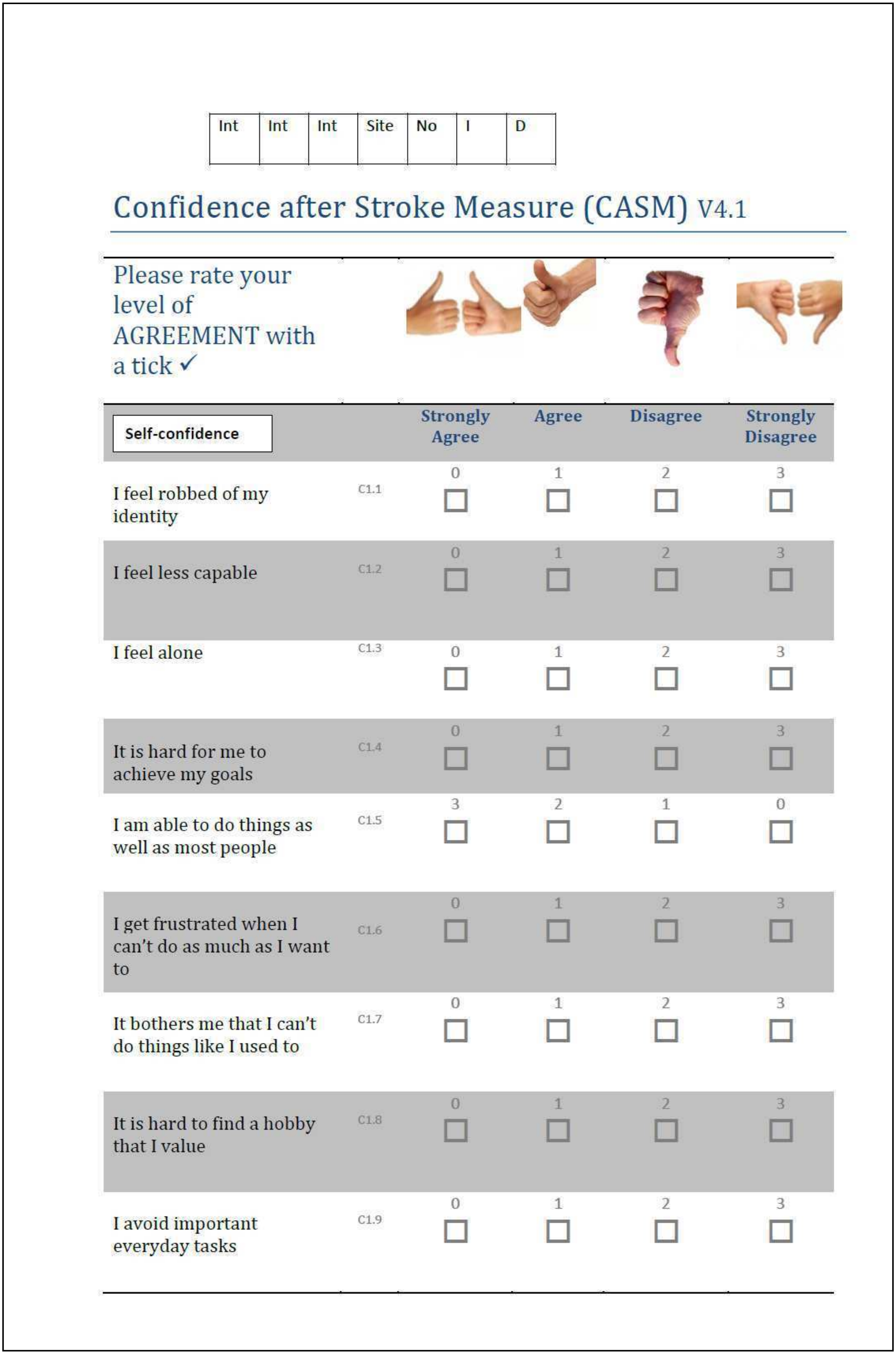
APPENDIX 1 CASM 27 ITEMS



Int	Int	Int	Site	No	I	D

Confidence after Stroke Measure (CASM) V4.1

Please rate your level of AGREEMENT with a tick ✓

Self-confidence		Strongly Agree	Agree	Disagree	Strongly Disagree
I feel robbed of my identity	C1.1	0 ☐	1 ☐	2 ☐	3 ☐
I feel less capable	C1.2	0 ☐	1 ☐	2 ☐	3 ☐
I feel alone	C1.3	0 ☐	1 ☐	2 ☐	3 ☐
It is hard for me to achieve my goals	C1.4	0 ☐	1 ☐	2 ☐	3 ☐
I am able to do things as well as most people	C1.5	3 ☐	2 ☐	1 ☐	0 ☐
I get frustrated when I can't do as much as I want to	C1.6	0 ☐	1 ☐	2 ☐	3 ☐
It bothers me that I can't do things like I used to	C1.7	0 ☐	1 ☐	2 ☐	3 ☐
It is hard to find a hobby that I value	C1.8	0 ☐	1 ☐	2 ☐	3 ☐
I avoid important everyday tasks	C1.9	0 ☐	1 ☐	2 ☐	3 ☐

Int	Int	Int	Site	No	I	D

Positive Attitude

Please rate your level of AGREEMENT with a tick ✓

		Strongly Agree	Agree	Disagree	Strongly Disagree
I believe I have inner strength	C2.1	3 ☐	2 ☐	1 ☐	0 ☐
I believe you can do anything if you try hard enough	C2.2	3 ☐	2 ☐	1 ☐	0 ☐
My attitude helps me to be confident	C2.3	3 ☐	2 ☐	1 ☐	0 ☐
I manage to solve problems if I try hard enough	C2.4	3 ☐	2 ☐	1 ☐	0 ☐
I am able to push myself	C2.5	3 ☐	2 ☐	1 ☐	0 ☐
I believe I can achieve what I want to	C2.6	3 ☐	2 ☐	1 ☐	0 ☐
I feel comfortable looking in a mirror	C2.7	3 ☐	2 ☐	1 ☐	0 ☐
I think positively about myself	C2.8	3 ☐	2 ☐	1 ☐	0 ☐

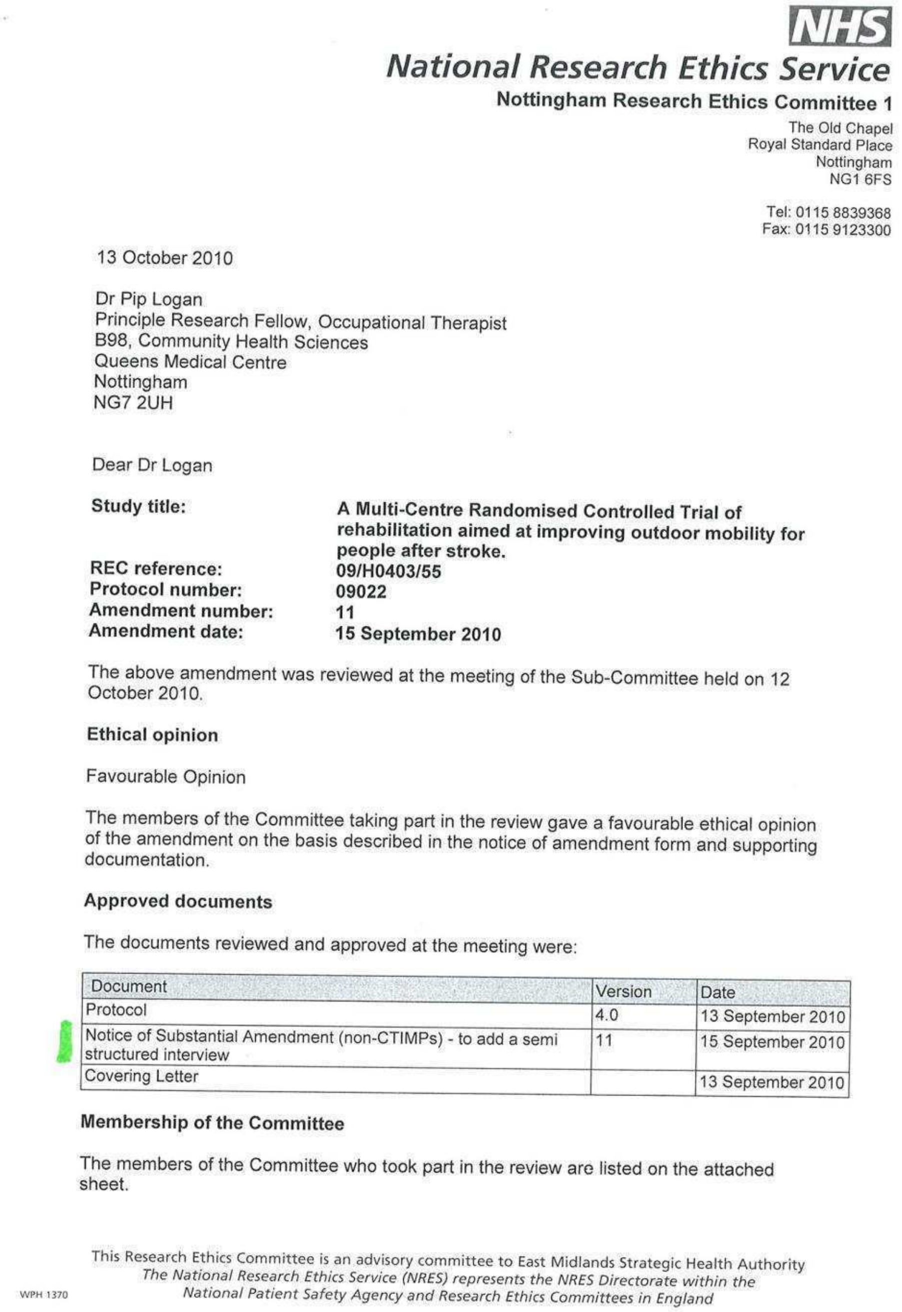
Int	Int	Int	Site	No	I	D

Social Confidence

Please rate your level of AGREEMENT with a tick ✓

		Strongly Agree	Agree	Disagree	Strongly Disagree
I feel other people judge how I look	C3.1	0 ☐	1 ☐	2 ☐	3 ☐
I am worried about how others see me	C3.2	0 ☐	1 ☐	2 ☐	3 ☐
I feel terrified meeting people I don't know	C3.3	0 ☐	1 ☐	2 ☐	3 ☐
I feel home is the only place where I am safe	C3.4	0 ☐	1 ☐	2 ☐	3 ☐
I feel scared to go out	C3.5	0 ☐	1 ☐	2 ☐	3 ☐
I do not feel comfortable in public places	C3.6	0 ☐	1 ☐	2 ☐	3 ☐
I feel people speak down to me	C3.7	0 ☐	1 ☐	2 ☐	3 ☐
I do not feel able to attend social events	C3.8	0 ☐	1 ☐	2 ☐	3 ☐
I am confident enough to leave the house	C3.9	3 ☐	2 ☐	1 ☐	0 ☐

APPENDIX 2 ETHICAL APPROAL LETTER: INTERVIEW STUDY



NHS
National Research Ethics Service
Nottingham Research Ethics Committee 1
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Tel: 0115 8839368
Fax: 0115 9123300

13 October 2010

Dr Pip Logan
Principle Research Fellow, Occupational Therapist
B98, Community Health Sciences
Queens Medical Centre
Nottingham
NG7 2UH

Dear Dr Logan

Study title:	**A Multi-Centre Randomised Controlled Trial of rehabilitation aimed at improving outdoor mobility for people after stroke.**
REC reference:	**09/H0403/55**
Protocol number:	**09022**
Amendment number:	**11**
Amendment date:	**15 September 2010**

The above amendment was reviewed at the meeting of the Sub-Committee held on 12 October 2010.

Ethical opinion

Favourable Opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

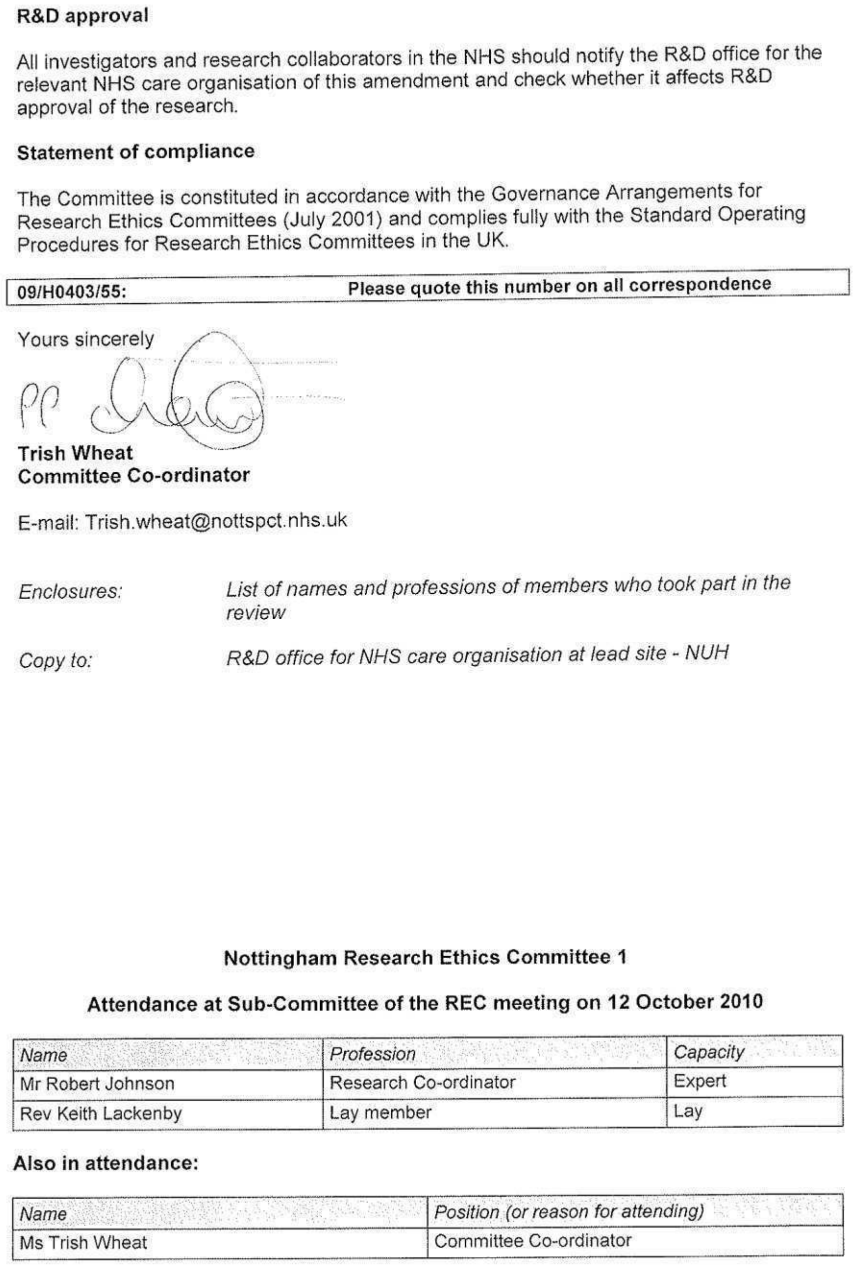
Document	Version	Date
Protocol	4.0	13 September 2010
Notice of Substantial Amendment (non-CTIMPs) - to add a semi structured interview	11	15 September 2010
Covering Letter		13 September 2010

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

This Research Ethics Committee is an advisory committee to East Midlands Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

WPH 1370



R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

09/H0403/55:	**Please quote this number on all correspondence**

Yours sincerely

Trish Wheat
Committee Co-ordinator

E-mail: Trish.wheat@nottspct.nhs.uk

Enclosures:	*List of names and professions of members who took part in the review*
Copy to:	*R&D office for NHS care organisation at lead site - NUH*

Nottingham Research Ethics Committee 1

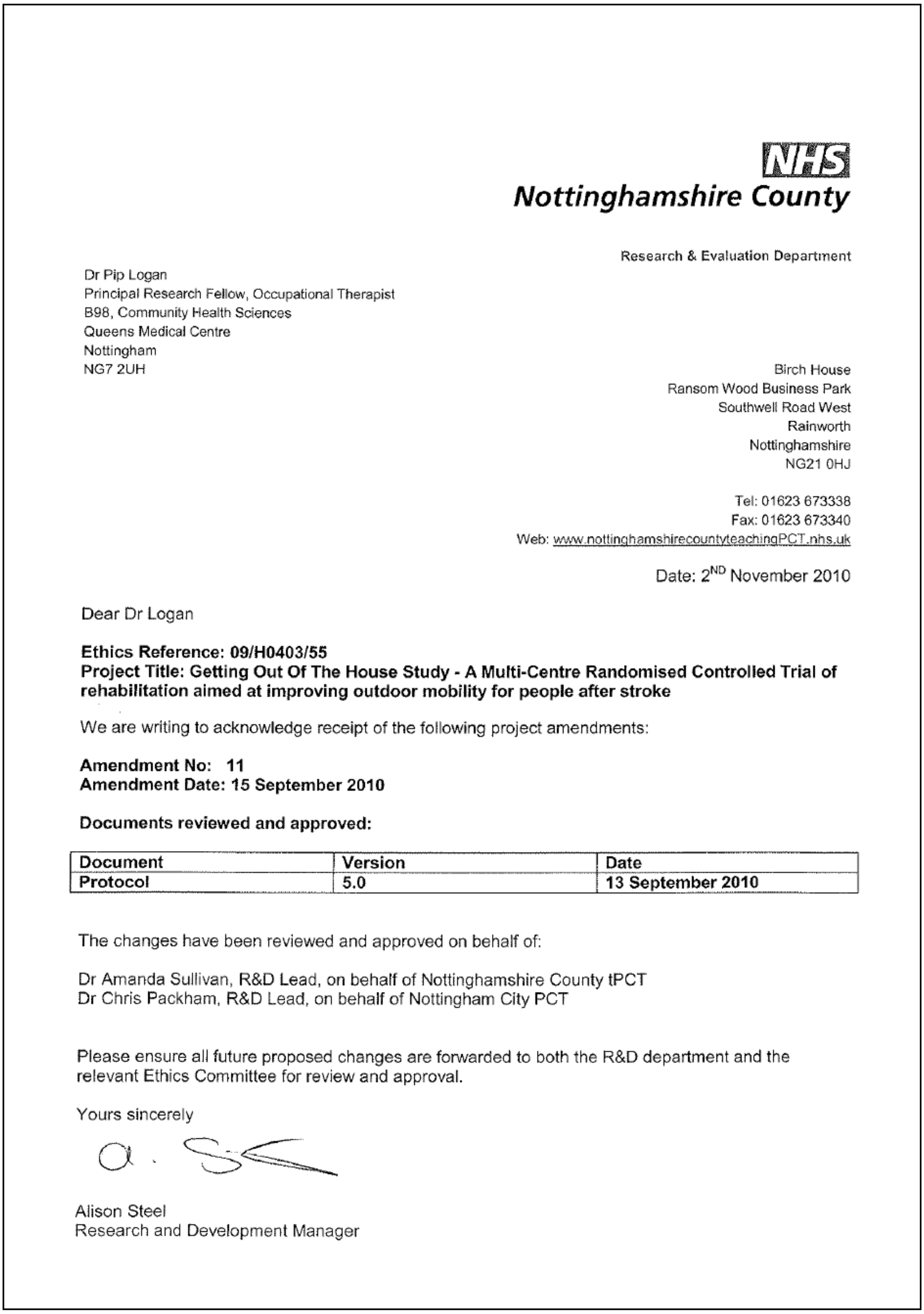
Attendance at Sub-Committee of the REC meeting on 12 October 2010

