The Meaning and Experience of Participation in Stroke Survivors

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Thesis submitted for the degree of Doctor of Philosophy
To
The Department of Human Communication Sciences
University of Sheffield

September 2013

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Abstract

In the UK, one in four men and one in five women will be expected to have experienced a stroke by the time they are eighty five (Daniel, Wolfe, Busch, & McKevitt, 2009). Medical advancements which make survival more likely mean that there is a growing population of people living with the long term impact of stroke.

The success of rehabilitation was traditionally judged by functional ability and coping with everyday tasks. The inclusion of the term ‘participation’, in the ICF (World Health Organisation, 2001) represents a shift in healthcare and research to a more holistic view of rehabilitation. Pre-defined measures of participation may not capture subjective experience, and little research exists which investigates participation in stroke survivors from a patient perspective. This research aimed to explore the meaning and experience of participation in stroke survivors.

These aims required the collection of deep, rich data, from a small sample of participants. A qualitative methodology was therefore needed, and Interpretive Phenomenological Analysis was identified as an appropriate approach by which to find the underlying essences of a multiplicity of experiences.

The central themes within the findings were ‘meaning’ and ‘experience’. ‘Meaning’ included the sub-themes ‘being actively involved’, ‘making meaningful choices’ and ‘being me’. ‘Being me’ described the relationship between self-identity, role and participation, which has not previously been explored in relation to stroke. Sub-themes of ‘experience’ were ‘acceptance’, ’coping’ and ‘new participation’.

The findings suggest that each stroke survivor has a unique experience of participation, therefore individualised approaches to rehabilitation may be most effective. Future research should include exploring the link between participation and self-identity in stroke survivors, in order to build on our understanding of the link between participation and self-identity in relation to stroke.

Acknowledgements

“My Lord, increase me in knowledge.” (Quran 20:114). I thank God for providing me with the opportunity to commence this work, and the means and grace by which to complete it.

I would like to acknowledge the participants of this project, who gave their time, and had the courage to speak candidly about difficult issues. There would be no thesis without them, and I hope I have done justice to their experiences.

Thanks to my supervisors, Professor Shelagh Brumfitt and Dr Susan Baxter, for their excellent and rigorous academic support, and to Shelagh for helping me to navigate this PhD around an unexpected and varied array of life events. Thanks to Rosemary Gravell for providing a second opinion on my data analysis, and others in Human Communication Sciences and ScHARR for methodological support and discussions. Thank you to my community representatives Eram and Aisha and also thanks to Dr Havi Carel, who brought phenomenology to life for me, and generously provided me with advance copies of papers.

I gained two important people in my life during the time I have been working on this research, my husband Abderrahim, and my son Hamza. Thanks to Abderrahim, who married me and the PhD, and who has supported me in every way imaginable to get to this point. And thanks to Hamza, the coolness of my eye, who slept well and let me study.

Thanks to my Mum and Dad, for instilling in me the confidence and resilience to undertake this challenge, and for the essential babysitting services, and also to my sister Sam, for babysitting and proof reading despite the demands of a young family. I have been blessed with good friends and of these I would specifically like to thank Alison, for babysitting, coffee and wisdom, Bahiya, for translating my recruitment materials, Hilary, for doing my transcribing with great attention to detail, and also proof reading, Rehana, for proof reading, and Tracy, for keeping chaos at bay.

Lastly I would like to remember by grandmother, Connie Munton, who passed away while I was doing this research. She had her own experience of stroke, as she cared for my grandfather, who had a stroke many years ago. I think her experience would be much different now, and I hope this research may in some way contribute to the further improvement of services for people affected by stroke.

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Chapter 1: Introduction

This thesis presents a qualitative research study, which aimed to understand the meaning and experience of participation in stroke survivors. The aim of this chapter is to introduce the reader to the research, and give them an overview of the thesis. I will explain the motivations for the research, based on research and policy context, and my own research and clinical background. This chapter will then outline the research questions, and how I will go about answering them. I will explain certain terms I have used within the thesis, and then explain the structure of the thesis.

Motivations for the study

In the UK, one in four men and one in five women will be expected to have experienced a stroke by the time they are eighty five (Daniel et al., 2009). Medical advancements which make survival more likely mean that there is a growing population of people living with the long term impact of stroke. In response to this, awareness about the long term needs of stroke survivors has been developing.

The National Stroke Strategy (Department of Health, 2007) suggests that quality stroke provision is where, *"A range of services are in place and easily accessible to support the long-term needs of individuals and their carers" (p44).* The National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party, 2012) suggest that in goal setting in long term stroke support, every patient should have their feelings and wishes acknowledged, participate in the process of goal setting if possible, and that goals should be meaningful and relevant. They suggest that support should be tailored towards individual needs. Similarly, The Stroke Association (The Stroke Association, 2008) recommend that a range of services should be in place to meet long-term needs.

This research was concerned with a medical condition, stroke, and with stroke survivors and their experiences following the stroke. However, it was not concerned with medical aspects of the condition, but the impact of the condition on stroke survivors' experience. Participation is a salient concept within health and rehabilitation practise and research, having grown out of a shift from a medical model to a more holistic biopychosocial model of healthcare (World Health Organisation, 2001). It is seen as an important concept in understanding the impact of stroke on a person's life (Cardol et al., 2002), however, there is no agreed upon definition of participation. Despite this there are many standardised measurement instruments used to assess the impact of stroke on participation. These are criticised for not reflecting the stroke survivors subjective understanding of participation, and a small body of qualitative literature has aimed to look at participation from the stroke survivors perspective. Only two studies look specifically at stroke and participation (Barclay Goddard, Ripat, & Mayo, 2012; O'Sullivan & Chard, 2010), neither of which are UK based, but there are other studies exploring participation in relation to aphasia, which is most commonly found in stroke survivors (Dalemans, Witte, Wade, & Heuvel, 2010), and others still examining participation in relation to other conditions (e.g. Hjelle & Vik, 2011). Such research has expanded the potential insight into the concept of participation, and particularly emphasises its personal meaning according to each individual stroke survivor. The lack of UK based research clearly suggests a need for further research in this area, to understand both the meaning and experience of participation in stroke survivors, which may have important implications for the way in which the term is used in a health rehabilitation context.

This research is funded by the Collaboration for Leadership in Applied Health Research and Care for South Yorkshire (CLAHRC SY). This is a five year pilot programme which aims to translate healthcare research into practise. My thesis forms part of the stroke theme, which aims to: reduce the number of strokes; improve long-term provision and effectiveness of rehabilitation in the community; support self-management; and encourage independence, recreation and employment for people living with stroke and their carers. (National Institute for Health Research, 2013). This thesis is relevant to all but the first of these aims.

Prior to commencing this research I was a recently qualified Speech and Language Therapist, with several years' research experience and a specific interest in stroke. I was working in research at the time when the CLAHRC SY was launched, and was aware of its aims and objectives, particularly of translating research into practise. This was especially interesting to me as someone who wanted a career which spanned both research and clinical spheres. On being awarded the PhD studentship, I had a broad research area predefined, ‘stroke’ and ‘participation’, and this was the starting point for my reading. I then found the place for my research, which I have described in relation to the previous research above.

Research questions

This study was concerned with the meaning and experience of stroke survivors in relation to participation. Based on the academic and wider background to this research, the research questions I proposed were:

What does the term ‘participation’ mean to stroke survivors? Rather than establishing a definition of participation, or presenting a list of activities that could be classed as participation, this question was about finding the common elements beneath the multiplicity of experiences that reveal the essence of participation, from the perspective of stroke survivors.

How do stroke survivors experience participation? This question aims to explore the experiences that stroke survivors have in relation to participation, following a stroke.

How the research questions will be answered

These questions were addressed within a qualitative paradigm, using Interpretive Phenomenological Analysis as a methodology. The research design was iterative, and the findings are made up of data from three sources, which used a variety of methods of data collection:

Source 1: Retrospective interviews with stroke survivors and carers more than one year post stroke, and a follow-up focus group with stroke survivors.

Source 2: Interviews spanning one year following stroke with a longitudinal cohort.

Source 3: Email interviews with stroke survivors more than one year post stroke.

I decided to use to the term ‘sources’ to describe the different elements of this study, in order to assist the reader in navigating the thesis. I use the term ‘stroke survivor’ throughout, also for ease of reading, and because it is a positive term which situates the stroke in the past. My participants responded positively to my use of the term, ‘stroke survivors’.

Structure of the thesis

The thesis is organised into seven chapters as follows:

Chapter 1: Introduction. This chapter provides a comprehensive picture of the research study, including its background, the origin of the research topic, the research questions, the approach, methodology and methods used to answer the research questions, and the contents of the thesis.

Chapter 2: Literature review. This chapter is divided into two parts. Part 1 provides background information about stroke, which is the context in which we are looking at the term participation. The term participation is then discussed, with particular focus on qualitative participation studies. Part 2 described literature which was identified following the data analysis, when other areas were highlighted as relevant. These areas are experience, loss, role and self-identity, and coping and acceptance.

Chapter 3: Methodology. This chapter is devoted to the consideration of the selection of the paradigm and methodology which underlie the methods used to answer the research questions. It explains the qualitative paradigm, discusses grounded theory and phenomenology, and provides a description of the chosen methodology, interpretative phenomenological analysis. It also discusses the concepts of reflexivity and quality in relation to qualitative research.

Chapter 4: Methods. This chapter outlines the design of the study, and the ethical considerations involved in this research. It justifies and describes the recruitment and data collection strategies, and goes through a step by step description of IPA analysis, describing any modifications that were made in order to accommodate the design of the research.

Chapter 5: Results. This chapter begins by evaluating the sources of the findings, and then presents tables giving information about the participants of each source. I describe three case studies in order to illustrate change over time and then describe the impact of stroke on the participants. I then move on to describe the findings, beginning with a visual representation of themes and subthemes, and going on to describe each in detail. The description is organised around the two central themes ‘stroke’, and ‘participation’.

Chapter 6: Case Studies. This chapter presents the longitudinal participants as case studies, and relates their individual experiences to the sub-themes presented in chapter 5.

Chapter 6: Discussion. This chapter indicates the contributions of this study by comparing the findings to previous research, and identifying areas where no previous research exists. It goes on to provide a critical evaluation of the methods of this study, and the implications of this for the limitations of the study. Finally, it makes suggestions of clinical implications and future research directions.

Chapter 7: Conclusion. This chapter concludes by reflecting on the whole thesis. It reiterates the research questions and how they were answered, and gives a summary of the most significant findings and how the findings relate to current literature. It also summarises the limitations of the study, and it’s clinical and research implications.

Summary

This chapter provides an overall picture of the study. At first, it introduces the background of the study, the motivations for undertaking the research and its purpose. It states the research questions and how they will be answered, before providing a description of the structure of the thesis. It is hoped that this orientates the reader, and prepares them for the Literature Review chapter, which follows, where I will describe in detail the literature relevant to the present study.

Chapter 2: Literature Review

The aims of this research were to look at the meaning and experience of participation in stroke survivors. In order to situate the thesis in the research landscape, I will begin by providing a background to stroke, followed by a look into the term 'participation' within the remit of health rehabilitation and research. I will then review qualitative participation studies. Up until this point, the literature presented is directly related to stroke and/or participation.

The literature review is presented in two parts. The first part was undertaken prior to data collection, in order to inform the research questions. This review provides a background to stroke, and then focuses on 'participation', and the way it has been used in health research and rehabilitation.

In order to minimize the influence of previous literature on my data collection process, I delayed a more detailed literature review until after data collection which forms the second part presented here. This includes an overview of the literature concerning the experience of stroke, establishing the place of my research in the wider research environment. Based on the collection of the findings and initial analysis, I was able to explore specific concepts in relation to stroke, including: loss; role and self-identity; and coping and acceptance.

Literature Review strategy

Seven electronic databases, and googlescholar, were searched for both the pre-data collection and post-data collection reviews. The period of time searched was 2000-present. Key publications from before this time were identified by hand searching the reference lists of relevant papers.

The search terms in the table below were entered separately using the "and" option in the search page of the database, or using the Boolean operator "and" depending on the style of the search engine. Initially, the terms were searched for in the abstract field. If this produced a very small amount of results, they were searched for in the main text. If they produced in excessive amount of irrelevant results, they were searched for in the title field.

Several journals which were found to have published many relevant papers were also searched using the same strategy as outlined above. All relevant papers had their references hand searched for further relevant references. Other publications were sought due to conversations with colleagues, attending seminars and other word of mouth methods.

Where the title of the paper appeared to be relevant, the abstract was sought. Given the wide scope of the literature review, each paper was judged according to its individual relevance, though papers not in the English language were excluded. Some papers opened up new areas of relevant literature, and others which at one point seemed relevant, may have been superseded by another more recent paper, for example in describing the impact of stroke, where there was a large amount of relevant literature, of two papers with similar results I would include the most recent.

Source type	**Source name**	**Search terms**	
		Pre data collection review	*Post data collection review*
Databases	Google scholar Medline Assia Caredata IBSS Scopus Social Care Online Psychlit	“stroke” and “impact” “participation” and “ICF” “participation” and “definition” “participation” and “defining” “participation” and “subjective” “stroke” and “participation” “qualitative” and “stroke”	“stroke” and “experience” “stroke” and “loss” “stroke” and “grief theory” “loss” and ‘illness” “stroke” and “role” “stroke” and “self” “stroke” and “identity” “stroke” and “coping” “stroke” and acceptance”
Journals	Disability and Rehabilitation Stroke International Journal of Qualitative Studies in Health and Wellbeing		
Additional search strategies	The reference sections of relevant papers were hand searched to identify further relevant papers.		

Table 1: Literature Review Strategy

Part 1: Pre-data collection literature review

Background to Stroke

What is stroke and how common is it?

A stroke occurs when the blood supply to a part of the brain is cut off and brain cells are thus damaged or die. This is a sudden occurrence and the immediate symptoms can include numbness, weakness or paralysis on one side of the body, slurring of speech or difficulty finding words or understanding speech. Some people lose their sight or have blurred vision, and others become confused or unsteady (The Stroke Association, 2008).

Almost one in four men and one in five women aged forty five years, are likely to have had a stroke by the time they reach the age of eighty five (Wolfe 2000). Over the past forty-fifty years the death rate from stroke has declined. This can be partly atrributed to advances in medical treatments such as the drug Thromolysis and blood thinning medications (The Stroke Association, 2012). However, survivors are often left with disabilities, with half of all the individuals who have experienced a stroke acquiring a long-term disability (Murray & Harrison, 2004). These can include physical, communicative and cognitive problems (The Stroke Association, 2008). Approximately a quarter of strokes occur in people below sixty five years (Daniel et al., 2009), which challenges the view that stroke is only an 'elderly' issue.

What happens after stroke?

Typically people with moderate to severe stroke experience a stay in an acute hospital ward, after which time they would be discharged home, or to a rehabilitation centre, to continue with their rehabilitation (The Stroke Association, 2008). It is usual to experience a significant amount of recovery in the first few weeks, with recovery of independence normally occurring within the first six months after stroke (Intercollegiate Stroke Working Party, 2012) but this process can continue for months and years (The Stroke Association, 2012). Although the impact of stroke is often long-term, stroke services are usually focused on acute care and early rehabilitation. Access to rehabilitation after this time is not common, however it has been found to be beneficial in maintaining functional gains and facilitating adjustment (Tarkka, Pikkanen, & Sivenius, 2005). The success of the transition from hospital to home is influenced by the availability of community services, family and friends (Wyller, Holmen, Laake, & Laake, 1998) and broader social networks.

Stroke is an acute event which often results in ongoing disability. For the purposes of management it can also be classified as a chronic disease, as it results in ongoing impairments that may be present for the rest of the survivors' life. Management of stroke is complex, as stroke survivors may experience a wide variation of symptoms, and many have co morbidities which exacerbate the impact of the stroke (Hankey, 2002). Recovery from stroke relies on the re-organization of brain tissue, referred to as neuroplasticity. This concept is not completely understood, but is thought to be influenced by active movement, skills learning and environmental factors.

Both the National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party, 2012), and the National Stroke Strategy (Department of Health, 2009) provide recommendations for people working with stroke, and these are used to inform policy which is grounded in evidence based practise. These recommendations represent the ideal level of support that stroke survivors should receive, and it cannot be assumed that this is what they do receive. However, the recommendations provide an understanding of current thinking around stroke. The goal of the National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party, 2012) is to improve the quality of stroke care, and the foundation of the guidelines is the International Classification of Functioning, Disability and Health (World Health Organisation, 2001). This will be discussed in more detail in the next section. They recommend that "Stroke services should respond to the particular needs of each individual patient" (Intercollegiate Stroke Working Party, 2012, p25). In reference to goal setting, a key feature of long term stroke support, they suggest that every patient should have their feelings and wishes acknowledged, participate in the process of goal setting if possible, and that goals should be meaningful and relevant. They also recommend that therapy should be continued for as long as gains are being made. The National Stroke Strategy (Department of Health, 2007) gives as a criteria as a marker of a quality service that *"A range of services are in place and easily accessible to support the long-term needs of individuals and their carers" (p44).* They also suggest that support should be tailored towards individual needs.

How does stroke impact upon survivors?

Five years post stroke, a third of survivors are likely to be severely or moderately disabled (Wolfe, 2000). Reduced walking ability and loss of confidence are common problems, as are problems using public transport and driving (Barnsley, McCluskey, & Middleton, 2012). In a study by Pound, Gompertz, & Shah, (1998) 63% of participants identified themselves as housebound. Even people with mild stroke can experience problems which limit their independence, such as with driving (Edwards, Hahn, Baum, & Dromerick, 2006; White et al., 2012). There are many 'hidden dysfunctions' caused by stroke, which may explain the continuing problems of people with 'mild stroke' which has not resulted in obvious disability. These include increased fatigue(Crosby, Munshi, Karat, Worthington, & Lincoln, 2012), cognitive difficulties, emotional problems and environmental sensitivity(Gunnel, Moller, & Blomstrand, 2004).

Barnsley et al. (2012), explored stroke survivors' feelings about travelling outdoors after their stroke. They found that various factors influenced outdoor travel, including emotional disposition, having meaningful destinations to travel to, their expectations of recovery and the influence of family and therapists. While providing a valuable insight into an important issue, this study excluded people who were unable to give consent (which would exclude many people with cognitive and communication difficulties), a substantial percentage of the stroke population.

There is a tendency for people to become socially isolated after a stroke (Northcott & Hilari, 2011), due to a loss of shared activities, reduced energy levels, poor mobility and other physical problems, as well as the unhelpful responses of others, aphasia, environmental barriers and changing social desires. Those with aphasia seem to experience the most negative responses from others (Davidson, Howe, Worrall, Hickson, & Togher, 2008; Northcott & Hilari, 2011), and even where friendships continued the quality of the friendship may change, as for example, conversational abilities and ability to engage in humour might be affected.

Survivors of stroke view recovery as a return to all aspects of their former existence (Thompson & Ryan, 2009), and Kirkevold (2002), found that changed roles and relationships were of more concern to stroke survivors than physical functioning. However, it has been found that the impact of stroke on a person's social roles and activities remain, even when physical abilities have been restored. This could be due to other more subtle changes experienced by people with stroke, for example changes in emotional intelligence (Hoffmann, Cases, Hoffmann, & Chen, 2010),which can impact on survivors ability to return to their former life. Depression is common in stroke survivors (Wolfe 2000), and a study by Lincoln et al. (2013) suggests that depression and anxiety in stroke survivors increases over time, with 29% experiencing anxiety and 33% depression, five years post stroke. People with stroke related emotional problems report higher unmet needs than people without, one to five years after their stroke (McKevitt et al., 2011).

While there is substantial evidence to suggest that stroke causes a major life disruption, Pound et al., (1998) put forward an alternative perspective from their interviews with older stroke survivors from the East End of London. They suggest that for their interviewees, stroke was just another element of growing older within the context of difficult socioeconomic circumstances, and was described as 'not that bad'. However, the researchers acknowledge the uniqueness of the particular group of participants, and so it is unclear to what extent these results can be applied to older stroke survivors in general.

Stroke impacts younger people in a different way, in that their roles often include financial and caring responsibilities. A summary of the literature by Daniel et al., (2009) suggested that just over half of stroke survivors of working age return to paid work between six and twelve months post stroke, and that 24-33% reported financial problems. Several factors enabled successful return to work following stroke, including vocationally focused rehabilitation, the flexibility of employers, social benefits and supportive family and co-workers. (Essue et al., 2012) report that stroke is associated with severe economic consequences, which are not buffered by having a high income prior to stroke.

Stroke is a common cause of aphasia, and about a third of people who have a stroke will have some degree of aphasia (Connect, 2013). Aphasia is a communication impairment caused by damage in the communication areas of the brain. It is a malfunction of language, which can involve difficulties in any combination of comprehension, expression, reading and writing. It is caused by a brain lesion most commonly caused by stroke. Eighteen months post stroke, 43% of aphasic patients still suffer from significant aphasia (Nyström, 2006).

Due to the unique impact of aphasia, it is an area that is studied as part of stroke but also as a phenomena in its own right. Researchers agree that aphasia causes a major change in the life of the aphasic person, having an impact on not only the more obvious areas where communication is needed, such as asking for things and giving information, but in more abstract ways such as being able to express emotions or understand jokes (Brumfitt, 1996). A study by Hilari, (2011) found that stroke survivors with aphasia participated in fewer activities than those without aphasia, even when matched for physical abilities, well being and social support. This study had a sampling strategy which ensured diversity, suggesting its validity. However, despite their efforts, only two of their twenty nine participants were under the age of fifty, making it difficult to generalize these results to younger stroke survivors.

Aphasia is well known to impact upon social relationships (e.g. Davidson et al., 2008), and studies that have quantified participation have shown it to be reduced in people with aphasia (Dalemans et al., 2010). Hilari, (2011), found that people with aphasia participated in fewer activities and reported worse quality of life following stroke than people without, even when matched on other factors such as physical ability and social support.

(Berges, Seale, & Glenn, 2012) highlighted a significant association between positive affect and social participation, while previous health conditions and other important life events such as bereavement can give the stroke a different context (Sumathipala, Radcliffe, Sadler, Wolfe, & McKevitt, 2012). Emotional and practical support from family and friends can buffer perceived needs, while overprotective attitudes can hinder independence. Mobility aids can facilitate adaptation to disability (Sumathipala et al., 2012).

The research cited above implies that recovery from stroke is a complex process, with the absence of a linear relationship between the physical impact of stroke and the resulting impact on the stroke survivors' life, but many mediating factors that may help or hinder the stroke survivors' return to pre-stroke activity. The literature also suggests that the impact of stroke goes far beyond simply 'not being able to do things' to affect the stroke survivors sense of who they are, and this in itself has consequences for other aspects of their life, such as relationships. Most research regarding the outcomes of stroke is based on participants who are no more than one year post-stroke, although we know that the impact of stroke reaches beyond this, and so our understanding of the long term impact of stroke is limited (McKevitt et al., 2011).

Models of illness and disability

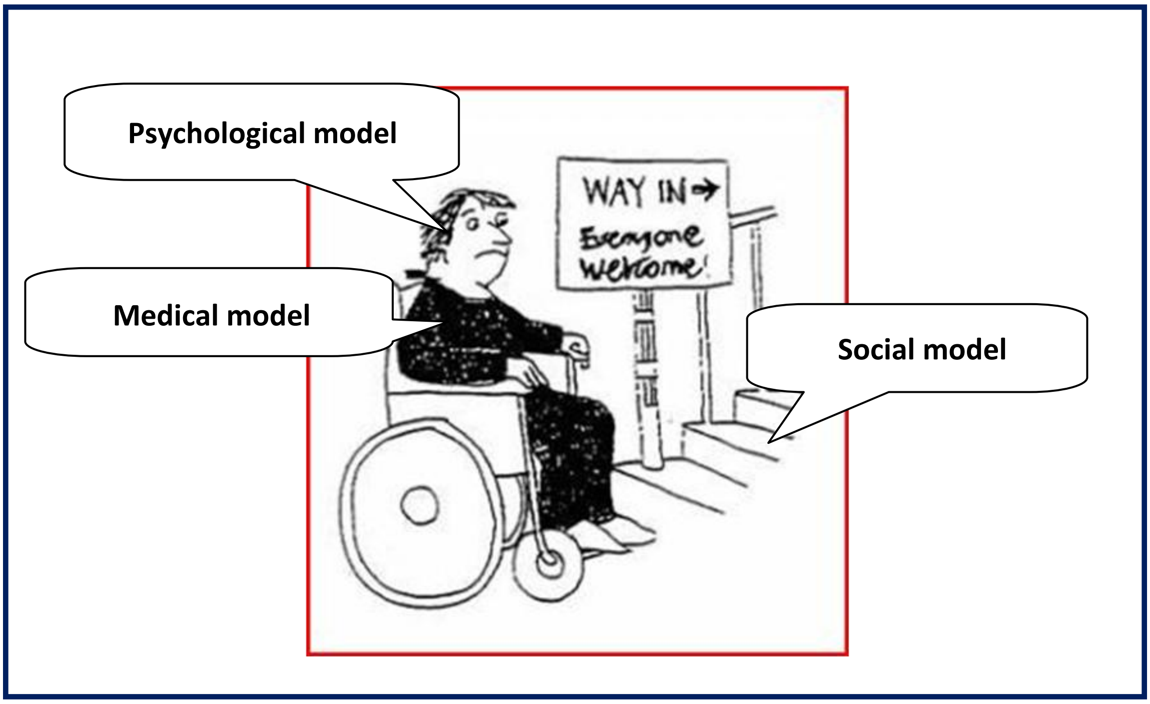

Figure 1: Models of illness and disability

Disability and illness has traditionally been viewed within what has come to be known as a 'medical model' approach, which views disability as situated within the individual, and focuses on prevention or cure, or where that is not possible, on caring for disabled people. Similarly, the 'psychological model', while taking account of the psychological impact as well as the physical impact of the disability, still locates the disability entirely within the individual (Marks, 1997).

However, within the social model disability is not simply an attribute of the person, but a complex collection of factors, many of which are created by the social and physical environment. *"Disability is located not solely within the mind or body of an individual, but rather in the relationship between people with particular bodily and intellectual differences and their social environment" (Marks, 1997).* Figure 1 represents an example of how these models may be applied to an everyday experience. The social model developed out of the political activism of disabled people, and still has strong links with the disability rights movement (Bickenbach, Chatterji, & Badley, 1999). The implications of the social model are that the treatment of disability should take into account social and environmental factors, and see these as having the potential to change in order to alleviate disability. Because health professionals act as ‘gatekeepers’ to services and resources for disabled people, this creates a power imbalance. Developments such as user groups, which enable the users of a service to have some control and input into its running and development, would be one way of addressing this power imbalance (Marks, 1997). Within a social model the environment or social context that the individual lives within would be seen as a key factor in their response to stroke (Brumfitt, 2000).

‘Participation’ in health rehabilitation and research

Understanding the term ‘participation’

Participation has both a lay meaning and a specific meaning related to health rehabilitation and research. The Oxford English Dictionary simply defines ‘participate’, as ‘to take part’, or ‘to share in’, which suggests an element of activity and a possible social element (Pearsall & Hanks, 2010). The success of rehabilitation and therapy has traditionally been judged by factors such as increased mobility, and the ability to carry out daily tasks. An understanding of the limitations of the medical model, and a move towards a more social model of disability has seen a shift in recent years to a more holistic view of rehabilitation. This means that assessing someone’s level of participation is considered as important in understanding the social impact of a disability on a person’s life, and tailoring support accordingly (Cardol et al., 2000). Therefore participation has become an outcome in its own right (Salter, Hellings, Foley, & Teasell, 2008). However, while it is generally accepted as an important construct, how it is defined varies widely within the literature.

The International Classification and Functioning, Disability and Health is a classification of health, and health related domains. The first version, the International Classification if Impairment, Disabilities and Handicaps (ICIDH) was published in 1980 (World Health Organisation, 1980). It aimed to incorporate a social model perspective, and one of its intended uses was for rehabilitation outcome measurement. At the level of disability and handicap, the ICIDH claimed to recognise the role of social and environmental factors. However, the model was criticised as the language it used did not reflect the view that disability is situated outside of the individual. In addition, from a rehabilitation point of view, there was no way of recording the environmental impact on peoples' lives.

This model underwent several revisions before the publication of the ICF, which has synthesised the biological and medical models to create a biopsychosocial model of functioning and disability, taking into account the interplay of individual, personal and environmental factors (Badley, 2008). The ICF views the patient in terms of: pathology (disease); impairment (symptoms/signs); activities (disability); participation (handicap). Figure 2 shows how the different elements of the ICF relate to the individual.

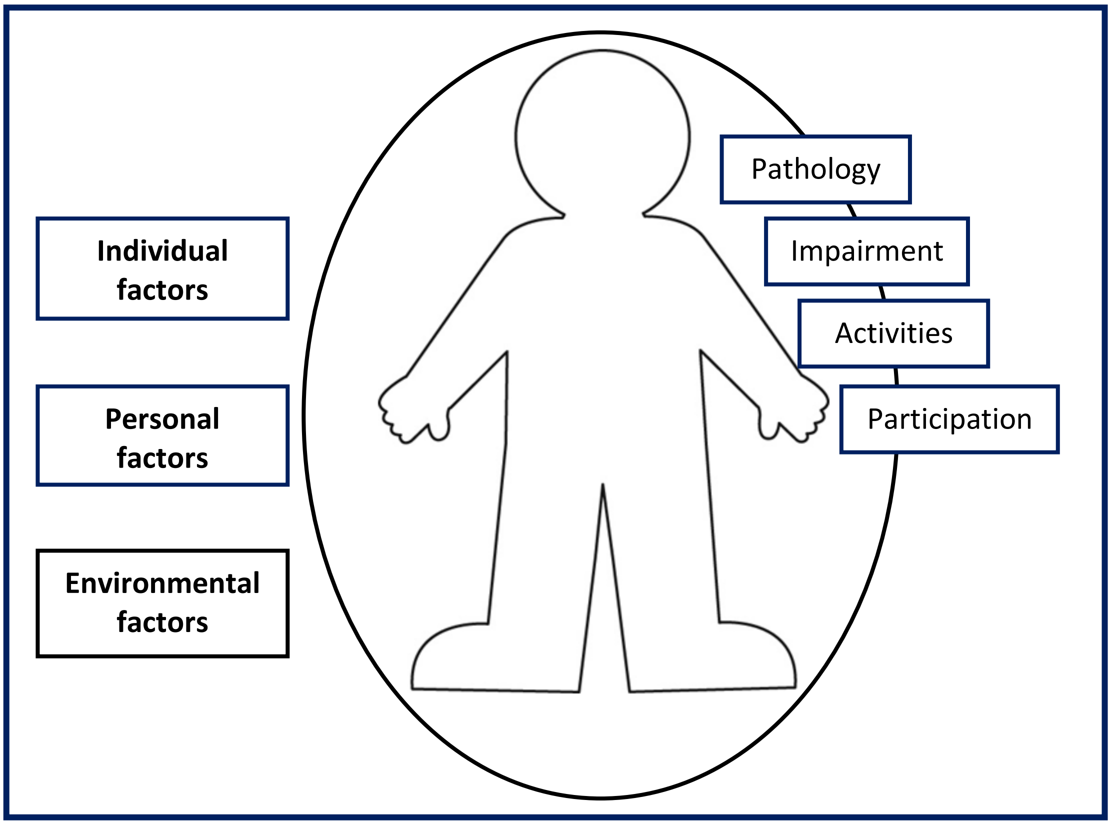

Figure 2: Representation of ICF view of illness and disability

The term 'handicap' was replaced with the term 'participation' in the ICF, which was defined as 'involvement in a life situation', It also contains a list of environmental problems which can be used to identify causes of disablement (Bickenbach et al., 1999). To identify problems, one uses a comparison to a 'norm', that is, a similar individual without a health problem. It contains two components for functioning and disability: body functions and structures; and activities and participation.

The activities and participation component is a single combined classification, however, it is generally recognised that for the successful application of the ICF a distinction between these components needs to be made. Some feel that a weakness of the ICF is that activities and participation are not clearly distinguished (Mars, Kempen, Mesters, Proot, & Van Eijk, 2008). The comparison to a norm used by the ICF also poses problems, as while this works well for some activities, for example, ability to eat following a stroke, it works less well for things such as recreation activities, which vary in their meaningfulness to different individuals. Criticism of the ICF is ongoing, including the issue raised by Perenboom and Chorus (2003, cited in Hemmingson and Jonsson 2005), of whether participation can accurately be assessed without taking into account the patients perception.