Name	*Profession*	*Capacity*
Mr Robert Johnson	Research Co-ordinator	Expert
Rev Keith Lackenby	Lay member	Lay

Also in attendance:

Name	*Position (or reason for attending)*
Ms Trish Wheat	Committee Co-ordinator

APPENDIX 3 NHS R&D APPROVAL LETTER



NHS
Nottinghamshire County

Research & Evaluation Department

Dr Pip Logan
Principal Research Fellow, Occupational Therapist
B98, Community Health Sciences
Queens Medical Centre
Nottingham
NG7 2UH

Birch House
Ransom Wood Business Park
Southwell Road West
Rainworth
Nottinghamshire
NG21 0HJ

Tel: 01623 673338
Fax: 01623 673340
Web: www.nottinghamshirecountyteachingPCT.nhs.uk

Date: 2ND November 2010

Dear Dr Logan

Ethics Reference: 09/H0403/55
Project Title: Getting Out Of The House Study - A Multi-Centre Randomised Controlled Trial of rehabilitation aimed at improving outdoor mobility for people after stroke

We are writing to acknowledge receipt of the following project amendments:

Amendment No: 11
Amendment Date: 15 September 2010

Documents reviewed and approved:

Document	Version	Date
Protocol	**5.0**	**13 September 2010**

The changes have been reviewed and approved on behalf of:

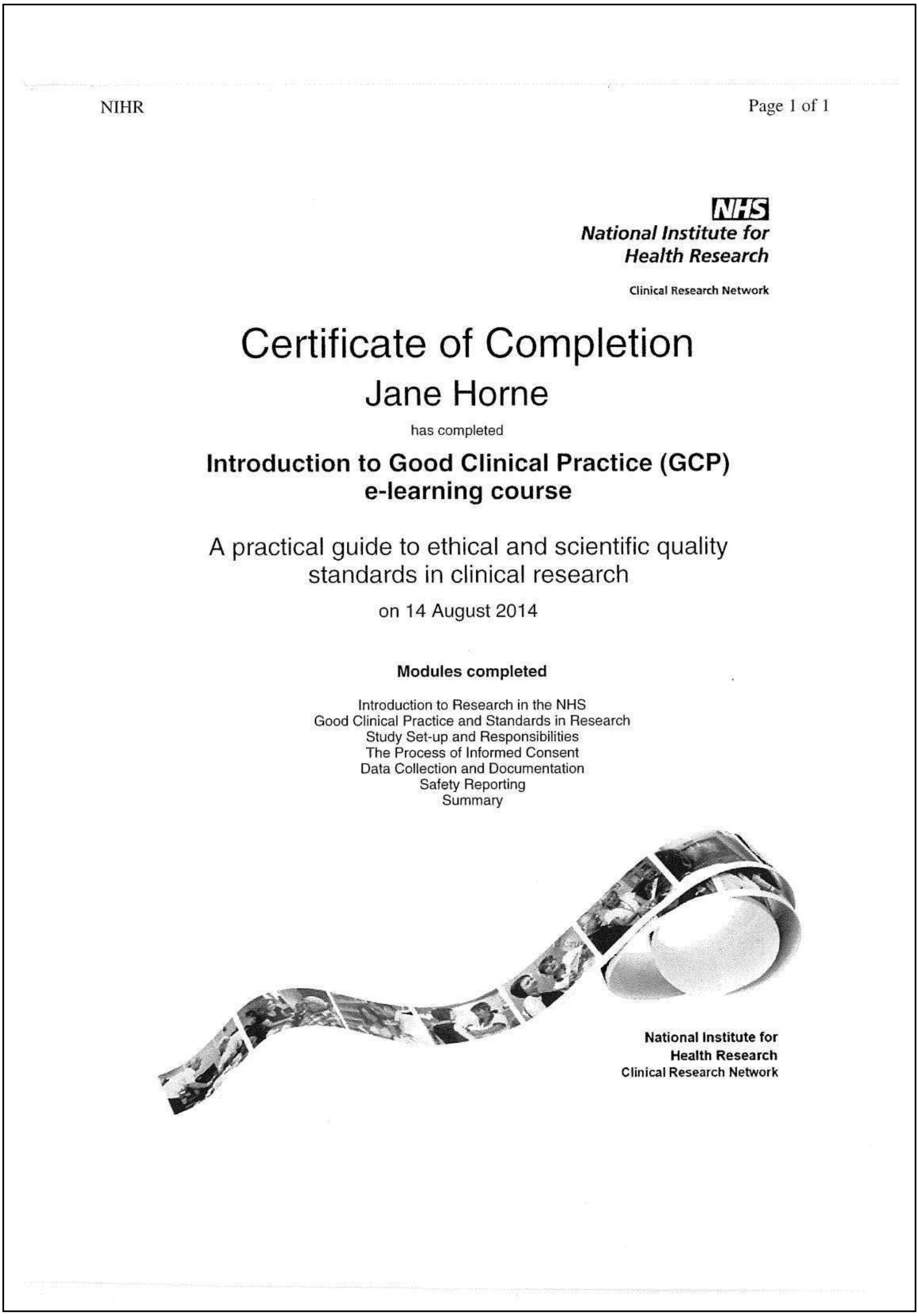
Dr Amanda Sullivan, R&D Lead, on behalf of Nottinghamshire County tPCT
Dr Chris Packham, R&D Lead, on behalf of Nottingham City PCT

Please ensure all future proposed changes are forwarded to both the R&D department and the relevant Ethics Committee for review and approval.

Yours sincerely

Alison Steel
Research and Development Manager

APPENDIX 4 GOOD CLINICAL PRACTICE CERTIFICATE



NIHR Page 1 of 1

NHS
National Institute for
Health Research
Clinical Research Network

Certificate of Completion

Jane Horne

has completed

Introduction to Good Clinical Practice (GCP)
e-learning course

A practical guide to ethical and scientific quality
standards in clinical research

on 14 August 2014

Modules completed

Introduction to Research in the NHS
Good Clinical Practice and Standards in Research
Study Set-up and Responsibilities
The Process of Informed Consent
Data Collection and Documentation
Safety Reporting
Summary

National Institute for
Health Research
Clinical Research Network

APPENDIX 5 NOTTINGHAM STROKE RESEARCH GROUP LETTER

SRN
Trent Stroke Research Network
Part of the Stroke Research Network

Trent Stroke Research Network

Division of Rehabilitation & Ageing
School of Community Health Sciences
B Floor, Medical School
Queen's Medical Centre
Nottingham NG7 2UH

NHS
National Institute for Health Research

Chair: *Professor Marion Walker* **Secretary and Treasurer**: *Ossie Newell MBE*.

Jane Horne
Research Occupational Therapist
University of Nottingham
Division of Rehabilitation & Ageing
B Floor
Medical School
Queen's Medical Centre
Nottingham NG7 2UH

14th January 2011

Dear Jane,

Thank you for presenting your proposed study on "Regaining Confidence post stroke: A stroke survivors perspective" to the Nottingham Stroke Research Consumer Group on December 22nd 2010. The group members found the proposal very interesting and wished to support it.

The group agreed that the loss of confidence can be a major limiting factor in regaining life after stroke. The group agreed that an early phase qualitative study to explore this area was needed before any active interventions were developed to specifically target this problem. It was felt the methodology planned in the study was robust and that appropriate supervision was in place.

The group recommended that any proposal arising from this qualitative study should be brought back to the group and also be sent to the Stroke Research Network Rehabilitation Clinical Study Group for comment prior to submission to any funding bodies.

The group wishes you every success with your study and look forward to hearing the results of your research endeavour.

Yours sincerely,

Marion Walker

Professor Marion Walker
Chair of Nottingham Stroke Research Consumer Group.

c.c. NSRCG members

Trent SRN of the Stroke Research Network (SRN) is part of the National Institute for Health Research (NIHR)

and is funded by the Department of Health.

APPENDIX 6 PILOT INTERVIEW FEEDBACK

Dairy Notes: JHP001

When the tape recorder was switched off the participant said:

You know, maybe I just have too much self esteem?

Feelings after interview:

Didn't feel for my first interview it went badly and was quite pleased with the skills I had demonstrated. Felt I demonstrated some of the skills advocated in active listening courses I had been on. However, recognised I have a lot to learn and practise was key.

Timing went well.

Immediately after the interview, I felt that I probably did not manage to collect data that was relevant to the study. Although the more I thought about it, the themes that seemed to emerge did seem to add to the concept of confidence. This was definitely confirmed when I transcribed the data. Lots of issues that were address in my literature review were being articulated.

Great experience transcribing first interview data. Did felt I was part of the data and got excited about the content. It enabled me to hear some of my mistakes and things that went well. Some things I would change:

- Not to ask multiple questions in one!
- When there is a pause allow more time for the participant to develop his thoughts
- Revisit questions and make sure each one that is being asked
- Are the questions relevant, in that they are ones likely to elicit meaningful data?

Observations:

No visible physical deficits: needs to be added to the questions – to look at if that makes a difference in terms of confidence.

Does it need to be added? Use observation/diary notes or scale (Rankin?).

Comment [IS1]: This is the classic, when the recorder is turned off you get great little nuggets of information. There have been papers written about this. Include it in your field notes.

Comment [IS2]: Reading the transcript reveals lots of active listening, especially if the participant is deaf, it doesn't seem he was intimidated, though perhaps he does have lots of self esteem!

Comment [IS3]: I don't think you should worry about this. It's your first interview and in a sense you will be developing your ideas and throughout the process. Sometimes you can have whole chunks of an interview that don't appear to useful. I think a lot of the process is getting through the non-useful mundane stuff to get the information you want. Sometimes you can have whole interview like that!

Comment [IS4]: Brilliant! I remember my first PhD interview so well, and it seemed to fit into the lit review, but my supervisor basically advised me to hold fire. Of course after that each and every interview was different, but I used quotes from that first interview in my thesis.

Comment [IS5]: So difficult not to do that! I'm guilty of it all the time. My last interview the GP said just give me a minute I need to unpack what you've just said.

Comment [IS6]: I think that comes from wanting to make the process comfortable for the participant.

Comment [IS7]: Don't be too hard on yourself. It's incredibly difficult to predict responses. By listening and transcribing you can begin to understand what questions and themes work well.

Comment [IS8]: So interesting. From my own personal experience my appearance was an important part of loss of confidence.

APPENDIX 7 GP LETTER: GETTING OUT OF THE HOUSE

Getting
out of the
House
Study

[Potential Participant Address]

<u>Getting out of the House Study</u>

An [occupational therapist / stroke consultant] involved in research has contacted the surgery and asked if [he/she] may get in touch with people who have suffered a stroke. [He/she] is interested in helping people get out of the house more often.

The findings from this study will be used to improve rehabilitation after stroke. Some further information about the project is enclosed with this letter.

As part of this project you will be offered information about travel and transport in your area and some people will be offered rehabilitation to help them get out the house more often. The team will be collecting information about how you have managed after having a stroke.

The information collected will be entirely confidential and only used for research purposes. You will be able to drop out of the study whenever you want and do not have to give a reason.

If you are interested then please sign the reply slip, and return it to ……………………..……….. in the enclosed paid envelope. The team will get in touch and arrange to visit whenever it is best for you.

If you want to talk to a member of the team then they can be contacted on xxxxxxxxxxxxxxxx.

Many thanks

Yours sincerely,

GP

Getting
out of the
House
Study

[Potential Participant Address]

Yes, I am willing for a member of the team to contact me at home to discuss this study.

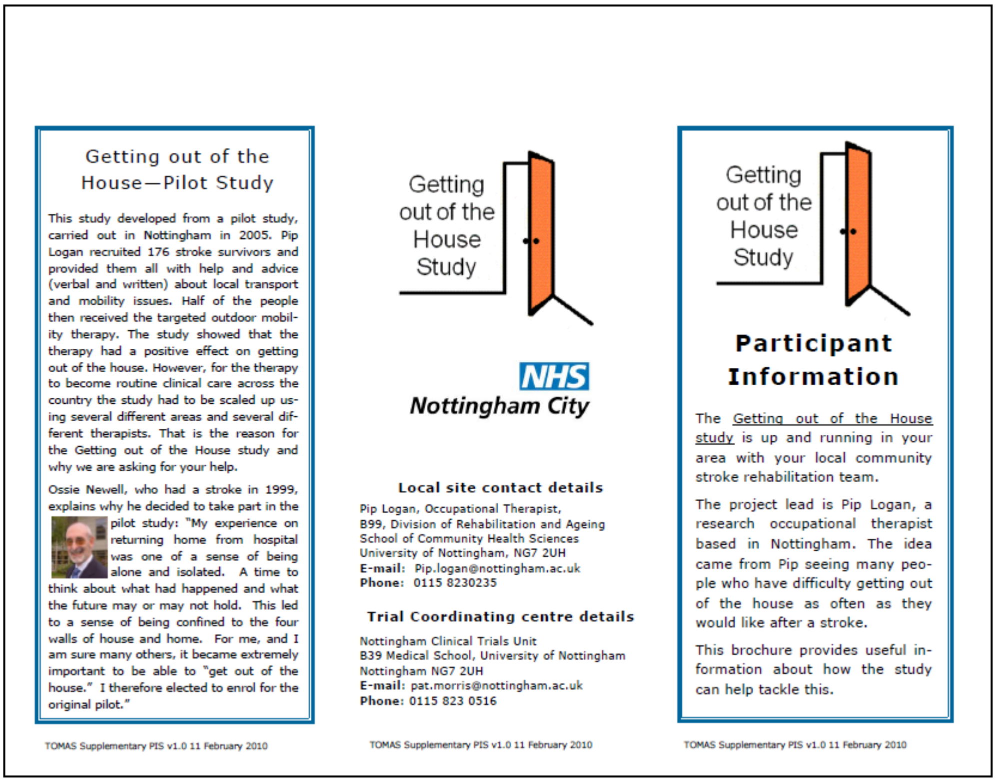
1) Name: ……………………………………………

2) Contact number……………………………………..

Please return in the pre-paid envelope provided.

Thank you for your help and time.

APPENDIX 8 PATIENT INFORMATION SHEET:GOOTH RCT



Getting out of the House—Pilot Study

This study developed from a pilot study, carried out in Nottingham in 2005. Pip Logan recruited 176 stroke survivors and provided them all with help and advice (verbal and written) about local transport and mobility issues. Half of the people then received the targeted outdoor mobility therapy. The study showed that the therapy had a positive effect on getting out of the house. However, for the therapy to become routine clinical care across the country the study had to be scaled up using several different areas and several different therapists. That is the reason for the Getting out of the House study and why we are asking for your help.

Ossie Newell, who had a stroke in 1999, explains why he decided to take part in the pilot study: "My experience on returning home from hospital was one of a sense of being alone and isolated. A time to think about what had happened and what the future may or may not hold. This led to a sense of being confined to the four walls of house and home. For me, and I am sure many others, it became extremely important to be able to "get out of the house." I therefore elected to enrol for the original pilot."

TOMAS Supplementary PIS v1.0 11 February 2010

Getting out of the House Study

NHS Nottingham City

Local site contact details

Pip Logan, Occupational Therapist,
B99, Division of Rehabilitation and Ageing
School of Community Health Sciences
University of Nottingham, NG7 2UH
E-mail: Pip.logan@nottingham.ac.uk
Phone: 0115 8230235

Trial Coordinating centre details

Nottingham Clinical Trials Unit
B39 Medical School, University of Nottingham
Nottingham NG7 2UH
E-mail: pat.morris@nottingham.ac.uk
Phone: 0115 823 0516

TOMAS Supplementary PIS v1.0 11 February 2010

Getting out of the House Study

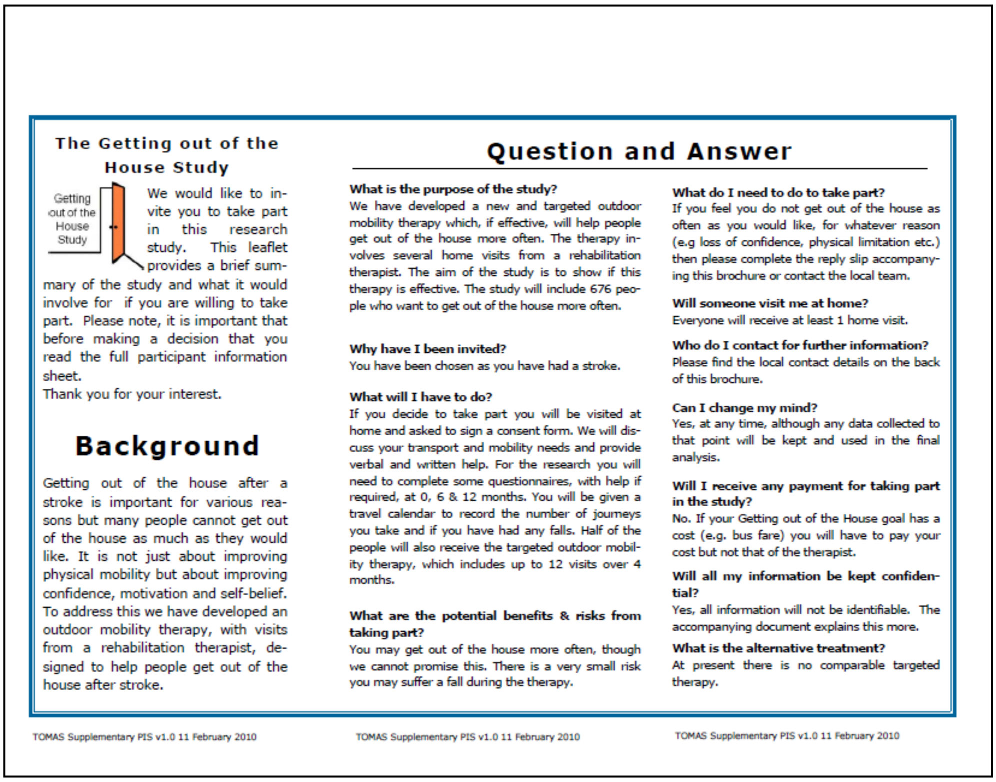
Participant Information

The Getting out of the House study is up and running in your area with your local community stroke rehabilitation team.