The concept of participation is recognised at policy level, and The National Clinical Guideline for Stroke (Intercollegiate Stroke Working Party, 2012) provide recommendations for people providing services to stroke survivors around, *"Community integration and participation" (piii)*. This includes advising the stroke survivor about potential activities, identifying and overcoming barriers to success, and referring the patient to community organisations that may be able to help them fulfil their goals.

The importance of participation is often explained by it being an element of 'Quality of Life' (Barclay Goddard et al., 2012). Quality of Life (QoL) is a term which refers to an individuals' total wellbeing, and in a health context, Health Related QoL (HRQoL) refers to the way illness and disability can impact upon this. Like participation, it is a term of growing importance, and is measured by assessing changes in physical, functional, mental, and social health (Testa & Simonson, 1996).

In summary, participation has grown to be an important concept in health rehabilitation and research, and this is exemplified in its inclusion in the ICF, where it replaced the term 'handicap'. It reflects a shift to a more holistic view of rehabilitation, and therefore can seen as having the potential to broaden the focus of rehabilitation beyond functional ability, and ability to perform everyday tasks, to elements of life that have more meaning for the individual patient. To understand the degree to which this potential has been fulfilled, I will describe studies aiming to evaluate to describe participation in stroke survivors and others.

Quantitative participation studies

Since the introduction of the term participation into the ICF, and its recognition as a key marker of rehabilitative success, there have been an increase in studies which have evaluated participation in stroke survivors. Salter (2007) reviewed the inclusion of social participation in randomised controlled trials of stroke from 1968-2005. Both the volume of trials and the percentage of trials including some measure of participation had risen over this time, but only 25% of the studies overall included an assessment of participation as according to the ICF definition.

Many quantitative studies of participation aim to discover which factors are associated with participation, for example, Schmid et al. (2012) discovered that balance self-efficacy but not physical aspects of gait, had an association with activity and participation, and Wolf (2012) found that perceived recovery level is a factor in physical activity participation following mild stroke. These studies provide valuable information, however, despite being based on the ICF model of disability, they focus on the personal, rather than environmental factors affecting participation, and they do not give us an insight into the patients' own perception of participation.

Desrosiers et al. (2005) measured participation in stroke survivors compared to a normal ageing population. To measure participation they used the Assessment of Life Habits (Noreau, Fougeyrollas, & Vincent, 2002) which was formed using the Canadian Disability Process (Fougeyrollas and Beauregard 2001, cited in Desrosiers et al., 2005), a model based on the interaction between the individual and the environment in creating the disability. The Assessment of Life Habits (Noreau et al., 2002) contains predefined areas of participation, including responsibilities and interpersonal relationships. While they found moderate disruption of participation in stroke survivors, and more restriction than in normal ageing, they concluded that *"...a part of the reduction in participation in activities of daily living and social roles after stroke is attributable to normal ageing and not entirely to the stroke itself" (Desrosiers et al., 2005, p356).* This study clearly defined participation, and differed from the majority of studies in that they based their definition of participation on the Disability Creation Process model rather than the ICF. The weaknesses of the study were that its participants were not randomly selected, and it excluded people with very mild or very severe stroke, as well as people with cognitive and communication difficulties.

Also comparing people with and without stroke, McKenna, Liddle, Brown, Lee, & Gustafsson (2009) examined role participation by analysing time-use data. They found that people with stroke spent less time in activities of daily living and volunteer work, and more time at home alone and engaged in solitary leisure. The data on time-use was coded into pre-defined categories, however, the participants assisted in clarifying the categories, so that the meaning of the activities was not lost. This study had small sample size compared to most quantitative studies.

Despite the increase in the number of studies which included standardised measurement instruments for participation, with many basing their definition of participation on the ICF, the impact of contextual factors on participation is still not well understood. Hoyle, Gustafsson, Meredith, & Ownsworth (2012), carried out a literature review of studies linking personal and environmental factors to participation, using the ICF as a model. They concluded that the area was not well documented and required more research. In addition to this, there are issues with the approach taken by many quantitative studies, which suggests that this approach cannot provide us with the complete picture of participation in stroke survivors. These issues include lack of clarity in defining participation, the difficulties of using predefined measures of participation, and the widespread exclusion of potential participants on the basis of cognitive and communication difficulties. These points will be addressed further in the following sections.

Difficulties in quantifying 'participation'

As demonstrated in the above studies, measurement tools have been created in order that 'participation' can be assessed as an outcome of rehabilitation. These tools generally list a set of activities which are seen as comprising participation, often related to components within the ICF. With pre-defined questions and closed response sets, these measurements do not enable us to understand the meaning of a stroke to an individual (Salter et al., 2008), and may point to a discrepancy between the goals of health professionals and stroke survivors, in relation to rehabilitation after stroke, as suggested by (Dowswell et al., 2000): *"such measures may be more relevant to the concerns of researchers than to those of patients and carers, for whom the lived experience of stroke is likely to be of greater importance"*.

There have been several attempts to review the effectiveness of these tools (Eyssen, Steultjens, & Dekker, 2011; Noonan et al., 2009; Perenboom & Chorus, 2003; Tse, Douglas, Lentin, & Carey, 2013). Tse et al., (2013) found that the Stroke Impact Scale (Duncan et al., 1999, cited in Tse et al., 2013), Assessment of Life Habits (Desrosiers et al., 2004, cited in Tse et al., 2013), and Activity Card Sort (Baum et al., 2008, cited in Tse et al., 2013), covered the ICF domains most comprehensively, but without exception, the reviews have found that instruments claiming to measure participation, only partly do so, when compared to the ICF domains, or other definitions. Many also measure constructs not related to participation. Eyssen et al., (2011) suggest that the cause of this is the lack of consensus around a definition of participation. The limitation of many measurement instruments is that they measure performance of an action, however Perenboom & Chorus, (2003) highlight that performance does not necessarily equate with participation, nor does participation equate with performance. For example someone with very limited physical abilities may participate by using the aid of other people to assist in performing the necessary tasks to fulfil their participation needs.

The review by Perenboon and Chorus (2003) consisted primarily of measurement instruments which were devised before the introduction of ‘participation’ into the ICF. However, the later reviews (Tse et al., 2013; Eyssen et al., 2011; Noonan et al., 2009) which included instruments created after, and often based on the definition of participation in the ICF, also showed that they only partly measured participation.

The introduction of the term ‘participation’ into the ICF inspired a large body of research into approaches to measuring participation, but it is clear that the lack of clarity about a definition of participation has led to ambiguity in attempts to measure participation. Moreover, measurements of participation generally focus on performance of particular activities or roles, which may not capture the full meaning of participation for an individual.

There is a dichotomy between definitions of participation, that tend to focus on a social or interpersonal dimension, to the measurements, where the emphasis changes to the individuals’ ability to perform tasks (Badley, 2008). The most significant difficulty with using standardised measurements, in that the patients’ voices are not heard, limiting our understanding of the subjective experience of participation.

Beyond quantifying: the need to understand the patient perspective.

Criticisms such as that of Perenboom and Chorus (2003), as to whether participation can accurately be assessed without taking into account the patients' perception, reflect a long standing criticism by the Disability Rights Movement, expressed in the social model of disability, that the needs of disabled people are frequently defined by health professionals, rather than by disabled people themselves. Hammel & Magasi, (2008) suggested that objective measures of participation do not capture the full meaning of participation, as viewed by the subject. They conducted focus groups with adults with disabilities, about the meaning of participation, and the barriers and supports to this. One participant stated: *"I want to be satisfied that I'm fully participating in my life. I don't care if somebody over there says they think I need to be doing more or less" (p7).*

A unique study into how participation may be measured which does not focus merely on ability to perform tasks, was suggested by Rochette, Korner-bitensky, Levasseur, & Recherche (2006). They suggest measuring 'optimal participation' by looking at the fit between an individuals' reality and expectations. They also discuss the concept of 'transition', whereby expectations have to be redefined following an event such as a stroke, in order to reach 'optimal participation'. This is one example of the way in which the concept of participation can be used taking into account the patient perspective, while still being of functional use in the rehabilitation process.

Dalemans, De Witte, Wade, & Van den Heuvel (2008) proposed that future research should be based on a 'clear conceptual framework and well defined concepts' (p1087), and that a priority should be to study the role of the environment in participation. This shows the need to build upon current understandings of participation towards an understanding which is rooted in the views of the people it is relevant to.

Following the introduction of the term participation into the ICF, a large body of research around participation was born. However, the lack of clarity around a definition of participation, and the lack of consideration of the subjective perspective, led to criticisms of this work. In response a small and growing body of research has emerged which takes a more subjective approach to the study of participation, using qualitative methodologies. I will now look at this area of research in detail.

Qualitative studies of participation

PARTICIPATION STUDIES IN NON-STROKE HEALTH RESEARCH

While the concept of 'participation' is relatively new in health and rehabilitation research, the importance of participation in relation to an individuals' well being has a long history in ageing research. The activity theory of ageing proposed that higher levels of participation in social and leisure activities, and replacement of relinquished roles, promoted well being in older adults (Havighurst 1961), with research showing that social activity was more influential to well being than formal or solitary activities (Longino and Cart 1982). Similar concepts can be found in the more recent concept of 'successful ageing' (Rowe and Kahn 1998), of which social engagement was one of three major elements. Social engagement involved both meaningful activities and maintaining close friendships. Appropriate participation allowed for role continuity which helped to maintain a sense of identity (Atchley 1989). Other theories emphasize the importance of adaptation to successful ageing, including the selection of appropriate social and leisure activities (e.g. Freund and Baltes 1998).

However, participation as a concept in its own right has gained importance within health and rehabilitation research, and following the identification of the need to move beyond measurements of participation, a small and growing body of qualitative research into participation has emerged, which aimed to view the experiences of participation in the light of the participants own understanding of the concept. This understanding has been expressed in terms of values, domains or categories, reflecting the aims to create a multidimensional and flexible definition or explanation of the experience of participation. For example Mars et al., (2008) identified that a definitive definition of social participation was not available, and wanted to *"develop a concept of participation which agreed with the experiences of older adults with a chronic physical illness" (p1299).*

For this purpose Mars et al. (2008) undertook a study aiming to look at the definition and experience of social participation from the perspective of people with chronic physical illness, using interviews and focus groups. Four domains of social participation were identified: social contacts and social activities, work and informal support, cultural activities and public events, and politics and media. While adults with chronic illness may have restricted their participation to certain domains, this did not mean that their definition was similarly limited. Social participation was seen as having three characteristics: social contact; contributing and receiving resources from society; and that for something to be considered social participation it had to be a positive experience. This study was done in Holland, with people with Diabetes and COPD. The specifics of the diseases, and the difference in care pathways and experiences between Holland and the UK, mean that we cannot assume it has significant relevance to the stroke population of the UK. However, it is of interest in that it was an attempt to establish a participant centred definition of participation, and the relationship between 'domains' and 'characteristics' is important to note. The term 'domains' appears to describe examples of participation, even though they may be broad, whereas the term 'characteristics' describes underlying features of participation.

Hammel & Magasi (2008), aimed to establish what participation meant to disabled people from an 'insider perspective', by conducting focus groups with people with disabilities regarding the meaning of participation. They recruited participants from state of the art rehabilitation centres in America. Peoples' experiences within the United Kingdom National Health Service (NHS) are likely to be very different, and this group can be assumed to be of a high social class and therefore well educated, meaning that the generalisibility of the study is limited.   They present the results as a cluster of values which defined participation to their participants: meaningful engagement/being part of; personal and societal responsibilities; having an impact and supporting others; social connection, inclusion and membership; access and opportunity; choice and control. In addition to this the issues of respect and dignity were critical within all of these values. Participants expressed that they needed to define and pursue participation on their own terms, rather than meeting predetermined societal norms, and while the values associated with participation were shared, the way these values were realized varied between individuals. They also found that participation often had a social element, but equally important were meaningful private activities, which may lead to personal meaning and satisfaction.

Also using interviews, Haggstrom & Lund (2008), studied participation in everyday life, by people with acquired brain injury. Five categories described their experiences: performing tasks, making decisions and exerting influence, being engaged in meaningful activities, doing things for others, and belonging. They also discovered that individuals adopted a variety of means to enhance their experience of participation, and the complexity of participation meant that it can only be understood through subjective experience and not through observation of performance of activities.

Hjelle & Vik, (2011) looked at the experiences of social participation by wheelchair users in Norway, using focus groups. Three main categories emerged: being engaged, being a member of society, and interacting as a citizen. Their participants felt that to them, participation meant being autonomous and making decisions about ones' own life.

The above studies all use qualitative methods such as semi-structured interviews and focus groups, to gain insight directly from disabled or chronically ill people of their experiences of participation. An alternative view was explored by Witso & Eide, (2011) who sought to understand professional carers' views of the participation in the everyday life of older adults receiving care in their own homes. They used focus groups and a grounded theory approach, from which emerged the core category, participation in ones' own life, and two other significant categories: carrying out tasks in everyday life, and interaction during service delivery. This study provides an alternative perspective to the previous mentioned studies which have all used interviews or focus groups with stroke survivors themselves. However, it is debatable how much of an insight professional carers really have into the participation experience of older adults, as their interaction with them is limited to particular times and situations.

The subjective nature of participation was reflected in these studies, both implicitly, through the multiplicity of the results, and explicitly, for example Haggstrom & Lund (2008) explained that the complexity of participation means it can only be understood through subjective experience and not through observation of performance of activities. Examples of participation varied widely, according to the various groups that were being studied. Examples included interaction in service delivery (Witso & Eide, 2011), having responsibilities (Hammel & Magasi, 2008), helping others or contributing to society (Haggstrom & Lund, 2008; Hammel & Magasi, 2008), and wider concerns such as politics and cultural events (Mars et al., 2008). Other factors were identified as necessary precursors for participation, including opportunity, respect and dignity (Hammel & Magasi,

2008) and choice (Adams, Leibbrandt, & Moon, 2010; Haggstrom & Lund, 2008; Hammel & Magasi, 2008; Hjelle & Vik, 2011).

Despite the heterogeneity of the experience of participation it does seem to have some associated features underlying it which make it a more common experience, including meaningful engagement (Adams et al., 2010; Haggstrom & Lund, 2008; Hammel & Magasi, 2008; Hjelle & Vik, 2011), value and satisfaction (Adams et al., 2010), belonging (Haggstrom & Lund, 2008), independence and contributing to wider society (Hjelle & Vik, 2011).

PARTICIPATION STUDIES IN STROKE RESEARCH

In 2004 Mckevitt, Redfern, Mold, & Wolfe, undertook a systematic review of qualitative studies of stroke, a total of 95 papers being included in the review. They found *"a sizeable body of qualitative research that seeks to document the longer term impact of stroke on patients" (p1501).*

My literature search found only two qualitative studies specifically on stroke and participation, which took place in Ireland (O'Sullivan & Chard, 2010), and Canada (Barclay-Goddard et al., 2012). O'Sullivan & Chard, (2010) aimed to describe the experience of stroke survivors returning to leisure activities following a stroke by using a phenomenological approach. They situated participation in leisure activities as essential for wellbeing and therefore a key aim of occupational therapists. Stroke had a clear impact on participation with less time being spent by stroke survivors on leisure activities and more time on passive activities alone. They identified four themes: re-engaging in leisure activities, acceptance of physical limitations, gratitude for help and support, and looking forward to the future, which together formed a description of the experiences encountered by stroke survivors returning to leisure activities (O'Sullivan & Chard, 2010). Most of the research on participation focuses on returning to former activities but O'Sullivan & Chard, (2010) found that people had engaged in new leisure activities post stroke which had a positive impact. This study had just five participants, which, while appropriate to the methodology, suggests caution in generalizing these results to stroke survivors in general.

Barclay Goddard et al., (2012), aimed to develop a model of participation post-stroke. They used the terms 'participation' and 'social participation' interchangeably. They adopted a mixed methods approach which aimed to address not only the activities engaged in, but the experience of this in light of the individuals' values and beliefs. From a previous study utilising standardised measurement instruments, they developed a model with the following categories: social function, role function, restricted roles and health efficacy. These formed the basis of the qualitative study, which used focus groups and 'photovoice', involving participants using photos to illustrate their experiences of participation. The model was further developed through these methods. Many participants identified a social element to participation, a sense of being active, and the importance of self selected activities. The meaning of activities was unique to each individual. The final model contained three categories: accomplishment, restricted roles and health efficacy, with physical environment and social support being overarching factors.

A UK study by Robison et al. (2009), while not specifically dealing with the concept 'participation', examines who or what helps in resuming previously valued activities post-stroke, which is similar to the definition of participation found in many studies. They interviewed stroke survivors and informal carers and discovered that valued activities related to: employment; domestic and social roles; hobbies; sports; and socialising. Up to 12 months after the stroke, resuming previously valued activities was affected by: physical and cognitive disabilities; environmental factors; adaptability of the individual; support from others; and professional help. When the valued activities could not be resumed, this influenced the stroke survivors' sense of self and quality of life, and the authors suggest that rehabilitation needs to support adaptation to a changed way of life.

In addition to the studies looking at participation in stroke survivors, there have also been qualitative studies into the participation of people with aphasia. Aphasia creates a disability which is quite distinct from other disabilities which may be acquired after stroke, so while it is an important area to look at for anyone studying the impact of stroke, it must also be remembered that what is relevant to people with aphasia may not be relevant to the stroke population as a whole.

Due to the challenges of doing research with people with aphasia, information about their own experience of participation is limited. Dalemans et al., (2008) carried out a literature review in order to find a description of social participation in working age people with aphasia. They found a lack of consistency in conceptual frameworks and small sample sizes, thereby concluding that little is known about how people with aphasia perceive their participation. They were able to conclude that there was a decrease in participation in domestic life, interpersonal life, education and employment.

A qualitative study in this area was carried out by Lyon et al., (1997), to evaluate an intervention for aphasic patients using communication partners. An aphasic person was paired with a 'communication partner' and the pair was given assistance in learning how to communicate fluently with each other. The communication partner would then act as a bridge between clinical therapy and real life participation. While they were unable to find evidence for treatment gains using standardized measures, informal measures showed notable improvements post treatment. Most notable was that it was not so much the restoration of the physical act of participation (which was also easiest to measure), but the quality of the experience, in that the aphasic person would lose themselves in the task at hand and have *"a diminished awareness of one's disabled self" (p703).*

A study by Howe, Worrall, & Hickson (2008), found barriers and facilitators to participation relating to other people, physical factors and societal factors, which also equate with pre-requisites, in that certain conditions need to exist in order for participation to be possible. This study was specifically of people with aphasia but did not see barriers as unique to people with aphasia. The authors suggest that people with aphasia are just one of the groups likely to be more vulnerable to environmental factors. This study addressed the difficulty of undertaking research with aphasic people by allowing multiple modes of communication within a semi-structured interview, including writing and gesture.

Dalemans et al., (2010) took a similar approach in addressing the lack of relevant research found in their literature review with a study that looks at social participation "through the eyes" of people with aphasia. They wanted to explore how people with aphasia perceive participation, and what factors influence social participation. People with aphasia and their caregivers kept diaries and were then interviewed. Participants were provided with stickers representing activities if they were expected to struggle to keep a written diary. Drawing and pictograms were used to facilitate the interviews. A key finding was that the meaningfulness of participation was more important than the 'doing' itself. This echoes what has been found in other participation studies (e.g. Haggstrom & Lund, 2008; Hammel

& Magasi, 2008), but perhaps is more salient in research with aphasic people due to the nature of aphasia, which can make interaction more difficult. They divided the factors influencing social participation into personal, social and environmental factors, which seems to echo the facilitators and barriers found by Howe et al., (2008).

The results from studies of participation with stroke survivors largely echo the findings from participation studies with other groups. However, there are some distinct elements of being a stroke survivor, such as the sudden onset of stroke, the improvement of symptoms post-stroke, and the residual disability that often remains, which make stroke unique, and this was reflected in the studies of participation and stroke. As is normal in qualitative research, the sample sizes were small, and along with the different health care situations in their respective countries, it is difficult to assume that these studies can be generalized to the UK stroke survivor population. They also deal with specific aspects of participation, such as social participation (Barclay-Goddard et al., 2012), and participation in leisure activities (O'Sullivan & Chard, 2010), rather than participation in general. This demonstrates the clear need for research in this area.

SUMMARY OF QUALITATIVE PARTICIPATION RESEARCH

I have already highlighted the difficulties of defining participation, and this lack of clarity is reflected in the various ways in which the term participation was used in the studies cited in the above studies. Only one study referred simply to 'participation' (Hammel & Magasi, 2008), while others used the terms 'social participation' (Barclay Goddard et al., 2012; Dalemans et al., 2008; Dalemans et al., 2010; Hjelle & Vik, 2011; Mars et al., 2008), 'life participation' (Ross, Winslow, Marchant, & Brumfitt, 2006) or 'community participation' (Howe et al., 2008) and others referred to participation 'in' something, for example 'participation in everyday life' (Haggstrom & Lund, 2008; Witso & Eide, 2011), or 'participation in leisure activities' (O'Sullivan & Chard, 2010).

While the aims of these studies were similar in exploring the meaning and experience of participation, there is great variation in the way that the findings have been presented. While there is much overlap between the findings of the studies, it is a challenge to look at the plethora of categories, domains, characteristics and themes, to perceive what these studies conclude about participation as a whole.

I have compiled the findings of the above studies into the following table, grouping together similar phrases, in order to further clarify this. Collectively, the results of these studies indicate that participation, as experienced by stroke survivors or people with illness or disability is social, active, positive and meaningful. It implies being part of something, having autonomy, and a sense of accomplishment. Participation involves having responsibilities, and giving as well as receiving from society. Peoples' ability to participate is often changed by stroke or other disabilities, but these changes are not only negative. It is affected by limitations and opportunities, and by social support.

Prerequisites	Domains	Characteristics	Experiences
Respect Dignity Acceptance of physical limitations Access and opportunity	Wider society Work, formal and informal support Social Role function Meaningful private activities Performing tasks	Social Contact Being useful Being wanted Meaningful Power to choose Active	Gratitude for help and support Looking forward to the future New leisure activities have positive impact Restricted roles

Table 2: Summary of qualitative participation study findings

Summary

I have sought to describe the concept of participation as it is currently understood within health rehabilitation and research, and presented here both quantitative studies of participation, which seek to measure the concept as an indicator of success of rehabilitation, and qualitative studies, which seek to explore the meaning and experience of participation for the individual. In relation to stroke I have demonstrated that understanding of participation in relation to stroke is both limited and inconsistent. There is a need to understand the stroke survivors' perception of participation, while also maintaining participation as a concept which can be functional in rehabilitation, therefore potentially provided rehabilitation which is more suited to the stroke survivors needs.

Part 2 – Post data collection literature review

Following the collection of data, a wider literature review was undertaken to explore existing literature regarding the experience of stroke in general, and specific concepts which began to emerge as significant in the findings.

The stroke experience

The term ‘participation’ is one lens through which to view the stroke experience, however, it overlaps with many other concepts and therefore it is essential to look at the wider literature about the experience of stroke. This will provide a deeper understanding of stroke and therefore the context in which we are viewing the term ‘participation’.

Studies which aim to understand the subjective experience of stroke provide a rich picture of life after stroke. The importance of the patient perspective has been highlighted by Kaufman (1988) and Prigatano (2011) who suggested that addressing patient concerns would increase engagement in rehabilitation.

Reviews by Lamb, Buchanan, Godfrey, Harrison, & Oakley (2008), Salter et al., (2008) and Satink et al., (2013) provide a selective overview of qualitative studies relating to the stroke experience. I will discuss the Satink (2013) review in a later section referring specifically to role, self and identity, as this is the focus of the review. However, many of the same papers are discussed in that review as in the reviews by Lamb et al. (2008) and Salter et al. (2008). Lamb et al. (2008) synthesised evidence from studies relating to the psychosocial spiritual experience of stroke, either in response to intervention or independently of intervention, within elderly individuals. The focus on elderly individuals is important to note, as the experience of younger stroke survivors may differ significantly due to their different life roles at the time of the stroke. They describe the synthesis process as an aggregation of findings to generate a set of statements that represent that aggregation, and this resulted in four main areas: sudden unexpected event; connectedness; reconstruction of life; and life altering event. As a sudden onset disorder, stroke is accompanied initially by shock, fear and confusion, though for people with co-morbidities it may not be so pronounced.

Connectedness is an important aspect of recovery, and can involve partaking in previously valued spiritual and religious activities. Recovery is a process of reconstruction which the patient in engaged with, and for most stroke survivors the stroke is perceived as a life altering event.

A qualitative meta-synthesis of studies concerning the experience of living with a stroke was carried out by Salter et al., (2008). They acknowledge that the process of meta-synthesis is ill-defined, due in part to the controversial nature of quality assessment of qualitative research, which will be discussed in more detail in relation to this thesis. Their findings were consistent with those of Lamb et al., (2008) in emphasising the life changing nature of stroke, which contributed to one of the main themes, 'Change, transition and transformation'. This theme further emphasised the transformative nature of stroke which, *"challenged the participants' sense of self and precipitated a sense of discontinuity"* (p597). The other main themes were 'loss' particularly loss of control, confidence and independence, and loss of self, 'uncertainty', about the future and also including fearing another stroke, 'social isolation' through either withdrawal or alienation from friends and family, and 'adaptation and reconciliation', including the mastering of new skills and generally adapting to post-stroke life, but with an emphasis on a return to a life that is meaningful for the individual.

Several studies were included in all three above mentioned reviews, including studies by: Burton (2000); Dowswell et al. (2000); Kvigne & Kirkevold (2003); and Nilsson, Jansson, & Norberg, (1997). Nilsson et al. (1997) aimed to elucidate the experience of stroke victims during the acute stage and within the first few months after stroke. They performed a qualitative analysis on interview data, based on Eriksons (1982, cited in Nilsson et al., 1997) theory of developmental crises, which are normal processes in human life which reflect development and maturity. The study excluded people with moderate to severe aphasia. They found evidence for every crisis mentioned in this theory, within stroke survivors, and concluded that, *"the phenomenon 'to meet with a stroke' seems to challenge the whole of the individuals being" (p953).* For example, one of the crises is labelled 'Autonomy versus shame/doubt', referring to the individual's ability to control their world. The stroke survivors in the study showed a firm will to regain autonomy, but this was accompanied by statements indicating shame and doubt, related to lacking ability. Nilsson et al., (1997) also address issues of identity, suggesting that stroke breaks the continuity of identity and therefore presents a high risk of identity confusion. They note attempts by participants to enhance continuity of identity by looking backwards at what they had been. Given the aims of this research, which were to explore developmental crises in relation to stroke, a longer follow up period would have been beneficial in this study.

A study drawing on phenomenological and feminist perspectives was undertaken by Kvigne & Kirkevold (2003) to understand the way in which women experience their bodies after stroke. In phenomenology the body is viewed simultaneously as subject and object, and feminist theory suggests that bodily changes must be understood in the context of gender. A woman's body with its particular biological functions places women in the world in a particular way, and this must be taken into account. The use of in depth interviews in this study, meant that people with significant cognitive or communication difficulties were not able to take part, limiting the scope of this study. Similarly to what was noted by Nilsson, in regards to understanding the current self by referring to the previous self, the women in this study understood their current body by comparing it to their past body and expectations of their future body. Participants described their pre-stroke bodies as strong, but also taken for granted. Stroke precipitated dramatic bodily changes, and Kvigne & Kirkevold (2003) summarise the post stroke experiences in three major themes: the unpredictable body, which was unable to do things that it had previously done automatically, and could not be relied upon; the demanding body, which had become more time consuming and dependant; and the extended body, where participants were forced to accept the assistance of aids such as wheelchairs and walkers. While the experience of bodily strangeness continued in the months after discharge, the participants gradually accepted the changed body as more familiar.

Understanding the limitations of quantitative research alone in providing insight to the stroke experience, Dowswell et al. (2000) undertook a qualitative study to complement a randomised controlled trial evaluating the effects of information provided to stroke patients and carers. The qualitative study aimed to examine the experience of patients and caregivers during the year following a stroke. They found that recovery was measured according to personal yardsticks, largely relating to the congruence between life before, and life after stroke, and also in comparison to other stroke survivors. The quantitative study interviewed respondents at 3, 6 and 12 months following stroke. However, it appears that the qualitative interviews were a single interview with each respondent. Had the researchers been able to collect qualitative data at several time points, as they did quantitative data, the qualitative study would have been strengthened considerably.

In contrast Burton (2000) conducted monthly interviews with six participants for 12 months following stroke, in order to understand the experience of living with a stroke. They found that recovery from a stroke involved restructuring and adaptation in multiple areas of life. The process of recovery had no perceived end-point, but was measured by engagement in the social world, over and above physical function alone.

Other studies not included in the above mentioned reviews have also sought to illuminate the experience of stroke, focusing on various aspects of the post-stroke experience. A study by Bourland, Neville, & Pickens (2011) explored the long term impact of stroke on quality of life, using a phenomenological design. Activity loss was a major theme, and quality of life was understood to be a constantly changing experience as: *"activities of value were lost or gained and as participants experienced changes in their perspectives, beliefs, values and behaviours" (p448).*

Kitzmuller, Asplund, & Haggstrom (2012), also looked at the long term impact of stroke, conducting retrospective narrative interviews with stroke survivors and carers to explore the experiences of family life following a stroke. They found that lack of communication and altered roles and relationships impacted on family relationships. Other researchers have highlighted coping strategies such as maintaining a positive attitude and asserting independence (Popovich, Fox, & Bandagi, 2007).

One aspect of stroke survivors lives is the assistive devices they may need to use due to disabilities acquired through stroke. This was studied by Pettersson & Appelros (2007), who suggest that: *"Understanding how individuals with disabilities experience their lived world in relation to assistive devices is a prerequisite for enhancing their participation and quality of life" (p15).*

They describe their study as 'lifeworld research', and used interviews and an analysis method which sought to highlight both segments of meaning and complete stories of participants, in order to understand the relationship that stroke survivors had with their assistive devices. Due to the need for participants to partake in a verbal interview, people with significant cognitive and communication problems were excluded, as is common in stroke research despite the large proportion of stroke survivors this excludes.

Among their findings were that devices were seen as positive, as they compensated for disability and assisted with the performance of activities, but they also had negative connotations, as their presence reminded stroke survivors of their disabilities. Another finding was that the issue of visiting the toilet was highly prevalent within all the interviews, and this issue had a significant impact of decisions about where to go and what to do: *"visiting the toilet largely determines what they* [stroke survivors] *do during the days" (p23).*

Pringle, Hendry, McLafferty, & Drummond, (2010) explored the experience of returning home, in stroke survivors with aphasia. They found that this time was associated with 'fathoming out', or gaining an understanding of the consequences of stroke, and adapting to this. Support at this time was highly valued. This study specified a very specific time period, which narrowed its scope but may also have deepened the insights available. It also had the strength of including people with cognitive and communication difficulties. Many of the studies in this section have failed include people with cognitive and communication difficulties, due to the difficulties these people may have in giving informed consent and engaging with the research process. However, due to the large number of stroke survivors who fall into this category, research that excludes such people cannot be seen as truly representative of the stroke survivor population.

Many studies highlight that the impact of the stroke is dependent on contextual factors, and Lobeck, Thompson, & Shankland (2005) looked specifically at the experiences of stroke in men at the time of retirement. They outline three major themes: ambivalence about retirement, in that retirement was seen as having both positive and negative aspects; the impact of stroke, which characterised by change and loss, including to identity; and healing and adjustment, the process of adjusting to losses and finding acceptance in oneself, including recognising that plans for the future would have to be altered. The findings also suggested that an interplay existing between the meanings given to the two events, and that for some men the stroke had led to a positive reframing of life, for example, an increase of closeness in their relationships with their wives. It appears that when stroke occurs at the time of retirement, the two events cannot be separated, as some aspects of retirement, such as loss of work identity, and echoed in post-stroke experiences such as loss of physical abilities.

Role and self-identity in relation to participation

Defining the concept of 'self'

A key factor in the experience of illness and disability, including stroke, is the loss of role, self and identity. Many studies aiming to explore the experience of stroke touch upon issues of role, self and identity in their findings. For example, Erikson, Park, & Tham (2010), in their study of 'what matters to persons after stroke', identified a core category 'not recognised as the person I am'. The concept of self has long been recognised, beginning with Descartes 'I think therefore I am', indicating the significance of self in consciousness. Our perception of things other than the self is objective, but when an individual perceives him or herself they are both the subject and the object simultaneously. Self esteem emerges from self perception, influenced by the gap between ideal self and actual self. Belief about personal effectiveness is an important aspect of self-esteem. Therefore if an individual is unable to perform a task that is highly valued, or to pursue aspects of their ideal self, this may create negative feelings. Interactions with others impact the way a individual sees themselves, and self-concept is believed to be influenced by comparing the self to significant people in our lives (Brumfitt, 1999).