The project lead is Pip Logan, a research occupational therapist based in Nottingham. The idea came from Pip seeing many people who have difficulty getting out of the house as often as they would like after a stroke.

This brochure provides useful information about how the study can help tackle this.

TOMAS Supplementary PIS v1.0 11 February 2010



The Getting out of the House Study

Getting out of the House Study

We would like to invite you to take part in this research study. This leaflet provides a brief summary of the study and what it would involve for if you are willing to take part. Please note, it is important that before making a decision that you read the full participant information sheet.
Thank you for your interest.

Background

Getting out of the house after a stroke is important for various reasons but many people cannot get out of the house as much as they would like. It is not just about improving physical mobility but about improving confidence, motivation and self-belief. To address this we have developed an outdoor mobility therapy, with visits from a rehabilitation therapist, designed to help people get out of the house after stroke.

Question and Answer

What is the purpose of the study?
We have developed a new and targeted outdoor mobility therapy which, if effective, will help people get out of the house more often. The therapy involves several home visits from a rehabilitation therapist. The aim of the study is to show if this therapy is effective. The study will include 676 people who want to get out of the house more often.

Why have I been invited?
You have been chosen as you have had a stroke.

What will I have to do?
If you decide to take part you will be visited at home and asked to sign a consent form. We will discuss your transport and mobility needs and provide verbal and written help. For the research you will need to complete some questionnaires, with help if required, at 0, 6 & 12 months. You will be given a travel calendar to record the number of journeys you take and if you have had any falls. Half of the people will also receive the targeted outdoor mobility therapy, which includes up to 12 visits over 4 months.

What are the potential benefits & risks from taking part?
You may get out of the house more often, though we cannot promise this. There is a very small risk you may suffer a fall during the therapy.

What do I need to do to take part?
If you feel you do not get out of the house as often as you would like, for whatever reason (e.g loss of confidence, physical limitation etc.) then please complete the reply slip accompanying this brochure or contact the local team.

Will someone visit me at home?
Everyone will receive at least 1 home visit.

Who do I contact for further information?
Please find the local contact details on the back of this brochure.

Can I change my mind?
Yes, at any time, although any data collected to that point will be kept and used in the final analysis.

Will I receive any payment for taking part in the study?
No. If your Getting out of the House goal has a cost (e.g. bus fare) you will have to pay your cost but not that of the therapist.

Will all my information be kept confidential?
Yes, all information will not be identifiable. The accompanying document explains this more.

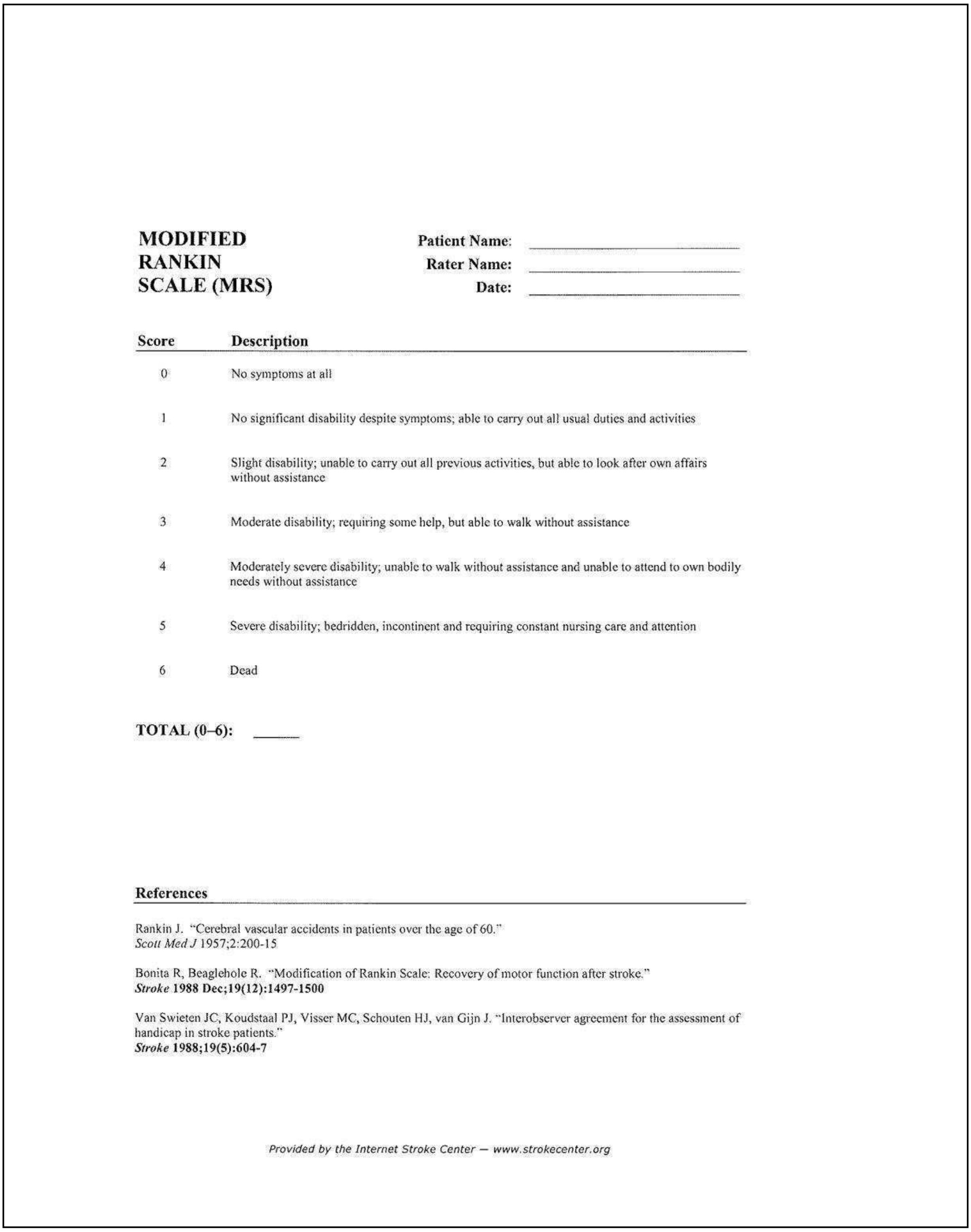
What is the alternative treatment?
At present there is no comparable targeted therapy.

TOMAS Supplementary PIS v1.0 11 February 2010

TOMAS Supplementary PIS v1.0 11 February 2010

TOMAS Supplementary PIS v1.0 11 February 2010

APPENDIX 9 MODIFIED RANKIN SCALE (MRS)



MODIFIED RANKIN SCALE (MRS)

Patient Name: ______

Rater Name: ______

Date: ______

Score	Description
0	No symptoms at all
1	No significant disability despite symptoms; able to carry out all usual duties and activities
2	Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance
3	Moderate disability; requiring some help, but able to walk without assistance
4	Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance
5	Severe disability; bedridden, incontinent and requiring constant nursing care and attention
6	Dead

TOTAL (0–6): ______

References

Rankin J. "Cerebral vascular accidents in patients over the age of 60."
Scott Med J 1957;2:200-15

Bonita R, Beaglehole R. "Modification of Rankin Scale: Recovery of motor function after stroke."
***Stroke* 1988 Dec;19(12):1497-1500**

Van Swieten JC, Koudstaal PJ, Visser MC, Schouten HJ, van Gijn J. "Interobserver agreement for the assessment of handicap in stroke patients."
***Stroke* 1988;19(5):604-7**

Provided by the Internet Stroke Center — www.strokecenter.org

APPENDIX 10 INTERVIEW GUIDE

1. **Tell me about what happened when you had your stroke?**

   Possible prompts:

   - What was it like getting back to everyday life?
   - How did your family/friends respond?

2. **Tell me about what confidence means to you?**

   Possible prompts:

   - Did you feel it played a part in your recovery?

3. **Think about your normal everyday activities after your stroke – talk me through what you were able to do and the things you were not able to achieve. How did you feel when you got dressed, cooked a meal, for example?**

   Possible prompts:

   - How did you manage these tasks and activities?
   - Were they the same as the ones you did before your stroke?
   - Describe them, which were easy and less easy?

4. **How do you think other people see you since having your stroke?**

   Possible prompts:

   - Supportive?
   - Do you think they do too much for you/not enough?
   - People you don't know well….are you comfortable with them?

5. **Since your stroke what have been the things that you have found difficult**

   Possible prompts:

   - Can you think of anything you have particular problems with
   - Barriers – what has got in the way of doing the things you would like

6. **Tell me about your hobbles, both before and after your stroke?**

   Possible prompts:

   - How different are they from before?
   - Barriers – what has got in the way of doing the things you would like
   - Hobbies you like to do with others

7. **How would you describe yourself?**

   Possible prompts

   - Confident?/positive

End the interview, with thanks, explaining there are no right or wrong answers.

Give time, to reflect, anything more to say? End with being positive about the process.

APPENDIX 11 RESEARCH DIARY

Diary Extract: Participant: JH12

Thoughts prior to interview: 2nd June 2011

A treating occupational therapist on 'getting out of the house study' gave me the details of this women, therapist had identified very low confidence in walking outside, during treatment.

Telephoned women, very positive on phone, gave me a number of suitable times of appointments to be interviewed, and appeared very willing. Very positive about therapist on study. Able to communicate well on phone, no needed for additional communication aids.

Capable women, walks outside with a stick. Easy access to shops in middle class suburb of city, I am familiar with this as I live not too far away. Big, old Victorian house, question whether it is easy to manage alone? Lives alone, has support from family. (Why does this matter to a confidence study is this me being a clinician?) Able to stand up and transfer perfectly, more than physical disability that impacts on her confidence. Has mild Aphasia, what impact might this have? (preconceptions?)

During the interview: 8th June 2011

Felt comfortable. Assertive women, initially asked about the recording process, I explained the process and clarified whether she was happy for the interview to be recorded. To which she replied 'yes, just interested.' Very opinionated, but very likeable. Had a great sense of humour and I got a sense she had great trust in me. During the interview she opened up about her family and got a sense she did not usually have an outlet for these concerns. Issues seemed appropriate and related to the concept of confidence.

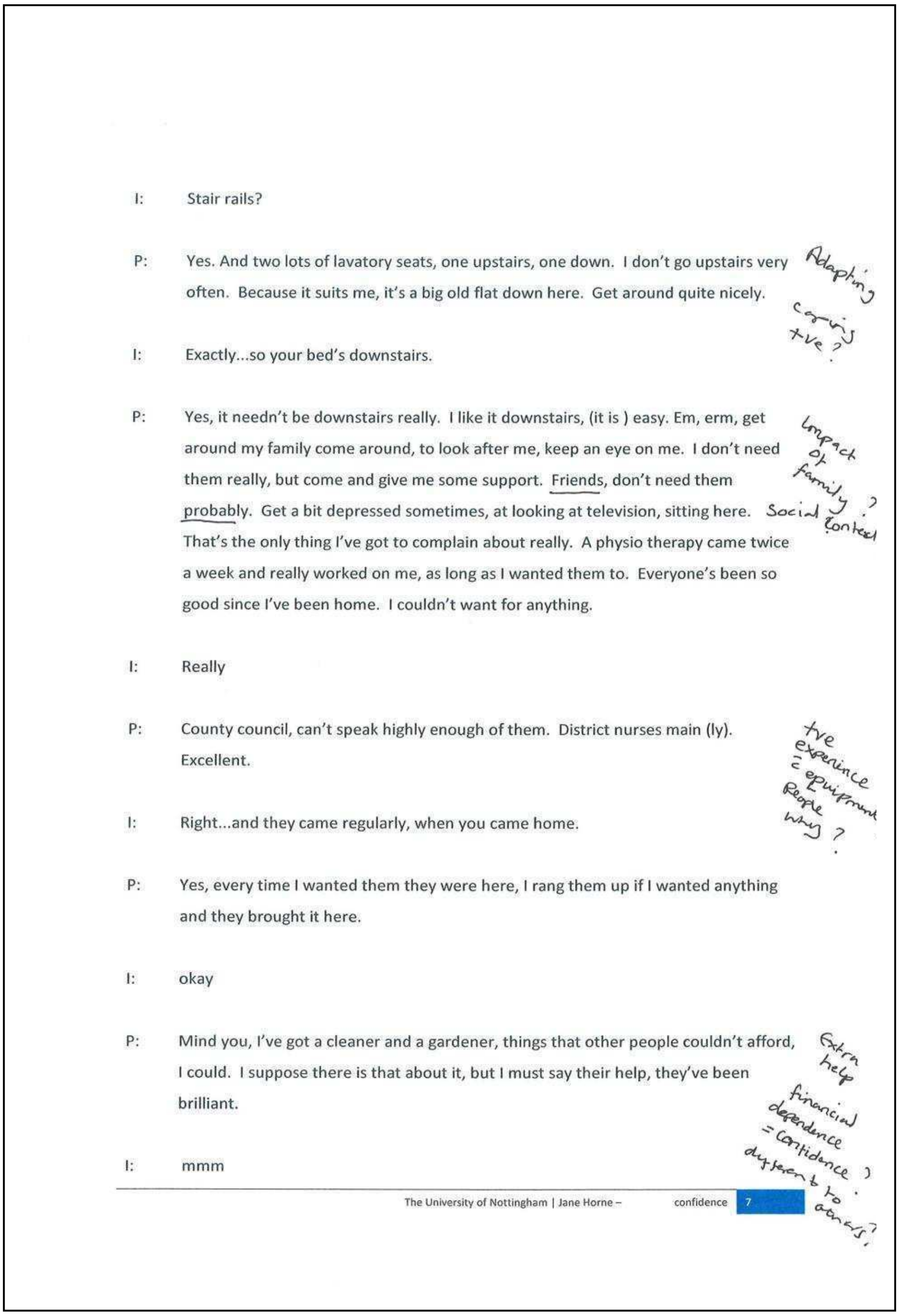
She asked how many people I was interviewing, when I said 12, she replied, 'gosh more than 12 people have had a stroke around here surely?' interesting perception. Justify? Immediately after I gave a justification for depth of interviews, not quantity she started…

before I was completely settled myself….'well, the first thing is.. too many people help me…. She clearly took my explanation as a que to start, indicating she already had some thoughts about what she wanted to say?

Post interview – transcription thoughts: 8th August 2011

Seem to have lost some skills. Interview questions became more leading and more clinical OT rather than researcher. Didn't use enough 'tell me' prompts? As the interview went on the style improved. On transcription this shocked me. Perhaps because it was the last interview, I went in overconfident, and lost some of that researcher thinking style that was needed. However, I did collect some really interesting data, with real depth and meaning around confidence, maybe because it was the last one I wanted it to be perfect, is there such a thing….

APPENDIX 12 IPA: INITIAL READING



I: Stair rails?

P: Yes. And two lots of lavatory seats, one upstairs, one down. I don't go upstairs very often. Because it suits me, it's a big old flat down here. Get around quite nicely.

Adapting

coping +ve ?

I: Exactly...so your bed's downstairs.

P: Yes, it needn't be downstairs really. I like it downstairs, (it is) easy. Em, erm, get around my family come around, to look after me, keep an eye on me. I don't need them really, but come and give me some support. Friends, don't need them probably. Get a bit depressed sometimes, at looking at television, sitting here. That's the only thing I've got to complain about really. A physio therapy came twice a week and really worked on me, as long as I wanted them to. Everyone's been so good since I've been home. I couldn't want for anything.

Impact of family ?

Social context

I: Really

P: County council, can't speak highly enough of them. District nurses main (ly). Excellent.

+ve experience ē equipment & People why ?

I: Right...and they came regularly, when you came home.

P: Yes, every time I wanted them they were here, I rang them up if I wanted anything and they brought it here.

I: okay

P: Mind you, I've got a cleaner and a gardener, things that other people couldn't afford, I could. I suppose there is that about it, but I must say their help, they've been brilliant.

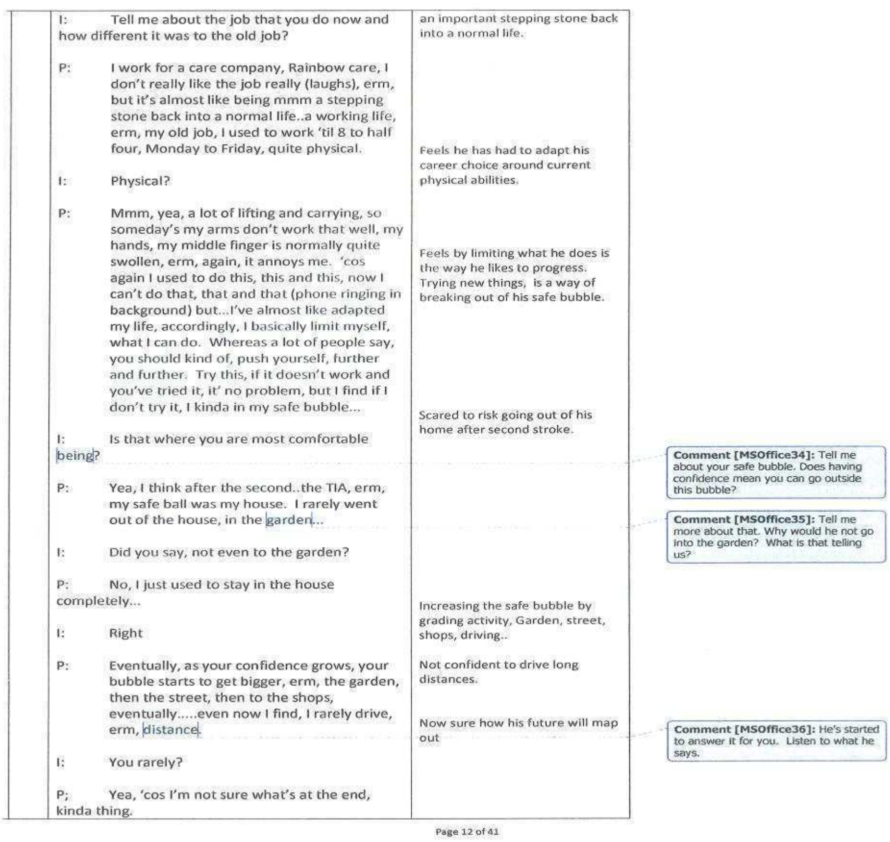
Extra help

financial dependence = confidence ? different to others ?

I: mmm

The University of Nottingham | Jane Horne – confidence 7

APPENDIX 13 EXTERNAL IPA EXPERT FEEDBACK



I: Tell me about the job that you do now and how different it was to the old job?

P: I work for a care company, Rainbow care, I don't really like the job really (laughs), erm, but it's almost like being mmm a stepping stone back into a normal life..a working life, erm, my old job, I used to work 'til 8 to half four, Monday to Friday, quite physical.

I: Physical?

P: Mmm, yea, a lot of lifting and carrying, so someday's my arms don't work that well, my hands, my middle finger is normally quite swollen, erm, again, it annoys me. 'cos again I used to do this, this and this, now I can't do that, that and that (phone ringing in background) but...I've almost like adapted my life, accordingly, I basically limit myself, what I can do. Whereas a lot of people say, you should kind of, push yourself, further and further. Try this, if it doesn't work and you've tried it, it' no problem, but I find if I don't try it, I kinda in my safe bubble...

I: Is that where you are most comfortable being?

P: Yea, I think after the second..the TIA, erm, my safe ball was my house. I rarely went out of the house, in the garden...

I: Did you say, not even to the garden?

P: No, I just used to stay in the house completely...

I: Right

P: Eventually, as your confidence grows, your bubble starts to get bigger, erm, the garden, then the street, then to the shops, eventually.....even now I find, I rarely drive, erm, distance.

I: You rarely?

P; Yea, 'cos I'm not sure what's at the end, kinda thing.

an important stepping stone back into a normal life.

Feels he has had to adapt his career choice around current physical abilities.

Feels by limiting what he does is the way he likes to progress. Trying new things, is a way of breaking out of his safe bubble.

Scared to risk going out of his home after second stroke.

Increasing the safe bubble by grading activity, Garden, street, shops, driving..

Not confident to drive long distances.

Now sure how his future will map out

Comment [MSOffice34]: Tell me about your safe bubble. Does having confidence mean you can go outside this bubble?

Comment [MSOffice35]: Tell me more about that. Why would he not go into the garden? What is that telling us?

Comment [MSOffice36]: He's started to answer it for you. Listen to what he says.

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APPENDIX 14 IPA STAGE TWO : TRANSCRIPT EXAMPLE

IDEA'S FOR THEMES	LINE	INTERVIEW	INTERPRETATION
Adjustment Work Meaningful role	1 2 3 4 5	M..I work for a care company, Rainbow care, I don't really like the job really (laughs), erm, but it's almost like being mmm a stepping stone back into a normal life..a working life, erm, my old job, I used to work 'til 8 to half four, Monday to Friday, quite physical.	**First sign of acceptance/adapting/adjusting into a different life?** ***'Normal life'*** **Regaining confidence** **Recognition he needs this role to get his life back to normality – job role? father role?** **Provider? Do any or all these roles tap into his confidence**
		Physical?	
Confidence is going outside his safe bubble	6 7 8 9 10 11 12 13 14 15 16 17	Mmm, yea, a lot of lifting and carrying, so someday's my arms don't work that well, my hands, my middle finger is normally quite swollen, erm, again, it annoys me. 'cos again I used to do this, this and this, now I can't do that, that and that (phone ringing in background) but...I've almost like adapted my life, accordingly, I basically limit myself, what I can do. Whereas a lot of people say, you should kind of, push yourself, further and further. Try this, if it doesn't work and you've tried it, it' no problem, but I find if I don't try it, I kinda in my safe bubble...	**Negative about self-image?** **Can vs can't** **Needs to feel confident and safe prior to moving on?** ***Limit myself*** **Why? Does he limit himself – afraid of failure? Not enough confidence to try more ?** ***Push yourself* Does he want to? Are these other people's words?** **Does he really believe it is no problem if he tries and doesn't succeed?** ***Safe bubble* – His level of confidence? Does having confidence mean going outside the bubble.**
		Is that where you are most comfortable being?	
Fear	18 19 20	Yea, I think after the second..the TIA, erm, my safe ball was my house. I rarely went out of the house, in the garden...	
		Did you say, not even to the garden?	
Avoidance Social fear?	21	No, I just used to stay in the house completely...	

APPENDIX 15 IPA STAGE FOUR: THEME DEVELOPMENT P03

-Table 1	‘Robbed of life’ Stoke Impact on Self
Loss of former self	Dignity
Identity	Dependence
Loss of function	Quietly confident pre-stroke
Engulfed in Grief/Loss	Physical change
Psychological distress	Inactivity affects confidence
Shock	

Table 2	Fear
Fear of another Event	Living with fear
Fear of social interactions	Fear of social events
Fear of being judged	Fear of others perceptions
Fear of what people think	Lack of knowledge
Uncertain future	Impact of second stroke
Fear of stigma	

Table 3	Confidence in team
Family support	Alone
Perceived lack of empathy	Rock
Psychological input (strategies)	Community stroke team
Family relationships	Social relationships
Fun	Meaningful
Impact of labels	

Table 4	Role confidence
Football	Role of Father
Role of Husband	Role of Worker
Habits and Routines	Loss of control
Stepping stone back to normal routines	

Table 5	Skill mastery
Practice	Going outside safe bubble
Positive reinforcement	Confidence linked to activity
Repetition	Loss of skill ability
Housework	Cooking
Success and achievement	Walking
Graded activities	Motivation
Avoidance	Goals

Table 6	Recovery journey
	Good days and bad days
Regaining confidence as a daily task	Long Road
Confidence - living your daily life	Early treatment
Temporal	Hope

Table 7	Reborn as a stroke survivor (Adaptation)
Coping	Change
Building a different identity	Engaging in meaningful activity
Acceptance	Independence
	Building a Balanced lifestyle

Table 8	**Self confidence**
Decreased self esteem	Confidence is intrinsic
Image – self concept	Impact of second stroke
	Can Vs I can’t (Self-efficacy)

Notes from diaries: ?Big confidence issues with fear of social interaction. Block to unlocking road to regaining confidence and adapting to a post stroke life. Other people’s perceptions and ‘fear’ main issues.

APPENDIX 16 IPA STAGE FOUR QUOTES P03

Themes	Page/line	Key words
Loss of former self		
Living with a new identity	14.10 24.7 44.11 44.6	Rebuild my life How I am now he's gone kinda different person
Grief/psychological distress	53.1 23.10 9.5 22.18	Perception of myself, was so low Really dark dark Crying just for nothing Black hole
Dignity	8.15	Embarrassing, humbling
Being a lesser person	10.4 13.10 32.10	With less capabilities I used to do that How I speak now is awful
Loss of control	21.18	You're fine you're over the worst
Pre-confident self	54.18	I can push myself to..
Fear		
.. of another stroke	12.14 13.4 25.8	It cemented the fear in my brain Always that question..erm, maybe Living with the fear
.. of social interactions	20.15 50.1	A lot of people in one room Basically avoid things, places, people
..of going out	37.4 19.3 26.6	It's hard to talk about The street, then the shops eventually Being confident to leave the house
..stigma/being judged	33.3 32.11	Strangers, that's when the problems arise I limit my vocabulary accordingly
..of what the future brings	25.11	Can't map the future at all
Team support		
Lack of support affects confidence	20.10 20.5 15.2	Somedays I feel helpless, alone [family/friends] no idea what's going into my head Aren't my real friends
Family support	40.2	..past two years, she's been my rock completely
Information/knowledge empowers	21.4	It's written down here and not by me..
Impact of therapists – meaningful?	27.3 29.19 29.21	They made it fun Trying to inspire me Different environment

APPENDIX 17 IPA STAGE FIVE: DIFFERENCES/SIMILARITIES P04

Table 1	'Loss of former self'
Shock	
Loss of function	Physical change
Dependence	
Loss and grief	
Dignity	
Inactivity	

Table 2	Fear
	Living with fear
	Fear of falls
	Uncertain future

Table 3	Confidence in Team
Support networks	Alone
Perceived lack of empathy	Positive friend
Psychological input (strategies)	Community stroke team
Fun/humour	Social relationships
	Meaningful

Table 4	Role confidence
Habits and routines	Role of friend
	Role of Worker
	Role of daughter
	Role of sister

Table 5	Self Constructs
	Self concept
Self Image	Self efficacy
Other people's perceptions (stigma)	Self esteem
	Self confidence
	Psychological distress

Table 6	Skill Mastery
	Success and achievement
Practice	Praise
Positive and negative reinforces	Goals
Graded activity	Temporal component
Fun/humour	Meaningful activity

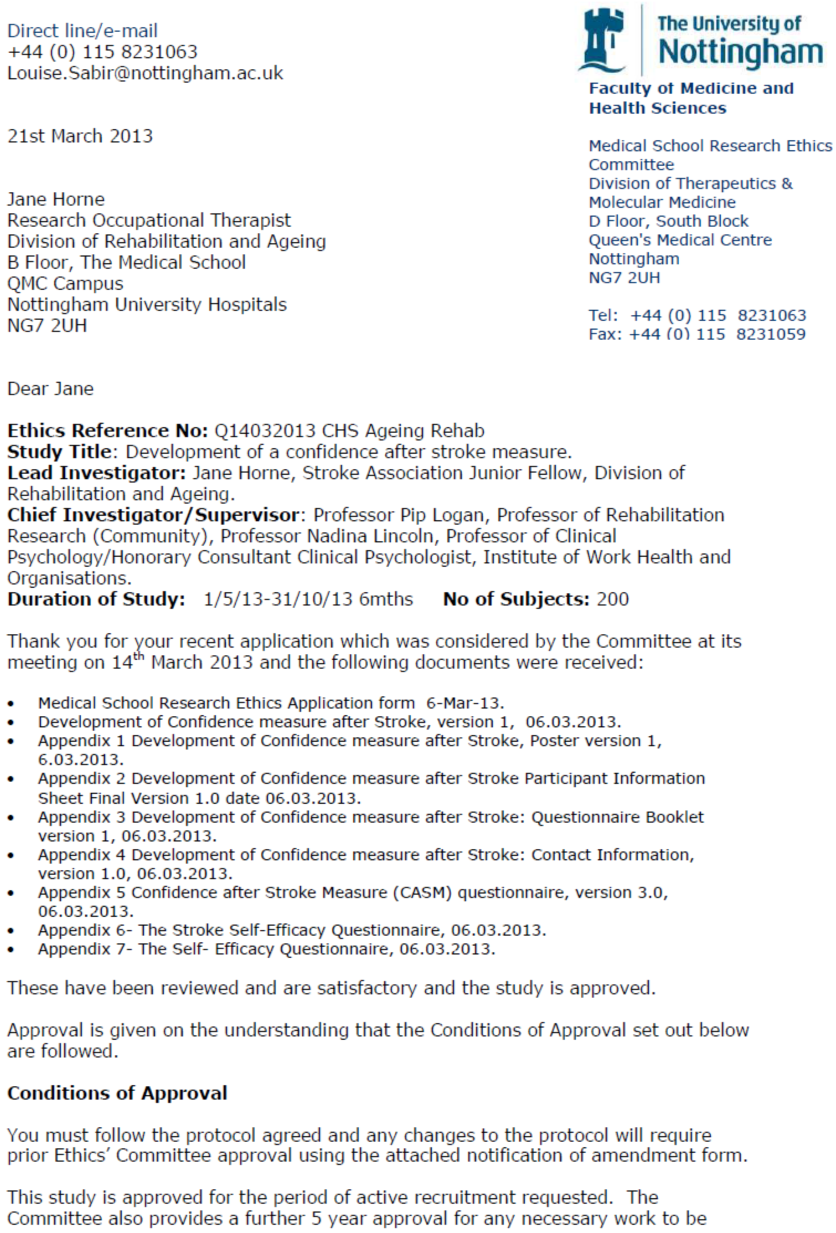
Table 7	Reborn as a stroke survivor (Adaptation)
Coping	Change
Building a different identity	Engaging in meaningful activity
Acceptance	Independence
Expectations	Building a Balanced lifestyle
Good days and bad days	Regaining confidence is a daily task
Hope	

Table 8	**Other**
	Stroke changed self-concept for the better

APPENDIX 18 EXAMPLE OF FINAL THEMES

Master table of themes for the group	
Identity: Feeling a lesser person	
Loss of identity	
Mick: *'..and I was kinda reborn, in this kinda different person'*	44.6
Bob: *'I used to be the life and soul of the party, and erm, when it h..it was a speech ther..er difficulty that caused the most problems. I was [pause] I would normally step in with a joke here and a joke there [pause]. Nothing. Now I can't tell jokes at all. No.*	13.5
Alison: *'I'm not what I was before the stroke, couldn't expect to be'*	44.11
Mick: *'I told people not to call me that anymore, cause he's gone'*	44.11
June: *..'Can't walk far, can't play badminton, I'm just a totally different person.'*	46.10
Ryan: *'..hill walking, Lake District, I'd got this thing about when I finished work, I wanted to do the Pennine Way with my lad'*	
Leon: 'As for reading and a lot of things, the most thing I miss is reading.'	11.9
Ryan: *'I'll never be a senior manager again, I never want to be either.'*	27.20
A. Fear	
Fear of another stroke	
Mick: *'Everytime I had a had a headache, I feel lightheaded, my leg hurts, there is always that question, erm, maybe [laughs] just kinda maybe'*	13.2
Mick: *It's always that kinda, it's always that living with the fear'*	35.8
June: *'..you never know what's going to happen tomorrow'*	17.6
Ted: '..*am I going to have another stroke? So that was on my mind'*	12.1
Barbara: *'..alert to any changes in my body at all, you know? Anything, because I think now, perhaps this is going to be the big one, you know?*	15.2
~Fear of falling	
Freya: *'..I've got this inner thing about falling, it's just such a [pause], that knocked me back a lot'*	58.11
Helen: *'I don't do gardening now, no. The reason is that I'm not stable enough on my legs, and if I bend I'd fall'*	19.3
Barbara: *' I was frightened of skidding, so he'd [physio] say 'oh you're not getting away with it, come on'*	15.16
Alison: *'I'm afraid of falling though, who's going to pick me up?'*	24.8
~Fear of Judgement	
Bob: ' *I'm not confident because I don't know what reaction I'll get from them'*	21.10
~Fear of going out	
June: *' Even now when I go out, I don't feel confident at all'*	38.5
Mick: *' I just used to stay in the house completely'*	18.21
Bob: *'..but a stroke, er, er [pauses] I thought about getting printed words, about where do you go, you know? Flash that to the [pause] I was confident, lack of confident and the bus*	26.4
Leon: *'..Confidence is something I believe in but, you know, like my walking for instance, how can I explain it? I walk inside here because the door is there, I hold onto there right? But if I get outside there is nothing to hold onto.*	16.3
Leon: *' you know, being confident of going outside and walking'*	23.9
June: *'I didn't have the confidence to go out, I was alright in my own surrounds.'*	31.2
~Fear of social interaction	
Ryan: '..*well at one stage I couldn't walk into a room with a lot of people in it.'*	15.7
Mick: *'basically avoided situations, places, people..'*	50.1
~Adjusting to fear	
Ryan *'I'm getting around it now'*	5.5

APPENDIX 19 ETHICAL APPROVAL LETTER: CASM DEVELOPMENT STUDY



Direct line/e-mail
+44 (0) 115 8231063
Louise.Sabir@nottingham.ac.uk

The University of Nottingham
Faculty of Medicine and Health Sciences

Medical School Research Ethics Committee
Division of Therapeutics & Molecular Medicine
D Floor, South Block
Queen's Medical Centre
Nottingham
NG7 2UH

Tel: +44 (0) 115 8231063
Fax: +44 (0) 115 8231059

21st March 2013

Jane Horne
Research Occupational Therapist
Division of Rehabilitation and Ageing
B Floor, The Medical School
QMC Campus
Nottingham University Hospitals
NG7 2UH

Dear Jane

Ethics Reference No: Q14032013 CHS Ageing Rehab
Study Title: Development of a confidence after stroke measure.
Lead Investigator: Jane Horne, Stroke Association Junior Fellow, Division of Rehabilitation and Ageing.
Chief Investigator/Supervisor: Professor Pip Logan, Professor of Rehabilitation Research (Community), Professor Nadina Lincoln, Professor of Clinical Psychology/Honorary Consultant Clinical Psychologist, Institute of Work Health and Organisations.
Duration of Study: 1/5/13-31/10/13 6mths **No of Subjects:** 200

Thank you for your recent application which was considered by the Committee at its meeting on 14th March 2013 and the following documents were received:

- Medical School Research Ethics Application form 6-Mar-13.
- Development of Confidence measure after Stroke, version 1, 06.03.2013.
- Appendix 1 Development of Confidence measure after Stroke, Poster version 1, 6.03.2013.
- Appendix 2 Development of Confidence measure after Stroke Participant Information Sheet Final Version 1.0 date 06.03.2013.
- Appendix 3 Development of Confidence measure after Stroke: Questionnaire Booklet version 1, 06.03.2013.
- Appendix 4 Development of Confidence measure after Stroke: Contact Information, version 1.0, 06.03.2013.
- Appendix 5 Confidence after Stroke Measure (CASM) questionnaire, version 3.0, 06.03.2013.
- Appendix 6- The Stroke Self-Efficacy Questionnaire, 06.03.2013.
- Appendix 7- The Self- Efficacy Questionnaire, 06.03.2013.