Terms such as 'self', 'identity' and 'self-concept' are often used interchangeably, with no clear definitions of the terms, rather the different terms used may reflect the different background of the researchers (Osborn & Smith, 2006). These terms generally refer to a set of concepts used by an individual to define themselves in relation to the world around them.

The self in stroke and aphasia

A thematic synthesis by Satink et al. (2013), presents patient views of the impact of stroke on their roles and self. In contrast to many studies which use these terms, they provide clear definitions of the terms. They define 'roles' as, *"sets of connected behaviours, rights and obligations related to social status, identity and self" (p1),* and 'self' as, *"a cognitive* *representation a person makes of his/her identity. Identity is the fact of being who or what a person is" (p1).* The strategy for synthesising is also well defined, and includes a quality appraisal. The authors note that most of the studies included in the synthesis excluded patients with severe cognitive and communication disorders. Three main themes were identified from the synthesis. 'Managing discontinuity is a struggle', refers to the perception of body, self and role as three separate and elements after the stroke, which was experienced as a threat to self and identity. 'Regaining roles: to continue or adapt?', described a desire for continue with pre-stroke roles and activities, by hoping that they could be reinstated or adapted. 'Context influences management of roles and self', describes the process of recovery as starting with a passive attitude and moving towards a more active engagement, depending on other contextual influences. This theme also includes the discrepancy between patient and health care provider goals that is mentioned in many studies of stroke. Taken a whole these themes describe the constant appraisal of roles and self following a stroke, and being at a mid-point between a past and future self. Satink et al. (2013) discuss the importance of the recognition of this by health professionals, and discuss the concept of patients becoming 'self-managers', able to reflect and work upon who they want to be and who they are able to be, following a stroke.

A study by (Secrest & Thomas, 1999), included in the above review and also in the reviews mentioned earlier, followed stroke survivors for two years following stroke. This length of time is unusual in stroke research, and a strength of the study. They found three interrelated themes which greatly influenced the sense of self: Independence/dependence; In control/out of control; and Connection with/disconnection from others.

Illness and disability is likely to impact upon a persons' sense of self, especially if this affects aspects of the self which are central to self image (Brumfitt, 1999). Much of the literature around the self in illness or disability comes from a narrative approach. The narrative approach is based on the assumption that a sense of self is created through narratives or stories told to oneself or others, which creates a sense of coherence from which the sense of self emerges. Chronic illness interrupts this narrative, undermining the sense of coherence, referred to as 'biographical disruption' and has been used to understand the experience of stroke (Ellis-Hill & Horn, 2000; Pound et al., 1998). Stroke survivors have described a fundamental change between pre and post stroke life, experiencing their body as separate, precarious, perplexing and unreliable. Ellis-Hill, Payne, & Ward (2000)described this experience as a 'self-body split'.

Carel, (2007) similarly makes use of Merleau-Ponty's distinction between the biological and the lived body in her phenomenological approach to studying illness. The lived body is the means by which the individual perceives and interacts with the world, with disruptions of bodily capacity not only impacting on the biological body, but also on the lived body, often transforming the persons' social world. As a result of not being able to participate in shared activities such as work and sports, the ill person is unable to maintain their social world.

Ellis-Hill & Horn, (2000) assessed self-concept following stroke, discovering that stroke survivors reported a negative sense of self even after a period of rehabilitation. Fraas (2011) further elaborated on how the sense of self is diminished in stroke survivors, *"psychological, cognitive, social and physical factors following stroke interrelate and influence each other, resulting in erosion of the natural or familiar sense of self" (p41).* Stroke often leads to debilitating conditions which are not immediately apparent, including communication problems, cognitive problems and tiredness. Research suggests that invisible disabilities are more difficult to incorporate into ones sense of self (Brumfitt, 1996).

A classic phenomenological study looking at self specifically in the context of stroke is Kaufmans (1988) work, 'Illness, biography and the interpretation of self following a stroke". This uses case material from one stroke survivor, to illustrate observations made during three years of fieldwork with people with stroke. Kaufman suggests that *"following a catastrophic illness, the individual needs to "repair" and "heal" the self by revising and re-creating the biography so that it makes sense in the light of the current changed circumstances of the individuals existence" (Kaufman, 1988).* Essentially the stroke survivor needs to re-evaluate elements of their life in order to create a coherent life story in the light of the stroke and its impact.

Kaufman (1988), describes three problems which she says seem to characterize the post-stroke experience: the discontinuity of life patterns, discovering that previous life patterns need revising in the light of the post-stroke situation; failure to return to normal, where even patients who appear to have recovered physically do not feel they have fully recovered; and the redefined self, trying to incorporate new experiences into the old sense of self in order to create continuity.

A study by Kitzmuller, Haggstrom, & Asplund (2012) focused on the alienation stroke survivors feel from their own body, as the unreliability and unpredictability of it leads them to objectify it. This along with negative judgments from others, and lost roles, threatens the sense of self. Self-concept may be strengthened by mastering important tasks.

The concept of 'biographical disruption' which occurs with sudden onset illness such as stroke, and the loss inherent in this, has been challenged by Faircloth, Boylstein, Rittman, & Young (2004). They found that stroke survivors often discussed the stroke as just one element of an ongoing life, and the authors describe this as 'biographical flow', as stroke mediates with other factors which impact upon how people account for the stroke within their life narrative. People may 'bracket off' the effects of the stroke, leaving their sense of self relatively unchanged, or it may become part of their ongoing life story. They may see stroke as a normal component of old age, they may have other illnesses or disabilities which stroke forms only a part of, or have previous knowledge of stroke which prepares them for its impact on daily life (Faircloth et al., 2004). This research stresses the importance of looking at the stroke in the context of the individual and their circumstances. Biographical disruption may explain the impact of stroke for some survivors, but not all. The meaning of illness in a persons' life depends on their everyday practical concerns.

It is believed that language plays a central role in self-identity, although the relationship has not been well explored (Brumfitt, 1999). Guise, McKinlay, & Widdicombe (2010) suggest that *"Stroke sufferers who experience aphasia may find that this affects their interactions with others, and that successful adaptation may involve a renegotiation of identity" (p77).*

Questions have been asked as to whether a person with severe language impairment can maintain a view of self, as for example Shotter (1956, cited in Brumfitt, 1996) suggests that the ability to talk to oneself is a means of maintaining a sense of self. However, evidence indicates that *"a sense of self can be preserved even in the most impaired communicator"* (Brumfitt, 1999, p9).

Close personal relationships may have a big part to play in this, as for example, if an aphasic persons' partner responds to them as if they were as they used to be, the aphasic person will experience continuity with their past self, whereas if they are treated as incompetent it will be difficult for them to relate to themselves in a positive way (Brumfitt, 1996).

This challenge to self is not necessarily experienced in the very initial stages post stroke, or if it is, its permanence may not be understood by the stroke survivor. Wood, Connelly, & Maly (2010) used a longitudinal grounded theory approach to look at the process of 'community reintegration' (re-establishing or developing new roles and relationships) following stroke, and identified a series of goals: gaining physical function; establishing independence; adjusting expectations; and getting back to real living. The final stage involves a balance between expectations and physical ability, echoing ideas about optimal participation (Rochette et al., 2006), and quality of life (Levasseur, Desrosiers, & Noreau, 2004). Not all participants were able to achieve this one year post stroke, and so it is not clear whether all stroke survivors ultimately achieve this.

A highly relevant study by Clarke, (2003), combines qualitative and quantitative methods in order to understand the experience of stroke. Their qualitative work helps to establish a relationship between sense of identity and wellbeing in the stroke survivor. They found that effects of physical and cognitive disabilities on the stroke survivors' wellbeing were dependant on the effects of disability on identity. They also found that social support, and educational resources from previous educational experiences could moderate adverse effects, as they assist in psychological adaptation. Some of their participants found ways of returning to their roles and activities, even in a modified form, which helped to preserve their identity.

The relation of role to self-identity

It has been reported in qualitative studies of stroke (including (Dowswell et al., 2000)(Burton, 2000), that stroke affects peoples roles, notably causing a loss of role, or as Dowswell et al., (2000) describes it, 'roleless-ness'.

By looking at personal construct theory (PCT) (Kelly 1955, cited in Brumfitt, 1999, 2000), we can start to understand the relationship between role and identity. PCT seeks to describe how we understand ourselves and other people. For example, we may possess the construct, ‘meeting new people is challenging’, while another person may possess the construct ‘meeting new people is exciting. ‘Core role constructs’ are constructs which are central to the self, and are used to maintain a person’s self-identity. The individuals core self can contain the persons construction of themselves, the way they believe other people see them, and the way they see their role in society (Brumfitt, 1999). If something such as a stroke occurs which creates a loss of role, the impact on the sense of self can be severe, and this can only be rebuilt by building new core constructs (Brumfitt, 2000).

Studies of sub-groups of stroke survivors further highlight the relationship between the impact of stroke and role, self and identity. Gender roles have been found to be significantly challenged for both men and women (Eilertsen, Kirkevold, & Bjørk, 2013; Green & King, 2009). Thompson & Ryan (2009) conducted a study into the impact of stroke on spousal relationships, and found that they were significantly affected by changes to ‘self’ experienced by the stroke survivor, including increased feelings and expressions of anger and frustration and a fall in sexual functioning and desire. This study excluded people with moderate to severe communication difficulties, and cognitive difficulties, and it may be that the findings would have been even more significant had these groups been included. There was also a perceived loss of control relating to role, identity and sense of self, in that they were unable to continue with what they saw as traditionally male and female aspects of their role.

The root cause of the feeling of loss associated with role change appears to be a discrepancy between expectations and reality. Individuals having a stroke at less than the average retirement age may experience a different and greater sense of loss than older people, due to still being active in work and social life (O’Connell et al., 2001). Conversely, stroke has been found to be less disruptive in the lives of older people, though it is the perception of oneself as ‘old’ or ‘young’, rather than the age itself, which is influential in this sense (Faircloth et al., 2004). This suggests that the greater the difference between expectation and reality, the greater the sense of loss of self.

Role, self-identity and participation

A study by Clarke (2003) which sets out to understand the experience of stroke, suggests a possible link between participation and role, self and identity, as the loss of activities appears to threaten the person's sense of identity, and those able to return to former activities in some form, felt their identity to be more intact. Maintaining group memberships has been found to increase well being after stroke, as this contributes to the continuity of social identity (Haslam et al., 2008). In the event of brain injury people have been found to make sense of themselves in terms of the meanings and experiences of social and practical activity (Fergus, Palmer, Becky, Psaila, & Shaw, 2008), which strengthens the argument for a link between participation and self, role and identity.

Charmaz, (2006) explicitly explores the relationship between participation (although she uses this term only as one among others, such as 'pursuits') and self-identity suggesting that *"new chronic conditions can force reappraisal of health status and reconstruction of self when they interfere with ordinary pursuits" (p27).* Measuring and marking these pursuits can become part of the person's self concept, as people measure the present against past and sometimes future involvements. Some pursuits can become distanced from the persons' sense of self, even if they once held importance, although lifelong involvements often provide markers by which the person may closely examine themselves. Strategies may be used to maintain the sense of self through involvements despite illness, for example, one of Charmaz' participants was no longer able to partake in horse riding, but still attended shows and in this way upheld the social element of that activity.

Role and self-identity in the context of rehabilitation

Ellis-Hill, Payne, & Ward (2008) developed the 'Life Thread Model' from the narrative theory, to apply what is known about the challenges to the self during stroke, to rehabilitation. They perceived a gap in traditional rehabilitation between professional and stroke survivor goals, the goal of the therapist being physical function whereas the goal of the patient is a return to pre-stroke life. Other studies support the existence of this discrepancy (Mckevitt et al., 2004; Sumathipala et al., 2012). While there is overlap between these aims, they are not necessarily the same thing. This discrepancy can lead to a lack of motivation on the part of the stroke survivor.

The Life Thread Model is based on the idea of life threads which represent the strands of ourselves which we create and recreate throughout our life (C. Ellis-Hill et al., 2008). These stories create a picture of our life, and ultimately a sense of identity. Some of these life threads will cross with those of other people as stories are created together out of shared memories. Following a stroke many of these threads may become broken or frayed, and the rehabilitation process should assist people in the process of making sense of what has happened to them, including supporting a positive sense of self.

In keeping with this approach, Fraas (2011) cites 'comprehensive-holistic stroke rehabilitation' as aiding a path towards a new self, by addressing cognitive deficits, emotional difficulties, social needs and functional skills, and the development of goals as a joint venture by patients and health care providers. Studies of this approach have shown it to be more effective than traditional, medically based intervention at integrating patients back into their communities and improving quality of life (Cicerone, Mott, & Azulay, 2008). In this context, successful rehabilitation would be an acceptance of altered abilities, the redefining of values to meet reality (Green & King, 2009), and development of coping strategies (Mckevitt et al., 2004). The experience of grief and reconstruction ultimately leads to the restoration of self, albeit a revised self (Eilertsen et al., 2013).

Loss, Coping and Acceptance in relation to participation

Loss

In their literature review of qualitative studies of stroke, Mckevitt et al. (2004) identified the pervading sense of loss experienced by stroke survivors. For example in a study by O'Connell et al. (2001), participants described the *"end of life as they knew it" (p121).*

What is the role of loss in stroke and how does it relate to participation? The loss of function that often accompanies a stroke and the psychological reaction to that of the stroke survivor is often accounted for by reference to bereavement models. *"Grief is a normal reaction to the loss of physical function" (Stewart & Shields, 1985, p447),* and Muller (1985, cited in Brumfitt, 2000) describes the depression that is common in the early stages of stroke as being part of the grieving process.

An example of such a model is that of Tanner and Gerstenberger (1988) who outlined the stages of grief experienced by people with neurogenic communication disorders (including aphasia): denial; frustration; depression; and acceptance. They suggested that three distinct dimensions of loss were experienced by stroke survivors: loss of person; loss of self; and loss of object. This model was criticised as being entirely based on death and dying literature, with no empirical or literature evidence from people with language disorders. Other researchers have also rejected the very principle of the application of psychological theories of loss and grief to physical disability, and it is *"firmly rejected within the U.K. disability studies literature" (Sapey, 2004, p90).*

The social model of disability challenged the notion that disability is within the individual and instead situated it in the environment. Viewing people with disabilities as having experienced 'loss' is seen as perpetuating views of disabled people as incomplete and vulnerable. Ellis-Hill et al. (2008) suggested that framing stroke in terms of loss and bereavement is a discourse of health professionals rather than stroke survivors. Watermayer (2009), proposes that *"the discourse of loss, incorporating the ideas of mourning, denial and acceptance, has functioned culturally as a means of achieving mastery over the dissonant and frighteningly unknown phenomena of disability" (p93).*

Watermayer (2009) juxtaposes disabled and non-disabled people, the victims and the perpetrators of 'loss discourse'. However, stroke and other sudden onset disability transforms a person overnight from being non-disabled to disabled. In this context it appears unrealistic to dismiss the sense of loss that may be felt by people who, within a moment may have lost their mobility, speech, cognitive function, and consequently their job or their role as mother or husband as they knew it. Watermayer, (2009), himself explained that he does not want to dissociate disabled people from loss, rather he feels that disabled people should not be singled out from the rest of humanity, who all experience loss in one form or another. *"To be alive, to grow and develop, to hope and relate means inevitably to experience loss" (p92).*

The use of the bereavement model in the context of stroke rehabilitation has also been challenged from an evidential perspective, by Alaszewski, Alaszewski, & Potter (2004), who interviewed both stroke survivors and professionals regarding the impact of stroke and the process of recovery and rehabilitation. They found that while the bereavement model was present in literature aimed at health professionals, and in health professionals accounts of stroke, it was absent from the account of stroke survivors and their carers. Moreover it was applied by professionals when a discrepancy developed between the goals of professionals and stroke survivors, with the goals of stroke survivors being viewed as unrealistic.

Coping

There is a long history of interest and research into how people cope with stressful situations, and researchers have used large scale quantitative studies in order to try to model peoples coping patterns. For example, Pearlin & Schooler (1978) suggested three main types of coping behaviour: eliminating or modifying circumstances which give rise to problems; perceptually controlling the meaning of experience to minimise it's problematic nature; and managing the emotional consequences of problems.

The transactional theory of stress and coping (Folkman, Lazarus, Gruen, & DeLongis, 1986) underlies much of the research into coping with stress (Brands, Wade, Stapert, & Van Heugten, 2012). Within this theory the appraisal of a situation as stressful results in cognitive and behavioural attempts to cope with it. Folkman et al., (1986) also suggested a 'goodness of fit' theory, based on the transactional theory, where the success of the coping strategy could be predicted by how well it fits the event. For example if an event was uncontrollable, such as an accident or sudden illness, then strategies to modify emotions and perceptions would be most effective. However, if an event was controllable, such as health problems caused by diet, then problem solving coping strategies would be most effective. However, there is little evidence to support the 'goodness of fit' theory.

Illness is recognised as one type of stressful life event, which has emotional consequences and necessitates adaptation (Ridder, Depla, Severens, & Malsch, 1997). The transactional theory is congruent with a biopsychosocial model of illness and disability, as it sees the perception of a stressful event as the interplay between the person perceiving it, and their environment. However, in applying the transactional theory to acquired brain injury, Brands et al., (2012) found that the theory lacked the ability to account for several coexisting stressors and strategies, which was essential when looking at coping with a condition which had a wide ranging impact, which could also apply to stroke. *"The general adjustment process usually starts with the (re-)learning of skills to manage the wide array of physical, cognitive and communication impairments. Then, when the patient begins to realize that the premorbid level of functioning is not going to be completely regained despite hard work, the* *process of building an entirely new perspective on life starts, which includes making adjustments of expectations about the future to restore and/or rebuild self-concept or self-image." (Brands et al., 2012, p841)*. Therefore, adaptation requires an interaction of two strategies, actively maximising the restoration of function, while also adjusting to the loss of function. This is also comparable to short term and long term goals. Short term goals are often based on easily measurable achievements, such as being able to climb the stairs. A related long term goal might be returning to live in ones two storey home. When there is a discrepancy between the goal and actual performance, adjustments may need to be made to the long-term goals, for instance, moving to a bungalow, or fitting a stair-lift. Emotional adjustment to the situation requires a balance between wanting to achieve the goals enough to persist, and being able to disengage when they are not possible.

This last point is also mentioned by Mattlin, Wethington, & Kessler (1990), who carried out a large scale study of coping in various stressful life situations. They found that the situation affects both the use and effectiveness of coping strategies. One such strategy is 'reappraisal', which can be maladaptive if it inhibits action to solve a problem. For example, someone might decide that going upstairs isn't so important after all, and therefore be unwilling to work on being able to climb the stairs. However, reappraisal can help when adapting to the death of loved one, for which there is no practical solution. This distinction between emotion focused and problem focused coping strategies is well known within the literature, in reference to coping strategies in general (e.g. Folkman et al., 1986), and the literature on coping in illness and disability (Ridder et al., 1997). Problem focused coping strategies have been found to be more affective, for example Schüssler (1992) found that control and acceptance are associated with active and problem-related coping, whereas emotional coping is more often found in people who do not accept their illness or feel they have any control over it.

In a large scale study of coping styles in people with chronic illness, Ridder et al. (1997), identified 10 clusters of beliefs about coping: autonomy; positive thinking; fatalism; resignation; dependence; social support; anger; expressing emotions; control; and denial.

Within this is a positive versus negative meaning of illness, where one person may see illness as a challenge, and another may see it as an enemy. The difference in perception will affect their coping styles. From these beliefs, Ridder et al. (1997) identified 3 coping styles within their participants: a balanced style, which allows positive coping strategies such as autonomy and acceptance; a militant attitude, which sees illness as the enemy which needs fighting, expressed in such beliefs as control and social support; and a fatalistic attitude, where illness is perceived as the enemy which cannot be beaten, expressed in beliefs such as resignation and fatalism.

Most studies of coping are from a quantitative perspective, however, Rochette et al. (2006) conducted a qualitative study to look at adaptation and coping following a first stroke. They found five themes related to coping: active and passive compensation; escape; change how the situation is perceived; and utilization of resources. They also discovered that where stroke survivors are unable to return to their former situation, using the coping strategy 'change how the situation is perceived' can lead to acceptance, which appears to be linked to an optimal quality of life. Similarly Popovich, Fox, & Bandagi (2007) found that coping strategies used by people who had stroke included maintaining a positive attitude and asserting independence as much as possible, during the acute period.

Acceptance

Acceptance has been linked to quality of life in a study by Kurpas, Mroczek, & Bielska (2013), who found that a higher score on the Acceptance of Illness Scale (Felton et al., 1984, cited in Kurpas et al., 2013) correlated with higher scores of quality of life outcome measures. Acceptance of illness is thought to reduce negative reactions and emotions and impact upon self-esteem (Kurpas et al., 2013). While acceptance appears to be an ideal goal in the case of someone with an illness or disability, Telford, Kralik, & Koch (2006) warned against the juxtapositioning of acceptance and denial. Their literature review found that this approach may deprive people of the opportunity to tell their own unique story of their experience, as the listener focuses on fitting their experience in with stages of adjustment, and expresses negativity towards the denial, which can become internalised. This echoes findings by Alaszewski et al.(2004), which suggest that bereavement models, which contain a stage of denial, tend to be applied to stroke survivors by health professionals when there is a discrepancy between the goals of the health professional and the goals of the stroke survivor, when the health professional views the goals of the stroke survivor as unrealistic.

However, acceptance does seem to be a beneficial trait. Townend, Brady, & McLaughlin (2007) studied the relationship between personal acceptance of disability and depression following a stroke and found that patients who were not depressed commonly reported having accepted stroke-related disability.

Many qualitative studies of stroke cite acceptance as a key point in the holistic rehabilitation process (Green & King, 2009; O'Sullivan & Chard, 2010). A study by Prigerson & Maciejewski (2008), combined the concepts of grief and acceptance, presenting them as two sides of the same coin, reactions to loss. Examining the stage theory of grief with bereaved people, they found that as grief decreases, acceptance increases, and their description of grief may be generalisable to other losses, such as loss of physical function, *"an emotional inability to accept the loss of something cherished" (p435).*

Acceptance of disability can be seen as a re-adjustment of a persons' value system, which Wright, (1983) proposes to be based on four major changes: enlargement of the scope of values, whereby the person begins to recognize the importance of values other than those lost; subordination of physique relative to other values, so that the person starts to value qualities other than physical; containment of disability affects, where the person 'possesses' the disability, rather it being a characteristic of them. This can be expressed in language as 'a person with a disability', rather than 'a disabled person'; and transformation of comparative status values to asset values, where a person sees the assets of particular qualities in context rather than compared to a standard value, e.g. a wheelchair may be appreciated as a tool for mobility, rather than seen as of less value than the ability to walk.

Acceptance of loss occurs over time and is influenced by many factors. Stroke survivors' sense of self is based on their former lives, roles, abilities and skills. Many will never be able to fully return to this, and this realization causes an intense sense of loss. Kouwenhoven, Kirkevold, Engedal, & Biong (2011) wanted to look at the experience of stroke survivors with early depressive symptoms. They found that the experience of loss was crucial within this population, and identified 3 'patterns of experience' within their participants: finding a restored self; trapped in a different life; and fighting to regain self.

We can see from the literature around coping and acceptance that there exist many theories with which to understand coping following illness or disability, and that the coping and acceptance concepts are clearly interrelated. Because these studies are quantitative, their generalisability may be good, however, they may also contain the same difficulties as quantitative stroke studies, in that by using predefined measurement instrument they may not reflect the subjective experience of the participants.

Summary

This chapter highlights that participation has become an important concept in health related research, however, no clear definition of participation exists, and the majority of studies have not addressed the subjective experience of participation (Cardol et al., 2002).

I have reviewed the small body of research which seeks to highlight the subjective experience of participation, and some of this relates to stroke. While the extant research does not agree on a definition of participation, and the heterogeneity of findings supports the notion that participation is highly subjective, there are some common features mentioned which indicate that participation, while being highly subjective, may have a underlying 'essence' which is more generalisable. Other salient concepts were also discussed, and I have examined theory and research in relation to stroke for role and self-identity, and loss coping and acceptance.

This chapter situates the present research within the extant research landscape, and provides a context for the research questions. The next chapter will explain the theoretical background to how I intend to answer these questions.

Chapter 3: Methodology

The methodology behind a research study is its foundation, as it guides the methods used to collect and analyse the findings, and the perspective from which the analysis is interpreted. This chapter presents an account of why Interpretative Phenomenological Analysis (IPA) was selected as the most appropriate methodology with which to answer the research questions, by describing the factors informing the methodology, and the relevant research traditions and theoretical underpinnings of the methods used in this research. Denzin & Lincoln, (2003)suggest five phases that define the research process:

1. To locate the researcher within the history and traditions of research, including acknowledgement of the self in relation to the present study.
2. To establish the researcher's theoretical paradigm or interpretative framework that guides the research process.
3. To select the research design which connects the theoretical paradigm to the strategies of inquiry and the methods for data collection.
4. To select the methods for data collection and analysis.
5. To establish the interpretative practice for presenting findings.

This chapter deals with phases 1 to 3, and phases 4 to 5 will be detailed in the methods chapter. I begin this chapter by restating the research questions, and then describe my own position in relation to the research. I then guide the reader through the process of selecting the research paradigm, approach, and methodology, which informed the study design. I conclude by highlighting the issues of quality and reflexivity.

Research Questions

The methodology used in research should have the primary purpose of best answering the research questions. As detailed in previous chapters this piece of research aimed to answer two questions:

What does the term 'participation' mean to stroke survivors? Hammel & Magasi, (2008) argued that objective measures of participation do not capture the full meaning of participation, as viewed by the subject. The literature review identified a scarcity of research which seeks to understand participation from a patient perspective, and even less that refers specifically to stroke survivors. The small but growing body of research which does exist in this area has not conclusively defined participation, but it has identified that its meaning is subjective, and so it is important to understand what participation means to stroke survivors. The first aim of this research was therefore to gain an understanding of what participation means to stroke survivors. Rather than focusing on specific examples of participation, which literature suggests are likely to be subjective, the purpose was to look for the essence which underlies the various expressions of what participation is and means. This takes into account that people's perceptions of participation may have changed because of their stroke experience, as major life events can cause people to question and re-evaluate their perceptions of reality. The first question provided a foundation for the second question, and helped to avoid weaknesses of previous studies where participation was ill defined.

How do stroke survivors experience participation? It is understood from the literature that stroke has a negative impact on participation, but we know little about the lived experience of participation by stroke survivors. This research aims to further the understanding of participation by exploring the experiences stroke survivors have of participation.

The researchers position

As suggested by Denzin & Lincoln (2003), the researcher, as well as the research questions will have an impact on the design of the research, due to *"conceptions of self and other and the politics and ethics of research" (p37)*. It is important to outline the position of the researcher and their particular interests in relation to the research, to provide clarity about this.

I have no more personal experience of stroke than the average person, that is, I have not been personally affected by stroke or been an informal carer for someone with stroke. However, I have had both clinical and research experience of working with people who have had a stroke, and other elderly and disabled populations. During my first degree, I helped to support myself by working as a care assistant with elderly and disabled people, visiting them at home. I later qualified as a Speech Therapist, and maintained an interest in working with adults.

My research experience has been within large randomised controlled trials, and smaller scale qualitative projects. While both of these have an important place within health research, I have always been more personally inclined towards the qualitative approach, which brings the researcher closer to the experience of the participant. I have also had first-hand experience of conducting standardised measures and scales with people for whom they were inappropriate, and sometimes upsetting. These experiences have undoubtedly influenced the development of my own methodology.

Prior to my experience in stroke research, I was involved in a research project with heavy drinkers. Both of these participant groups are challenging in their own ways. The heavy drinkers were often difficult to contact, and could be volatile or emotional during the interviews. Stroke survivors were also often emotional, and issues with cognitive and communication problems were challenging. The aggregate impact of my past experience has led to a strong feeling about the importance of research which is ultimately relevant and useful to the population being studied and respects the participants as sources of valuable information no matter what their level of cognitive or physical disability.

This thesis is the result of a PhD studentship funded by the National Institute for Health Research (NIHR) Collaboration in Leadership in Applied Health Research and Care for South Yorkshire (CLAHRC-SY), as part of the Stroke Theme, under the stream ‘participation’.

This research is funded by the Collaboration for Leadership in Applied Health Research and Care for South Yorkshire (CLAHRC SY). This is a five year pilot programme which aims to translate healthcare research into practise. My thesis forms part of the stroke theme, which aims to: reduce the number of strokes; improve long-term provision and effectiveness of rehabilitation in the community; support self-management; and encourage independence, recreation and employment for people living with stroke and their carers (National Institute for Health Research, 2013). This thesis is relevant to all but the first of these aims.

Alongside the initial literature review, efforts were made to establish the local situation, in regards to stroke. Sheffield has an Acute Stroke Unit, where all people hospitalised following a Stroke will be treated. Following the acute phase, they will be discharged to their homes if well enough, often with the support of home based rehabilitation or attending a day centre. If they are not well enough to be discharged home they will go to an intermediate care unit, where they will receive rehabilitation until able to go home, or into some form of supported housing if needed. At the commencement of this research, Sheffield had recently funded the services of the Stroke Association's Family and Carer Support Service. This service is no longer funded.

The Stroke Association is a national charity concerned with prevention, treatment and rehabilitation for stroke patients, through research, campaigning and educating and the provision of Life After Stroke Services (The Stroke Association, 2009). The Stroke Association recommend that, *"A range of services should be in place to support the individual long-term needs (including non-medical needs) of stroke survivors, their families and carers" (The Stroke Association, 2008, p29).*

The Family and Carer Support service is one such service, which aims to give practical information and emotional support to stroke survivors, their families and carers. The service makes contact with people when they have been admitted to hospital following a stroke, and provides support for as long as is needed, ensuring continuity through the acute and rehabilitation phases, and back into the home and community (The Stroke Association, 2009).

Prior to commencing this study, I met with key people from the Stroke Association, who provided further information about the aims of the Family and Carer Support Service. They emphasised the need for research around the area of participation, which corresponded with what I had been reading in the stroke literature. Much of their work concerns participation, and is very much client centred, making it difficult to measure the effectiveness of their interventions.

This research is based within the local South Yorkshire area, where I have lived, studied and worked for over ten years. My experience of the area is that is it a multicultural area and my experience of research and healthcare has been that the needs of ethnic minorities are often not met. This has led to a belief in creating research strategies which are inclusive and inviting to people from ethnic minorities.

These experiences have impacted the design of the research process in the following way:

- The research should be an iterative process allowing feedback from the participants, to ensure it is accurately reflecting their needs and opinions.
- The methodology should be specially designed to be inclusive to people with cognitive and communication problems, and people from ethnic minorities.
- The methodology should have room for flexibility, to ensure that participation is possible for all potential participants.

More detail on how these concerns have affected the research will be provided in the methods section.

A researcher may situate themselves within a paradigm and approach that agrees with their wider life philosophy, that is, they have a conviction in the effectiveness of certain methods because they believe in the underlying philosophy of those methods. My perception of ultimate truth is defined by faith, and as a researcher I do not associate myself with a particular ideology. Rather, I see different ideologies as being able to provide diverse views of the topic under study, and in designing this study selected the paradigm and approach which I felt would most effectively answer the research questions. However, prior knowledge and experience of certain perspectives and methods will have influenced my choices to some degree. Figure 3 shows the situation of my research within the qualitative paradigm, and the theoretical and methodological perspectives which were influential in the design of the study. I then explain this in detail.