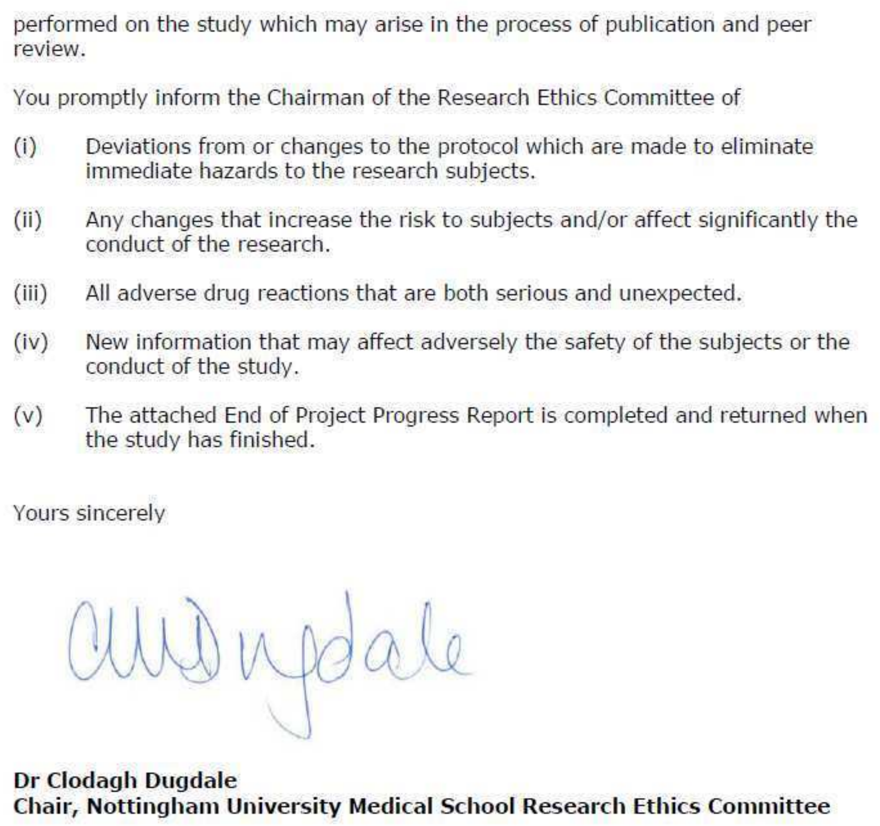
These have been reviewed and are satisfactory and the study is approved.

Approval is given on the understanding that the Conditions of Approval set out below are followed.

Conditions of Approval

You must follow the protocol agreed and any changes to the protocol will require prior Ethics' Committee approval using the attached notification of amendment form.

This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be



performed on the study which may arise in the process of publication and peer review.

You promptly inform the Chairman of the Research Ethics Committee of

(i) Deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subjects.

(ii) Any changes that increase the risk to subjects and/or affect significantly the conduct of the research.

(iii) All adverse drug reactions that are both serious and unexpected.

(iv) New information that may affect adversely the safety of the subjects or the conduct of the study.

(v) The attached End of Project Progress Report is completed and returned when the study has finished.

Yours sincerely

CMDugdale

Dr Clodagh Dugdale
Chair, Nottingham University Medical School Research Ethics Committee

APPENDIX 20 INITIAL ITEM POOL: 95 STATEMENTS

Statements +VE n=47+1	**-VE** n=47
Theme: Identity	I do not feel the same person since my stroke
I am confident I know enough about my stroke	I feel I've been robbed of life
People accept me as I am now	I feel less capable since my stroke
	I struggle to recognise who I am
Theme: Fear	**I fear having another stroke**
	Fear of hurting myself stops me from doing things
	I feel scared to go out
	Fear makes me stop trying things
	I have a fear of falling
	I have a fear of failure
	I fear what the future brings
Theme: Roles	
Voluntary roles have helped to regain confidence	It is hard to find a role I feel is important
My partner is my rock	
Theme: Doing	
I have learnt to do things differently since my stroke	Even though I practice tasks, they don't improve
My 'significant other' encourages me to do things	My participation in activities has decreased
I try to accomplish new skills	I feel I try to do too much too soon
I do well when I break things down into small achievable tasks	I avoid activities even though they are important
I get opportunities to practice doing things	I have lost skills since my stroke
I achieve more when I know what I am doing	I feel terrified when I try to do something
I am able to do things at my own pace	I get frustrated about my lack of activity levels
I practice activities on my own	It is hard for me to achieve my goals
When I succeed it boosts my confidence	I do not do the things I used to
I get excited about learning new things	Fear of having another stroke stops me from doing things
Being physically active has always been important	
My partner helps me learn new tasks	
My friends encourage me to try new things	
One-one sessions in rehabilitation gives me confidence	
Theme: Social confidence	I feel embarrassed in public places
I am confident to leave the house	I do not feel comfortable in public places
I am confident in my home environment	I am worried about how others see me
Going out is very important to me	When I go out I don't feel confident at all
My friends treat me the same as always	People talk to me as if I am daft
It is exciting meeting people I don't know	I feel terrified meeting people I don't know
	I do not feel able to walk into a crowded room
	Stigma prevents me from attending social events
	I feel people speak down to me
Theme: Attitudes and Beliefs	
My attitude helps me to be confident	I am not a confident as I was before my stroke
I think that 'I can' rather than 'I can't'	Other people's comments knock my confidence
I believe I can achieve what I want to	
Other people would say I was confident	I do not feel able to achieve what I would like
I feel I can push myself to achieve when I want to	I will not try things in front of others
My friends push me to achieve more than I think I can	I do not feel I have enough support
There are a lot of people I can go to for support	I feel people overprotect me
I am able to push myself	Looking good is a waste of time
I believe you can do anything if you try hard enough	I feel I don't have much to be proud of
I get a lot of positive feedback from my family	I am inclined to think I am a failure
I believe I have inner strength	I wish I could have more respect for myself
When people tell me I've done well it makes me feel more confident	I find it difficult to handle unseen circumstances
I am able to do as well as most people	I feel helpless
I feel I am a person of worth – at least compared to most people	Negative feedback in hospital lowered my confidence
I manage to solve problems, if I try hard enough	I feel alone
I can usually handle what comes my way	I have bad days
I take a positive attitude towards myself	I have never liked mirrors
I like myself	
I have good and bad days	
I feel good about the help I got from my stroke team	
There are people I can go to for support	
The stroke group I attend gave me confidence	
Most days I am able to motivate myself	
I reward myself when I have achieved something good	
Other	
I am confident that my environment is suitable	

APPENDIX 21 REDUCED ITEM POOL: 67 STATEMENTS

Statements 67	
+ve	**-ve**
Theme: Identity	
I am confident I know enough about my stroke	I feel I’ve been robbed of life
People accept me as I am now	I feel less capable since my stroke
Theme: Fear	
	I fear having another stroke
	Fear of hurting myself stops me from doing certain activities
	I feel scared to go out
	Fear makes me stop trying things
	I have a fear of failure
Theme: Roles	
	It is hard to find a role I feel is important
Theme: Doing	
I have learnt to do things differently since my stroke	Even though I practice tasks, they don’t improve
My ‘significant other’ encourages me to do things	My participation in activities has decreased
I try to accomplish new skills	
I do well when I break things down into small achievable tasks	I avoid activities even though they are important
I get opportunities to practice doing things	I have lost skills since my stroke
I achieve more when I know what I am doing	I feel terrified when I try to do something
I am able to do things at my own pace	I get frustrated about my lack of activity levels
I practice activities on my own	It is hard for me to achieve my goals
When I succeed it boosts my confidence	
I get excited about learning new things	
Being physically active has always been important	
Theme: Social confidence	
I am confident to leave the house	I do not feel comfortable in public places
I am confident in my home environment	I am worried about how others see me
	When I go out I don’t feel confident at all
	I feel terrified meeting people I don’t know
	I do not feel able to walk into a crowded room
	Stigma prevents me from attending social events
	I feel people speak down to me
Theme: Attitudes and Beliefs	
My attitude helps me to be confident	
I think that ‘I can’ rather than ‘I can’t’	Other people’s comments knock my confidence
I believe I can achieve what I want to	
Other people would say I was confident	I do not feel able to achieve what I would like
I feel I can push myself to achieve when I want to	I will not try things in front of others
My friends push me to achieve more than I think I can	I do not feel I have enough support
There are a lot of people I can go to for support	I feel people overprotect me
I am able to push myself	Looking good is a waste of time
I believe you can do anything if you try hard enough	I feel I don’t have much to be proud of
I get a lot of positive feedback from my family	I am inclined to believe I am a failure
I believe I have inner strength	I wish I could have more respect for myself
When people tell me I’ve done well it makes me feel more confident	I find it difficult to handle unseen circumstances
I am able to do as well as most people	
I feel I am a person of worth – at least compared to most people	
I manage to solve problems, if I try hard enough	I feel alone
I can usually handle what comes my way	I have bad days
I take a positive attitude towards myself	
I have good and bad days *neutral	

APPENDIX 22 EMAIL CORRESPONDENCE: OCCUPATIONAL THERAPISTS

From: Horne Jane
Sent: 12 November 2012 12:35
To: Names of [Occupational Therapist's]
Subject: Confidence Measure

Hi all,

I would really value your view as a therapist, on the development of my confidence questionnaire.

It may need explaining. I am asking psychologists/researchers/therapists to comment and give feedback on the content of the attached questionnaire.

My PhD is focussed on developing a confidence measure, with the aim of having a measure, within a stroke domain that will identify low to mid confidence levels. Firstly, to help with the management of confidence as stroke survivors continue to their lives after stroke, particularly as confidence is often considered a benchmark to recovery in stroke rehabilitation. Secondly, it is envisaged that the measure could also be used to capture any confidence component, when testing the effectiveness of complex interventions after stroke.

I have completed the first stage, which was to explore the meaning of confidence with stroke survivors, by conducting a qualitative study. I have combined this data with the literature within stroke, sport and education (the latter two, because confidence is already being measured in these areas) to inform the development of the confidence questionnaire. I have used participant's own words with the aim of capturing some of the themes which emerged from the interview study.

At this pre-test stage, I have got 67 statements which will be tested with groups living in the community, to examine if it is ‘confidence’ we are measuring. Eventually I am looking to reduce the measure, ideally to about 20 items in the final confidence measure. Initially though, I just want to test with a dozen or so clinical and research professionals as to whether there are any areas of omission. Any areas that the wording is questionable, ie, will stroke patients understand it, words even as basic as activity or roles (I know we know what they mean, but that perhaps is the danger!). Or anything you spot as a clinician, that you feel needs changing or adjusting.

I envisage the ‘look’ of the questionnaire will change over time, so don’t worry too much about aesthetics at the minute. When we have got to the stage when the items have been reduced, I will look at more ‘ key words’ and attempt a more aphasia friendly version. Any comments you have on this issue would be appreciated. It would also help if you would comment on the use of the visuals, ie, use of thumbs up and thumbs down instead or as well as the words: strongly agree, agree, neither agree or disagree or neutral?, disagree, strongly disagree? My favoured measure is a Likert scale at present. How easy would that be to administer as a clinician? Would it give you meaningful data?

Your help with this is very much appreciated, please email or telephone if you feel you need more clarification. I will keep you informed, on the measure's development.

Best wishes and many thanks.

Jane Horne
Research Occupational Therapist

School of Community Health Sciences
Division of Rehabilitation & Ageing
B Floor
Medical School
Queen's Medical Centre
Nottingham NG7 2UH
Tel: +44 (0) 115 8230274
Fax +44 (0) 115 8230231

APPENDIX 23 EMAIL CORRESPONDENCE TO PSYCHOLOGISTS

From: [Academic Supervisor]
Sent: 14 November 2012 15:57
To: [12 Stroke Experienced Psychologists]
Cc: Jane Horne

Subject: Confidence measure

Dear All

Please could you offer us some advice. Jane Horne is developing a confidence questionnaire as part of her PhD. We would value your opinion on the first draft.

The PhD is focussed on developing a measure of confidence, in order to evaluate a regaining confidence intervention.

Jane has completed the first stage, which was to explore the meaning of confidence with stroke survivors, by conducting a qualitative study. She has combined this data with the literature within stroke, sport and education (the latter two, because confidence is already being measured in these areas) to inform the development of the confidence questionnaire. She has used participant's own words to try and capture some of the issues which emerged from the interview study.

At this pre-test stage, she has 67 draft statements. These will be refined and then tested to see whether they measure ‘confidence’, in both healthy elderly and stroke patients. The aim is to be left with 20 items or less that will form the final confidence measure. Initially though, would like the opinion of clinical and research professionals as to whether there are any areas of omission. She would like to know whether any questions are ambiguous, i.e. will stroke patients understand it, or anything you feel needs changing or adjusting.

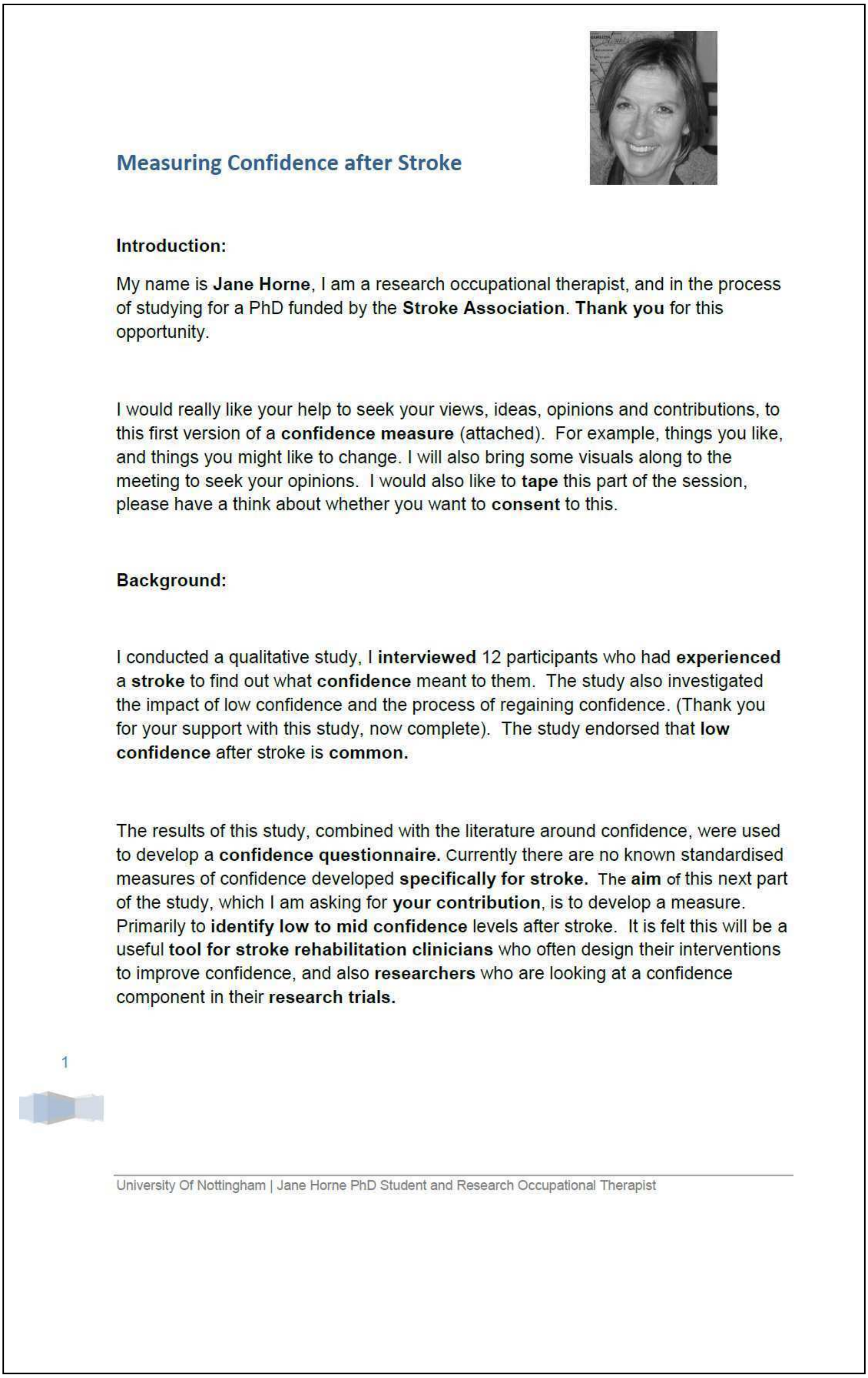
We envisage the ‘look’ of the questionnaire will change over time. It would also help if you would comment on the use of the visuals, i.e. use of thumbs up and thumbs down instead or as well as the words: strongly agree, agree, neither agree or disagree or neutral? How easy would the questionnaire be to administer? Would it give you meaningful information?

Your help with this is very much appreciated. Please email if you feel you need more clarification.

Thanks

Nadina

APPENDIX 24 STROKE RESEARCH GROUP INFORMATION



Measuring Confidence after Stroke

Introduction:

My name is **Jane Horne**, I am a research occupational therapist, and in the process of studying for a PhD funded by the **Stroke Association**. **Thank you** for this opportunity.

I would really like your help to seek your views, ideas, opinions and contributions, to this first version of a **confidence measure** (attached). For example, things you like, and things you might like to change. I will also bring some visuals along to the meeting to seek your opinions. I would also like to **tape** this part of the session, please have a think about whether you want to **consent** to this.