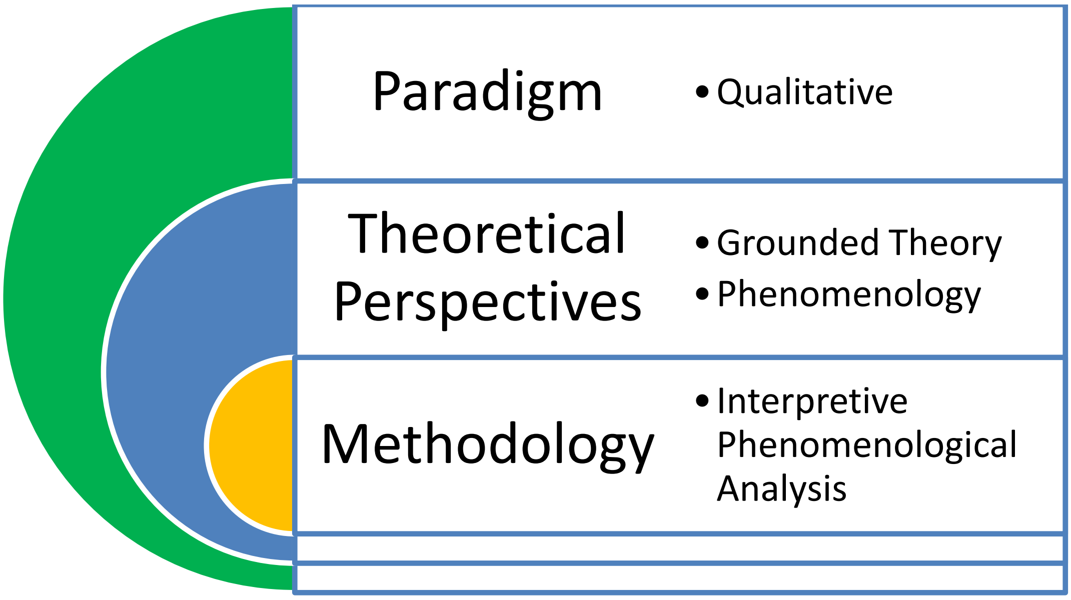

Figure 3: Representation of research approach

Research Paradigm – Qualitative Research

The research questions of this study focused on understanding meaning and experience, in a specific population and in a local area. This required the collection of deep, rich data, as found in qualitative research. At the current point in time, both quantitative and qualitative methods are used within the fields concerned with the study of people, including health research. While some see them as opposing positions, a more balanced view is that they can be complimentary to each other, each bringing a different insight to a problem. Some researchers see qualitative research as a necessary precursor to quantitative research, in order to identify relevant areas for research. However, Glaser & Strauss, (1967) are opposed to the view that qualitative research is only useful as a precursor or in combination with quantitative research, proposing that qualitative research has value in it's own right, though often a complete understanding of a phenomena is gained through using both.

The quantitative literature around participation in stroke survivors, gives an insight into the extent to which people are affected by stroke, and what factors may have most effect on participation. The limited amount of qualitative work in this area has an impact in two main ways. Firstly, the definition of participation is unclear and not based in the views of stroke survivors themselves. It is also suggested by some studies that it is the quality, rather than the quantity of participation which impacts on quality of life. The area lacks an understanding of what participation is like for stroke survivors. This has begun to be addressed, for example in studies by Barclay-Goddard et al. (2012) and O'Sullivan & Chard, (2010).

In order to contextualise qualitative research, I will briefly explain the history of gaining knowledge about people, which is related to the fields of anthropology, psychology, sociology and health research. This area as a research interest has its beginnings around the early nineteen hundreds, and started by emulating the approaches found in natural sciences. This is what we know as quantitative or positivistic research. In quantitative methodology the researcher is a tool in the process, which uses large data sets, and numerical analysis, to come up with generalisations about large groups. In the mid twentieth century post-positivistic movements developed, which challenged some elements of positivistic thinking such as that scientific methods could uncover objective reality, and emphasised the importance of understanding as well as explaining human thought and behaviour. This was a philosophical movement which was certainly not limited to thoughts about appropriate aims and methods of research, but questioned the very nature of existence (Denzin & Lincoln, 2000). The qualitative research movement developed out of this, challenging the view that an objective reality existed, as people's experiences are bound up in time and place, and the minds of people. From this perspective, the preciseness, objectivity and potential for duplication which is valued in quantitative research is neither possible nor desirable (Rooney, 2005). Here, the researchers' subjectivity is central to the research process, as rather than being a 'tool', they come to the research with life experience, opinions and preconceptions (Charmaz, 2006). From the 1960's onwards qualitative research grew and developed, and is now an accepted discipline within psychology and social sciences. Table 3 shows the main areas of difference between qualitative and quantitative approaches.

Quantitative Approach	**Qualitative Approach**
Emulates natural sciences, reality is objective and therefore it is possible to uncover the truth.	Developed in response to the study of people, reality is subjective; there is no objective truth to uncover.
Deductive, and breaks phenomena down into independent and dependent variables.	Inductive, and sees phenomena as holistic and interdependent systems.
Researchers as tool.	Researcher as interpreter.
Large data sets, numerical analysis and generalisations about large groups.	Small data sets, explaining and/or interpreting, in depth insights into small groups.

Table 3: Qualitative and quantitative research approaches (based on Denzin & Lincoln, 1998, 2000; Rooney, 2005)

Denzin and Lincoln (2000, adapted from Patton, 2002) have traced 6 phases of the development of qualitative research, which help explain the varying positions within qualitative research:

- The “traditional period” up to nineteen forties where colonial researchers influenced by positivism, aimed for objectivity.
- The “modernist phase” up to the nineteen seventies, where qualitative researchers emphasised procedural formalism in order to be accepted within social science.
- The “blurred genres phase” up to the mid nineteen eighties where multiple alternative approaches emerged and competed, resulting in the plethora of jargon and labels now present within the qualitative paradigm.
- The “crisis of representation” followed, which was a growing awareness of issues such as gender, power and race which undermined traditional notions of validity and neutrality.
- The “fifth moment” describes recent history where the creative and interpretative nature of qualitative research is challenged and questions asked about how the quality of qualitative research can be evaluated.
- The “post experimental phase” where the boundaries of qualitative research are widened, and can include autobiographical and poetic representations, and multi-media forms.

In deciding on the most appropriate approach a researcher does not need to commit themselves ideologically to a particular position, but from the current vantage point can look out at the rich tapestry of methodology and methods developed over the last one hundred years, and select the most appropriate to meet the aims of the study.

Ultimately, qualitative research involves making sense of, or interpreting, phenomena in their natural settings, using a variety of empirical methods which provide rich data that describe events and meanings in people's lives. Qualitative researchers often use a variety of methods in order to achieve better understanding of the subject (Denzin & Lincoln, 1998).

Qualitative approach

Having reflected on the aims of the research, identified my own position, and situated the research within the qualitative paradigm, it was then necessary to explore the vast and varied positions within this approach. These tend to be categorised in different ways, by different authors and for different purposes. By the term 'qualitative approach', I am referring to ways of looking at the world which have developed under the umbrella term 'qualitative'. These include both ways of explaining the world which have implications for research, and models for carrying out research based on certain beliefs and assumptions.

Creswell, (2006)identified five qualitative approaches to enquiry. This is not a definitive list, but includes approaches that may be considered in order to fulfil the aims of my study:

- Narrative research
- Phenomenology
- Case Study
- Grounded Theory
- Ethnography

Narrative research refers to any text or discourse focusing on stories told by individuals. It is generally used to study one or two individuals, reporting and chronologically ordering the meaning of their experiences. In the context of qualitative research, case studies similarly focus on a small amount of individuals, collecting data from many sources for one case, and are appropriate where there are clear boundaries of the case being studied and a need for in depth understanding. These are not appropriate methodologies for this study, which seeks to understand the experiences of a larger group of people, and look for similarities underlying the individual experiences.

Ethnography focuses on an entire cultural group (that may be for example ‘native American Indians’, or a single but complete stroke support group), and describes and interprets the groups shared values and behaviours using participant observation. This was not suitable for this research, as the group I am studying is not a discreet group and I am seeking to understand similarities between individual’s experiences, rather than how people interact with each other.

Phenomenology and Grounded Theory were the approaches which appeared to be the most appropriate to the research questions, and had been used in previous studies with similar aims. Phenomenology was ultimately the most influential approach to the research design, which was also influenced by ideas within Grounded Theory.

Grounded Theory

Grounded theory is a methodological strategy that seeks to construct theory about issues of importance in peoples’ lives (Glaser & Strauss, 1967), based on the principle that there are no preconceived ideas to prove or disprove, but rather issues of importance to participants emerge through the collection of data, which is then analysed by constant comparison, to generate theory that is *grounded* in the data (Mills, Bonner, & Francis, 2006). This was considered as a relevant methodology for this research, as it is suitable for exploring areas within which little is known and no previous reliable theories exist.

The central elements of Grounded Theory are:

- Concurrant data analysis and collection: Data analysis starts immediately and runs concurrently with data collection. For example, the analysis of the first interview will influence the content of the second interview, and this will carry on throughout data collection.
- Comparative analysis: data is coded into categories, and data within and between categories are constantly being compared to develop understanding.

- Theoretical sampling: rather than identifying all participants at the beginning of the research, new participants are sought according to areas of need identified through comparative analysis.
- Memos: memos are kept to keep track of thoughts which come out of the above processes.

Glaser & Strauss (1967) describe using different types of data collection as *'slices of data', "different types of data give the analyst different views or vantage points from which to understand a category and develop its properties" (p65).* There are no limits on the range of techniques that can be used, which is a useful concept in relation to including people with cognitive and communication problems, and people who may not speak English, and may require different techniques in order to make their voices heard.

Since their publication in 1967, Strauss seperated from Glaser and developed Grounded Theory in a different way, the main differences being that broad research questions can be identified prior to the study, as suggested by personal experience and literature, and subsequent stages are thus more guided. Strauss also introduced the concept of 'axial coding' as a way of organising and developing categories. Glaser continued to develop grounded theory in line with his original ideas. The two approaches are now known as Glaserian and Strausserian grounded theory.

Constructivist Grounded Theory, a later development of Grounded Theory takes into account the role of people as constructors of events, so the data that a theory is developed from will have been filtered through the eyes of participants, and once more through the eyes of the researcher. The resulting theory is therefore "a co-construction between researcher and participant" (Charmaz, 1990). For example, it would be naive to think that a researcher will come to an area of research as a blank canvas, they will bring with them the general perspective of their discipline, previous experiences in the field, research interests and their own personal history (Charmaz, 1990). This perspective is more congruent with the wider qualitative tradition that the Glaserian perspective which sees the researcher as a tool in the process.

Many of the principles of Grounded Theory appealed to me as a researcher, such as the concept of 'emergence', and as I had some (limited) previous experience of Grounded

Theory I adopted some of these principles early on in the research process. For example I tried to let the research questions ‘emerge’ from my reading around stroke and participation, as questions that needed answering, attempting to leave aside my own preconceived ideas and interests.

One of the factors that appealed to me about Grounded Theory was the concept of ‘researcher as a tool’, found in Glaserian Grounded Theory, which is in some ways similar to how the researcher is viewed in a quantitative context. Researchers naturally have a strong desire to accurately reflect the phenomena they are studying, and it can be hard to accept as a researcher that you will have an influence in the research process. Grounded Thoery seemed to offer a systematic way of working through the data which could minimize the subjective influence of the researcher.

Initially I felt that Grounded Theory would be the appropriate approach for this research, and the initial analysis of source 1 data drew upon the principles of grounded theory. However, as the research developed and my research questions were clarified, I realised that I was trying to capture the ‘essence’ of participation, and understand the lived experience of participation following stroke. Grounded Theory aims towards explaining social processes and producing a theory (Willig, 2001), and it started to become obvious that Grounded Theory no longer ‘fit’ the research that I was doing.

Grounded Theory was intended by it’s original creators, Glaser and Strauss (1967), to be a complete methodology providing a clear structure to be followed, and resulting in a ‘theory’ grounded in data. Since its inception, many variations have been devised, and many researchers now draw upon the principles and methods of Grounded Theory, without using the methodology in it’s complete form, and without aiming for a theory. For example it is common to read of studies which have used analysis from Grounded Theory but have not collected data according to it, or reached a theory. In this way it can be seen as contributing to the rich tapestry of qualitative research methods. Here the principles of grounded theory, such as letting issues of importance emerge through the data, were influencial to the development of the methodology.

Phenomenology

Phenomenology has been described as *"the exploration of subjective experience" (Spinelli, 1989).* The word 'phenomenology' comes from 'phenomena', meaning, 'that which shows itself', emphasising the contrast between the appearance of things and the reality of things. Meanings are therefore constructed, and in this regard it draws on principles found within the social theories, Social Constructionism and Symbolic Interactionism. Social Constructionism assumes that knowledge is sustained by social processes, so that people construct knowledge through their daily interactions. Further to this, knowledge and social action go together, so the constructed knowledge about something informs the social response to it. For example the belief that alcoholism is an illness, necessitates a 'helping' response, rather than imprisonment (Burr, 1995). However, this does not account for the individual differences in the way people in the same society or situation respond to things. Symbolic interactionism similarly sees knowledge as social and subjective, and is based on three central premises (Blumer 1969): That people act towards things on the basis of the meaning that thing has for them (things here referring to objects, people, organisations, categories of people etc); The meaning of things arises from social interactions with other people; As things are encountered meanings are modified through an interpretive process. Meaning here is not intrinsic, as it is in the positivistic stance, nor is it from just one persons psyche, but arises out of interactions between people. *"The meaning of a thing for a person grows out of the ways in which other persons act toward the person with regard to the thing" (Blumer 1969, p4).*

Phenomenology focuses more on the cognitive processes that lead us to our perception of reality and sits at the juncture between actual reality and people's perception of reality. We draw our perceptions of reality from culture, and when this reality breaks down we question our perception (Spinelli, 1989). Stroke is often experienced as a life changing event, as it alters people's life, role and identity suddenly and often drastically. Phenomenology would aim to explore the meaning of this change to the individual.

It was the growing importance of terms 'essence' and experience' within the development of my research questions which led me to consider that phenomenology could provide the appropriate approach to my study. I was asking myself the question, how can I stay true to the subjective nature of peoples experiences, while bringing those experiences together in a way which can be useful?

Phenomenology has a strong philosophical component, but applied to research has the following characteristics:

1. It is concerned with the study of lived experience in humans.
2. It believes that these experiences are conscious.
3. It aims to describe the essence of experience, rather than to explain or analyse.

Dahlberg, (2006) defines an essence as *"a structure of essential meanings that explicates a phenomenon of interest. The essence or structure is what makes the phenomenon to be that very phenomenon" (p11).*

Researchers working from a phenomenological perspective look for these essences in 'lifeworld descriptions', such as interviews, which must be rich enough to illuminate essences and show many variations and examples. We can use a simple analogy to illustrate this. We can easily identify the main features of a cat: having four legs, a tail, pointy ears and whiskers. We also need to understand what distinguishes a cat from a dog, a mouse, and other things which also have four legs, a tail, pointy ears and whiskers. For this we might need to describe its size, the noise it makes, the shape of its body and face. But a cat can come in a myriad of different forms, which we need to illustrate with examples, perhaps including a skinny white cat, a small ginger cat and a large black and white cat. We may also need to discuss aspects which challenge the essence, for example that a tiger and a lion are considered cats too, despite their size. What similarities do these animals have with the domestic cat? All of this brings us closer to understanding the true essence of 'cat', and when we understand that it guides the variations and boundaries that we apply. In the words in Husserl (1973, cited in Dahlberg, 2006), *"a unity runs through this multiplicity of successive figures" (p13).*

Phenomenology focuses on describing what participants have in common as they experience a phenomena. It is appropriate for this research as it aims to understand several individuals common or shared experiences, and looks for the 'essence' of those experiences. Having reviewed the literature in this area, it appeared that indivdual experiences of participation became undermined in the attempt to measure the concept, while efforts to represent individual experiences resulted in a confusing array of defining features of participation. I felt that taking a phenomenological approach would help to bring individual experiences together in a coherent way, while not losing the individual detail which is so important in understanding the experience of participation. As well as developing a deeper understanding of a phenomena, when a understanding is gained of the 'essence' of the experience, this can be used to develop practices or policies which are highly relevant to the experiences of people (Dahlberg, 2006).

So what does it mean to 'do' phenomenology? The phenomenological perspective accepts the researcher as part of the same world that they are investigating, and in order to make it possible to distinguish ourselves from the phenomena under study a researcher has to adopt a 'phenomenological attitude'. This has been given different names by different writers, but involves drawing oneself back from the phenomena, acknowledging ones feelings about it, and putting those feelings to one side in order to view the phenomena from different angles. Interpretative Phenomenological Analysis proposes a particular method of doing this, which will be discussed in the next section.

Two major principles define phenomenological research. The first is "phenomenological deduction", the setting aside in brackets ones assumptions, so that one can begin to understand other ways of looking at the world (Raskin & Robbins, 2010). In this regard there is some similarity with Glaserian Grounded Theory, which believes that by doing qualitative research in a structured way, it is possible that the researcher be a 'tool' in the process, which was one of the appealing factors to me about Grounded Theory. However, the phenomenological perspective takes into account the role of the researcher and provides a reflexive strategy for dealing with this, which is more in keeping with the qualitative paradigm.

The second principle is "eidetic reduction", which refers to the essences which emerge from the ambiguities of lived experience, which may be similar but are never identical. The researcher develops an emergent essence out of multiple descriptions of the life world (Raskin & Robbins, 2010). This is highly relevant to this research, particularly in answering the first research question, which can be seen as trying to find the 'essence' of the term ‘participation’ by looking for similarities in the different ways it is viewed and experienced by the participants.

Phenomenology has been used as an approach for studying health and illness from various perspectives, including social sciences and psychology. This approach enables a researcher to look at the ill person as whole, and their relationship with their physical and social environment, *“phenomenology can be specifically applied to the first person experience of illness in order to illuminate this experience and enable healthcare providers to enhance their understanding of it” (Carel, 2011, p33).*

It has been used in the study of stroke, and around issues of self-identity, and many examples of these studies have been provided in the literature review. Phenomenology has been the most relevant and influential theoretical perspective and therefore has had most influence on the methodology chosen, which is a close following of Interpretative Phenomenological Analysis. The methodology has also been influenced by, and retained some aspects of, Grounded Theory.

Research Methodology – Interpretative Phenomenological Analysis

Why is IPA an appropriate methodology for this research?

Having reflected on the aims and context of this research, and on the position of the researcher in regards to the subject area, I have situated this research within a qualitative paradigm, drawing on the theoretical perspectives of Grounded Theory and Phenomenology.

The ‘fit’ of phenomenology with the aims of this research, led me to look at Interpretative Phenomenological Analysis, which is a way of analysing qualitative data drawing on principles found in Phenomenology. IPA compares individual cases to build a picture of the ‘essence' of a phenomena. This fits in with my aim to go beyond ‘examples’ of participation, to find the qualities which define participation to stroke survivors. *“Interpretative Phenomenological Analysis is a qualitative research approach committed to the examination of how people make sense of their major life experiences”* (Jonathon A. Smith, Flowers, & Larkin, 2009).

IPA has been predominantly used within the field health psychology, and more recently has gained popularity within social, clinical and counselling psychology. However, its founder, Jonathon A Smith (2004) encourages looking for a match between the research question and the principles of IPA, in order to decide if IPA is an appropriate methodology for research. For researchers wishing to explore personal lived experiences and how people make sense and meaning from those experiences, IPA is worth considering.

IPA has already been used to look at meaning and experience in stroke survivors. Murray & Harrison, (2004), used Interpretative Phenomenological Analysis to look at the meaning and experience of being a stroke survivor and identified 'disrupted embodiment and the loss of self' as a major theme. It is particularly appealing for a researcher like me who is new to phenomenology, as it offers a structured route through the process of analysing findings according to the principles of phenomenology.

What is IPA?

IPA is relatively new, being devised as a methodology in the 1990's, but it draws on concepts and ideas which have been around for much longer, namely phenomenology, hermeneutics and ideography (Smith et al., 2009). Phenomenology has been discussed in detail above, and I will now briefly describe hermeneutics and ideography.

Hermeneutics

Hermeneutics is the theory of interpretation, and originated with Biblical texts, to answer the questions:

- What are the methods and purposes of interpretation?
- Can the original intentions of the author be uncovered?

Interpretation is both grammatical and psychological, as both the text itself and the wider context within which it was produced are interpreted. The researchers analysis may produce meaningful insight which goes beyond explicit statements of the participants, but these are taken as equal to, rather than more valid than, participant statements (Jonathon A. Smith et al., 2009). The resulting analysis comes from:

- A systematic and detailed analysis of the text itself.
- Connections which emerge through oversight of a larger data set.

- Dialogue with psychological theory.

The connection with phenomenology is that it seeks meaning which may be hidden by appearance, so meaning is sought through the interpretation of texts (Smith et al., 2009). This is done by not only analysing what participants have said, but by asking questions of the findings to explore why things have been said, and what underlying subconscious processes may have contributed to this (Osborn & Smith, 2006). In lay mans terms this may be described as ‘reading between the lines’.

Hermeneutics recognises the researchers’ preconceptions, which it calls ‘fore-structures’, *“The fore-structure is always there, and is in danger of presenting an obstacle to interpretation. In interpretation, priority should be given to the new object, rather than to ones pre-conceptions...while the existence of fore-structures may precede our encounters with new things, understanding may actually work the other way...having engaged with the text, I may be in a better position to know what my preconceptions were. This is an important and neglected way of considering what happens in interpretation” (Smith et al., 2009, p65).*

So fore-structures are cyclical and will change during interpretation. Hermeneutics also has a way of understanding the relationship of the part to the whole, which it calls the ‘hermeneutic circle’. To understand the part you need to understand the whole, and to understand the whole you need to understand the part (Smith et al., 2009). This reflects back on some previously mentioned concepts in Grounded Theory, of analysis being iterative involving a constant comparison of new findings to the summary knowledge of the already collected findings.

IPA accounts for researcher reflexivity by performing a “double hermeneutic”, where the end result of a study is the participants subjective interpretation of the subject matter, which is then interpreted by the researcher. In this regard the researchers subjectivity is incorporated into the research (Raskin & Robbins, 2010).

Ideography

Ideography is concerned with ‘the particular’, and within IPA this means that analysis should be in-depth, thorough and systematic, and normally uses small samples. It does not necessarily focus on the individual but can offer a unique perspective to various phenomena of interest (Smith et al., 2009). Ideography is concerned with analytical induction, the method for attempting to derive theoretical explanations from a set of cases. An initial tentative hypothesis is proposed which is then tested against each of the cases in turn. The hypothesis is continually revised, which is again, an iterative procedure. This normally results in a revised hypothesis which account for most of the data (Jonathon A. Smith et al., 2009). IPA adapts these methods for moving from single case studies to more general statements, but also allows access to the individual claims of any of the individuals involved (Jonathon A. Smith et al., 2009), and the experiences of individuals should not be lost in the description of the phenomena as a whole.

Phenomenology defines the aims of IPA, which are to uncover the essence of people's experience of a phenomenon. Hermeneutics is the tool of IPA describing how we engage with the data, and ideography defines the way that findings are brought to light and how a hypothesis emerges from the data.

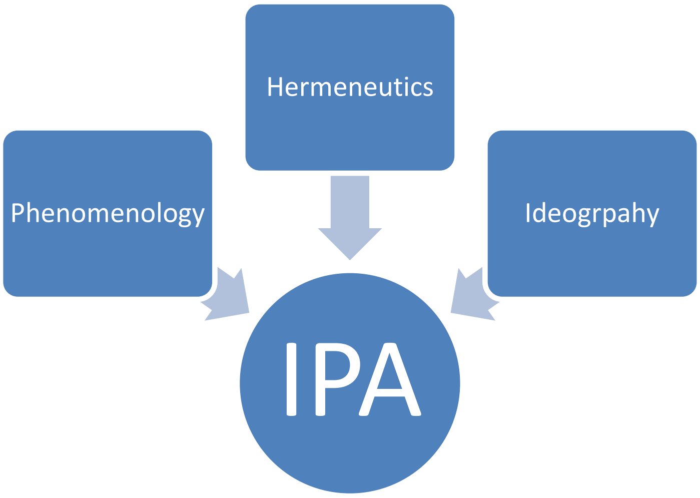

Figure 4: Visual representation of IPA

There are three characteristics which should be present within IPA research. It should be:

- Idiographic – providing a detailed analysis of each case.

- Inductive – themes should emerge from the findings, similarly to Grounded Theory, where themes emerge from the data, rather than testing against a hypothesis based on current literature.
- Interrogative – seen in relationship to existing literature rather than being considered in isolation, therefore the discussion of the findings in relation to the literature review can be seen as an extension of the analysis

IPA necessitates access to rich, detailed, personal accounts. However, IPA does not dictate particular methods. Rather it provides us with a partial map of the territory which we need to cross, and the individual researcher should choose and justify the best route for their purposes. *"The underlying qualities of an IPA researcher are: open mindedness; flexibility; patience; empathy; and the willingness to enter into, and respond to, the participants world" (p55, Smith et al., 2009).*

Like any methodology, IPA has potential weaknesses, depending on the particular circumstances in which it is being used. The analysis is based on the words of participants, as they describe their experiences. It is questionable whether all people have the necessary linguistic skills to describe their experiences in the depth needed for this sort of analysis. This is particularly questionable when working with people who may have aphasia, and when people have English as a second language, or don't speak English at all and are being interviewed via an interpreter.

IPA also relies in a certain amount of skill in the researcher. Firstly, we could question whether the 'bracketing off' of one's own perception can really be complete, and it seems likely that subconscious perceptions will still remain and influence the analysis process to some degree. Secondly, the interpretation of not only the descriptions provided by the participants, but the subconscious processes behind the descriptions, requires of the researcher a certain level of skill and insight. The way these particular issues have been addressed will be explained in the methods section.

Ensuring quality in Qualitative Research

The features of qualitative research make it the more appropriate choice for answering some research questions. For example, it allows for a detailed exploration of particular concerns or experiences related to a topic. It has had to overcome some prejudices to be accepted as a valid research method in health research, however it can now be said that *"qualitative methodologies genuinely offer a complementary set of investigative approaches which can bring fresh insights into health and illness" (Yardley, 2000, p116).*

Ensuring quality in qualitative research is of utmost importance, however, it does not have the same established conventions for ensuring quality as are found in quantitative research. The classic standards by which to judge research are reliability and validity. In quantitative terms, reliability refers to the potential for the research to be replicated and produce the same results, and validity refers to whether the research actually measures what it proposes to measure. It is obviously not appropriate to judge qualitative research by the same criteria as quantitative research. For example, a sample size large enough to be representative, which is a key marker of quality in quantitative research, cannot be analysed in depth and so would not be appropriate for qualitative research. Many have objected to the application of terms such as reliability and validity, normally applied to quantitative research, to qualitative research. Some qualitative researchers have claimed that reliability and validity are simply not applicable to qualitative research, as multiple realities may be applied to any situation and each is valid on its own terms (Kelle, 1995). Other researchers have objected to qualitative research making claims to reliability and validity, as they do not use scientific methods. However, it is not possible to study all phenomena using scientific methods, and non-scientific methods have proved valuable in many circumstances (Kelle, 1995) so how do we judge quality on research that uses other methods?

Although the need for clear and transparent approaches for judging the quality qualitative research is accepted by the majority of researchers, the way in which this should be done has been widely debated (Oakley, 2000). While some researchers advocate a clear criteria for judging the quality of qualitative research, similar to those applied to quantitative research, others see this is neither possible nor desirable (Buchanan, 1992). Some argue that quality in qualitative research cannot be determined by following set criteria, as qualitative researchers from different disciplines and theoretical backgrounds may have different criteria for assessing the quality of a study (Sandelowski, Docherty, & Emden, 1997). A middle ground has been established by some qualitative researchers, who suggest that general questions can asked in regards to quality, but the diverse nature of qualitative research inhibits translating these questions into strict criteria (Murphy, Dingwall, Greatbatch, Parker, & Watson, 1998).

I have subscribed to the middle view, understanding the necessity of evaluating the quality of research, while recognising that the diversity of qualitative research methods precludes the use of a uniform criteria for quality.

Lincoln & Guba, (1985) offered equivalent concepts to reliability and validity, which are relevant in the context of qualitative research. Although some researchers feels uncomfortable with providing alternatives to the terms used in quantitative research, feeling that this is too prescriptive, I found these terms to be a useful way of categorising different types of quality concerns. I have incorporated later work by Pope & Mays, (1996) into these explanations:

- Credibility (roughly equivalent to internal validity): this can be increased by the researcher having extended engagement with the subject matter, incorporating into the methodology a way of ascertaining whether participants recognise the findings to be true of their experiences; using reflexivity, that is to reflect on the researchers role in the research, so that the researchers background position should be clearly stated (Mays and Pope 1996); and triangulation, using multiple sources of data and methods.
- Dependability (roughly equivalent to reliability): this is linked to credibility and cannot be established until credibility is established. This can be increased by keeping an audit trail of the research process, including how data was collected and analysed and also the thoughts and feelings of the researcher throughout the process. This means that the evidence can be judged according to how it was collected and analysed (Mays and Pope 1996). Mays and Pope (1996) also introduce the concept of attention to negative cases, elements in the data which contradict the emerging explanation, which can lead to a refined analysis. This moves qualitative research away from its reputation as a closed and mysterious process to one that is transparent, allowing the reader to understand how initial, simple systems of classification developed into more sophisticated coding structures.

We can also add the concept of ‘transferability’ (Tracey, 2010), which can be seen as roughly equivalent to ‘external validity’, and refers to the likelihood of findings to have meanings which can be transferred to others in similar situations.

Yardley (2000) developed a checklist of factors to be considered in judging the quality of qualitative research, many of which overlap with Lincoln and Gubas’ concepts of credibility and dependability:

- Sensitivity to context: While a familiarity with current literature is essential in all research, it is even more so in qualitative research as it can affect the sophistication of the interpretation of data. The researcher should also be familiar with previous approaches to researching the subject, terminology used, and the socio-cultural setting of what is being studied.
- Commitment and rigour (similar to credibility): Prolonged engagement with the topic through the literature but perhaps also experience of a personal or professional level, completeness of data collection and analysis, including the ability of the sample to provide ‘saturation’.
- Transparency and coherence (similar to dependability): The clarity of the presentation of analysis, and the fit between the research question, the philosophical perspective, and the methods used.
- Impact and importance: The contribution of the research, in relation to the particular aims of the research. This is also referred to by Spencer, Ritchie, Lewis & Dillon, (2003) as ‘contributory’, that is advancing wider knowledge. They also emphasise that is should be ‘credible in claim’ making well founded and plausible arguments about the significance of the evidence.

I will discuss the specific ways that the design of the methods had attempted to incorporate safeguards of credibility and dependability in the methods chapter. As a methodology, IPA has a means of incorporating reflexivity, which will be further discussed in the methods section. The structured nature of IPA, which provides steps for the researcher to follow, also contributes to dependability.

I have summarised the points mentioned in the chapter into Table 4, providing a check list which will be referred to later to evaluate the quality of this research.

Does the researcher show extended engagement with the subject matter/sensitivity to context?
Has the researcher reflected on their role in research?
Is there a fit between the research questions, the philosophical perspective and the method?
Is there an audit trail of the research process?
Has triangulation been used?
Has the researcher tried to ascertain whether participants recognise the findings to be true to their experiences?
Is the data collection and analysis complete?
Is there clarity of presentation of the analysis?
Has the researcher shown attention to negative cases?
Does the analysis reach a level of abstraction?
Does the research contribute to and advance knowledge?
Does the researcher make well founded and plausible claims about the significance of findings?

Table 4: Quality in qualitative research

Reflexivity: the role of the researcher

Previous positivistic models viewed validity as dependant on the objectivity of the researcher. However, the qualitative research movement has shifted the emphasis from seeking objective truth, to an understanding that many different interpretations of reality can be valid (Willig, 2001). Etherington, (2004)describes research reflexivity as *“the capacity of the researcher to acknowledge how their own experiences and contexts (which might be fluid and changing) inform the process and outcomes of inquiry” (p.31).*

Rather than seeking to eliminate the effects of the researcher, we can use reflexivity to understand and report these effects (Holliday, 2007). By being aware of oneself in the research, one can limit the effects of oneself on the data (Lietz, Langer, & Furman, 2006).

Towards the beginning of this chapter I explained my own position in relation to the research, and how this impacted the design of the research. I will revisit this in the discussion chapter, where I will reflect upon how my beliefs and experiences may have influenced the analysis process. The importance of this has already been touched upon in my explanation of IPA. An awareness of one’s’ own responses during the research process is essential in being able to move past this to understand the perspective of the participant. My role as a researcher is to interpret the stories of the participants, and my experiences and beliefs will influence my interpretation of the findings. Therefore I am presenting one interpretation of many possible interpretations.

Summary

This chapter aimed to guide the reader through the decision making process which led to the situation of this study within a qualitative paradigm, a phenomenological approach and using Interpretative Phenomenological Analysis as a methodology. This is intended to fulfil the first 3 phases that N K Denzin & Lincoln, (2003) suggested define the research process:

1. To locate the researcher within the history and traditions of research, including acknowledgement of the self in relation to the present study.

2. To establish the researcher's theoretical paradigm or interpretative framework that guides the research process.

3. To select the research design which connects the theoretical paradigm to the strategies of inquiry and the methods for data collection?

I have also highlighted issues around quality and reflexivity. This chapter will be referred back to in the discussion chapter, to evaluate the effectiveness of the methodology in answering the research questions, and exploring any issues which arose with the methodology. This will also be an opportunity to review the quality of the study, and how my own position as the researcher may have influenced the findings.

Having explained the theoretical basis for the design of this study, I will now describe and justify the study design, in the methods chapter.

Chapter 4: Methods

This chapter will provide a detailed description and justification of the study design, recruitment and data collection, and data analysis procedures This is intended to fulfil the last two phases that Denzin & Lincoln (2003) suggested define the research process:

4. To select the methods for data collection and analysis.

5. To establish the interpretative practice for presenting findings.

Study design

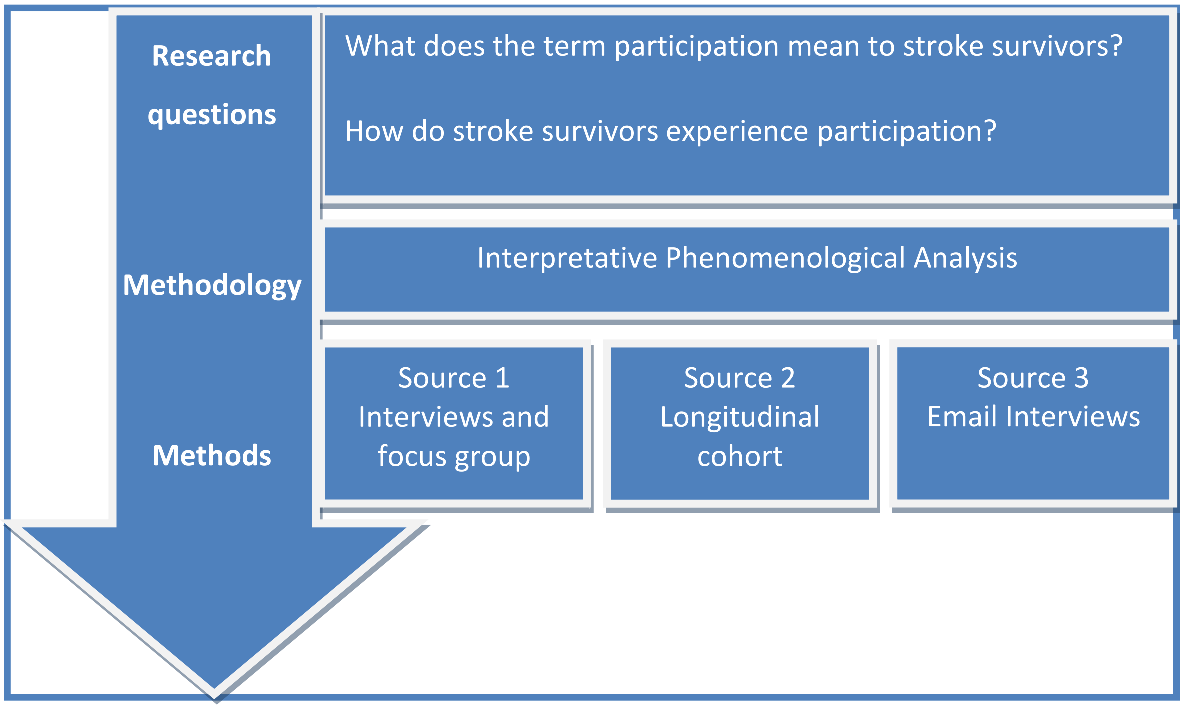
Research questions
What does the term participation mean to stroke survivors?
How do stroke survivors experience participation?
Methodology
Interpretative Phenomenological Analysis
Methods
Source 1 Interviews and focus group
Source 2 Longitudinal cohort
Source 3 Email Interviews

Figure 5: Visual representation of study design

This study aims to explore the meaning and experience of participation to stroke survivors. A range of methods were used within this study, and can be viewed as three separate sources of data:

- Interviews with stroke survivors or carers 1 year or more post stroke, and a focus group with the same participants (Source 1)
- Interviews with a longitudinal cohort of stroke survivors over the first year following stroke (Source 2)
- Email interviews with stroke survivors using online stroke support groups, one year or more post stroke (Source 3)

This study was intended from the outset to be an iterative process. It cannot be said to be ‘participatory research’, as I did not consult people who had a stroke about the design of the research. However, the design of the research is intended to allow the research to be shaped by the participants. For example, the first research question seeks to allow people who have had a stroke to define what participation is, before going on to look at the experience of participation. I will briefly explain some of the principles behind, ‘participatory research’ and ‘user involvement’, as the underlying principles are similar.

Participatory research is about respecting and understanding the people being researched, giving power to local people and acknowledging their understanding of their situation, and recognising the rights of whom the research concerns (Cornwall & Jewkes, 1995). In a clinical context, the equivalent of this is ‘user involvement’, which is now being promoted in health and social care sectors and was born out of the social model of disability. It means involving in a decision making or evaluation process, the people it concerns, e.g. the users of a service. It is generally felt to be beneficial for both those consulted and those consulting. It is important to gain an understanding of how those affected by services feel about them, and represents a ‘bottom up’ approach (Cornwall & Jewkes, 1995).

Other relevant studies have also used an iterative approach, for example, Bent, Jones, Molloy, Chamberlain, & Tennant, (2001) used focus groups in their study of participation of young adults with a disability, enabling the young people to influence the research design from the beginning. From a methodological point of view, it can make research more flexible and iterative, involving cumilative learning (Cornwall & Jewkes, 1995), and is therefore well suited to qualitative methods.

The research questions and design developed throughout the study, and each source was designed in response to the findings from the previous source. This allowed me to develop the study according to the key issues that were emerging from the data. At the time of source 1, the research aims were very loosely defined, and I was looking at stroke and participation in general. At the beginning of collecting findings for source 2, research questions regarding meaning and experience were clearly defined. By the end of collection of findings for source 2, and prior to collection of source 3 findings, the central themes had been identified. Therefore the findings from earlier stages of the research influenced the development of the later stages. Carers were included in source 1, but as the research design developed I felt that it was more appropriate to the research design to focus on stroke survivors, so there were no carers in source 2, or 3, although sometimes carers were present in interviews.

Figure 6 illustrates the phase of design at the beginning of data collection for each phase.

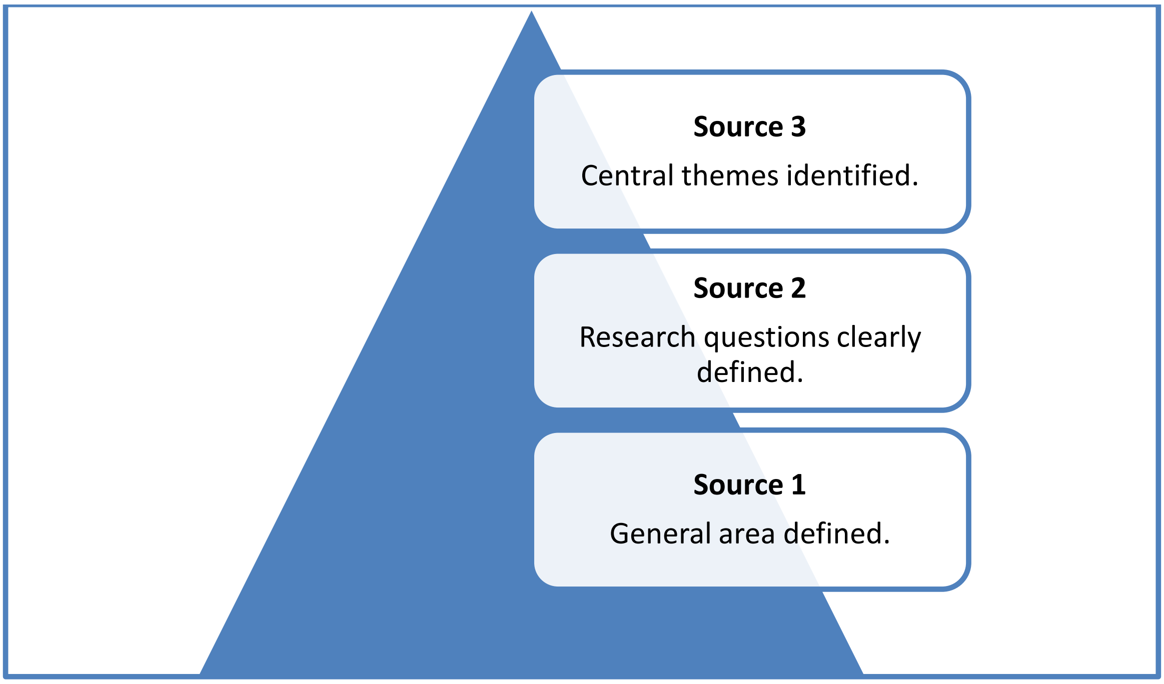
Source 3
Central themes identified.
Source 2
Research questions clearly defined.
Source 1
General area defined.

Figure 6: Visual representation of emergent design

Triangulation

Triangulation is a research approach which uses multiple data sources with a single focus. The advantages of using triangulation are that it enhances the richness of the data collected, helps to explore similarities and differences between different situations and groups of people, and adds to the credibility of the research (Lincoln & Guba, 1985).

Triangulation can be used in theory, methods, data and investigators (Lincoln & Guba, 1985). Theoretical triangulation is the use of several hypotheses that are tested within the same set of data, data triangulation involves the use of more than one source of data which have the same focus, and investigator triangulation is the involvement of more than one investigator within the same study. Lastly, methodological triangulation involves the use of two or more methods of data generation within one study, and is the most commonly used form of triangulation.

This study takes findings from three sources, each of which used a different method, providing a different way of looking at the research questions, enabling a deeper understanding of the issues than would have been possible with just one research method. The goal of triangulation is not to arrive at consistency across data sources or approaches, but in fact inconsistencies provide the opportunity to uncover deeper meanings in the data (Patton, 2002).

Source 1 - Interviews and focus group

The primary aim of this source was to explore the meaning of participation to stroke survivors and their carers. There were various factors to take into account when deciding how to obtain participant views. It was decided to use interviews as the primary means of data collection, so that participants would have the opportunity to express their views in their own words. This was followed up by a focus group consisting of the interviewees. Themes relevant to the meaning of participation were presented in the focus group, from the findings of the interviews. The feedback from the focus group further developed and refined the findings.

Semi-structured interviews

Semi-structured interviews were conducted with participants (people more than 1 year post stroke, and their informal carers), to ascertain the meaning of participation. Potter & Hepburn, (2005), describe the use of the term ‘semi-structured interviews’ as confusing, preferring the term qualitative interviews. However, I have maintained the use of the term ‘semi-structured’ as it describes the design of my interviews, where I used a set of predetermined questions as a guide, but allowed the interviewee space to develop the interview in the way that was relevant to them. This type of interview is the standard way of collecting phenomenological and other types of qualitative data (Camic, Rhodes, & Yardley, 2003; Smith, 2003). Most IPA studies are based on semi-structured interviews with English speaking adults (Smith, 2004).

As with all methods, semi-structured interviews have some limitations. They rely on the participant’s willingness to self-disclose, which will vary between participants, and participants are under pressure to produce answers within a short time frame (Egan, Chenoweth, & McAuliffe, 2006). There are also limitations that originate in the researcher, and in order to ensure that the interviews are used in the most effective way possible in presenting the participants experiences, I have considered some of the points made by Potter & Hepburn (2005). They mention the 'footing' of the interviewer and the interviewee, and their 'stake and interest' that is, are they speaking as individuals or from a group identity? Perhaps they are representing an institution. While the relevance of this is limited to my own study, I will reflect in the discussion on the possible perceptions and misconceptions of the interviewees in reference to my role.

Potter & Hepburn, (2005) suggest that the way interview quotes are often presented in qualitative findings, as complete sections of text from the interviewee, without showing the interaction from the researcher, do not reflect the context of the statement and what may have prompted it. They suggest that by presenting a whole section of the transcript, features are highlighted that are missed in standard presentation. However, the method of presenting the data that they suggest is close to the method that would be used in conversational analysis, and while I believe the point they make is very valid, the reality of presenting a findings chapter for this study in such a way, would pose its own problems. Firstly, it would become over-long, and secondly, it would be difficult to maintain the flow of describing the interpretative analysis. Also, as this is an interpretative analysis, while I am aiming to embody the detailed accounts of individuals, it is the interpretation itself which is represented in the analysis.

A potential pitfall of the interview process is that the interview can become flooded with social science categories and theories (Potter & Hepburn, 2005). The methodology of this study, which necessitates an emergent path towards developing themes, safeguards against this danger, although it would be naïve to imagine that a researcher does not come to the interview with preconceptions, as we have discussed in the methodology chapter. I have used reflexivity to enhance my awareness of what I bring to the interview. IPA suggests a method of reflexivity whereby after an initial reading of the interview transcript, the researcher 'brackets off' their preconceptions by noting down thoughts and feelings about the interview and the participant, before proceeding with the analysis. This assists the researcher to move beyond their own perceptions to engage with the participant's experience.

Focus group

Six months after the last interview took place, a follow up focus group with the stroke survivors was undertaken, which allowed for dialogue to develop, and for the researcher to feedback the results of the interviews for modification and further clarification. A focus group is the selecting and gathering together of people into a small group, in order to discover their views on a particular topic. Focus groups have been described as a mid-point between one to one interviews and a normal social situation (Schostak & Barbour, 2005). They give the researcher the opportunity to ask open ended questions around a topic, yet the group interaction means that the focus is taken away from the interviewer/participant relationship, and onto the relationship between the participants. Schostak & Barbour, (2005)describe this as *"a social process through which participants co-produce an account of themselves and their ideas which is specific to that place and time" (p43).*

In regards to using other methods of data collection within an IPA methodology, Smith (2004) recommends proceeding with caution, for example he raises a concern that in focus groups, participants may not feel able to partake in such a detailed exploration of personal experience as with a semi-structured interview. However, as my focus group was in addition to the interviews (with the same participants) this is not a concern.

Focus groups are appropriate when investigating complex behaviour and emotions, as the conversation that emerges between people who have a similar experience can be rich in information. The people in the focus group will ask *each other* the relevant questions, that the researcher may not have considered asking (Morgan, 1998). *"Focus groups work best when a limited number of compatible people have the opportunity to discuss their shared interests within an opening and non-threatening environment, while guided by a skilful moderator" (Morgan, 1998, p63).*

The data that is produced by a focus group is conversation. In order to direct these conversations into the appropriate direction to produce relevant conversations to the research aims, Morgan, (1998), suggests that the researcher needs to consider the topic under question and how the participants will feel about the topic, the kinds of questions that will stimulate relevant discussion, and what the role of the moderator should be. These points were taken into account in the design of the focus group.

Source 2- Longitudinal cohort

A broad finding from analysis of Source 1 interviews was that there is a need to understand the process of change which occurs in people who have had a stroke, during the time when they are attempting to re-engage with life. In order to examine this process from the perspective of the individual's experience a longitudinal cohort study was decided upon. It was felt that three semi-structured interviews over the course of a year following discharge home from hospital or a rehabilitation facility, would allow a comprehensive investigation of the phenomenon. In depth interviews were carried out at baseline, 6 and 12 month time points.

One of the purposes of exploring the meaning of participation in Source 1 was in order to provide a firm foundation for investigating experiences of participation. As Source 1 identified that participation is highly subjective to the individual, the focus of Source 2 was to elicit peoples experiences post-stroke, and obtain information about participation through this, rather than providing participants with a definition or examples of participation which they would then compare themselves to.

The considerations regarding semi-structured interviews have already been described in reference to Source 1. To embark upon a longitudinal study, the researcher should have a clear objective, that is, what is it about the nature of what we want to find that makes a longitudinal approach appropriate (Molloy et al., 2002)? In the case of this study, source 1 interviews suggested that stroke precipitated a change in peoples' experience of participation, and what it meant to them. Participants' retrospective reflections had given some insights into this change, but I felt that to have contact with stroke survivors at regular intervals during the first year at home following a stroke, would further illuminate the process of change.

In addition to the most obvious advantage of a longitudinal approach, the opportunity to study changes over time, there are also other benefits. Seeing the same person at different time points allows the researcher to see the difference between what people say and what they do (Thomson, 2007). For example, while interviewing a heavy drinker entering treatment, you might record their determination to change, however, only meeting them again at a later point will tell you if that change has happened and the reasons for the outcome. This approach is also able to tell us ‘how’ something happens over time, not just what has occurred (Thomson, 2007).

A longitudinal study implies several ‘waves’ of findings, and Saldana (2003) uses the analogy of an ‘ocean’ to describe findings from a longitudinal study, as opposed to the ‘landscape’ analogy which one might use to describe a non-longitudinal qualitative study. Whereas a landscape is vast and detailed, but static, an ocean in constantly moving and changing, and the ‘waves’ will bring different things to the shore at different times.

There is no agreement as to what length of study constitutes a longitudinal study, although the Inventory for Longitudinal Studies in the Social Sciences (Young, Savola and Phelps 1991, cited in Saldana, 2003) has an inclusion criteria of a minimum length of one year for studies. In fact, the length of the study will be determined by what is sought from it (Molloy et al., 2002). The time span of a year was chosen for this study, as it was felt that this would allow enough time for the participant to experience a return to their pre-stroke life.

Source 3 – Email interviews

Dochartaigh (2002)acknowledges the role of the internet in modern life and the impact that has on research, *“it is necessary to develop a new set of research skills which addresses the challenges which the internet presents” (p6).*

One of the biggest advantages of the internet is that it opens up the opportunity to contact people we may not otherwise have been able to contact (Dochartaigh 2002). Using email interviews is a way of opening up the research to people who may otherwise not come into contact with researchers. Illingworth (2001, cited in McCoyd & Kerson, (2006), suggest that internet based research can *“potentially overcome some of the barriers imposed by more conventional research approaches” (p391).* Ison (2009), writes specifically about using email interviews in research with people with verbal communication problems. Computer mediated communication (CMC), such as text messages, are now used by most people and can offer particular advantages for people with verbal communication problem. A-synchronous communication such as emails and online discussion groups, provide the further benefits of giving people time to respond.

The advantages of using email interviewing include the flexibility of data collection, which can take place of any time and place, and across great distances (Egan et al., 2006; Ison, 2009), the opportunity for extensive communication and that the interview can be completed at the convenience of the participant. Researchers have found that the greater sense of privacy allows for greater disclosure of things that might be too embarrassing or sensitive to talk about face to face (Egan et al., 2006; McCoyd & Kerson, 2006). It also allows opportunity for reflection which results in more depth and more thoughtful responses (Egan et al., 2006; Ison, 2009). Seymour, 2001 (cited in Ison, 2009) suggests that email interviews may make the process of interviewing more balanced between the researcher and the interviewee, as the interviewee is equally able to control and influence the direction of the interaction. Egan et al., (2006) trialed the use of email interviews with people with traumatic brain injury, a condition which has many similarities with stroke, in that it may present cognitive and linguistic barriers. In addition to the benefits cited by other researchers they found that, *"the data indicates that people with a TBI are capable of greater insight, reflection and humor than indicated by previous research" (Egan et al., 2006, p1283).* At a practical level, data collection and transcription are simultaneous, saving time and money (Ison, 2009).

Limitations of email interviews include the exclusion of people who are not able to use computers, which can also be related to age and culture. Ison, (2009) advises against using email interviews in isolation, because of this. In general, caution needs to be used when using the internet, as the lack of face to face contact means that the procedures which apply to non-internet research may need to be changed or modified. For example, extra care should be taken to ensure that participants feel listened to and that their contribution is valued (Ison, 2009). Dochartaigh (2002) devised a list of 'netiquette', standards for behaviour when using the internet, which I adhered to through the process of conducting the email interviews:

- Re-read email messages or posts before sending for spelling or other mistakes.
- Keep a polite tone, as it is easy to misunderstand the tone of the written word.
- Keep in mind that email is not secure (details about ensuring confidentiality are discussed later).

- Sign your messages, as it is not always obvious to the receiver where the message has come from.

While email interviews are not commonly used in IPA studies, used in triangulation with semi-structured interviews, they can be seen as adding to the richness of the data collected, as according to Smith (2004) *"It is possible to collect rich verbal accounts by other means" (p50).*

An online study of people with disabilities found that participants used the internet to develop and maintain friendships (Seymour and Lupton 2004, cited in Ison, 2009). There are several online support groups specifically for stroke survivors, and it was decided to undertake a small amount of email interviews with stroke survivors using online support groups, as an exploratory exercise, and with the purpose of further widening the inclusivity of the study, to people who may not normally have the opportunity to be involved in research. As the email interviews took place when some analysis of sources 1 and 2 had already taken place, they also provided an opportunity to further explore some emerging themes.

Recruitment and data collection

Including people from ethnic minorities and people with aphasia

Census data shows that 9% of Sheffield's population are from non-White ethnic backgrounds (Office for National Statistics, 2001). People from ethnic minority groups are known to be under-represented in research. A review of exclusion criteria used in trials (Hussain-Gambles, 2004), found that many had blanket exclusions for ethnic minority participants, but exclusion is not necessarily explicit. For example studies which exclude people who do not speak English will automatically exclude many people from ethnic minorities. *"The exclusion of people from ethnic minorities from clinical trials is not only poor science because it challenges the external validity of findings, but it also raises issues around equity in healthcare provision" (Hussain-Gambles, 2004, p386).*

Much of the discussion around the under-representation of ethnic minorities in research comes from the US, where legislation has been developed to ensure representation of ethnic minorities in health research. There is no such legislation in the UK (Hussain-

Gambles, 2004). Multi-Centre Research Ethics Committees in the UK have acknowledged the potential problems in obtaining informed consent from people for whom English is not their first language, and ask for 'special arrangements' to be made. However, they do not specify what these 'special arrangements' should be (Hussain-Gambles, 2004).

Wendler, et al., (2006), dispute the claim by some commentators that people from ethnic minorities may be less willing to partake in research. They conducted a literature review of studies reporting consent rates by race and ethnicity. They found that while rates of participation differed significantly between minorities and non-minorities, actual consent rates, that is, those who agreed after having been invited to take part in research, showed small differences. They suggest that the low rates of ethnic minorities taking part in research may be due to factors such as whether they are informed of research, whether they are eligable, and accessibility to research. They found significant differences in the number of minority and non-minority people invited to partake in research. They conclude that *"efforts to increase minority participation in health research should focus on increasing minority access to participation, not changing minority attitudes"* (Wendler, et al., 2006).

Other reasons suggested in the literature for the under-representation of ethnic minorities in research include attitudes of health providers (stereotypes and myths about ethnic minorities), cultural barriers, logistical challenges, costs, and inappropriate recruitment strategies (Hussain-Gambles, 2004). They suggest the use of 'community link workers' who may be able to provide a bridge between ethnic minorities and research. They also suggest developing culurally senstive research methods to ensure that issues such as language and beleifs are appropriately addressed. I have adopted these ideas within this study, as will be detailed below.

One third of people will have communication difficulties following a stroke (Department of Health, 2009) and 22% will have some sort of cognitive impairment (Douiri, Rudd, & Wolfe, 2013), but including people with communication and cognitive difficulties actively in research is challenging for a variety of reasons, including practicalities, costs and ethical considerations. These issues have meant that such people have been routinely excluded from stroke research. Not only do people with aphasia have a right to be involved in research, but it is essential for the generalisability of results (Palmer, 2009).

A systematic review of studies on stroke (Townend et al., 2007) found that nearly half of 129 studies excluded people with aphasia. This limitation has resulted in the loss of valuable perspectives and experience, and data sets lacking richness and breadth of representation (Connect, 2007). In order for the research to truly represent local stroke survivors, the research was designed to be widely accessible and enabling, to people who are underrepresented in research, but known to make up a significant proportion of the local community of stroke survivors, specifically people with cognitive and communication difficulties, and people from ethnic minority backgrounds. In reference to Interpretative Phenomenological Analysis, Smith, (2004) suggests that *“practitioners conducting research...can draw on their own professional experience with clients to help them modify existing protocols when collecting data” (p49).*

Smith (2004), recommends reflecting upon the benefits that may be gained by modifying the interview method, e.g. by using an interpreter, as compared to what may be lost through the lack of shared language between researcher and participant. We can apply this equally to people with aphasia.

In order to be able to include ethnic minorities in the research, without excluding on the basis of language, I recruited two volunteers who were speakers of common minority languages spoken in Sheffield, Punjabi/Urdu and Arabic. I advertised for volunteers in the Sheffield University prayer rooms, and through the Sheffield Professional Muslim Women’s Network, which has an e-group. I asked for people with some relevant previous experience, and offered the opportunity of gaining some research skills. I had two responses from this group, one from an Urdu speaker and one from an Arabic speaker. Both were female, and worked in the voluntary sector with people from their communities, the Arab and Urdu speaking communities. They each attended a one to one session that I designed and delivered, on basic research skills and interviewing techniques. They also each attended one interview with me, as part of their training. The community representatives were also available for source 2, to translate Information Sheets and Consent forms and assist with the interviews where necessary.

In taking consent from and interviewing people with aphasia, the following guidelines were referred to, as appropriate to the level of aphasia and the information being shared:

- Face the speaker
- Reduce background noise
- Ensure the room is well lit to enable non verbal communication
- Speak one at a time
- Slow down and give the participant time
- Use short sentences with one key word
- Use gesture and encourage participant to use gesture
- Write key words and encourage participant to write key words
- Draw and encourage participant to draw
- Use pictures/objects, and encourage participant to point to pictures and objects.
- Ask questions with yes/no answers
- Encourage patient to describe if they can't think of a word

(adapted from Palmer, 2009).

Robson, (2002) suggests that the strength of the semi-structured interview lies in its flexibility. In order to take into account the specific communication and cognition difficulties which could arise with this population the interviews were able to be adapted to the needs of the individual and any form of communication could have been accepted (e.g. use of spontaneous gesture, writing) so creating flexibility in means of communication. However, while many participants had aphasia, all were able to communicate verbally within the interview.

Carers were interviewed in their own right[1], rather than being recruited in order to obtain proxy information on the stroke survivor. However, their insights into the stroke survivors situations have been used to enhance the findings, and one stroke survivor with severe aphasia requested that her husband be present in the interview, in order to help her if she got stuck.

Proxy information from carers is commonly used in research with people with cognitive problem, such as in dementia research. The carers' views on the participants' opinions and feelings cannot be assumed to be accurate, and studies have found discrepancies. MacKenzie, Robiner, & Knopman (1989) show that in depression measures for people with dementia, carers tended to report the people with dementia as more depressed than the participants themselves. However, while proxy information cannot be considered as equivalent to obtaining views from the participants, in context in can enhance the overall understanding of the participants' situation. Qualitative research provides a particularly good opportunity for this, so that *"caregivers may also be a valuable source of information regarding the phenomenological perspective of their relative" (Cotrell & Schulz, 1993).*

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[1] Carers were originally interviewed with the intention of looking at the impact of stroke on carers as well as stroke survivors. However, with the development of the study it was clear that this was out with the scope of the current study.

Due to the difficulties of obtaining information from people with aphasia, researchers have also used proxy information with this group. In a study to assess agreement between proxy and self report on a health related quality of life measure, Hilari, Owen, & Sharon, (2007), found that people in regular contact with the aphasic person could reliably report on their quality of life. The present study did not specifically set out to obtain proxy information. However, the availability of information from carers, and the flexibility of the methodology, allows the carer perspective to add to the overall picture of the participants.

Ethical considerations

Informed consent

"Voluntary informed consent is considered by many as the central norm governing the relationship between the investigator and the research participant" (Kimmel, 1988).

Penn, Frankel, Watermeyer, & Müller (2009) state that adequate informed consent consists of three elements: being based on complete, accurate and understood information, being voluntary, and the person consenting having decision making capacity. This becomes a challenge when a researcher wishes to carry out a study involving people as participants who may not be able to reliably give informed consent, as is the case for some people with cognitive and communication difficulties. However, the benefits of including such groups in research make it necessary to find a means of ensuring that such people *can* give informed consent.

The Mental Capacity Act (2005) provides the following guidelines for taking consent from vulnerable people who may not be able to make decisions:

- Every adult is presumed to have the capacity to make their own decisions unless it is proved otherwise.
- A person must be given all practicable help to make their own decision, before it is presumed that they are unable.
- An unwise decision is not treated as a lack of capacity.

- A decision made on behalf of someone believed to lack capacity must be in their best interests.
- A decision made on behalf of someone believed to lack capacity must be the least restrictive option.

My understanding of issues of consent with aphasic participants developed throughout the study, as I was able to attend a training day on informed consent with aphasic people. This was between designing source 1 and 2. Therefore the procedure for gaining consent in source 1 was based on a method used for people with cognitive and communication diffculties, which I had designed for a previous trial, gained ethical approval and used with success.

After attending the training I was able to improve this considerably, and so the consent procedure in source 2 is more developed. The training day highlighted the following points:

- Because someone is unable to access a certain type of information, that does not mean that they can be considered as unable to give consent.
- To give informed consent, a person must be able to understand and retain information, take that information into account as part of a decision making process and communicate that decision.

(Palmer, 2009).

This led to the development of a consent procedure involving a screening tool, and research materials aimed at three different levels of understanding, which is discussed in more detail in the recruitment methods section.

Protection, wellbeing and right to withdraw

Interviews were conducted at participants' home, workplace, or public place depending on their preference. I contacted a peer for reasons of safety before and after each interview and informed them of the location and expected duration. The focus group took place at University premises.

Because the longitudinal interview participants had only just been discharged home, were undergoing rehabilitation, and at a potentially stressful and difficult stage, it was more important than ever to prioritise the participants welfare. Sensitivity and understanding were used when making appointments and dealing with any cancellations or other difficulties. The participants were informed of their right to end the interview or refuse to answer certain questions if they wanted, though none used this right.

While the potential for harm is minimal consideration was made of the lack of face to face contact of email interviews, which may make it more difficult for the interviewer to pick up on any distress that the participant may feel in response to questions. To ensure participants did not feel under pressure to discuss things they did not feel comfortable with, it was made clear to all participants that they should skip any questions they did not feel comfortable answering.

Confidentiality and anonymity

The participants were informed about confidentiality procedures, and during the focus group participants were asked not to share the conversations had within the focus group, outside of the focus group.

Most of the practical and ethical issues of conducting a longitudinal cohort study are the same as in single semi-structured interviews, however some issues become intensified due to the longitudinal element. For example, contacting participants but also maintaining that contact over a period of time (Saldana, 2003). Issues of confidentiality can be amplified as the participant becomes more relaxed and speaks more naturally over time, perhaps being more likely to mention names and places.

All face to face interviews and the focus group were digitally recorded and labelled with a code to protect confidentiality. Participants' personal details were deleted from transcripts, and kept separately from personal information such as names and addresses, which were stored in a secure location in accordance with the Data Protection Act (1998).

Email participants were informed about the confidentiality of the procedure. Emails regarding consent were printed off and stored in a secure location in accordance with the Data Protection Act, (1998) and the original email deleted. During the process of email interviewing, the email account was checked daily for responses, which were then copied into a word document with any identifying information taken out. Emails were then deleted.

Ethical approval

A separate application for ethical approval was made and obtained for each source, from The University of Sheffield, Human Communication Sciences Research Ethics Review Panel (see Appendix 1 p253-255). Since participants were not recruited through the NHS there was no need for NHS ethical approval. The design of source 2 was commended by the ethics panel for its aphasia friendly recruitment materials.

Participant selection

Selection criteria were kept to a minimum, so as to encourage diversity within the participants.

Source 1

The selection criteria for source 1, was having had a stroke one or more years previously.

Source 2

The selection criteria for source 2, was having been discharged home from hospital or rehabilitation centre within the previous month, following a stroke.

Source 3

The selection criteria for source 3, was having had a stroke one or more years previously.

Sample size

Since IPA is concerned with obtaining a detailed, interpretative account of individual cases, it is suggested that this can only be done with a small number of cases. Smith & Osborn, (2008) recommended six participants IPA studies typically use small samples to allow a detailed, interpretive account of each case. Significant time is needed to reflect on, and analyse, data, and this process can be restricted by too many participants, who can produce an overwhelming amount of data (Smith et al., 2009). Four to ten participants is recommended for a post-graduate research project.

Source 1	12 participants
Source 2	6 participants
Source 3	5 participants
Total	**23 participants**

Figure 7: Number of participants per theme

The total number of participants involved in this study was 23. However, this is split between three sources, and each individual source has a sample size more typical of IPA research.