Background:

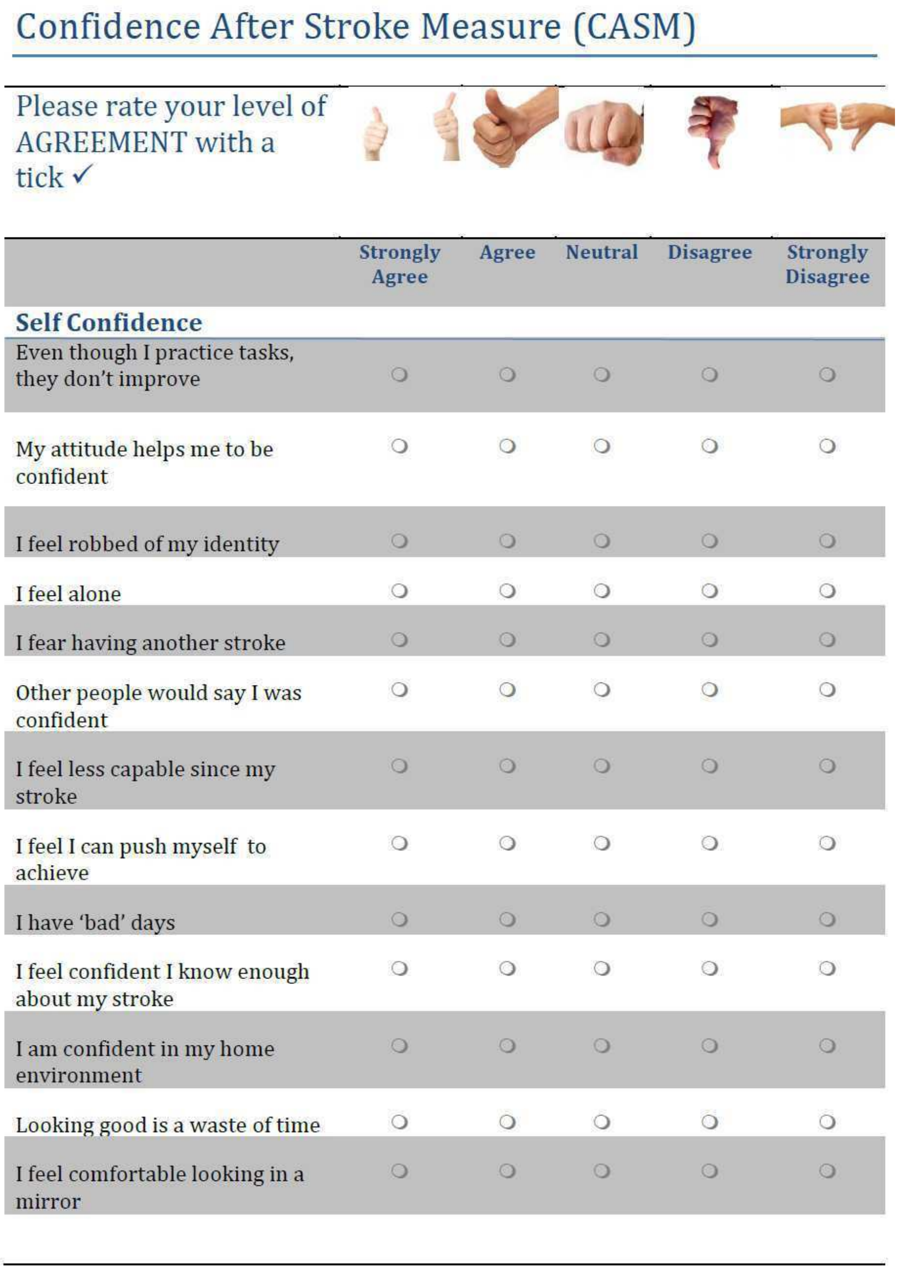
I conducted a qualitative study, I **interviewed** 12 participants who had **experienced** a **stroke** to find out what **confidence** meant to them. The study also investigated the impact of low confidence and the process of regaining confidence. (Thank you for your support with this study, now complete). The study endorsed that **low confidence** after stroke is **common.**

The results of this study, combined with the literature around confidence, were used to develop a **confidence questionnaire.** Currently there are no known standardised measures of confidence developed **specifically for stroke.** The **aim** of this next part of the study, which I am asking for **your contribution**, is to develop a measure. Primarily to **identify low to mid confidence** levels after stroke. It is felt this will be a useful **tool for stroke rehabilitation clinicians** who often design their interventions to improve confidence, and also **researchers** who are looking at a confidence component in their **research trials.**

1

University Of Nottingham | Jane Horne PhD Student and Research Occupational Therapist

APPENDIX 25 PILOT VERSION OF THE CASM



Confidence After Stroke Measure (CASM)

Please rate your level of AGREEMENT with a tick ✓

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Self Confidence					
Even though I practice tasks, they don't improve	○	○	○	○	○
My attitude helps me to be confident	○	○	○	○	○
I feel robbed of my identity	○	○	○	○	○
I feel alone	○	○	○	○	○
I fear having another stroke	○	○	○	○	○
Other people would say I was confident	○	○	○	○	○
I feel less capable since my stroke	○	○	○	○	○
I feel I can push myself to achieve	○	○	○	○	○
I have 'bad' days	○	○	○	○	○
I feel confident I know enough about my stroke	○	○	○	○	○
I am confident in my home environment	○	○	○	○	○
Looking good is a waste of time	○	○	○	○	○
I feel comfortable looking in a mirror	○	○	○	○	○

					
I can usually handle what comes my way	○	○	○	○	○
I feel I do not have much to be proud of	○	○	○	○	○
I am inclined to believe I am a failure	○	○	○	○	○
I wish I had more respect for myself	○	○	○	○	○
It is hard for me to achieve my goals	○	○	○	○	○
I find it difficult to handle unforeseen circumstances	○	○	○	○	○
General Self-Efficacy					
My attitude helps me to be confident	○	○	○	○	○
I think that 'I can' rather than 'I can't'	○	○	○	○	○
I avoid everyday tasks even though they are important	○	○	○	○	○
I take a positive attitude towards myself	○	○	○	○	○
I believe I can achieve what I want to	○	○	○	○	○
I do not feel able to achieve what I would like	○	○	○	○	○
I am able to do things as well as most people	○	○	○	○	○
Fear of hurting myself stops me from doing certain activities	○	○	○	○	○
I have a fear of failure	○	○	○	○	○

					
I achieve more when I enjoy what I am doing	○	○	○	○	○
I am able to push myself	○	○	○	○	○
I believe you can do anything if you try hard enough	○	○	○	○	○
I believe I have inner strength	○	○	○	○	○
Fear makes me stop trying things	○	○	○	○	○
I manage to solve problems if I try hard enough	○	○	○	○	○
Social Confidence					
I do not feel comfortable in public places	○	○	○	○	○
I am confident to leave the house	○	○	○	○	○
I am worried about how others see me	○	○	○	○	○
I feel terrified meeting people I don't know	○	○	○	○	○
I do not feel able to walk into a crowded room	○	○	○	○	○
Other people's comments knock my confidence	○	○	○	○	○
I try not to do things in front of others	○	○	○	○	○
When I go out I don't feel confident at all	○	○	○	○	○
People accept me as I am now	○	○	○	○	○
I feel other people overprotect me	○	○	○	○	○

Jane Horne 2012 [V3]

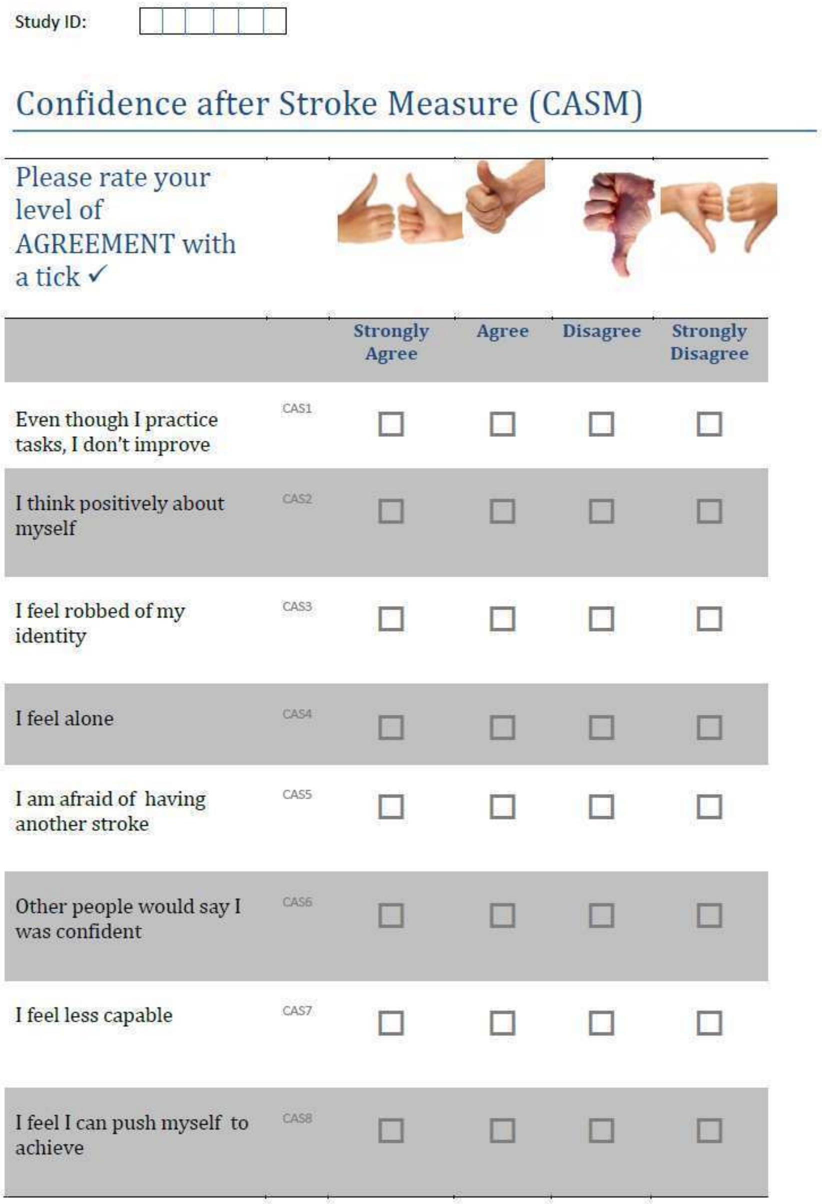
					
Stigma prevents me from attending social events	○	○	○	○	○
I feel other people judge how I look	○	○	○	○	○
Doing					
Doing 'everyday things' have decreased	○	○	○	○	○
I have learnt do to things differently since my stroke	○	○	○	○	○
I do well when I break things down into small achievable tasks	○	○	○	○	○
I try to carry out new skills	○	○	○	○	○
I have lost skills since my stroke	○	○	○	○	○
I get opportunities to practice doing things	○	○	○	○	○
I feel scared to go out	○	○	○	○	○
Being physically active has always been important	○	○	○	○	○
I achieve more when I know what I am doing	○	○	○	○	○
I am able to do things at my own pace	○	○	○	○	○
It is hard to find a hobby that I feel is important	○	○	○	○	○
I feel terrified when I try to do something	○	○	○	○	○
I get frustrated when I can't do as much as I want to	○	○	○	○	○

					
I practise everyday activities on my own	○	○	○	○	○
I get excited about learning new things	○	○	○	○	○

Team Confidence

My 'significant other' encourages me to do things	○	○	○	○	○
Other people push me to achieve more than I think I can	○	○	○	○	○
There are a lot of people I can go to for support	○	○	○	○	○
I don't feel I have enough support	○	○	○	○	○
I get a lot of positive feedback from my family	○	○	○	○	○
Health professionals have been encouraging	○	○	○	○	○
I feel people speak down to me	○	○	○	○	○
When people tell me I've done well it makes me feel more confident	○	○	○	○	○

APPENDIX 26 FIRST VERSION OF THE 53 ITEM CASM



Study ID: ☐☐☐☐☐☐

Confidence after Stroke Measure (CASM)

Please rate your level of AGREEMENT with a tick ✓		Strongly Agree	Agree	Disagree	Strongly Disagree
Even though I practice tasks, I don't improve	CAS1	☐	☐	☐	☐
I think positively about myself	CAS2	☐	☐	☐	☐
I feel robbed of my identity	CAS3	☐	☐	☐	☐
I feel alone	CAS4	☐	☐	☐	☐
I am afraid of having another stroke	CAS5	☐	☐	☐	☐
Other people would say I was confident	CAS6	☐	☐	☐	☐
I feel less capable	CAS7	☐	☐	☐	☐
I feel I can push myself to achieve	CAS8	☐	☐	☐	☐

Study ID: ☐☐☐☐☐☐

Please rate your level of AGREEMENT with a tick ✓

		Strongly Agree	Agree	Disagree	Strongly Disagree
I am confident in my home	CAS09	☐	☐	☐	☐
I feel comfortable looking in a mirror	CAS10	☐	☐	☐	☐
I can usually handle what comes my way	CAS11	☐	☐	☐	☐
I do not have much to be proud of	CAS12	☐	☐	☐	☐
I believe I am a failure	CAS13	☐	☐	☐	☐
It is hard for me to achieve my goals	CAS14	☐	☐	☐	☐
It is difficult to handle situations that are unplanned	CAS15	☐	☐	☐	☐
My attitude helps me to be confident	CAS16	☐	☐	☐	☐

Study ID: ☐☐☐☐☐☐

Please rate your level of AGREEMENT with a tick ✓

		Strongly Agree	Agree	Disagree	Strongly Disagree
I avoid important everyday tasks	CAS17	☐	☐	☐	☐
I believe I can achieve what I want to	CAS18	☐	☐	☐	☐
I am able to do things as well as most people	CAS19	☐	☐	☐	☐
I worry I am not safe to use electrical equipment or appliances	CAS20	☐	☐	☐	☐
I have a fear of failure	CAS21	☐	☐	☐	☐
I achieve more when I enjoy what I am doing	CAS22	☐	☐	☐	☐
I am able to push myself	CAS23	☐	☐	☐	☐
I believe you can do anything if you try hard enough	CAS24	☐	☐	☐	☐
I believe I have inner strength	CAS25	☐	☐	☐	☐

Study ID: ☐☐☐☐☐☐

Please rate your level of AGREEMENT with a tick ✓

		Strongly Agree	Agree	Disagree	Strongly Disagree
I manage to solve problems if I try hard enough	CAS26	☐	☐	☐	☐
I do not feel comfortable in public places	CAS27	☐	☐	☐	☐
I feel home is the only place where I am safe	CAS28	☐	☐	☐	☐
I am confident enough to leave the house	CAS29	☐	☐	☐	☐
I am worried about how others see me	CAS30	☐	☐	☐	☐
I feel terrified meeting people I don't know	CAS31	☐	☐	☐	☐
I do not feel able to attend social events	CAS32	☐	☐	☐	☐
Other people's comments knock my confidence	CAS33	☐	☐	☐	☐

Study ID: ☐☐☐☐☐☐

Please rate your level of AGREEMENT with a tick ✓

		Strongly Agree	Agree	Disagree	Strongly Disagree
I worry I will fall and hurt myself when I am out	CAS34	☐	☐	☐	☐
I feel I am not very good company	CAS35	☐	☐	☐	☐
I feel other people overprotect me	CAS36	☐	☐	☐	☐
I don't like people seeing me using aids, such as, walking aids	CAS37	☐	☐	☐	☐
I feel other people judge how I look	CAS38	☐	☐	☐	☐
It bothers me that I can't do things like I used to	CAS39	☐	☐	☐	☐
I have learnt to do things differently since my stroke	CAS40	☐	☐	☐	☐
I do well when I do 'a bit at a time'	CAS41	☐	☐	☐	☐

Study ID: ☐☐☐☐☐☐

Please rate your level of AGREEMENT with a tick ✓

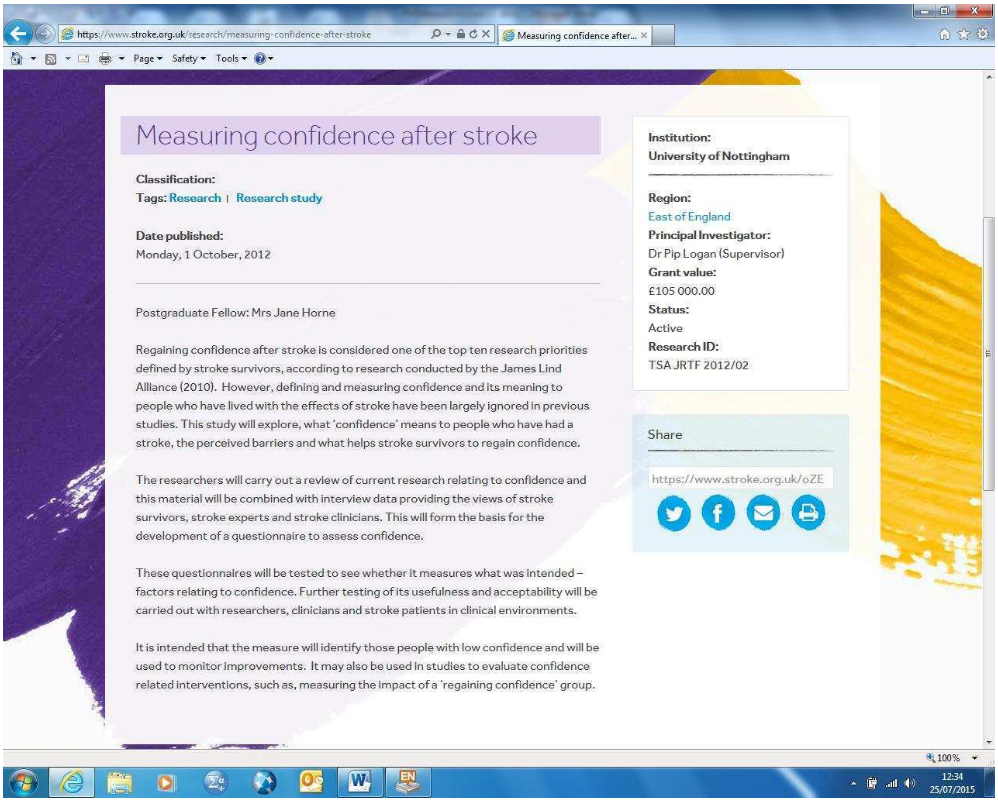
		Strongly Agree	Agree	Disagree	Strongly Disagree
I feel scared to go out	CAS42	☐	☐	☐	☐
I am able to do things at my own pace	CAS43	☐	☐	☐	☐
It is hard to find a hobby that I value	CAS44	☐	☐	☐	☐
I feel terrified when I try to do something new	CAS45	☐	☐	☐	☐
I get frustrated when I can't do as much as I want to	CAS46	☐	☐	☐	☐
I get excited about learning new things	CAS47	☐	☐	☐	☐
My family/friends encourage me to do things	CAS48	☐	☐	☐	☐
Other people push me to achieve more than I think I can	CAS49	☐	☐	☐	☐

Study ID: ☐☐☐☐☐☐

Please rate your level of AGREEMENT with a tick ✓

		Strongly Agree	Agree	Disagree	Strongly Disagree
I get a lot of positive encouragement from my family/friends/neighbours	CAS50	☐	☐	☐	☐
I am encouraged by my health professionals	CAS51	☐	☐	☐	☐
I feel people speak down to me	CAS52	☐	☐	☐	☐
When people tell me I've done well it makes me feel more confident	CAS53	☐	☐	☐	☐

APPENDIX 27 STROKE ASSOCIATION WEB SITE PROJECT INFORMATION



Measuring confidence after stroke

Classification:
Tags: Research | Research study

Date published:
Monday, 1 October, 2012

Postgraduate Fellow: Mrs Jane Horne

Regaining confidence after stroke is considered one of the top ten research priorities defined by stroke survivors, according to research conducted by the James Lind Alliance (2010). However, defining and measuring confidence and its meaning to people who have lived with the effects of stroke have been largely ignored in previous studies. This study will explore, what 'confidence' means to people who have had a stroke, the perceived barriers and what helps stroke survivors to regain confidence.

The researchers will carry out a review of current research relating to confidence and this material will be combined with interview data providing the views of stroke survivors, stroke experts and stroke clinicians. This will form the basis for the development of a questionnaire to assess confidence.

These questionnaires will be tested to see whether it measures what was intended – factors relating to confidence. Further testing of its usefulness and acceptability will be carried out with researchers, clinicians and stroke patients in clinical environments.

It is intended that the measure will identify those people with low confidence and will be used to monitor improvements. It may also be used in studies to evaluate confidence related interventions, such as, measuring the impact of a 'regaining confidence' group.