Of the twelve participants in source 1, the six people who were stroke survivors were invited to the focus group. It was felt that the views of people who had had a stroke, many of whom had communication problems, would be better heard without the presence of family members who could communicate without difficulty. Four out of six attended the focus group, one had agreed to attend but could not make it on the day due to illness, and one declined to attend. Of the four who attended, three had some degree of aphasia.

Recruitment strategy

Source 1

A notice was put on 'Sheffieldforum', an internet site for discussions and information, and the researcher spoke to a women’s health group for Asian women. Other participants were recruited via word of mouth, and through contacts at the University.

Source 2

Participants were identified through the Stroke Associations’ Family and Carer Support Service. The Family and Carer Support Service make contact with people in the South Yorkshire region, directly following a stroke. Depending on the severity of the Stroke they may see patients for the first time either in hospital or at home. If the patient accepts the service offered, the Stroke Association remain in contact with the person for as long as the person needs.

After initially meeting with a senior member of the Stroke Association, a meeting was arranged with the staff of the family and carer support service. I sent a letter prior to this meeting (see Appendix 2.2.1, p266), and at the meeting went through a power point presentation to explain the research (see Appendix 2.2.2, p267). At further meetings it was decided how patients should be recruited.

Source 3

Contact was made with key contacts at 'Aphasia Now', and 'Speakability', both of which have online support groups, and the online support group 'Behind the Gray'. With the permission of the group moderators, a message was posted on these forums, with a brief description of the research and an invitation to take part, with my email address as a contact (see Appendix 2.3, p271).

Recruitment procedure

Source 1

Participants were asked to contact me/a community representative of the appropriate language, directly, at which point an appointment was made to inform them in more detail about the research, and gain their consent. These meetings took place either at the participant’s home or place of work, at the University, or in a public place depending on the participants’ preference.

The potential participant was informed about the research with the aid of an Information Sheet (see Appendix 3.1, p272-305), by the researcher or a community representative who spoke their language. They were then asked to sign a consent form (see Appendix 3.1, p323-331). Both Information Sheet and Consent forms were available in English, Urdu and Arabic.

All participants were screened with the Six Item Cognitive Impairment Test (Callahan, Unverszagt, Hui, Perkins, & Hendrie, 2002) which is designed for use with potential research participants to ascertain whether they had cognitive problems which would impact upon capacity (see Appendix 3.1.1, p272). These questions, and researchers’ observation, were also used to judge whether participants with aphasia were capable of giving informed consent. For participants with significant cognitive or communication problems the following procedure was planned.

- If the participant refuses to take part in the research, this is the accepted answer.
- If the participant agrees to take part in the research, a relative/carer will be asked to confirm that they believe the participant understands what is involved, and would normally agree to being involved in such a project.

However, none of the participants required this procedure. One participant was a non-English speaker, and required recruitment materials in Urdu. Consent was taken with the help of a community representative.

Source 2

As this study aimed to follow people throughout their first year at home following a stroke, the Stroke Association identified people anywhere between the acute stage, and discharge home, as being suitable for the research. If they identified a suitable person either in an acute or rehabilitation setting, they would mention the research to them at that point, and ask their permission to revisit the topic when the patient is at home. They also inserted the following sentence into their own consent form:

> *"We may ask you at a later point whether you wish to be involved in research. Please tick this box if you do not wish to be asked"*

If the patient gave permission to be asked about the research at a later point, the Stroke Association would wait until the patient was at home, and then ask for permission for me to contact them. If a patient was discharged straight to home the Stroke Association will immediately ask them for permission for me to contact them.

Once the patient consented to being contacted, the Stroke Association passed their contact details to me, I made contact with the participant or their family member/carer, and arrange to see them at their own home, giving two hours as an expected appointment time.

In order to minimise the passing of contact details by email or telephone, the Stroke Association would contact me to tell me they had a potential participant and I would visit their office in person to get the contact details.

Prior to telling the potential participant about the research, I did a screening test (See Appendix 3.2.1, p335) to ascertain the persons level of understanding, and from this identify which of the three Information Sheets to use.

- 4+ key word level (Info Sheet 1)
- 3 key word level (Info Sheet 2)
- 2 key word level (Info sheet 3)

(See appendix 3.2, p341-362).

Source 3

When an email was received from a potential participant expressing their interest in being involved, I would email them the Information Sheet (see Appendix 3.3.1, p364), stating that they should ask any questions if they needed to, and that once they were happy they should send me an email including the following paragraph:

"I have read the information sheet and have had the opportunity to ask questions. I understand that taking part in the study is voluntary and I can withdraw at any time with no negative side effects. My responses confirm my ongoing consent".

A total of seven people responded to the invitation. Three had concerns about navigating the consent procedure because of language or cognitive difficulties, two of these did not give consent, and one was able to provide consent with reassurance, so a total of five consented. Two of these were recruited from Aphasia Now, one from Speakability, and three from Behind the Gray.

Data collection process

For source 1 and 2, Interviews were recorded on a digital recorder, for transcription. Notes were taken throughout the interview, which allowed for immediate reflection on content of future interviews prior to detailed analysis.

Source 1

Semi-structured interviews were conducted with participants (people more than 1 year post stroke, and their informal carers), to ascertain the meaning of participation.

Interview schedule-Source 1-Stroke Survivors

1. Can you tell me what happened around the time you had the stroke?
2. Can you tell me what life is like now?
3. What does the word participation mean to you?
4. Is participation important to you?
5. What prevents you from participating in the way that you would like to?
6. What helps you to participate (personal, physical and environmental factors)?

Interview Schedule-Source 1-Carers

1. What does the word participation mean to you?
2. What does participation mean to you in your own life?
3. How has (stroke survivors) stroke impacted on your participation?
4. Has (stroke survivors) stroke impacted on your participation?
5. What helps you to participate (personal, physical and environmental factors)?
6. What do you think participation means to (stroke survivor)?

The interviews were guided conversations, and I did not always need to use the questions, or may have phrased them differently. The interviews did not necessarily follow the order of the interview schedule.

The finer details of the interview varied throughout the collection process, as themes emerged which I further explored with later participants. For example, the early interviews suggested a difference in age and stage of life, as to how much of an affect stroke had on identity, and so I made a point of discussing this in later interviews. The source 1 and 2 interviews made particular use of the strategy ‘funelling’ (Ison, 2009), whereby the interviewer starts by ascertaining an overall description of the phenomena and gradually moves on to asking about the finer details.

The community representative assisted with the interview with the non-English speaker. She asked the questions in the interview schedule, and translated the answers to me so I could ask further questions.

Five of the participants in Source 1 had Aphasia. All were able to communicate verbally in the interview, but one needed her husband to assist her.

Themes relevant to the meaning of participation were presented in the focus group, from the findings of the interviews:

- Taking part in
- Meaningful activities
- Loss and self-identity
- Changing over time

Because the participants were already known to me, I was able to make preparations based on my knowledge of their communication abilities. Therefore, themes were represented verbally, in writing, and with pictures (see Appendix 4.1.2, p382). Large sheets of paper and pens were placed on a central table, which the participants could draw or write on if they chose. Only one of the participants used this option, the others preferring to communicate verbally, however, I wrote key words down as they became relevant throughout the focus group. The feedback from the focus group further developed and refined the findings.

Source 2

In the first interview with the longitudinal participants, I used an interview schedule as a guide, but as with the interviews in Source 1, it was used as a prompt rather than followed rigidly.

Interview schedule-source 2

1. Can you tell me what happened around the time you had the stroke?
2. What was life like before you had the stroke?
3. How have things changed since the stroke?
4. What are your hopes for the future?

Subsequent interviews varied between participants as they were based on previous interviews, but began with a summary of what they had told me last time I saw them. Interviews were recorded on a digital recorder, for transcription. Notes were taken throughout the interview, which allowed for immediate reflection on the content of future interviews prior to detailed analysis.

Source 3

The following questions were sent to the participants by email:

Interview schedule-source 3

1. How old were you when you had your stroke?
2. How long ago was your stroke?
3. Has your stroke impacted on your everyday life?
4. If so, how?
5. Has your stroke had an effect on your roles in life?
6. Has stroke affected the way you see yourself?
7. Do you think being male has made any difference to the way the stroke has affected you?
8. Has your age made any difference to how the stroke has affected you?

I then used the strategy 'recursive questioning' (Ison, 2009), whereby the answers to one set of questions leads to the next set of questions. This enabled me to encourage the participants to elaborate on certain points, and to clarify others. This took approximately three to four emails from each participant.

Data analysis

"In order to generate findings that transform raw data into new knowledge, a qualitative researcher must engage in active and demanding analytic processes throughout all phases of the research. Understanding these processes is therefore an important aspect

not only of doing qualitative research, but also of reading, understanding, and interpreting it." (Thorne, 2000, p68).

While approaches to qualitative analysis vary, they are united by particular features:

- They aim to explicate the ways in which people in particular situations understand and manage their day to day situations.
- Many interpretations are possible but some are more compelling due to internal consistency or theoretical considerations.
- Standardised instrumentation is rarely used, the researcher being the 'measurement device'.
- Most analysis is done with words.

(Miles & Huberman, 1994).

Qualitative data analysis relies on inductive reasoning to interpret structure meanings derived from data. It must go beyond simply explaining how something occurs to offering an explanation as to why something occurs. This involves using specific strategies of analysis to move from raw data to an original and reasoned representation of the matter being studied (Thorne, 2000). There are various ways in which qualitative data can be analysed, including:

- Constant comparative analysis, a concept originally found in grounded theory (Glaser & Strauss, 1967), which involves taking one piece of data and comparing it to all similar pieces of data in order to develop an understanding of possible relations between the data.
- Ethnographic analysis, involving an iterative approach, where ideas that arise from fieldwork such as observations are translated into a written form (Thorne, 2000).
- Narrative analysis, which seeks to discover how people make sense of and understand their lives by detecting the narrative themes in the accounts they give about their lives (Thorne, 2000).
- Discourse analysis, which consists of critical enquiry into the way language is used to undercover the influences behind our thoughts and behaviours.
- Phenomenological approaches, which rather than seeking differences and similarities seeks to uncover the structure or essences of an experience (Thorne, 2000).

IPA studies attempt to understand the way that the individual makes meaning out of experience and are inductive in approach, moving from a descriptive to an interpretive understanding (Smith et al, 2009).

There are three characteristics which should be present within IPA research. It should be:

- Idiographic – providing a detailed analysis of each case.
- Inductive – themes should emerge from the findings, similarly to Grounded Theory, where themes emerge from the data, rather than testing against a hypothesis based on current literature.
- Interrogative – seen in relationship to existing literature rather than being considered in isolation, therefore the discussion of the findings in relation to the literature review can be seen as an extension of the analysis

(Smith & Osborn, 2008).

Although there is no single prescribed method of data analysis for IPA, I have used the steps suggested by Smith et al. (2009) to guide me in analysing the data in way that is consistent with the phenomenological approach. As a novice phenomenologist I followed these steps quite closely, while also incorporating some principles from Grounded Theory approaches which I found useful, such as memo writing. I also found it necessary to modify and add to the steps, because of the number of participants, most notably by using NVIVO. NVIVO is a computer programme available to assist with qualitative analysis and is an aid to sorting and organising sets of data.

The introduction of computer programmes to aid qualitative analysis in the 1980's, which became known as CAQDAS (computer assisted qualitative data analysis software) was met with some suspicion. However, over time *"...it became clear that although computers cannot analyse textual data in the same way as they analyse numerical data...there are mechanical tasks involved in interpretive analysis, most of which are concerned with the management of data material."(Kelle, 1995).* As computer use in general has become widespread, such programmes have become an accepted element of qualitative analysis. They generally include the following functions:

- Mechanisation of cut and paste techniques.
- A facility to record memos.
- A feature for defining relationships between codes.

(Kelle, 1995).

It has been suggested that they may increase the rigour of qualitative research, as they make the process more systematic and transparent, and may also increase the creativity of the researcher, by freeing the researcher from the laborious cutting and pasting tasks that accompany analysing qualitative data by hand. Others worry that qualitative researchers using computer programmes to aid analysis may become alienated from the data *(Kelle, 1995),* and that computer programs may threaten the heterogeneity of methodologies which is a valued feature of qualitative research (Welshe, 2002).

I myself, having experimented with NVIVO previously, made the initial decision to analyse the data by hand, as I had previously felt that the computer programme created a barrier between me and the data. The volume of data and the practicalities of analysing by hand led me to look at NVIVO again. I persisted, and found that as I became more familiar with the functions of NVIVO, it seemed less like a barrier and more of a useful too. I can compare it to driving a car. When I first started learning to drive, I was very conscious of operating a machine, moving the wheel in order to turn left or right and changing gears to match my speed. Fifteen years later, the car feels like an extension of myself, and I use its functions automatically in order to get where I need to go. Similarly in NVIVO, I soon began to use its functions automatically, and it made the journey of analysis smoother.

NVIVO was chosen over other software packages, firstly on the recommendation of colleagues. I liked its simplicity, and that documents could be imported directly from word processing packages for coding. I also liked the memos feature, as memos were something I used a lot in the process of collecting and analysing data.

I used the functions within NVIVO in the following way:

- Annotations: making notes about the data (this was always in addition to hand written notes).
- Coding: to code the interviews into themes and sub-themes. NVIVO allows you to see current codes at a glance and so see if the data fits into a current code or if it needs a new code.
- Treenodes: to organise themes and sub-themes.
- Relationships: to note possible links between themes.
- Memos: for everything else, including ideas, thoughts and feelings, comparisons between participants.

Source 1 and 2 interviews were transcribed by a third party (for examples please see Appendix 4.1, p374 and Appendix 4.2, p386), and then checked for accuracy and removal of any identifying information, before beginning the analysis process. For the analysis of the email interviews, the content of the emails were copied and pasted into one document, and any identifying information was removed (see Appendix 4.3, p418). They were then ready for analysis.

Analysing longitudinal data involves looking at the data in two directions, to view the findings between participants, and also over time, which is termed 'diachronic analysis' by Thomson, (2007). In order to capture the 'over time' element which makes longitudinal cohorts different from other qualitative interviews, it is necessary to view all multiple interviews with each participant as one body, as well as separately along with other interviews in their time frame. This gives the researcher a sense of the 'story' of the participant (Thomson & Holland, 2003). Beyond this, Saldana (2003) recommends collecting all passages which have the same or similar coding together, which builds towards seeing the story for each theme.

Part of seeing the findings from different time points as a whole, and looking at change over time involved asking questions of the data, for example, Molloy et al., (2002, p38) suggests asking the following questions:

- Has any change occurred?
- What has changed?
- How or through what mechanism has change occurred?
- Why has change occurred?

In qualitative longitudinal studies 'histories' can be created, and the individual becomes *"an object of enquiry in their own right and not simply illustrative material to flesh out findings established elsewhere" (Thomson, 2007, p573).*

Interviews from the longitudinal cohort (Source 2) were analysed in the same way as the individual interviews. When all the interviews were complete and analysed, the findings were collected into a table which had participants along the top, and themes down the side, in order to bring together the two direction analysis. A summary of each participants experience at each interview was included, and an additional box 'reflections on change', which was a summary based on the questions that I asked of the findings (see Appendix 4.4.3, p426). As well as being a recommended method of viewing longitudinal data, the use of tables is an idiographic method of bringing together in depth analysis of individual cases, used by IPA researchers (Smith, 2004). In order to highlight the process of change, three participants from the longitudinal cohort are presented as case studies, and the sub-themes applied to each of them.

After the analysis of Source 1 interviews, the key themes relevant to defining participation were presented to the interview participants in a focus group, and their responses assisted in the development of the analysis, making this an iterative process. The three sources together yielded a large amount of findings, all of which were analysed. However, as the central themes emerged, it was clear that some of the findings would not be used as they related to matters of outside the scope of this thesis. On understanding the central themes, all of the interviews were reread in the light of this, and some findings were recoded.

Figure 8 shows the steps of IPA analysis set out by Smith et al. (2009). In this section I will describe the steps and how they were used to guide my analysis, using examples from my findings to illustrate. It is necessary for clarity to present this in a linear fashion, but in reality the process was much more fluid, moving back and forth between the steps as my understanding of the findings, and also the method, developed.

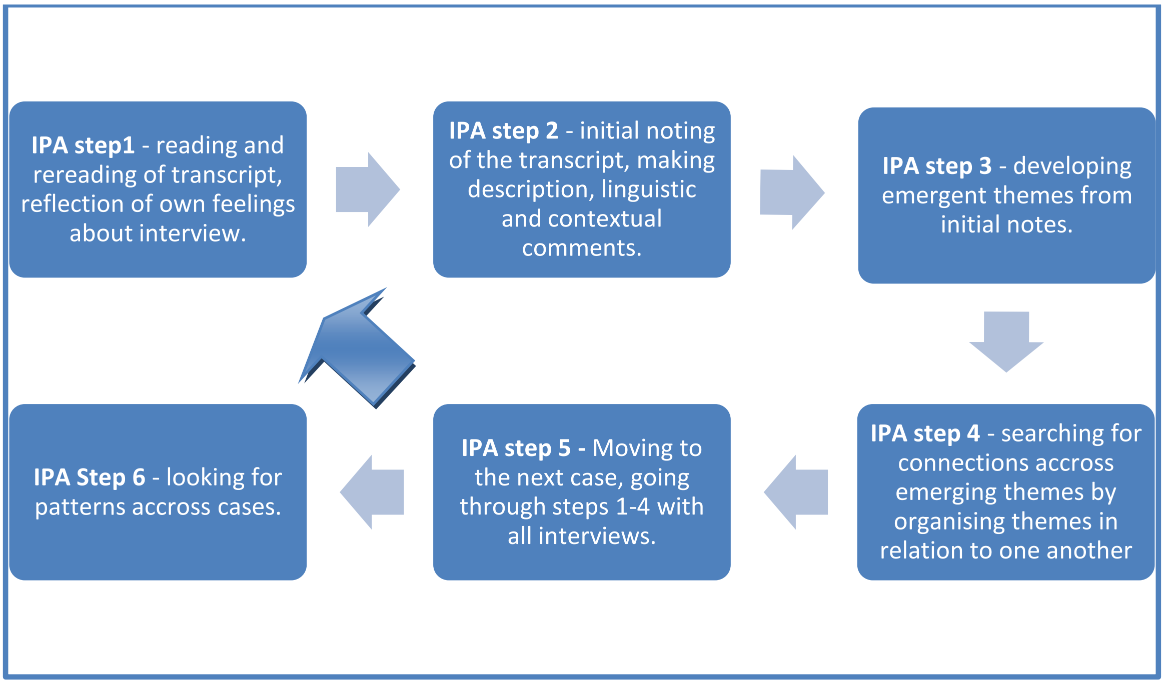
IPA step1 - reading and rereading of transcript, reflection of own feelings about interview.
IPA step 2 - initial noting of the transcript, making description, linguistic and contextual comments.
IPA step 3 - developing emergent themes from initial notes.
IPA step 4 - searching for connections accross emerging themes by organising themes in relation to one another
IPA step 5 - Moving to the next case, going through steps 1-4 with all interviews.
IPA Step 6 - looking for patterns accross cases.

Figure 8: Steps of IPA analysis

Step 1: Reading and re-reading

The purpose of this stage is to immerse oneself in the transcript, and attempt to slow down and engage with the data, bracketing off one's own preconceptions. This is in order to become closer to the lived experience of the participant. Becoming aware of one's' own perceptions raises ones awareness of possible bias, and helps to counter it.

I first listened to each interview while reading through the transcript, and repeated the reading of it until I felt it had become familiar to me. I reflected on my own feelings during the interview, and what I felt while reading the transcript. This, and notes made at the time of the interview, formed the 'bracketing off', which allowed me to engage with the transcript in a different way. I give an example from Claire and Jeremy (synonyms), a stroke survivor and his wife.

> *"When I met Claire and Jeremy I quickly categorized them as a particular 'type' of people. This was confirmed by the way they both spoke of their lifestyle before. I felt that while Claire was open about the difficulties of her caring role, Jeremy used a lot of stock phrases to cover up his vulnerability and try to appear the man he wanted to be".*

I have used this example as this was where I noticed the most contrast in the way I engaged with the transcript before and after bracketing off. My perception of Jeremy was influenced by my categorisation of him as a particular sort of person, and after acknowledging this I saw many things in the transcript which I had not previously seen.

Step 2: Initial noting

This is the most time consuming step, and is very exploratory. The transcript is examined in great detail, and everything of interest is noted. This process helps to *"identify specific ways by which the participant talks about, understands and thinks about an issue"* (Smith et al., 2009, p83). The result is that the transcript is now accompanied by a set of notes comprising of:

- Descriptive comments, summarising what has been said
- Linguistic comments, focused on exploring the specific use of language
- Conceptual comments, focused on engaging at a more conceptual level.

This process was initially done by hand (see Appendix 4.4.1, p423), and then transferred into annotations to the text within NVIVO, or memos for longer notes. Below are examples of the three different types of notes:

- Descriptive comments, e.g. *"Having support from spouse reduced fear".*
- Linguistic comments, e.g. *"The way Mary spoke about her old self and her old life, seemed to me to indicate a split within her. There was a sense of the old self carrying on in some parallel universe while her conscious self was stuck in the post stroke situation. She says of reading "it's better than being in this real world". I'm interested in her use of 'this' rather than 'the', which almost suggests there is more than one, she is in 'this' one, but the other one still exists for her. Her stroke wrenched her from her old life so suddenly that maybe this is the sense that she has been left with".*
- Conceptual comments, e.g. *"There appears to be a relationship between acceptance and participation. Firstly, an acceptance of the current situation can lead to solutions which ultimately benefit participation"*.

At this stage the analyst is encouraged to think freely, as stronger interpretive claims can be checked at later points in the analysis.

Step 3: Developing emergent themes

This stage attempts to reduce volume, while retaining detail, by making a concise statement to summarise important parts of the transcript and your notes from the previous steps. I did this by hand initially by making a note of a possible theme, and putting a code next to each comment in the transcript which may be relevant to that theme (see Appendix 4.4.1, p423). This was later done directly in NVIVO, creating a node for each tentative theme, and then 'coding' each note into a theme, or more than one theme (see Appendix 4.4.2, p425).

In order to maintain closeness to the descriptions of the participants, I used the words of the participants to describe the themes where possible. Examples of tentative themes at this stage included, *"participation in the world of strokeness", "acceptance of lack of control"*, and *"good days and bad days".*

Step 4: Searching for connections across emergent themes

This is the charting, or mapping of how the themes fit together, and should initially be very explorative. You are turning the participants ‘story’ into a visual model that enables you to pick out the important aspects.

Initially this and the previous two steps were done separately, and by hand (see appendix 4.4.1, p423) for example of diagram of emergent themes). The codes were collected and put into themes, and these themes were added to and new themes added, with each interview that was analysed. When I first started to use NVIVO, I went through this process by hand before transferring the information into NVIVO. As my confidence with NVIVO grew, and I moved onto later transcripts, I was able to do steps 2 and 3 using annotations and memos in NVIVO, and step 4 by coding sections of the transcript into Tree Nodes, and using memos to explain more complex relationships between different themes (see Appendix 4.4.2, p425). This is an example of a memo concerning a relationship between themes:

> *“There is no doubt that stroke affects role and identity, which is attested to in the literature, and my participants reiterate. I think participation has a two way presence in this. Ability to participate affects role and identity, and a changed identity also affects ability to participate”.*

Step 5: Moving to the next case

It is essential that each transcript be viewed individually, and this involves another type of bracketing off, that of bracketing off the ideas emerging from the analysis of previous transcripts during the first steps of analysing the current transcripts. For this reason I found it necessary to limit myself to analysing only one or two transcripts in any one day, to allow space to view each transcript in its own right.

Steps 1 to 4 were completed for all interviews in source 1 and source 2. The themes were then viewed in the light of the research questions, and some were set to one side, as possibly being outside of the scope of the research. These however, were constantly reviewed in the light of the ongoing analysis. The email interviews in Source 3 were specifically designed the further probe issues that had already been identified in the analysis. They were coded in the same way as Source 1 and 2.

Step 6: Looking for patterns across cases

This involves comparing individual cases to find commonalities and often involves a reconfiguring and relabeling of themes, as something from one case is illuminated by something from another.

I found that this naturally happened throughout step 1-5, assisted by using Tree Nodes in NVIVO. When carrying out steps 3 and 4, looking for emergent themes and connections across emergent themes, notes from a new transcript could be compared to the existing tree nodes and either coded to an existing node, or to a new node. Memos were used to help highlight differences between cases. This is an example of such a memo:

> *"I'm interested in the contrast between Elliot and Christina. Elliot was a working age man when he had a stroke. He has clearly experienced a huge change in role and identity within the family, going from 'the dad' who was the problem solver, to what he is now which he compared to being like having your granddad around. This is in contrast to Christina, who gave the appearance of being more severely affected (both have aphasia) but who did not feel that her role had hugely changed. Was this because she was retirement age and female?"*

In regards to the longitudinal cohort, I was trying to understand patterns over time as well as between cases. Tables of themes were used to be able to view the longitudinal analysis in two directions, over time, and between cases (see Appendix 4.4.3, p426).

These six steps were followed for each of the three sources, and resulted in a large amount of data, notes and themes. I also at this point had some drawings of potential connections between themes.

Some time was spent thinking about and experimenting with the way the themes connected, with the help of the memos. Some themes were clearly not relevant to the theme of participation, and were put to one side, and this included all themes about caring, which had come from the carer interviews in source 1. Others had a central role, and some smaller themes became subsumed within larger themes, e.g. 'age' and 'gender' both became subsumed within 'role change'. Once the main themes had been clarified, tables were created to show the relevance of each theme to the participants (see Appendix 4.4.3, p426).

At this point a fellow researcher read three coded research interviews, and gave her feedback as to the clarity of the themes, whether things were coded in the most relevant places, and general comments on the logic and appropriateness of the coding. There were no significant points of disagreement.

While I have presented the analysis here as a linear process, the reality is that new realisations occur throughout the process, which result in a renaming or reorganising of categories, and the writing of the results chapter itself is part of the analysis, as changes and moments of clarity occur as you start to tell the story of your participants.

Summary

In this chapter I have described the design of the study, which is iterative and involves the triangulation of retrospective interviews and a focus group, interviews with a longitudinal cohort, and email interviews. I have explained how accessibility to under-researched groups was incorporated into the design, and I given details of the recruitment and data collection process. I have provided a step by step guide as to how the data was analysed, which gives context to the interpretive analysis I will be presenting in the next chapter.

Chapter 5: Findings

This chapter will present an interpretative account of the transcripts of:

- Retrospective interviews with stroke survivors and carers(S1)
- Longitudinal cohort interviews with stroke survivors(S2)
- Email interviews with stroke survivors(S3)

In Source 1, carers of stroke survivors were also interviewed, and their data has enhanced the findings. A follow up focus group involving some of the source 1 interview participants has also contributed to the analysis (FG).

This analysis aims to answer two questions:

- What does the term participation mean to stroke survivors?
- How is participation affected by stroke?

Before presenting the analysis itself, I will describe the sources in some detail, and explain my experiences of gathering data for each of them, based on a research diary kept throughout the process. The purpose of this is to demonstrate my reflexivity throughout the process, and provide the reader with a context in which to view the analysis. I will then present tables of participant characteristics for each source, before providing details about the impact of stroke on my participation, and mediating factors, which are presented as background information to the analysis.

The analysis is presented as two super-ordinate themes, ‘meaning’ and ‘experience’. These are visually represented along with their subordinate themes below. The quotations used to illustrate the interpretations of the findings are italicised, and enclosed within quotation marks. They have been modified for the purposes of maintaining confidentiality by the changing of names of people and places. Occasionally two separate but related pieces of dialogue have been put together, and the dialogue in between removed if that was not relevant. This has been done by inserting “...”. References to non-spoken communication are shown between square brackets, and any words that I have added for clarity are also shown between square brackets.

The language used by the participants has been maintained in the transcription, including the use of unusual words or grammar by participants with aphasia, and local dialect. I have added words only where it is essential for understanding.

The quote is followed by a pseudonym of the participant it came from, and either S1 (source 1), S2 (source 2), S3 (source 3) or FG (focus group) to indicate which source of findings it is taken from.

Evaluation of the sources

Gubrium & Holstein, (2002) refer to 'reverberations' within interviews, as a way of understanding that the qualitative interview is not a discreet event, but is influenced by many things, including the way the participants have been recruited, perceptions of the research process and the researcher, and the researchers own preconceptions. To illuminate these potential reverberations, I will describe my experiences of data collection in each source.

Source 1 – Retrospective interviews and focus group

Source one participants were recruited by a variety of means, and this affected the interaction I had with the participants. The majority of participants in Source 1 were recruited via contacts at the University, and two of the 'word of mouth' participants were contacted via this group, so I have grouped my experience of them with the University contacts group. This group were all aphasic, and were known to the University for being willing to participate in research. They were easy to make contact with, and understood the process of research. They were all several years post-stroke, and because of their involvement in stroke research and other types of stroke activity, they were able to not only reflect on their own experiences, but also the changes in availability of support over the years since they had had a stroke. I personally enjoyed these interviews very much. These were inspiring people, and I may have felt comfortable with them as they were from similar backgrounds to me, being white, middle class and well educated. All but one of these participants were interviewed in their own homes, and having access to their homes helped me to build a picture of their lives. One participant chose to be interviewed in the University, and although he was comfortable in this situation as he had been there many times before, I feel like I had less of a sense of what his life was like through not seeing his home.

I had two other participants who were recruited by word of mouth. One, a carer, was a friend, and this influenced the interview. She often spoke about things on the basis of knowledge I already had of her situation, such as the number of children she had, and her husbands' health problems, and I had to prompt her to go over the information in a more logical way. However, as she was familiar with the research process through her own work, there was a level of understanding about what was required. I have to consider that her account of her situation may have been modified due to our friendship. While I explained the confidentiality of the interview to her, there was no way of me keeping the information she told 'me as a researcher', confidential from 'me as a friend'. Having a friend as a participant is not ideal, however, as she was of South Asian origin, I felt it would be of value to include her, as stroke research lacks the perspectives of ethnic minorities. The other word of mouth participant was an Uncle of a friend, whom I had never met. Again, despite my emphasising confidentiality, I have to accept that his account may have been influenced by concerns about confidentiality. This participant preferred to be interviewed at work, and this added to the impression I had that he wanted to keep me 'at arms length'. I feel this may have been related to him being an older Muslim male, and me being a younger Muslim female, where there would naturally be a relationship of deference from me to him. For me to see him at his workplace, which was a business he had built, wearing a suit and sitting in his office chair, may have helped him maintain a sense a power in the relationship. This masking of vulnerability is not only applicable to this situation, but it is with this participant that I noticed it more. When I contacted the participant to ask him to be involved in the focus group, he very politely declined. I think this was partly because being interviewed was really just a favour to his niece, and he had no real interest in being involved in the research process.

I recruited one stroke survivor through posting on the website 'sheffield forum', and was also able to interview his daughter. Both chose to be interviewed in public places, due to having noisy dogs at home. I met Tony, the stroke survivor, in a cafe in a park near where we both lived. He selected this place as being easy for him to get to, and it was also somewhere that I was familiar with. Like the participants I recruited through University contacts, Tony was intelligent and articulate. However, his background was entirely different. He was a working class man, who lived in an area considered ‘rough’ that he had lived all his life. It was obvious throughout the interview that he was very community minded, and prior to his stroke had been active in the local community in many ways. As with the other participant who I did not interview at home, I felt I was lacking a picture of his life, although it was different being in a public setting of his choice, than to meeting in the University, which was completely impersonal.

Meeting Tonys’ daughter was a less comfortable experience, in a busy cafe in town. This was a surprising interview, as Tonys’ daughter explained her role as a carer for her father, and how this had changed her life. She had previously been quite rebellious, but the responsibility for caring for her father had given her a new perspective on life. This seemed at odds with Tonys’ description, that his children did not really understand the impact of his stroke, and how disabled he was. This is a very interesting insight into the differing perspectives two people can have of the same situation, and illustrates the double hermeneutic in phenomenological research, that the researcher is interpreting an interpretation of events by the interviewee.

Five of the twelve participants had aphasia, but all except one were very articulate. The main impact of the aphasia on the interviews was that things might be expressed in unusual ways, but the aphasia did not appear to prevent the expression of ideas, thoughts and feelings. However, the willingness of the aphasic participants to talk at length, may have been a way of controlling the process according to their abilities, as they would sometimes struggle to understand and answer questions. The most difficult question was about the meaning of participation, and I developed a variety of ways of asking about this, including giving examples of what participation meant for me. One aphasic participant had much less expressive ability, and at her request had her husband in the interview with her, and she would sometimes ask his help in explaining what she was trying to say. I did find this interview very stilted, and at the time I felt I wasn’t getting a good understanding of the participant. However, when I read the transcribed transcript, I realised that there was more information there than I thought.