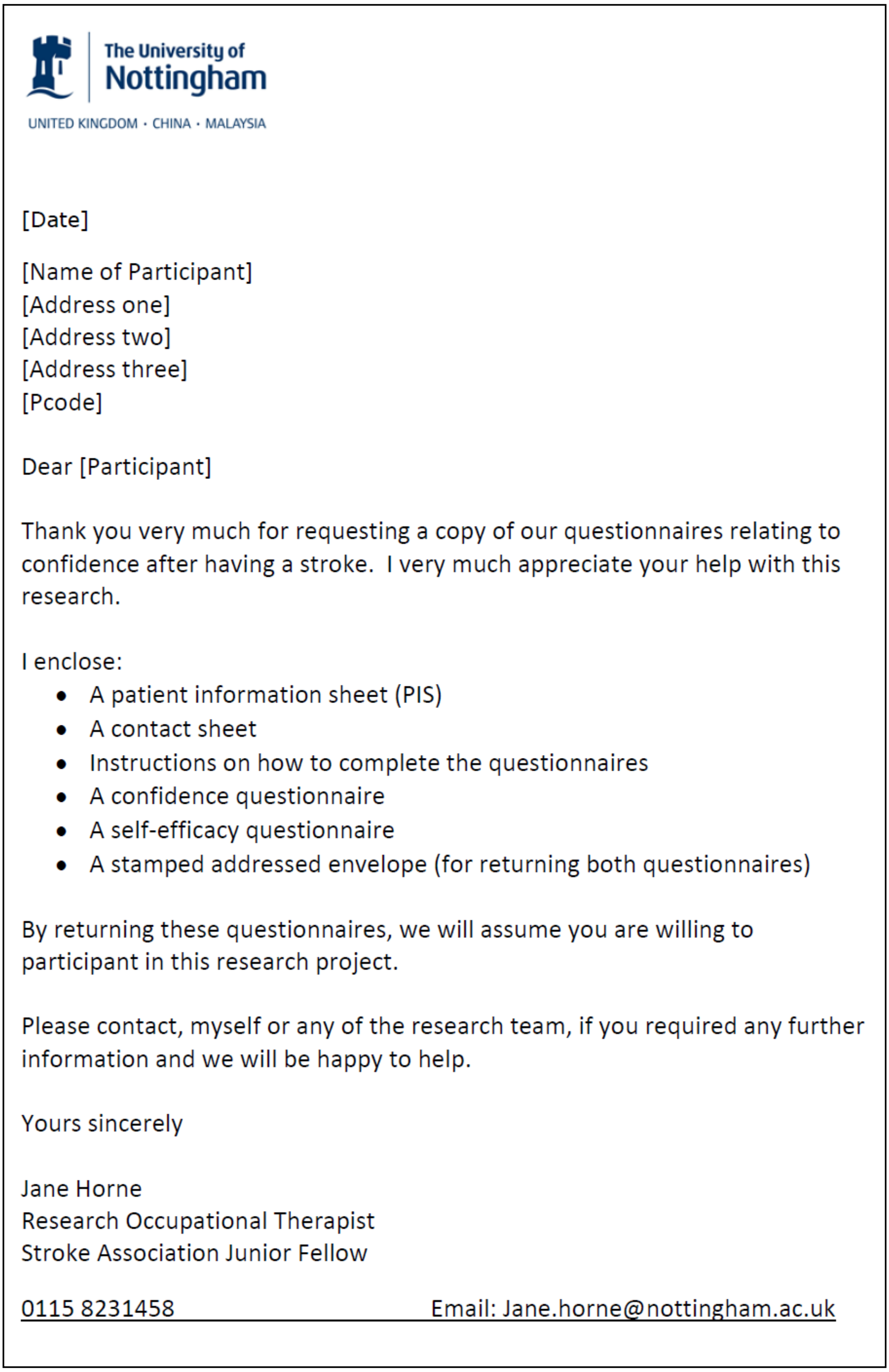
Institution:
University of Nottingham

Region:
East of England
Principal Investigator:
Dr Pip Logan (Supervisor)
Grant value:
£105 000.00
Status:
Active
Research ID:
TSA JRTF 2012/02

Share

https://www.stroke.org.uk/oZE

APPENDIX 28 PARTICIPANT LETTER



The University of
Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

[Date]

[Name of Participant]
[Address one]
[Address two]
[Address three]
[Pcode]

Dear [Participant]

Thank you very much for requesting a copy of our questionnaires relating to confidence after having a stroke. I very much appreciate your help with this research.

I enclose:

- A patient information sheet (PIS)
- A contact sheet
- Instructions on how to complete the questionnaires
- A confidence questionnaire
- A self-efficacy questionnaire
- A stamped addressed envelope (for returning both questionnaires)

By returning these questionnaires, we will assume you are willing to participant in this research project.

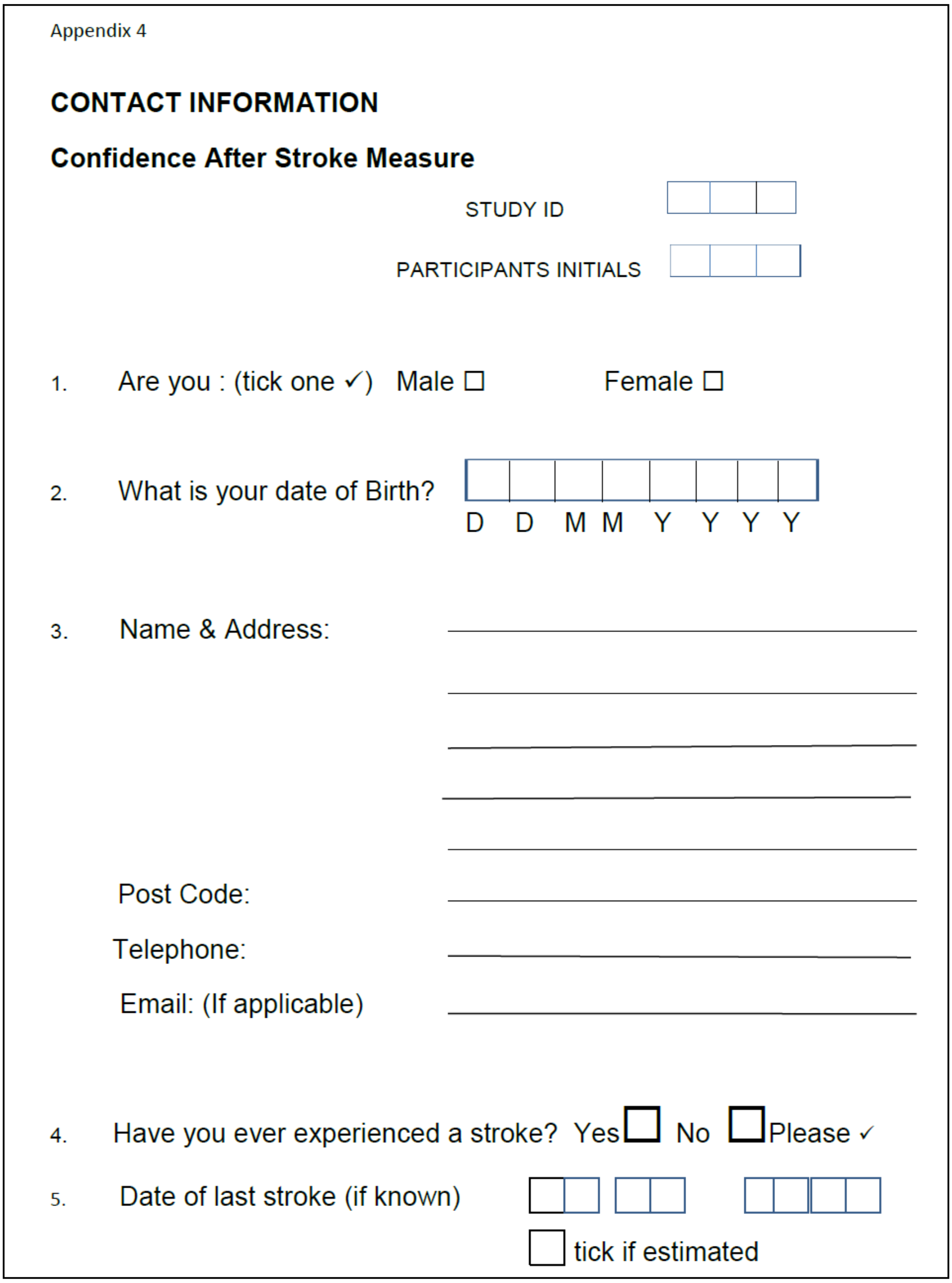
Please contact, myself or any of the research team, if you required any further information and we will be happy to help.

Yours sincerely

Jane Horne
Research Occupational Therapist
Stroke Association Junior Fellow

0115 8231458 Email: Jane.horne@nottingham.ac.uk

APPENDIX 29 CONTACT SHEET



Appendix 4

CONTACT INFORMATION

Confidence After Stroke Measure

STUDY ID ☐☐☐

PARTICIPANTS INITIALS ☐☐☐

1. Are you : (tick one ✓) Male ☐ Female ☐

2. What is your date of Birth? ☐☐☐☐☐☐☐☐
D D M M Y Y Y Y

3. Name & Address: ____________________
____
____
____
____

Post Code: ____________________

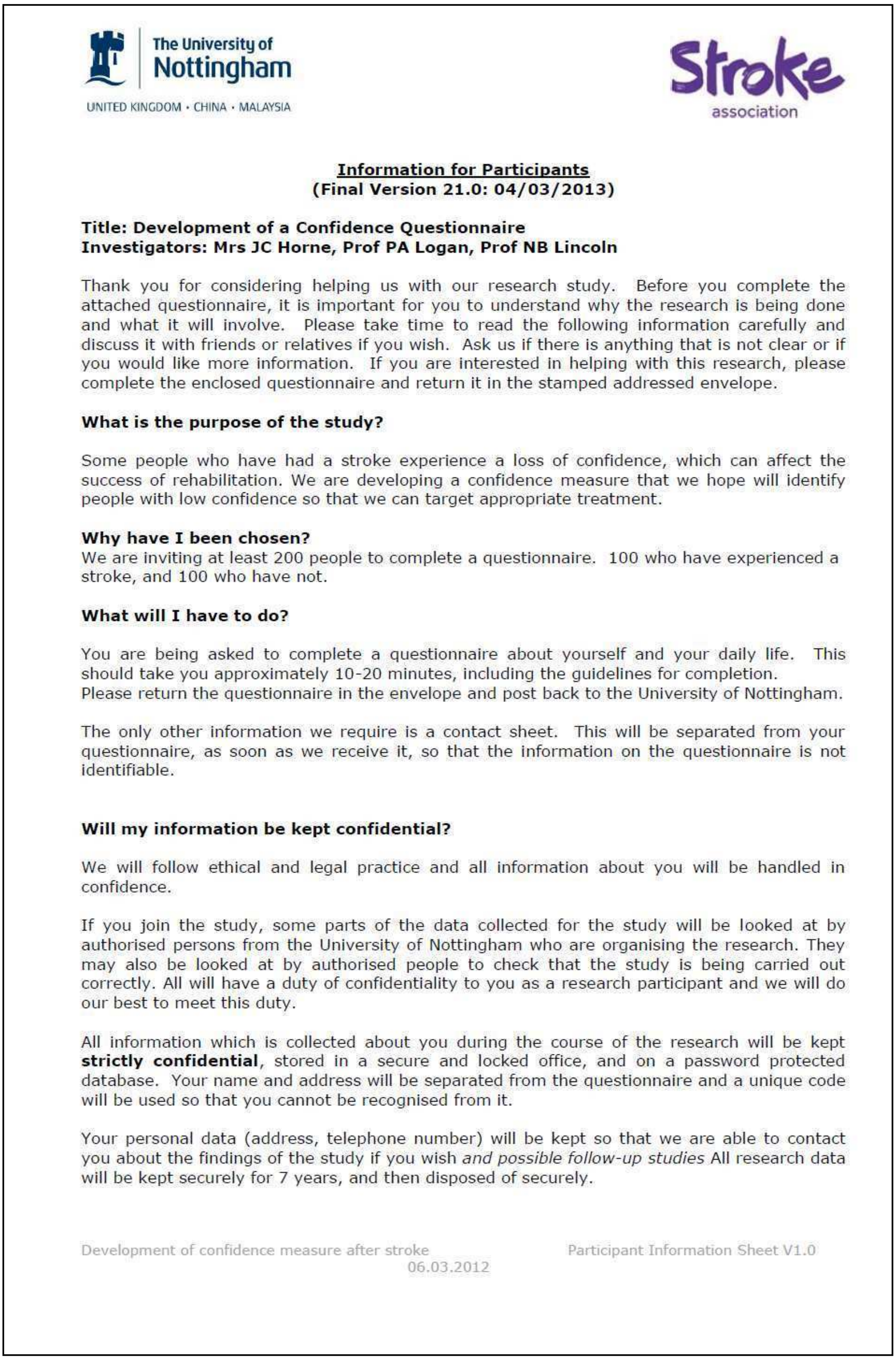
Telephone: ____________________

Email: (If applicable) ____________________

4. Have you ever experienced a stroke? Yes ☐ No ☐ Please ✓

5. Date of last stroke (if known) ☐☐ ☐☐ ☐☐☐☐
☐ tick if estimated

APPENDIX 30 INFORMATION SHEET



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Stroke association

Information for Participants
(Final Version 21.0: 04/03/2013)

Title: Development of a Confidence Questionnaire
Investigators: Mrs JC Horne, Prof PA Logan, Prof NB Lincoln

Thank you for considering helping us with our research study. Before you complete the attached questionnaire, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends or relatives if you wish. Ask us if there is anything that is not clear or if you would like more information. If you are interested in helping with this research, please complete the enclosed questionnaire and return it in the stamped addressed envelope.

What is the purpose of the study?

Some people who have had a stroke experience a loss of confidence, which can affect the success of rehabilitation. We are developing a confidence measure that we hope will identify people with low confidence so that we can target appropriate treatment.

Why have I been chosen?
We are inviting at least 200 people to complete a questionnaire. 100 who have experienced a stroke, and 100 who have not.

What will I have to do?

You are being asked to complete a questionnaire about yourself and your daily life. This should take you approximately 10-20 minutes, including the guidelines for completion.
Please return the questionnaire in the envelope and post back to the University of Nottingham.

The only other information we require is a contact sheet. This will be separated from your questionnaire, as soon as we receive it, so that the information on the questionnaire is not identifiable.

Will my information be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, some parts of the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Your name and address will be separated from the questionnaire and a unique code will be used so that you cannot be recognised from it.

Your personal data (address, telephone number) will be kept so that we are able to contact you about the findings of the study if you wish *and possible follow-up studies* All research data will be kept securely for 7 years, and then disposed of securely.

Development of confidence measure after stroke Participant Information Sheet V1.0
06.03.2012

What will happen if I don't want to carry on with the study?
Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?
The results of the study will be presented at conferences arranged by professional organisations which are attended by healthcare professionals, as well as at local stroke groups such as the Nottingham research stroke consumer group. The results may also be published in a scientific journal. There will be no way that you could be identified in any published reports.

Who is organising and funding the research?
The research is organised by the University of Nottingham and funded by the Stroke Association.

Contact for further information

Jane Horne
Tel: 0115 8231458
E-Mail: jane.horne@nottingham.ac.uk

Or

Prof. Pip Logan
Tel: 0115 823 0235
Email: pip.logan@nottingham.ac.uk

Thank you for reading this information

APPENDIX 31 THE SSEQ

The STROKE SELF-EFFICACY QUESTIONNAIRE

These questions are about *your* confidence that you can do some tasks that may have been difficult 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*

Not at all confident

Very confident

How *Confident* are you *now* that you can

1. **Get yourself comfortable in bed every night**

Not at all confident — Very confident

0 5 10

2. **Get yourself out of bed on your own even when you feel tired**

Not at all confident — Very confident

0 5 10

3. **Walk a few steps on your own on any surface inside your house.**

Not at all confident — Very confident

0 5 10

4. **Walk about your house to do most things you want.**

Not at all confident — Very confident

0 5 10

5. **Walk safely outside on your own on any surface.**

Not at all confident   Very confident

0   5   10

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 every day.**

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 32 PARTICIPANT INSTRUCTIONS

Questionnaire Booklet:

We have attached two questionnaires, and we would like you to help with our research by completing **BOTH** questionnaires and returning them in the stamped address envelope provided.

We would like this information as soon as possible, after you receive it, and NO LATER than ONE MONTH, in order to complete the research to the required timescale.

1. Confidence Questionnaire: 53 items

We want to know your level of **AGREEMENT** with each statement. For example, *I feel scared to go out*' you might 'strongly agree' with this statement, or just 'agree' with this statement. If however, if you do **not** feel scared to go out you would 'disagree' with the statement or 'strongly disagree' depending on how strongly you feel.

Please use a **black** pen to tick the box that most applies to you. For example, I do not feel 'scared to go out' so this would be my answer to that statement:

Example: I feel scared to go out:

Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree ☑

As I do not feel scared to go out, I have ticked 'strongly disagree'

Please answer every one of the 53 items on the questionnaire. Please DO NOT leave any blank ones, answer the closest 'fit' to how you feel.

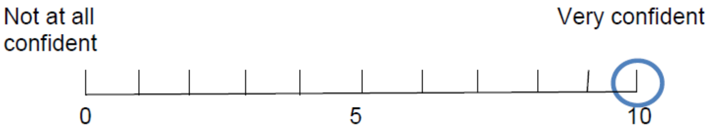
PTO…

2. The Self Efficacy Questionnaire: 13 items

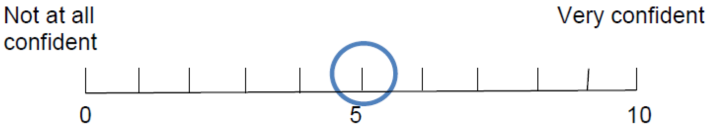
Please rate your strength of confidence about achieving each of items.

There is a 0-10 scale, where 0 is absolutely no confidence, and 10 is complete confidence about accomplishing the task. The measure asks you to rate your PERSONAL capability to accomplish each item.

Please use a **BLACK** pen to **circle** the box that most applies to you. For example, as I feel very confident that I can get out of bed, on my own even when I feel tired. I would circle 10.



Other questions you might feel less confidence about. For example, I do not do exercise every day, but do on some days. I do not feel confident that I could do my exercise programme every day on my own. So I would answer for question 10.



I am fairly confident, but not very confident. So I would rate my confidence on this question about half way up the scale.

Please use the enclosed Stamped Addressed Envelope to return BOTH questionnaires, once completed.

A contact sheet is also enclosed, by completing this sheet you are implicitly agreeing to be involved in our research. We will use this sheet to send out the first questionnaire again, so we can compare the answers you have given.