Through a friend who worked for a Muslim women's organisation, I was invited to attend a health session for older Asian women, where I explained my research and asked people to take part, or let other people in the community know about the research. Many of the women in the session were older, and did not speak fluent English, and so the women running the group translated my explanation. The women's group was not specifically for stroke survivors, and so I had not expected to recruit directly from the session, but hoped that someone might pass my details on if they knew of a stroke survivor. However, one attendee was a carer for her husband who had had a stroke, and although she did not feel she could ask her husband to take part, she was happy to be interviewed herself. This was the only interview in which I needed to use a translator, and I passed her details to the community representative, in order for arrangements to be made. From this moment on, I became a bystander in the process. Even though I 'directed' the interview through asking questions, the bond was between the community representative and the interviewee, and I was in the sidelines.

Following the interviews, the participants were invited to attend a follow up focus group, and four participants attended. Out of the four participants, three already knew each other and sometimes socialised together. The other participant, Tony, had not met the others before. However, he was talkative within the group and the other participants responded well to him. It was interesting to see the participants, whom I had previously met alone, together in a group situation. I presented to them my findings on what participation meant, to which they commented and developed ideas further. I was careful not to comment on what any of the participants had said in the previous interviews, other than anonymously, however, they themselves often recognised their quotes and were happy to elaborate. Three of the focus group participants had aphasia, two of them communicated well in the focus group setting, but one, whose aphasia was more severe, struggled to participate. I regularly summarised the conversation for her and gave her opportunities to comment, and the other participants were considerate towards her, giving her time to speak. However, her contribution was very limited.

In summary, this was a very heterogeneous group, and the experience of working through the interview schedule varied greatly depending on the many individual differences between the participants. However, the semi-structured interview format allowed me to maximise the opportunity for understanding the experiences of this varied group. Some of the limitations of using interviews with this group will be considered in the discussion chapter.

Source 2 - Longitudinal cohort

The participants in source 2 differed from those in source 1, in that they were all recruited via The Stroke Association. The impact of recruitment via 'gatekeepers' is examined in the discussion chapter, but there are other factors about this recruitment process which will have impacted upon the interviews. Each of the participants was supported by the Family and Carer Support Service at some stage after their stroke, and therefore the sample may not represent other stroke survivors who did not have this support. There were many examples throughout the interviews of the benefits of this service on the participant's lives, and it cannot be assumed that all stroke survivors receive this support. The connection of my research project with The Stroke Association, gave an added element of trust, as the participants saw it as an extension of their contact with The Stroke Association. There was also the risk of confusion about my role, as is common when people have recently had a stroke, due to the volume of appointments and different professionals that they see at this time. If I felt that there was any confusion in this regard, I explained my role and suggested that the participant spoke to their contact at The Stroke Association with any other concerns.

The longitudinal cohort offers a different relationship with the participants than a retrospective interview where the researcher and interviewer meet just once. I saw the longitudinal cohort three times over the course of one year, and often had more than one telephone conversation with them in order to arrange the interview. With each participant I built up some sort of relationship, and this was impacted upon by the fact that I was noticeably pregnant at the first interviews, which meant that the participants took more of an interest in me as a person that I had experienced before in interviewing. By the second interviews I was heavily pregnant and received some gifts for the baby. While personal interactions such as this need to be carefully managed in the interviewing process, I feel that it ultimately benefited the study, as the participants who had taken a particular interest in me were perhaps more open about their own lives than they would have been otherwise.

All of the source 2 participants were interviewed in their own homes, and as in source 1, I felt this added to the picture I built of them. It was also very important for them to be interviewed at home at this time, and not asked to go anywhere, as travelling even short distances would have been difficult for all of them when I first saw them, and by 12 months, still difficult for most of them. With a longitudinal cohort, there is the added concern of whether it will be possible to make contact with them for follow up interviews. I had issues with only two participants in this regard. John was difficult to get hold of for the second interview, and the first time we arranged it he was not in when I went to his house. When we successfully met for the interview, he explained that he was very busy with new hobbies and friends. He appeared to be willing to carry on with the research, and I had no problem contacting him for the third interview. I was able to contact Sandra for the first two interviews, but I was unable to contact her for the third interview. After telephoning three times, and calling round to her house, I decided not to attempt further contact. I may have persisted more with another participant, but Sandra had been bed ridden by the stroke, and I knew from previous interviews that her emotional state was that of despair. For this reason I did not feel it was appropriate to continue attempting to contact her.

Although none of the participants has aphasia, the interviews differed according to personality and communication style. Three of the participants were very open and expressive, whereas the other three were slightly more reserved. Both Wallace and Colin were friendly but not very talkative, and had their wives in the interview with them, who often contributed. Eva was very quiet, and I found it difficult to establish a good conversational style with her. She did not often offer information spontaneously, and needed a lot of prompting. Often, when listening to the interview later, I would realise she had started to open up towards the end of the interview, and I would question whether I should have stayed longer in order to hear more from her.

With April, the opposite was true. My interviews with April were very long, and it was difficult to direct her towards the topics that I wanted to discuss. In my second and third interview with April, she was very caught up in things that had happened to her in the days before the interview, and seemed unable to focus on anything else. This was in some ways frustrating, but I reminded myself that one of the benefits of a qualitative interview is that you hear what the participants wants you to hear, not what you as a researcher want to hear. Aprils' home was also a challenge, as she appeared to be a hoarder and every inch of space was covered pots, pans, papers and packages. Each time I went she managed to clear a small space for me to sit. Despite the challenges I enjoyed interviewing April, as she was an unusual and interesting person.

There was wide variation in the ages of this group (58-81), and in their personal lives. However, as they had all returned home from hospital following a stroke within the previous month, at the first interview, their situations were somewhat similar. A year on, it was possible to look back and see the variation in their trajectories after this point, details of which will be given in the analysis.

Source 3 - Email interviews

As with the previous source, the nature of how the participants were identified had an impact on the type of participant. Successful use of computer technology by people with disabilities is thought to be related to independence, quality of life, control and empowerment (Ison, 2009). This suggests that people recruited through internet support groups may not be representative of the stroke survivor population as a whole. This is even more so in this study because the majority of people who have a stroke will be over 65 (The Stroke Association, 2008), and computer use is generally associated with younger people. Indeed, the participants in this source were all under 65.

The process of conducting email interviews was entirely different to the process of conducting sources 1 and 2. This was something new to me and relatively new to the research scene in general. I could find little guidance on how to go about the process, and so based the design on other papers I had found which also used email interviews. I was somewhat nervous about the consent procedure and making the ethics application, and was very pleased when it was approved. It was very straightforward to get agreement from group moderators to post a message on support groups asking for participants, and appeared to be something they were familiar with. This again leads to the possibility that the people who reply are accustomed to taking part in research.

Going through the consent procedure involved several emails, and unfortunately I lost two potential participants during the process. This is obviously a disadvantage of the process, as this is much less likely to happen face to face, where you can provide guidance and reassurance on the spot. However, I did speak to one participant who was struggling with the process over the phone, and this was a good way to provide the sort of personal contact and reassurance which one would provide face to face. As with face to face interviews, some of the email interviewees were more expressive than others. Whereas some answered my questions in paragraphs, others answered my questions in one or two word answers. While I had the opportunity to ask for more detail in subsequent interviews, it was more difficult to build up a conversational atmosphere than it would have been face to face. Interestingly, it was the male interviewees who were most succinct in their answers.

There were definitely benefits to the email interviews, in that they gave both me and the participant time in which to compose questions and answers. Many times I would listen to a recording of a face to face interview and wish I had followed up on a comment that I had overlooked at the time. With the email interviews, I had time to read over responses several times, and pick up on every point which was of interest. It normally took three to four responses from the participant before I was able to email and thank them for their time and I had expected it to be more than this. For the interviewees, they had time to collect their thoughts and write a considered answer, unlike in a face to face interview where the answer is spontaneous. Obviously there are advantages and disadvantages to both of these situations. There are of course, other things missed through not seeing and meeting the participants, such as body language, intonation and other non-spoken information.

A major disadvantage to the email interviews was that, never having met the participants, it was very difficult to build up a picture of each individual, and when working with the email data, I found that I constantly needed to check where quotes had come from, whereas with the face to face interviews I always knew exactly which participant quotes came from. I found this made the analysis more difficult, but it could be that this lessened the influence of my own perceptions of the participant, and made me deal with the data more objectively. The data that came from the email interviews is qualitatively different from that of the face to face interviews, as one is written description and the other is transcribed conversation. This makes it stand out from the analysis, however quotes from the interviews are labelled ‘S3’ so that the reader is aware that it is an email interview quote.

Participant characteristics

Source 1 participants										
Pseudonym	**Gender**	**Age at interview**	**Age at time of stroke**	**Communication difficulty**	**Ethnic Origin**	**Language**	**Communication difficulty**	**Marital status**	**Lives with**	**Recruited via**
Abid	Male	66	65	Mild aphasia	Pakistani	English 2nd language	Aphasia	Married	Wife and adult children	Word of mouth
Christina	Female	68	66	Moderate aphasia	German	English 2nd language	Aphasia	Married	Husband	University contacts
David (husband of Christina)	Male	68	Carer	None	White British	English	None	Married	Wife	University contacts
Elliot	Male	56	52	Mild/moderate aphasia	White British	English	Aphasia	Married	Wife and children	University contacts
Jeremy	Male	48	45	Moderate aphasia	White British	English	Aphasia	Married	Wife	University contacts
Claire (wife of Jeremy)	Female	47	Carer	None	White British	English	None	Married	Husband	University contacts
Mary	Female	54	45	Mild/moderate aphasia	White British	English	Aphasia	Married	Husband and children	Word of mouth
Victor (husband of Mary)	Male	55	Carer	None	White British	English	None	Married	Wife and children	Word of mouth
Maryam	Female	41	Carer	None	British Pakistani	English	None	Married	Husband and children	Word of mouth
Nur	Female	58	Carer	None	Pakistani	Punjabi	None	Separated	Children	Roshni Asian womens service
Tony	Male	60	59	None	British Pakistani	English	None	Separated	Children	Sheffieldforum
Rosemary (daughter of Tony)	Female	16	Carer	None	British Pakistani	English	None	Single	Father and brother	Sheffieldforum

Table 5: Source 1 Participant characteristics

Source 2 participants							
Pseudonym	**Gender**	**Age at 1st interview**	**Communication difficulty**	**Language**	**Ethnic Origin**	**Marital status**	**Lives with**
April	Female	78	None	English	White British	Single	Alone
Colin	Male	68	None	English	White British	Married	Wife
Eva	Female	58	None	English	Black Jamaican	Divorced	Alone
John	Male	64	Mild dysarthria	English	White British	Widowed	Alone
Sandra	Female	69	None	English	White British	Married	Alone
Wallace	Male	81	None	English	White British	Married	Wife

Table 6: Source 2 participant characteristics

Source 3 participants								
Name	**Gender**	**Age at first interview**	**Age at time of stroke**	**Communication difficulty**	**Ethnic Origin**	**Language**	**Marital status**	**Lives with**
Andrew	Male	45	43	None	White British	English	Separated	With parents
Catherine	Female	52	51	Mild dysarthria	White British	English	Single	Alone
Gerald	Male	53	51	None	White British	English	Married	Wife and children
Wilfred	Male	62	55	Aphasia	White British	English	Married	Wife
Sue	Female	63	51	Aphasia	White British	English	Separated	Alone

Table 7: Source 3 participant characteristics

Participant age ranges for each source	
Source 1	48-68 (carers 16-68)
Source 2	58-81
Source 3	45-63

Table 7: Age ranges for each source

Impact of stroke and contextual factors

The findings regarding the impact of the stroke and other contributing contextual factors echoed what has been found in numerous previous studies, as detailed in the literature review. These findings are presented prior to the analysis, in order to provide a context in which to discuss the meaning and experience of participation.

Physical and cognitive impact of stroke

The main effects of stroke experienced by participants were mobility problems, aphasia, tiredness and cognitive problems. Although there is no 'typical' stroke survivor, as the impact of stroke depends on the type of stroke and the area of the brain affected, each of the participants has a unique set of difficulties due to the stroke.

Mobility problems

The majority of participants were able to walk, except for Sandra. However, hand and leg weakness, and other issues, had an impact on day-to-day life.

> *"I am now unable to. Drive; Dress myself fully – can't cope with buttons, zips or tie laces; Type with two hands; Eat with both a knife and fork; Run" (Andrew/S3).*

Mobility problems had an impact on what the participants were able to do.

> *"Now it might take me an extra half an hour to actually get ready and mobilise myself to get out and do something, whereas before I could be straight out of the door, straight in my car...like every Tuesday I used to take my mate's widow to the cemetery, but I just can't do that now so she has to go on her own on the bus" (Tony/S1).*

Aphasia

Many of the participants were affected by some degree of aphasia, causing difficulty in understanding, speaking and also skills such as reading and writing. The presence of aphasia appeared to intensify the impact of the stroke.

> *"The first one wasn't too great, the second one, because of Christina's certain...loss more of speech.."(David/S1).*

Further to this, the nature of aphasia had an impact on stroke survivors at a more fundamental level as it affected how they were able to interact with others.

> *"what's the other thing? Laughing. I can have the odd laugh. But you know jokes, the high, high, what's your brain, the high bits...people always say to you, when you've had your aphasic, your intelligence is exactly the same, and that's crap, it's absolutely not true. It isn't. This is, y'know, sometimes my sons will send me a text with something funny. And I look at it and...y'know if it's something, not jokes, but some things are a bit funny sometimes, you can still laugh about it, y'know someone falls over, erm, but the jokes is...gone...it's not just the words it's the what's the word..." (Elliot/S1).*

Tiredness

Nearly all of the stroke survivors referred to the tiredness that they experienced following the stroke. This was not an ordinary tiredness, and could last up to years after the stroke. It had to be incorporated into daily life.

> *"Jeremy has a sleep every afternoon, so whatever I'm doing, we have to factor that into what's happening. So if somebody says something about the afternoon, it's not always easy for me or both of us to be involved, because we've got to work out what time we're doing things in the morning, to allow Jeremy a sleep every day, so that does impact, we have to be back here and him settled". (Claire/S1).*
>
> For aphasic people, the tiredness was intensified by doing things where they needed to talk.
>
> *"I usually, even now, by 7.30 at night I go to bed, incredibly tired. Even talking, I need to do this, but afterwards, and that's most people with aphasic is. It's not only trying to get the words but you've got to find a little wire..." (Elliot/S1).*

Cognitive problems

Participants experienced cognitive problems such as short term memory loss, or the inability to process information.

> *"David. That's one thing that's affected Christina is memory, that's just come to mind, and writing is difficult, the spelling, both English and German, both languages.*
>
> *Researcher. And in what way has your memory been affected?*
>
> *Christina. Well sometimes David says something and er I don't remember that he said it before*
>
> *David. and sometimes names, people's names, she knows them but she can't...in fact there are times when Christina'll say 'oh your daughter's rang', and I'll say 'which one?', she can't remember which one". (Christina/S1).*

This had an impact upon life in various ways, including performing everyday tasks.

> *"like my memory went when I had stroke and if I meant to cook a dinner, I'd turn gas on and forget to light it" (Tony/S1).*

It also affected participants' ability to participate in certain activities.

> *"Erm, even at church, I tried, I can't go because it's noise, singing, er, reading, understanding. Trying to understand what the vicar's saying. And they'll say it's in Bible number...or you'll get a reading, and they'll say it's in book number, singing book. It's in number 24...by the time I'd found what 24 was, they'd finished". (Elliot/S1).*

Practical impact of stroke

The physical impact of stroke had led to practical changes in life. In general more change was experienced by those who had experienced more severe post stroke difficulties, however, even mild aphasia and tiredness could have a significant impact on the stroke survivor's life.

Work and study

Many participants' lives had been completely disrupted by the stroke and they had stopped working or studying.

> *"I had just got a degree at [age] 50 at Sussex University doing History of Art and thought I was do PhD afterwards. Of course it did not happen - so the social and emotional aspects were huge". (Sue/S3).*
>
> *"Since I was 15 years I've worked, and that's totally in a minute gone. Money has gone." (Elliot/S1).*

This impact of these changes was far reaching, affecting financial stability, changing peoples' roles within their family, and undermining people's sense of self. While, over time, people adapted to their new life, there was still a sense of what had been lost.

> *"At night time, if we're not doing anything, it's the case of thinking as to what life was with my job and all the rest of it, and now it's totally different" (Jeremy/S1).*

Driving

Many of my participants were unable to drive following a stroke. While some participants such as Mary were never able to resume driving, others, including John, were able to drive when they had recovered some of their physical abilities. Although Wallace was physically able to drive a few months after his stroke, he had lost the confidence to do so.

Not being able to drive had an impact on independence, meaning that the stroke survivors became reliant on others.

> *"Colin. When it gets warmer he's going to come up... when his days off like and we'll have a walk round.*
>
> *Researcher. Oh, that's nice. Yeah.*
>
> *Colin. And he'll take me golfing.*
>
> *Researcher. Umm.*
>
> *Colin. Which, err, it's not too bad really.*
>
> *Researcher. Yeah.*
>
> *Colin. I look forward to that, an I?" (Colin/S2).*

Even for participants who were relatively mobile, not being able to drive restricted the range of activities they could be involved in, and public transport was often not a viable alternative.

> *"The difference between being able to drive a car, and then only being able to get to places on a bus. And I keep thinking to myself, well you could do that Mary, you could get on a bus and you could go out onto the Peak District or whatever. And then I think, well could I? Why? How on earth am I going to find out what number, and when I'm supposed to get off, and all those sort of things" (Mary/S1).*

Relationships with family and friends

Relationships were affected by the stroke, as will be discussed further in the description of the interpretative analysis, and for two participants the stroke had precipitated a divorce.

> *"I've had a divorce, she couldn't cope with, she were going out, obviously she were fed up, she were going to her mother's and not coming home, and going out drinking, so i said I did not agree with that, and I couldn't go out, so it has altered a lot of things." (Tony/S1).*
>
> *"My situation is completely different now. My marriage has ended after my wife became emotionally abusive, controlling and violent." (Andrew/S3).*

Other relationships were also affected, and participants often lost friends following the stroke.

> *"I get very lonely at times and go days with seeing anyone." (Catherine/S3).*

Inability to tolerate environmental factors

Aphasia and other cognitive problems associated with stroke led to some of the participants being unable to tolerate environmental factors. Participants with aphasia, for example, found it very difficult to communicate in a group situation, or with background noise.

> *"I have problems talking, one to one's not too bad, put me in a group, and I lose it, even if it was like five of us in this room here with no other sound on, I'd still not be able to follow everybody's conversations." (Mary/S1).*

These problems mean that a lot of normal activities, especially social and public activities, become difficult for the stroke survivors.

> *"It might be the time of the day, the length of time things take, crowds as well, erm, some restaurants we can't go to because it's noisy in the background so he can't keep up with the conversation because there is background noise going on, and if it's busy people are pushing into him, so he's conscious of his arm, and his balance and things, so a lot of things like that that we've sort of, not chosen to do, that we used to do before. Like going to concerts at the arena and stuff like that, and going to football matches and stuff like that, we've not done purely because of the crowd situation, that it's too much" (Claire/S1).*

Even factors such as the weather could restrict the stroke survivors.

> *"Sometimes when he wants to go to the shop but it's like, say, like today's weather he wouldn't mind it, but say like last night when it were right windy and stuff, if that were like, in the day time then he wouldn't have gone outside. The weather affects him." (Rosemary/S1).*

Emotional impact

The emotional impact of stoke on the participants was complex and changing, however, anger and frustration, and fear were mentioned most frequently.

Anger and frustration

Anger and frustration were common emotions for the stroke survivor. People with aphasia found it frustrating that they were unable to communicate with the people around them.

> *"That was the frustration I think more than anything else. Well, because when someone was saying, look Jeremy, what do you think about this, this and this, I couldn't talk." (Jeremy/S1).*

> *"If I try and come across with what I want, and I can't get it over well and the more I'll try to do that, the more I'll get really really frustrated, that's what I hate. Yeah, that's a horrible feeling frustration." (Mary/S1).*

Physical disabilities also caused frustration, and Eva described how she would do her best to exercise by walking around her living room, but felt angry about how little she was able to do.

> *"I don't know, I just get up and walk up and down and I get angry." (Eva/S2).*

Being unable to continue with the activities they had done pre-stroke also caused anger and frustration.

> *"He gets right angry with himself sometimes, do you know like because he can't do what he wants to do, he gets right angry with himself, he gets quite mad and stressed out." (Rosemary/S1).*

Fear

Fear was mentioned repeatedly by participants. The stroke itself, being sudden and unexpected, caused a great deal of fear.

> *"It frightened you to death, yeah you think you're gonna be crippled or whatever, you know you don't think they are ever gonna get right." (John/S2).*

Some of this fear was related to the impact of the stroke, for example, some participants were prone to seizures and feared this happening, especially in public.

> *"If you're younger you might go to a pub, they'd be, lots of people, talking very loud, they'd be music, TV, it's like wow, and you can have seizure as well which is well worth it. Erm, I can't do things like that I get quite scared." (Elliot/S1).*

Others were fearful because there physical problems made them prone to accidents.

> *"You fear in shower and that if you don't get you foot in an' that. You fear that, don't you?" (Colin's wife/S2).*

The participants with cognitive problems were often fearful of being lost and confused. Elliot dealt with this by only going to places he knew well. Others took people with them if they needed to go anywhere.

> *"...well if I go shopping I have to take someone with me, because I can't go on my own, I try but it's not very good. Because I'm frightened that I don't go to the right place." (Christina/S1).*

Mediating factors

There is not a simple relationship between the problems experienced as a result of the stroke, and the impact of the stroke on the participants' lives. There are many factors within the life of the stroke survivor which mediate with the impact of the stroke and affect the situation of the stroke survivor.

Family and social network

The stroke survivor's family and social network appeared to have a great impact on their situation, and particularly the presence of a spouse can mean that the stroke survivor is enabled to continue their previous participation, even if in a modified form. Wallace and his wife continued to see friends, although he is now reliant on his wife to choose his clothes, and to get around safely. His friends are understanding about the impact of stroke.

> *"...but our friends understand that I am not as quick as...and me thought process aren't quite as quick as they used to be [laughs] and it doesn't really matter." (Wallace/S2).*

Having family around can also modify the emotional impact of the stroke.

> *"Reseacher. Umm, umm. So you have some days where it gets you down and some days you, you just get on with it.*
>
> *Eva. That is when me daughter's here.*
>
> *Researcher. Umm.*
>
> *Eva. Yeah.*
>
> *Researcher. That's a better day is it?*
>
> *Eva. Better days when my daughter's here.*
>
> *Researcher. Yeah.*
>
> *Eva. We can, we can sit down and we can talk." (Eva/S2).*

Other medical problems or illnesses

Many of the stroke survivors had further setbacks following the stroke, which had an impact on their recovery. The immediate impact of April's stroke was that she was unable to walk or talk. She recovered well, but not completely, and her recovery was set back by a suspected repeat stroke. Twelve months after being discharged home, her speech was good and she was able to walk but she did not go out very often and was struggling to cope in the house. Similarly, Colin and Sandra also experienced setbacks when they had falls. Colin had experienced very little change in his condition since returning home from hospital, with his mobility quite limited he was reliant on friends and family to leave the house. A fall in the bath which hurt his shoulder reduced his mobility further. Sandra had been severely affected by her stroke, and a fall at home which resulted in a broken hip, had taken away any further hope of ever walking again.

> *“...what bit of hope I got 6 months ago, I haven’t got now.” (Sandra/S2).*

Age

Age was mentioned as a factor in recovery, in that recovery may be more difficult for someone older.

> *“I honestly think that if I had been older say in my 80s I would not have bothered as much as I have done to try and get better, especially if I have been on my own.” (Catherine/S3).*
>
> *“I was initially half-paralysed but have since made a very good recovery – surpassing all predictions. I have high hopes and dreams for a full recovery because I am relatively young.” (Andrew/S3).*

Age also affects the likelihood of having other conditions which may hinder recovery from stroke.

> *“Researcher. Has your age made any difference to how the stroke has affected you?*
>
> *Gerald. I guess so, I don't have ailments except from the stroke.” (Gerald/S3).*

For the older stroke participants, the natural decline of certain functions that comes with age, combined with the effects of the stroke.

> *“April. What’s the good in putting things away if you can’t see them, that’s my problem that I haven’t got a very good memory now...*
>
> *Researcher. Mmm, is that since the stroke your memory loss or has that just been a gradual thing, coming with age*
>
> *April. No that’s age.” (April/S2)*

Summary

I have provided a description of the impact of stroke on the stroke survivors in this study, in order to set the scene for the analysis which follows. This provides a context in which the reader can view the interpretative analysis.

Visual representation of themes and sub-themes

Themes and sub-themes are represented visually below, in relation to the central concept, participation.

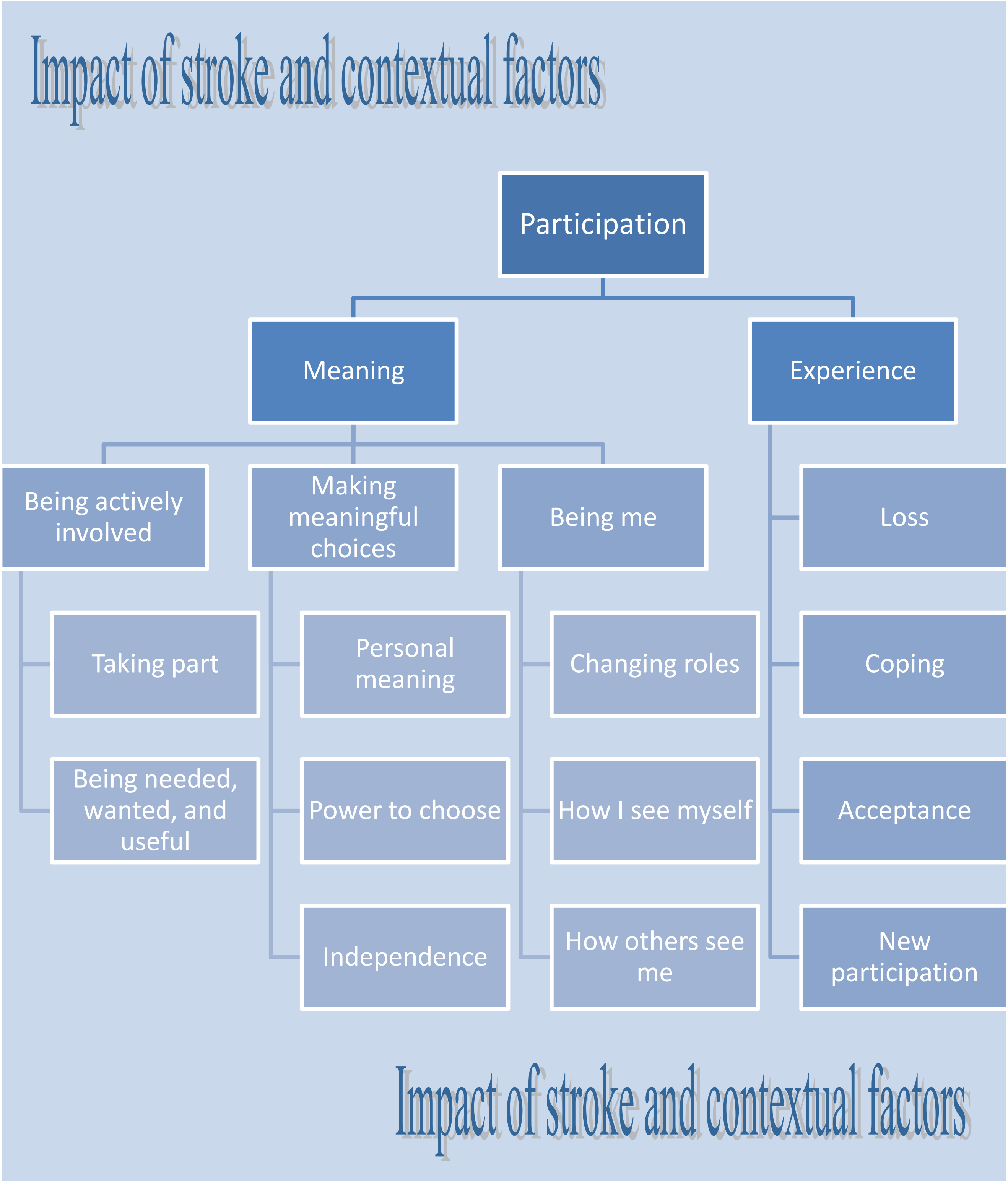
Impact of stroke and contextual factors
Participation
Meaning
Experience
Being actively involved
Making meaningful choices
Being me
Loss
Taking part
Personal meaning
Changing roles
Coping
Being needed, wanted, and useful
Power to choose
How I see myself
Acceptance
Independence
How others see me
New participation
Impact of stroke and contextual factors

Figure 9: Visual representation of themes

Description of themes and subthemes

Meaning

Stroke survivors were specifically asked what participation meant to them. In addition to this, the way people spoke about their lives gave the opportunity to explore the meaning of participation, and what distinguished participation from other activities. The impact of having a stroke on participation had led stroke survivors to reflect on the meaning, and it was often through what was lost that the true nature of participation became apparent.

> *"I think that most of the time, people get on and do things, get on with their lives, see people, do things, go to work, blaadiblaa, without the word participation ever entering their heads, and it's only when that participation has been withdrawn, if you like, from them that you begin to think how much you value that." (Victor/S1).*

I will now describe the themes and sub-themes which constitute the meaning of participation for stroke survivors in this study.

Being actively involved

The first sub-theme of meaning is 'being actively involved'. Words that people used to describe participation had common elements which suggest an active involvement. This included 'taking part' and 'being needed, wanted and useful'. This suggests that it means not only being present, but having an active role.

Taking part

> *"it means taking part, being one of the team...a cog within a wheel..." (Tony/S1)*

The stroke survivors described how participation meant being part of something, which involved working in co-operation with others.

> *"I was in forces for 3 years so I participated in a lot of team work and you work better as a team. Sometimes if you do things on your own it doesn't work out properly, but if there's two or three of you, different ideas and merge your tactics" (Tony/S1).*

While this could be experience of work, study, or involvement in community activities, others used partaking in the research as an example of taking part.

> *"...when you like, co-operate with someone, and take part in something, like with the study you're agreeing to let people have information and your opinions and stuff." (Rosemary/S1).*

Participation also meant to take part in day-to-day life, and this could be compromised by the impact of the stroke. For example Jeremy's wife describes how his cognitive problems prevent him from taking part in the running of the household.

> *"...and it's like the post comes and Jeremy can read part of it but he can't read it all so he doesn't understand the context." (Claire/S1).*

Merely being present at an activity did not necessarily constitute participation. Physical and communication problems meant that even if they could be physically present in a situation, stroke survivors were often not fully included in it, and communication was particularly important in this regard. Elliot talks about his role in the family.

> *"...the communication is between them. I mean I'm still in it but I'm much less. It's rather like having your granddad at home or something like that y'know." (Elliot/S1).*

For some participants, while they had found ways of maintaining their former activities, these activities lacked the active element that is important to participation. Christina was supported by her husband, family and friends in maintaining social contacts, but was not able to join in as she would have done before. Abid had found a way to continue to have a presence in his workplace, but was not able to do much of the work.

> *"I sort of come here into the office in the afternoon and he comes in the morning and I come the afternoon, but basically I don't do any work." (Abid/S1).*

Being needed, wanted and useful

> *"...to be useful in my life, I don't want to sit down and do nothing." (April/S2).*

Participation had an element of being needed and wanted, and people gave examples of times they had been asked to do things, such as helping with arrangements.

> *"...being asked to be involved...like my sister-in-law got married and we were asked to do y'know, organise our clothes and things like that, and my daughters were asked to be bridesmaids for the day, and who was going to go where and when and where we were all going to meet" (Maryam/S1).*

Stroke survivors often felt less needed as other people in their life had taken over certain responsibilities that they could no longer manage.

> *"I was the dad, dad had to sort some things out, d'y'know what I mean, if there were some problems, but now the lads talk to my wife." (Elliot/S1).*

Many of the stroke survivors felt that they were no longer able to participate in their previous useful activities, such as working and contributing to family life, or being part of the community.

Elliot and Jeremy had both become involved in helping others with stroke, and in stroke research. The nature of these activities, which involved helping people and feeling useful, had given them an active role which was lacking in other areas of life.