There are no RIGHT or WRONG answers, we are asking for you to complete both questionnaires, on how you feel on the day.

Thank you, your help is invaluable.

APPENDIX 33 NRES ETHICAL APPROVAL LETTER

NHS
Health Research Authority
NRES Committee South Central - Hampshire A
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 342 1381

22 July 2014

Prof Pip A Logan
University of Nottingham, School of Medicine,
Room B108a, B Floor, Division of Rehab and Ageing, QMC,
Nottingham
NG7 2UH

Dear Prof Logan

Study title:	**Confidence After Stroke Measure**
REC reference:	**14/SC/1154**
Protocol number:	**14068**
IRAS project ID:	**158459**

The Proportionate Review Sub-committee of the NRES Committee South Central - Hampshire A reviewed the above application on 22 July 2014.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager Mrs Vicky Canfield-Duthie, nrescommittee.southcentral-hampshirea@nhs.net.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

1. Please add the name of the Ethics committee to the Participant Information Sheet

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

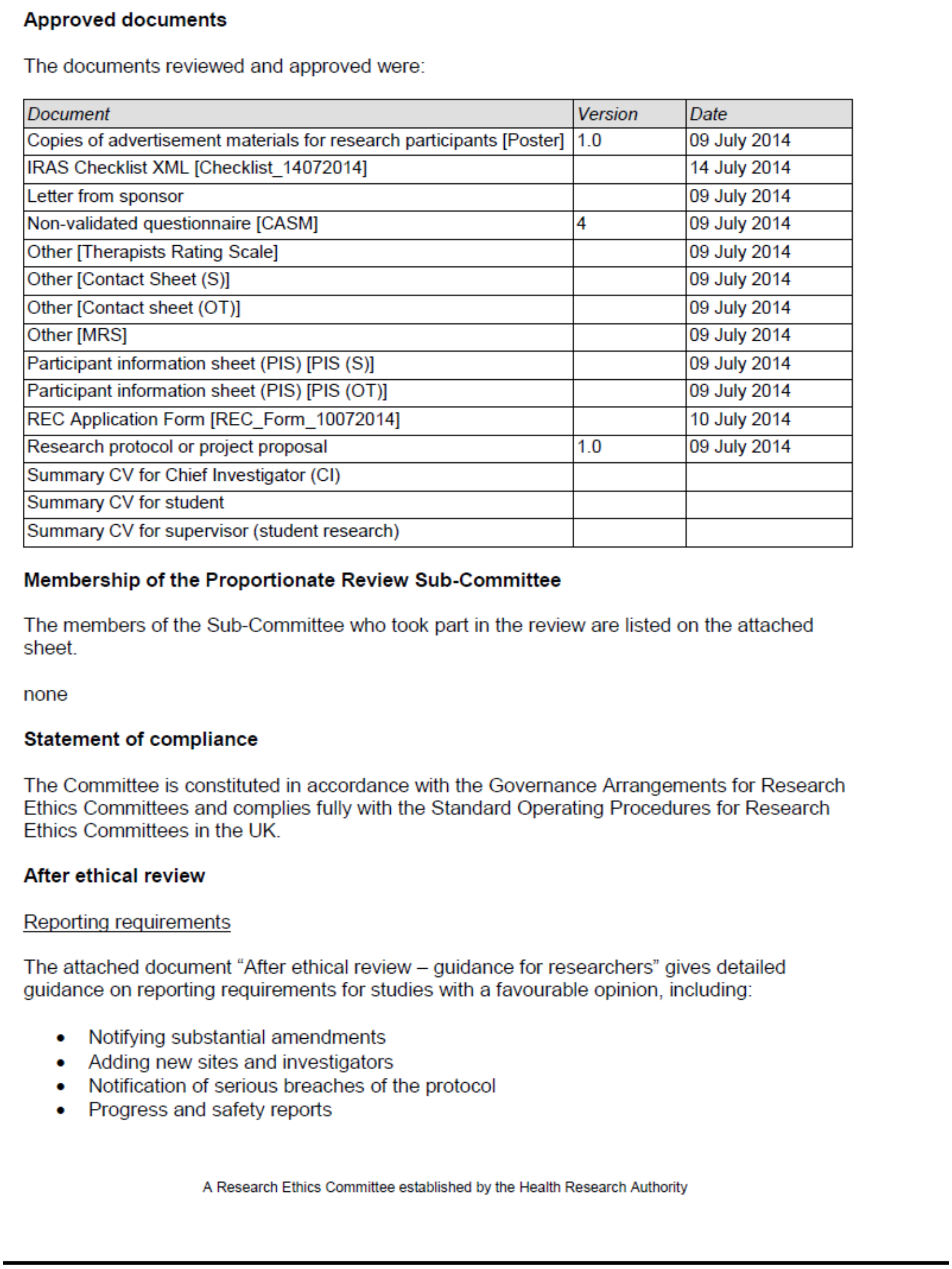
To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion").



Approved documents

The documents reviewed and approved were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Poster]	1.0	09 July 2014
IRAS Checklist XML [Checklist_14072014]		14 July 2014
Letter from sponsor		09 July 2014
Non-validated questionnaire [CASM]	4	09 July 2014
Other [Therapists Rating Scale]		09 July 2014
Other [Contact Sheet (S)]		09 July 2014
Other [Contact sheet (OT)]		09 July 2014
Other [MRS]		09 July 2014
Participant information sheet (PIS) [PIS (S)]		09 July 2014
Participant information sheet (PIS) [PIS (OT)]		09 July 2014
REC Application Form [REC_Form_10072014]		10 July 2014
Research protocol or project proposal	1.0	09 July 2014
Summary CV for Chief Investigator (CI)		
Summary CV for student		
Summary CV for supervisor (student research)		

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

none

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports

- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

14/SC/1154 **Please quote this number on all correspondence**

Yours sincerely

Dr Simon Kolstoe
Chair

Email: nrescommittee.southcentral-hampshirea@nhs.net

Enclosures:	*List of names and professions of members who took part in the review* *"After ethical review – guidance for researchers" [SL-AR2]*
Copy to:	*Ms Angela Shone* *Ms Shirley Mitchell, Nottinghamshire Healthcare NHS Trust (Nottingham Community Health Services)*

APPENDIX 34 VAS OCCUPATIONAL THERAPISTS RATING SCALE

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

S3 ☐☐

Therapists number 1-6

☐☐☐☐☐☐

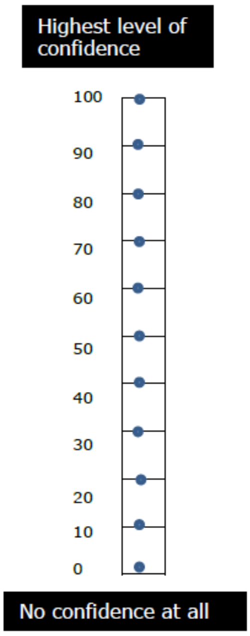
Participant Initials Site 1-3 n=1-20

To help you say how confident a person is we have drawn a scale.

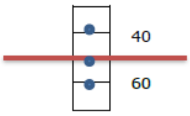
- The highest level of confidence is 100
- lowest level of confidence is 0

We would like you to indicate ANYWHERE on this scale how low or high you think this person's confidence level is today.

Please do this by drawing a line, through the scale at whichever point on the scale indicates **your opinion** of their confidence level today.

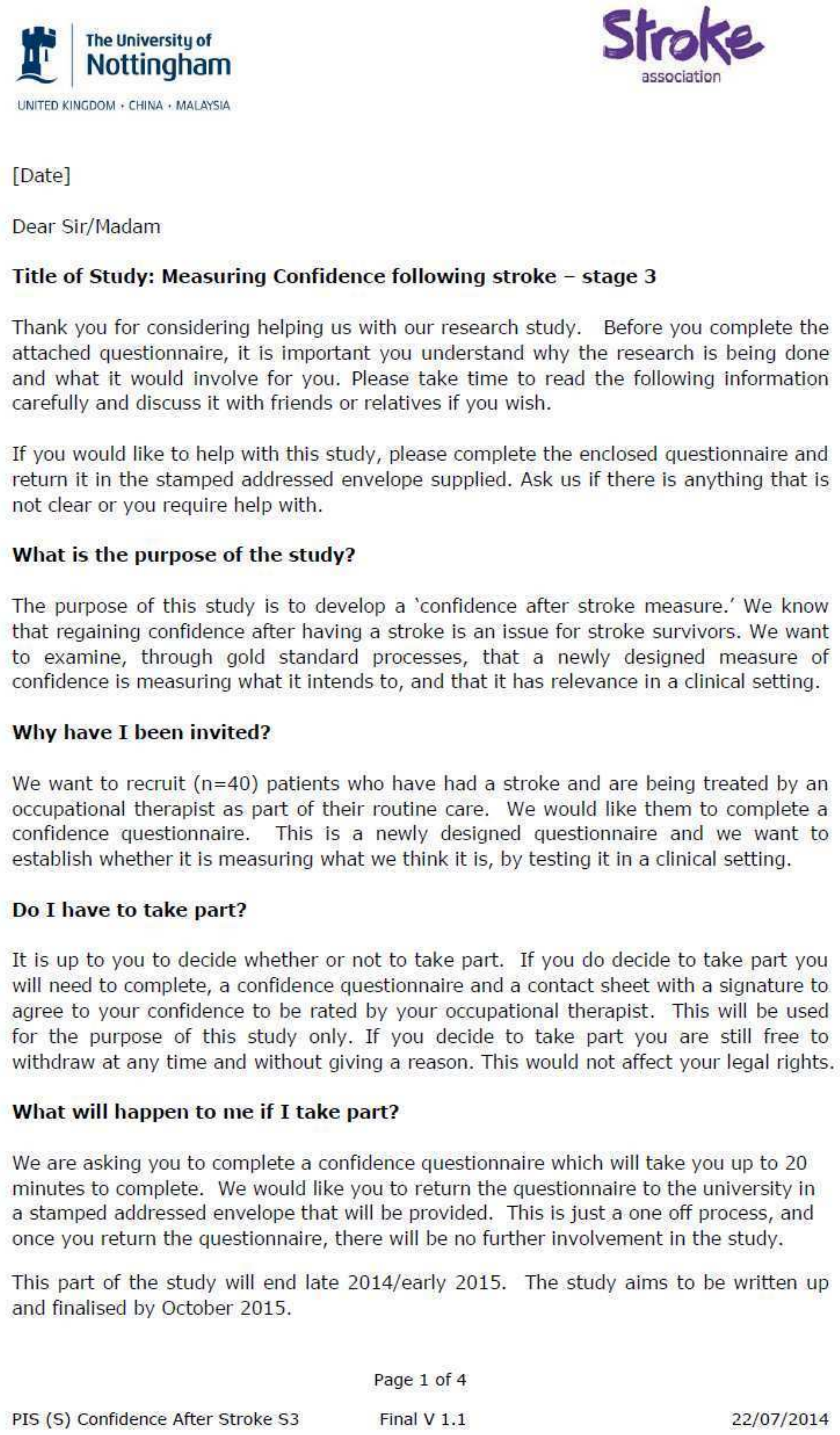


For Example:



This would indicate mid confidence level scoring 50 on this scale

APPENDIX 35 PATIENT INFORMATION SHEET



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Stroke association

[Date]

Dear Sir/Madam

Title of Study: Measuring Confidence following stroke – stage 3

Thank you for considering helping us with our research study. Before you complete the attached questionnaire, it is important you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with friends or relatives if you wish.

If you would like to help with this study, please complete the enclosed questionnaire and return it in the stamped addressed envelope supplied. Ask us if there is anything that is not clear or you require help with.

What is the purpose of the study?

The purpose of this study is to develop a 'confidence after stroke measure.' We know that regaining confidence after having a stroke is an issue for stroke survivors. We want to examine, through gold standard processes, that a newly designed measure of confidence is measuring what it intends to, and that it has relevance in a clinical setting.

Why have I been invited?

We want to recruit (n=40) patients who have had a stroke and are being treated by an occupational therapist as part of their routine care. We would like them to complete a confidence questionnaire. This is a newly designed questionnaire and we want to establish whether it is measuring what we think it is, by testing it in a clinical setting.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will need to complete, a confidence questionnaire and a contact sheet with a signature to agree to your confidence to be rated by your occupational therapist. This will be used for the purpose of this study only. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

We are asking you to complete a confidence questionnaire which will take you up to 20 minutes to complete. We would like you to return the questionnaire to the university in a stamped addressed envelope that will be provided. This is just a one off process, and once you return the questionnaire, there will be no further involvement in the study.

This part of the study will end late 2014/early 2015. The study aims to be written up and finalised by October 2015.

Expenses and payments

Participants will not be paid to take part in the study.

What are the possible disadvantages and risks of taking part?

It is unlikely that any risks to yourself as a result of completing the rating sheets will occur.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help us to develop a valid and reliable tool that measures confidence after a stroke. This is likely to help identify people that might have low confidence after their stroke, in order to offer appropriate treatment. We hope this questionnaire, will enable clinicians to monitor confidence levels and will help to evidence improved confidence following a stroke.

What happens when the research study stops?

The study will be written up, and submitted for publication in a clinical journal. The researcher has experience of disseminating research results at international conferences and to local stroke groups, and would be keen to disseminate the results of this study.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting, Marion Walker, Head of division of rehabilitation and Ageing on: 0115 823 0246 **e:** h.taylor@nottingham.ac.uk.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data (address, telephone number) will be kept for a year after the end of the study so that we are able to contact you about the findings of the study. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

Although what you say when you complete the questionnaire is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?

The results of this study aim to be available after October 2015. The results form part of a PhD qualification. You will not be identified in any report/publication. If you are interested in seeing a copy of the results, please email the researcher Jane.horne@ nottingham.ac.uk after this date.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by the Stroke Association.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by
NRES Committee South Central - Hampshire A Research Ethics Committee.

Thank you so much for taking the time to read this, and your help would be greatly appreciated.

Best wishes

Jane Horne
Research Occupational Therapist

APPENDIX 36 MR M CASE VIGNETTE

Case Study One

Mr M lives in a London Suburb with his wife and two sons. He completed his undergraduate degree in the mid 1980's became a teacher, travelled and worked in USA and Canada, prior to moving back to the UK. When moving back to the UK, he worked in the computer industry, initially for a multinational company, and then started his own business with his business partner. His business was very successful until eight months ago, when he experienced a stroke. He has not returned to work since his stroke. He is 59.

Pre-stroke Activities

Mr M states his wife would tell you that he was too confident before his stroke! He played semi-professional football for 10 years when he returned from his travels. He replaced his football playing with golf, later in life, achieving a handicap of 7. He was a county level squash player, and 'fairly decent' at most racquet sports. He enjoyed participating in activities that involved all members of his family. The roles of being a Son, Father and Husband were particularly important to him.

> *'Please allow me to offer an apology for listing my successes in sport, I am trying to underline the fact that I believe I was fairly well co-ordinated and confident prior to my stroke. Since my stroke confidence has been much harder to experience…'*

Impact of Stroke

> Modified Rankin Scale: 3.
> 'Moderate disability; requiring some help, but able to walk without assistance'

Memory has been severely impaired since his stroke, impacting on Mr M's extended activities of daily living, needing verbal and visual prompts in some of activities he wants to do. Early in recovery from stroke he describes being very influenced by those around him. When attempting to swim on holiday, he was very conscious of other people watching and what they might think about him.

He is very goal orientated, and places value on successes.

Context

Mr M's family and close friends have supported him throughout his stroke recovery journey.

His father despite being disabled was a confident man. He describes himself and his brothers as being very confident growing up, but this was not the same for his wife, who Mr M describes as not as confident, and introverted.

Case Study Two

Mrs C lived in a Bungalow with her husband. She has grown up children who have emigrated and live in another country. She was an administration manager by profession, and enjoyed her professional responsibility, until she experienced a stroke whilst at work at the age of 59. She has not worked since her stroke.

Pre Stroke Activities

Mrs C worked full time, and her leisure time at the weekends were spent gardening, cooking, visiting places of interest and going out for meals. She particularly enjoyed her trips to the cinema with friends and her husband. She considers herself to be sociable, but also enjoyed her own and husband's company around her home, reading and listening to music.

Impact of Stroke

> Modified Rankin Scale: 4
> 'Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance.'

Mrs C, had moderate to severe aphasia after her stroke, she describes how she felt at that time.

> '*When I left hospital I felt as though my body and brain abandoned me. I felt powerless and attacked on all sides. I couldn't talk and make myself understood. I generally couldn't make sense of spoken words because a lot of people talked too fast for me to understand them. Everything I once enjoyed doing had gone. I couldn't read and music sounded too loud and noisy. I basically lost the use of my left side of my body. I worried about everything as the weeks went by. I am naturally sedentary, and easily discouraged, but I had to confront my fears.'*

Mrs C, had difficulty mobilising after her stroke. She was able to transfer independently, and able to walk with one when she left hospital. She had limited moment in her left upper limb making any tasks in the kitchen difficult.

Context

She believes '*people can make you lose your confidence without realizing how much damage they do.'*

Mrs C, has her own home, has a supportive husband and now lives for today, and does not look back on her 'old life' or too far forward.

APPENDIX 38 MRS F CASE VIGNETTE

Case Study Three

Mrs F lived in a large three storey house, in the suburbs of Nottingham. Her elderly parents had lived in the house, and it was in a poor state of repair, however, it was her family home and she lived there alone with her two cats. Mrs F was a care worker, she worked permanent night shifts, and feels, in hindsight, she was not living a very healthy lifestyle. She was 54 when she experienced a stroke.

Pre Stroke Activities

Mrs F was not a particularly social person prior to her stroke. She slept in the day, on the days she worked, and enjoyed a lifestyle around her home, with a trip to the library, and into town, most weekends. In her own words she lived a sedentary lifestyle, and spent a lot of time on her own. Pre stroke she wore a lot of make-up. Reflecting on that time, she feels 'it was a mask' to help her feel more confident that she felt. She had a few friends that she liked to meet in town. She loved reading and her hobbies included, sewing, crafting and doing jigsaws.

Impact of Stroke

> Modified Rankin Scale: 4
> 'Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance.'

Mrs F, returned to her home after an extended period of rehabilitation. She soon realised her home was unsuitable now she was a wheelchair user. She was keen to move house. She was able to transfer independently and able to mobilise short distances with a frame indoors. She used a motorised wheelchair for outdoor use. She was able to wash and dress independently. Functionally, she did not have any use of her left upper limb.

Context

She was motivated to achieve her goals of getting upstairs independently, and cooking her own meals. During her stay in hospital she developed a close friendship with someone who encouraged her to do well, and celebrated her successes. He was able to push her to do more than she felt able to do herself.