> *"So if I can help the students as to what's happened to me then I'll do it and also when I go to physio with the students, the students, the students are, how can I say they're not English, they're Asian, or their nationality is different, so when they come into the hall, or when they come to do physio, a lot of them don't, are not 100% as to what to do. So when I know exactly what to do. I will say, what do I do now? Do I get on the bed or something, or do I go to this side or that side. And then the students will suss out as to what they've got to do as well. So I can help them as well." (Jeremy/S1).*

Making meaningful choices

The second sub-theme of meaning was 'making meaningful choices'. It was evident that participation involved an element of choice, and this manifested in the three main ways, 'personal meaning of participation', 'the power to choose', and 'independence'.

Personal meaning of participation

It was clear from the wide range of examples given for 'participation', that participation is a subjective concept, and whether activities are seen as participation depends on their meaning to the individual. A wide range of examples were given by participants as illustrating 'participation' suggesting that participation is highly subjective to the individual. Broadly they included.

- Society level activities such as politics, community and charity work.

  "...with other people for the good of the community." (David/S1).

- Work.

  "I'm married to my office, I work very, very, hard." (Abid/S1).

- Family and home.

  "It means looking after my family like I always have done." (Tony/S1).

- Friends and socialising.

> *"I was an incredibly social person, the rest of the time if I wasn't here with my family and stuff I had a wide circle of friends, so I used to love going out or having people round or stuff like that." (Mary/S1).*

- Everyday tasks such as housework, cooking and eating, walking the dog.

> *"Even if it's as boring as cleaning up or whatever." (Mary/S1).*

- Hobbies, such as walking, reading, and sports.

> *"...of course I was sewing, now I can't do any." (Christina/S1).*

Family was a big factor for all participants, and work was for those who had been working prior to having a stroke (Abid, Elliot, Jeremy and Mary). Abid, Christina and Mary specifically mentioned friends and social life, and Abid and Tony also talked about a community level participation. Abid's was a more formal involvement in politics, whereas Tony's was an informal but important participation in the life of his local community.

Ultimately it was the meaning that the activity had for the individual, rather than the activity itself, which defined it as participation. For example both Christina and Eva mentioned sewing as a hobby they had before the stroke. Christina had been a talented seamstress, which her husband was keen to emphasise, and for Eva, sewing was a connection with her past in her native country.

> *"I sew from back home so from when I was a teenager" (Eva/S2).*

As well as being unable to partake in some forms of participation, there were also examples of where an activity that was previously meaningful had lost its meaning due to the stroke. For example, Mary's relationship with food had changed.

> *"I used to like parties y'know, I used to like people coming round and making food for them, stuff like that so, I can't say, food doesn't have the, I don't like, the food doesn't attract me like it used to. I actually do [whispers] 'microwave things' and stuff, which er, it's a good job my mother's not here." (Mary/S1).*

Mary needs to partake in eating for survival but the meaning of it has changed for her, and it is no longer a form of participation.

The power to choose

The wide range of examples given for participation show it to be highly subjective, and so personal choice is essential to its essence – choice in what to participate in, but also the power to choose, both of which can be influenced by stroke.

The distinction between activity and participation was discussed in the focus group, where one participant suggested that personal choice was central to the distinction, participation being.

> *"...something that you like doing and you want to be doing it..."(Tony/FG)*,

and activity being,

> *"...something that you've got to do." (Tony/FG)*.

This relates to other comments in the interviews about participation containing an element of choice, for example Tony's sixteen-year-old daughter Rosemary attended college as well as caring for her father, and defined participation by referring to group activities in her classes, suggesting that something compulsory may not be considered as participation.

> *"...you might take part in it and you might not, it's up to you." (Rosemary/S1),*

For people with stroke, a degree of choice may be removed if they are not able to participate in the way they would wish to. For Tony, being outdoors and doing outdoor activities was one of the main ways he participated. Since his stroke he was not physically able to do many of the things he used to do, and even simply going for a walk outside seemed daunting.

> *"...even though I love being outside I've got no confidence to do it any more." (Tony/S1).*

Sandra was reliant upon carers coming into her home, and so was not even able to choose when to eat or drink, or use the toilet. We can compare Sandra to Eva, who was also reliant on others but had a little more physical ability. At times Eva chose to do more for herself than she was advised to do, to try and maintain her sense of control.

> *"...sometime I use this to to like how they showed me at the hospital to push this in the kitchen and move around the sink or you know to help myself because I can't give*

> *them all the all the what you call it I have to have some for myself. [laughter] I can't let them take away everything." (Eva/S2).*

By exercising choice in this way, Eva is demonstrating how central choice is to the essence of participation.

Independence

What became apparent initially during the analysis was that participation was seen as something done with others, involving interaction. When I presented this to the focus group, they felt that doing things alone was also an important aspect of participation.

> *"It's being involved with other people and doing things with others and individually as well." (Jeremy/FG).*

For example, being able to do loved activities alone, which had always been done alone, was a form of participation. The need to have someone with them for such activities, which was often the case following a stroke, could make the activity seem less like participation, which refers to an element of independence. It was not only important to be able to do loved activities alone, but to have time alone to contemplate life was seen as a way of participating in ones' own life.

Mary explains how she feels a lack of participation even in the mundane aspects of life.

> *"I have to wake up in the morning and see if this is one of the days where I will be able to do what I want to do. Even if it's as boring as cleaning up or whatever, but if I have bad days, it's not just like a one on one off or whatever, sometimes a bad day can be three days, in which case, if you walked in this house after that they'd be dog hair everywhere, it'd just be sheer filth y'know, but I see muck or whatever, and there's days when I just have to let it go, I can't do it. I can't participate in those sort of things which I'd have done every single day without thinking about it." (Mary/S1).*

Being me

The third sub-theme of meaning was 'being me'. It has been demonstrated that participation means to be actively involved and to make personal choices. But it is also apparent that participation has a more profound meaning for stroke survivors, that of defining who they are. 'Doing' and 'being' were often mentioned simultaneously, suggesting that they are intertwined.

> *"...participation is being [able] to do..." (Elliot/S1).*

> *"I cannot be the same person as I was before, as due to my mobility I am unable to do the same things." (Catherine/S3).*

Stroke, which had an impact on what the participant could do, ultimately had an impact on their sense of self.

> *"I want to be me again...I know I had a mild stroke but whether I had the stroke or whether I'm not I want to be me." (April/S2).*

> *"I want old Mary that I used to know, because I want to be that person that I was...I've lost so much of the Mary that I used to know, sometimes I look back and I'm not exactly sure how much of it I am anymore." (Mary/S1).*

The way Mary spoke about her old self and her old life, seemed to indicate a split within her. There was a sense of the old self carrying on in a parallel universe while her conscious self was stuck in the post stroke situation. She says of reading.

> *"...it's better than being in this real world." (Mary/S1).*

Mary's use of 'this' rather than 'the', suggests there is more than one, she is in 'this' world, but the other world still exists for her. Her stroke wrenched her from her old life so suddenly that this may be the sense that she has been left with.

Three elements appeared to contribute to the challenge to self: changing roles; how I see myself; and how others see me.

Role change

The impact of stroke on participation meant that stroke survivor's roles often changed. This was most notable in the younger participants, who had often been working and actively bringing up children prior to the stroke.

> *"Nine times out of ten my husband, who's been working all day has to do the cooking when he comes in because by that time I'm absolutely shattered. And going from being the person who actually totally did run this house, I don't, I feel incredibly uncomfortable." Mary/S1).*

My initial impression from the analysis was that age and gender were mediating factors in the impact of stroke, as they clearly played a role in determining the impact of stroke. However, on closer examination I came to the conclusion that they also formed a part of the theme 'role change', as much of the impact of age and gender was that it determined the roles that people had prior to stroke. This was seen implicitly as the role change was notably less dramatic in the older, retired participants. It was also explicitly mentioned by some participants. Over the course of the year following his discharge home, John seems to be gradually accepting himself as 'old'. This is done with humour and seems to be part of a positive acceptance of his situation. Sandra on the other hand, mentions being too young to go into a care home.

> *"I'm not old enough to go into a home. I don't want to be surrounded by really really old sick people yet." (Sandra/S2).*

Claire, the wife of Jeremy, who was 45 when he had his stroke, reflects on how the impact of stroke may differ with age.

> *"...perhaps when people are older, they're quite happy not to participate as much, and perhaps if you're retired and elderly, and you did not perhaps do a lot of things before, you know you were quite happy to sit in and read and watch telly and do a bit of shopping and things like that, but we had more of an active life than that." (Claire/S1).*

This certainly seemed to be demonstrated by Wallace. His relationship with his wider family was not affected by the stroke, as the expectations on him as a grandparent centred on visiting and being visited, which continued as before. However, if he was a parent to young children, or working to support family, the impact could have been very different.

Some participants questioned whether the changes they had experienced would have taken place anyway, as part of the ageing process. Stroke may illuminate the ageing process, or make it progress more quickly.

> *"See some of this is difficult to separate, whether my levels of participation in social activities were getting less anyway, for various reasons, or whether it's, I think it's a combination of the two, the impact of the stroke and the kind of natural or...tendency that is there anyway." (Victor/S1).*

However, role change seemed to be experienced by all participants to some degree, for example Wallace, while retired, still had an active role at home prior to his stroke, doing DIY and gardening. Tony was retired from the armed forces, but still very active in his local community, taking boys on outdoor excursions and assisting elderly people. They all felt the loss of useful activity in their life.

> *"...people don't tend to come and see you as much as they used to, cos you're of no use to them really. Can't take the kids out any more y'know, can't pick the kids up and swing 'em round, how to climb trees and tie proper knots in climbing rope." (Tony/S1).*

April and Sandra had both had caring roles prior to the stroke, April staying with her family in a different city when needed, and Sandra living with her elderly mother. Catherine had been a manager of a care home prior to her stroke. None of them were able to continue this following the stroke. Having been involved in the caring profession or caring for a relative, and then being in need of care, led the stroke survivors to reflect on the change.

> *"Being a registered care manager, and working in care for over 30 years I thought I knew it all. But looking back I really had no idea, how it was not to walk." (Catherine/S3).*

The participants' roles in their relationships changed, as they often became reliant on a partner for help.

> *"She were always there but now I realise she's gotta be there...I might as well cut me throat if it weren't for her." (Colin/S2).*

Having to rely on others was an issue for many participants.

> *"I used to be very independent, and I could do most things. Now I have to rely on others although I do try and I hate asking for help." (Catherine/S3).*

John had experienced a dramatic role change as he had been a publican prior to the stroke, living above the pub, and was unable to return there after his stroke. This had meant a complete change in his social life, as well as his work. A few months prior to the stroke he had lost his wife to cancer, which added to the complete change. At the end of twelve months at home, with relatively good health, John had embraced the life of a retired single person.

> *"...best job I've ever had." (John/S2).*

There were other examples of how role change could have a positive impact. When I met Eva she was a person with ongoing illnesses and disabilities, and her role in life was defined by this. Her daughter came once a week to take her shopping, and she was reliant on home help. The stroke compounded her difficulties but did not change her role.

However, at twelve months she reported that her son had become ill with depression and spent time in hospital. Eva had suffered with depression herself, and her son had become reliant on her, often coming and sitting with her to talk things through. This had given her a new role which took the focus away from her own problems.

> *"Like my son problems, that was my problems as well...But he's in hospital at the moment, so, that problem has dissolved mine a bit. S-So...so I have to say that I'm cop-coping a little bit better." (Eva/S2).*

Gerald had refused to take on the role of a disabled person, and feels that this attitude helped his recovery.

> *"I'm convinced that my refusal to be disabled helped me. I was described as the fastest recovering adult the rehabilitation centre had ever seen." (Gerald/S3).*

This awareness of changing roles and trying to modify this, was common among the stroke survivors. The most notable example of this was Abid, who worked out a way of maintaining his role in the workplace despite not being able to carry out a lot of the work. He sold half of his accountancy business to his friend's son, who did most of the work, while Abid came into the office in the morning. While he was not able to do very much work, his continued presence helped to maintain business contacts, and he was able to maintain his perception of himself as a useful working man, as well as keeping him financially stable.

How I see myself

It was acknowledged by participants that the stroke had an impact on their identity, but many referred to feeling that they were the same person inside.

> *"I am me. I think the same I can do most things but slower." (Andrew/S3).*
>
> *"I'm sure people think my brain is affected, although I'm still the same person inside." (Catherine/S3).*

Colin, Eva and Wallace did not appear to experience a significant change in the way they perceived themselves, and this probably relates to the minimal role change they experienced. Personality may also play a role, for example Colin came across as a traditional man with a stoical outlook, and explained that he never really felt upset or depressed about things.

For other participants, the impact of stroke on participation changed the way that they saw themselves. Mary is acutely aware of her inability to perform tasks that she would have done every day without thinking about it prior to her stroke.

> *"If I now had to pick up something that I could have done with my eyes shut when I was at work, I wouldn't be able to do it, any of it. And that upsets me greatly." (Mary/S1).*

The findings suggest that often the impact of stroke can result in negative self-image and decreased confidence.

> *"I now feel I am a vulnerable adult who is a burden on society...you feel you need to be a strong virile person but appear and feel quite the opposite." (Andrew/S3).*
>
> *"You can't tie your shoelaces at 64 year old, and you can't write your name, it's like being a child again." (John/S2).*

While many participants described such negative emotions, there were examples of stroke survivors maintaining their self-image even in the face of considerable difficulties. For Abid the experience of being ill was new to him, and being a well person seemed to be part of his identity.

> *"I came here in 1967, and I have been living here for the last 42 years, and this is the first time that I've been to hospital" (Abid/S1).*

After his stay in hospital, Abid wrote the hospital a letter to thank them for looking after him. This could be interpreted as him situating himself as a healthy person who temporarily entered the world of ill people, therefore helping him to maintain his identity. Similarly, April reports that she received a phone call from a fellow patient in hospital, who thanked her for keeping her spirits up, and April had told me how she had been chatting to all the patients and trying to find ways to help people, when she was a patient herself. Again we can see the identification of self with an aspect of pre-stroke health, as April had previously been a mid-wife so had a caring role.

Sandra's stroke and subsequent fall left her with severe disabilities, but her intellect and communication were unaffected, and it was apparent that she had taken very clear control of her situation through these means, so even though she was forced to be physically passive, she was able to express her opinions and therefore maintain some control, and therefore I think, her sense of herself as a capable woman.

> *"...well I feel that it's me that's coping with it and I have to know just how much there is...and you know, it's me that should be able to tell them what it's like and what I need really." (Sandra/S2)*

Even her period in hospital where she had felt bullied by the ward sister, had less affect on her sense of self as she felt clear about whose fault it was. She blamed the ward sister who put her in a private room for her slow recovery, rather than putting all the focus for recovery on herself.

Looking at the longitudinal interviews we can see how people changed the way they saw themselves during the year following the stroke. In her first interview, April identified with her former caring role and saw herself as active and useful, but by six months, when she had not been able to resume her role, the focus changed and her sense of self seemed to reflect her current situation more. April described herself as 'lazy' at six months, and is self critical, but does reflect on the need to accept the consequences of the stroke.

> *"You can try as much as you can to get back to the old life but you're never going to get back there I don't think." (April/S2).*

By 12 months, she seems to have moved towards this.

> *"I never mind I'm quite happy because you know but I never used to be in the house when I worked ...I worked day night day night day night and I lived in the clothes you know I did not have to wear ordinary clothes because I had, I lived in my uniform all the time so you know I never worried and we did in those days we used to work long hours ...this is my time now and I don't worry I think well you know I've always got something to do." (April/S2).*

John slowly starts to see himself as 'old' over the course of the year, but this seems to be a positive thing for him, as by 12 months he is comparing himself favourably to others of the same age. Perhaps it is a way of maintaining a positive self-image to move from seeing himself as a young man who had a stroke, to an older man who is in good health for his age. Reaching his official retirement date seemed to help this transition. Wallace also compares himself favourably to others of a similar age.

How people saw themselves also had an impact on their attitude to rehabilitation following the stroke.

> *"I was quite determined and I thought to myself I'm not going to be like that." (April/S2).*
>
> *"I couldn't walk for the first couple of months, so my son bought me a wheelchair. I had longer hair and my son said I looked like Father Ted, y'know cos my hair's grey, so I threw the wheelchair and forced myself to get a walking stick and walk up and down, so y'know you have to push yourself." (Tony/S1).*

Self-image seems to have an impact on confidence which in turn affects participation.

> *"...where did Mary's emotions go, I was an incredibly strong woman, could always look at things to see the different sides and stuff, I knew how to work them out, and, y'know I don't think there's ever been a time up until this thing, where I would ever walk away from something, y'know, I'd always stick at something if I was convinced that I could do something, I'd just keep on and keep on, so that side of me has totally gone, and I don't know if that is because of the confidence and stuff but I really don't know." (Mary/S1).*

The stroke survivors demonstrated that the stroke had affected the way they saw themselves, and many actively strove to maintain a positive self-image and adapt to new circumstances. Ultimately many people who have had a stroke are required to come to terms with seeing themselves differently, and finding worth in different qualities.

> *"I assumed that I had to make a living for the benefit of my family and put that before them often but now I put them first. It probably changed because I can't work as long post stroke." (Gerald/S3).*

How others see me

It was not easy to distinguish between the participants' awareness of how they saw themselves, and how others saw them. For example April's determination to manage her own self care could be seen as being conscious of how she appears to others. Colin did not make any reference to the perceptions of others, but John and Sandra seemed most affected by the views of others, possibly because of the severity of the role change they had experienced.

Throughout the course of the interviews, a picture is created of who the pre-stroke person was. This is done subtly, and maybe subconsciously, through a series of references. It illuminates the importance of self-image, and that self-image has taken on importance through being challenged. Maybe this is a way of saying 'this is who I really am', as stroke changes the way people perceive the stroke survivors.

Other people's reactions often brought home to stroke survivors how they appeared following their stroke.

> *"I couldn't work out why everybody looked as sad as they did, y'know, I've never seen Victor upset, what's this about, I must make people think that I'm OK, I don't want to see that on people's faces. So I think a lot of that was I was worried what other people perceived me as." (Mary/S1).*

Sandra saw a reflection of herself in a doctor she had known for years, who was shocked to see her after the stroke.

The perception of others also influenced the opportunities people had for participation, and their willingness to participate. Eva and Wallace both mentioned not wanting to be a burden on others. For Eva this prevented her from asking for much help from her family, and for Wallace this was a fear he had in relation to his wife.

Aphasia could also cause people to respond differently to stroke survivors, and the people in the stroke survivors' lives varied in how skilled they were at communicating with the aphasic stroke survivor.

> *"Claire's mum and her partner talk to me no problem at all, but Claire's dad and her sister and her husband have real problems talking to me." (Jeremy/S1).*

> *"I think certainly the way people respond to her and particularly the way they respond to her aphasia is pretty crucial, erm, y'know the more people erm, how can I put this? The more people...respond to what Mary's trying to communicate and don't get hung up on the process if you like of communication, and that can be quite difficult for people I think because talking to somebody with aphasia is pretty novel for most people and they do get, they are struck by the aphasia rather than what people are trying to tell them. So the quicker people respond to Mary rather than her speech, and can show that they're comfortable in her presence, that makes an enormous difference. And I also think the less they, the less they respond to her illness and her disability, y'know, the less they think of her in terms of someone who has had a stroke, and more as a whole person, that's...and...the friends and people that she knows that she's still in contact with, they very much do that." (Victor/S1).*

The desire not to appear disabled had pushed Tony to manage without his wheelchair, but he then experienced the problem of ‘invisible disability’, where people’s expectations of him would be unrealistic because he did not appear disabled. Other participants were concerned that they appeared drunk or stupid, because people did not know what was wrong with them.

> *“And the other thing is I must look like I’m drunk. Because I can’t get my, I’m not steady either” (Mary/S1).*

Sandra does not see many of her friends, and she feels they are embarrassed to see her. She is self-conscious about going out when she does get opportunities because.

“you don’t look alright.”(Sandra/S1).

John lost most of his pre-stroke friends, and felt that because people did not know what to do or say, they stayed away. While he was readjusting to his new role as retired person, he was conscious of where he fitted and how he was perceived. For example he attended a stroke group but felt it was for ‘old women’. He went on a cruise which he enjoyed, but felt self-conscious of being alone.

> *“You feel like a hindrance to everybody.” (John/S2).*

Others had a more positive experience with friends, such as Wallace, who was able to carry on his social life with friends who made allowances for his post-stroke memory, and Christina's husband states.

> *“I find that people are very understanding towards Christine, very understanding.” (David/S1).*

Christina and Wallace both had well-established social networks that had responded well to the impact of stroke. Mary found that being with old friends who really knew her made her feel more like her old self.

> *“A couple of mates who’ve known me virtually all my life are good at helping me like that. Because if they’ve known me for long enough they know what the old Mary would have said at that bit. So they’ll actually say, oh, do you mean so and so, yep, and, or occasionally this, no that, no, yes” (Mary/S1).*

Abid mentioned that he sometimes needed to ignore his family's concern for him in order to continue to participate in the way that he wished.

> *"...my family in the sense that, they don't know, they don't want me to do any participation, active participation in the politics, because they think it's y'know, they think y'know, I don't feel well health-wise and they are worried for me. But sometimes I listen to them and sometimes I don't listen to them." (Abid/S1).*

John is also jokingly aware that crown green bowling, his new hobby, is seen as an 'old person's' game. John has been conscious of people's perceptions of him, and felt some stigma, but had continued to try to participate. Other participants had found it less easy to overcome the stigma.

> *"I feel very vulnerable...I now limp and feel vulnerable when faced with groups of teenagers mocking my limping." (Andrew/S3).*

'How others see me' demonstrates a two-way relationship between 'being me' and participation. Participating helps people to feel like themselves, while 'being me' also gave people the confidence to participate. 'Being me' is an important aspect in the meaning of participation, and seems to be profoundly affected by people's experience of participation following stroke.

Experience

As people spoke of their experience following stroke it was possible to ascertain various elements of experience, which were loss, coping, acceptance and new participation. Loss was experienced to some degree by all participants, though there was wide variation in the nature of the loss and its severity. Coping strategies were used by all participants throughout the time following their stroke, and changed according to their situation. Acceptance was an issue for all participants, as even those who did not reach it were aware of it as a goal.

Loss

The first sub-theme of experience is 'loss'. Without exception, the stroke survivors felt a sense of loss immediately after their stroke, and usually into the years following. The loss was at many levels, beginning with loss of function, and ultimately entailing loss of participation.

Other areas of loss included marriage breakdown, being unable to continue to work or study, being unable to look after pets, and loss of friends and social networks.

> *"I think there's no doubt that Mary does feel very, feels very much a lack of her previous social networks, and the role that she played within those." (Victor/S1).*

Those participants with aphasia were especially affected by a sense of loss.

> *"I used to speak quite a lot, and I always add something to the conversation, to friends, and if there is debate, and I will always pass off questions and I basically ... I can't speak." (Abid/S1).*

As one eloquent email interviewee suggests, perhaps this is because language is so much a part of who we are as people.

> *"Voice is our primary means of expression, it is at our very core. Language is the critical component of identity, and the currency of friendship. Without language, the aphasic sufferer feels bereaved and degraded." (Wilfred/S3).*

For Mary, aphasia affected an important part of her personality.

> *"I've just always had a thing about words. You come out with a word and I think, where did that originally come from? Or play around with words, and I was very quick at making puns and jokes about words and things like that, can't do any of that." (Mary/S1).*

Similarly, people avoided physical confrontation because of physical weakness.

> *"...all your confidence just slips away." (Tony/S1).*

Mary, who loved to debate with people, no longer felt able to do so because she knew her aphasia would leave her in a weak position in an argument.

> *"I've changed drastically in terms of the way I talk to people, even if I think somebody's in the wrong and something I know is correct or whatever, I'll never argue with anybody. Because I know if it comes down to, right let's have an argument about it, I wouldn't be able to. I don't bother. Cos I think, well if you challenge me, I will not be able to erm, win that challenge. So all that's, the confidence I would have, and the sociable bit of me wouldn't have been phased by anything that anybody anywhere..." (Mary/S1).*

Stroke undermines people's confidence, and that lack of confidence leads them to feel unable to do the things that they want to do.

> *"The other thing is it's how it's affected my confidence. The confidence thing is enormous. And I wonder if a lot of these things I tell you, if I could just find some more confidence somewhere I might be able to push myself more." (Mary/S1).*

When stroke survivors spoke about how their participation had changed, it was often with a profound sense of loss, comparable to grief. What they had lost was more than just an activity such as work or socialising. The loss of role associated with changing participation had led to a loss of sense of self.

> *"Loss of role, loss of everything, has completely gone. And loss of identity. People, my wife will say, well you're still Elliot, I still love you, and I'm like, yes I accept that, but I'm not what I was." (Elliot/S1).*
>
> *"Well I'm 80...so that when we reach that age... and you've been active all your life... not sat down and done nothing, um, it really does have a lot effect on you." (Wallace/S2).*

The change for many from pre-stroke to post-stroke life was overwhelming.

> *"...just turned my life upside down." (John/S2).*

The stroke survivors demonstrate how central loss is to their experience of participation, and how the loss of participation impacts upon their sense of self.

Coping

The second sub-theme of experience is 'coping'. At all stages after a stroke, it was clear that a wide variety of practical and emotional coping strategies were employed to enable participation. The development of effective coping strategies was linked to acceptance, as an acceptance of a situation or current level of ability, led the stroke survivors to a 'working with what I've got' attitude.

> *"It's just working your way round it." (Tony/S1).*

Colin's main coping strategy was to make use of aids around the house. He had accepted his physical limitations quite early on, and seemed very willing to make use of aids as a way of maximising what he could do. Although he did not explicitly speak about emotional coping strategies, at six months, when his physical condition had not improved, he and his partner both spoke about problems they were having with the health service, perhaps as a way of externalising the reasons for the lack of change.

> *"Interviewer. So how have things been since last time I saw you?"*
>
> *Colin. Nay, not nearly too bad, but..."*
>
> *Colin's partner. It's... I don't think nowt's changed m'self. ..he can't use his hand yet"*
>
> *Interviewer. "Right. OK."*
>
> *Colin's partner. There's no cor.... There's no, err, correspondence between different departments, d'you know what I mean?"*
>
> *(Colin/S2).*

Eva used fairly consistent coping strategies throughout the year, which was a combination of aids around the house and home help, and her own efforts to do what little she could in order to maintain her sense of independence. However, she modified the latter slightly after having a fall, for fear of falling again.

> *"...after I have the shower they will... like the floor...to clean ...because I can't clean it, mop there...because I fell down because it's wet." (Eva/S2).*

Sandra's stroke and subsequent fall left her with severe disabilities, but her intellect and communication were unaffected, and it was apparent that she had taken very clear control of her situation through these means, so even though she was forced to be physically passive, she was able to express her opinions and therefore maintain some control, and therefore I think, her sense of herself as a capable woman.

> *"...well I feel that it's me that's coping with it and I have to know just how much there is...and you know, it's me that should be able to tell them what it's like and what I need really" (Sandra/S2).*

Eva attempted to carry on doing whatever small things she could around the house, and many people mentioned a determination to manage self-care.

> *"I managed to walk to the toilet. Toilet's most important <laughter>...It is. It is. Everything else. It's the dignity of being able to go to the toilet." (April/S2).*

Colin and Wallace both rely heavily on their partners for support. Wallace needs his wife to help him remember things and assist him with practical things that he finds difficult.

> *"Margaret really has to get me clothes ready to dress me...because I can't tell you know, when it comes to cream, white, I can't, can't tell...and I have got a pair of*

> *shoes that, two pair of shoes, a black pair and a brown pair...I could have a brown one on, and a black one <laughter>" (Wallace/S2).*

Other people are often used to reduce fear, as many things that previously would have been straightforward, are the source of fear and anxiety following the stroke. Having someone with them seemed to be a common coping strategy used by stroke survivors.

> *"...well if go shopping I take someone with me, because I can't go on my own, I try but it's not very good, because I'm frightened that I don't go to the right place" (Christina/S1).*

While having another person with you can be viewed as a coping strategy, it can also be viewed as a modification of participation as things that might be preferred to be done alone now need assistance.

A common emotional coping strategy was to make comparisons with others who had had a stroke.

> *"I mean if you've got a stroke like some of them and they really couldn't do anything and you want to sit and weep for them don't you." (April/S1).*

April's coping strategies changed throughout the year, to reflect her situation. When I first spoke to her, she spoke of the coping strategies she had used in hospital to aid her recovery, and would use at home to enhance her mobility.

> *"I want to be able to get down those steps outside and get up. And this morning I had a try and I walked down the steps and I walked up I took me, I need my stick." (April/S2).*

At 6 months, when progress had not been as swift as she hoped, her coping strategies had moved to managing around the home, ensuring she could participate in looking after herself.

This remained at 12 months, when she had also developed emotional strategies to come to terms with the situation.

> *"If I can't do it, I can't do it and I just have to you know I see, I try the best as I can but you can only try...I have a dinner in my fridge that I, if I'm really hungry and I can't get myself I can get that dinner out...One of those readymade tins... And I don't get worked up about it because I think as long as I'm eating...and that I have to accept things." (April/S2).*

We can see that all of the participants used some forms of coping strategies, regardless of the level of their disability. Some participants used particularly creative coping strategies to work out solutions to the problems they faced due to the stroke. Abid worked out a way of maintaining his role in the workplace despite not being able to carry out a lot of the work. He sold half of his accountancy business to his friend's son, who did most of the work. Abid came into the office in the morning and while he was not able to do very much work, his continued presence helped to maintain business contacts, and he was able to maintain his perception of himself as a useful working man.

> *"I'm very active in the sense, and in the business my job is to get the business because I know a lot of people for the last 25 years, so my job is to get the business, and his job is to get it done." (Abid/S1).*

At each interview John appears to be using three types of coping strategies. Practical, using aids around the house, which he relies on heavily at first but by 6 months he has limited this to just a bath board; comparing himself to others to assess both his progress as a stroke survivor and his general health compared to his age group; and trusting the opinions of health professionals, which he uses to reassure himself. We can see his progression over the year by looking at how he compared himself to others.

> *(From first interview) "...you can't tie your shoe laces at 64-year old, and you can't write your name, it's like been a child again." (John/S2).*
>
> *(From 2nd interview) "I got me house sorted since, well I say sorted but...not bad for a bloke on his own, who's old [laughs]".*
>
> *(From 3rd interview) "But you don't realise how old you are really. I never for one minute, me, think I'm 65...I think I'm about 23".*

As well as coping strategies developing in order for facilitate participation, participation itself was a coping strategy for the emotional impact of the stroke. Jeremy, Elliot and Tony all speak about the importance of 'keeping busy'.

> *"...otherwise you go stagnant don't you, just sit in the house and stagnate." (Tony/S1).*

Although Jeremy and Elliot both seemed to gain something from being involved with stroke research and other similar things, they also both made references to the fact that doing something was what mattered, not necessarily what it was. Jeremy later talked about how if he is not busy he thinks about life before the stroke, so being busy may be a tactic to not dwell on the past.

It is apparent that a wide range of coping strategies are used by the participants, demonstrating that stroke survivors adapt to their situation and find ways to maximise participation, even if it may still be relatively limited.

Acceptance

The third sub-theme of experience is ‘acceptance’. The initial stages of stroke are often characterised by intense feelings of loss and grief, whereas coming home seems to be a time of optimism and looking to the future, with high expectations for recovery and resuming normal life. However, six months after coming home, some participants were dealing with the disappointment that recovery had not been as swift or complete as they had hoped.

It seemed necessary for the stroke survivors to reach a degree of acceptance regarding their current situation and abilities, in order to develop coping strategies and move on.

April was determined and optimistic when she was first discharged home, and was working hard to improve, but by six months had realised that she would not make a full recovery, and talked more of herself as an older person.

> *“But when you get older, you get in a way like this.” (April/S2).*

With John we see a big change between the first and second interview. When first discharged home John is still shocked about the change in his life.

> *“I can’t believe it... it were emotional, I mean you’re frightened to death, I mean you can’t walk, I mean I have always been fit and I have never been to doctors in me life and one minute I mean...” (John/S2).*

By six months he had accepted it and found ways to move on. When he reflects back on how he felt earlier on, he described how he lost his wife, and then had the stroke which meant he lost his work and home as a publican.

> *“It were too much to get used to all at once.” (John/S2).*

By 12 months.

> *“I’ve accepted what I’ve got.” (John/S2).*

Jeremy displays acceptance in describing how he feels he and his wife do all that they can with their current situation.

> *"I think we've done as much as we can do really, y'know, going to meetings, going to town and all the rest of it, seeing people and so on, and that, y'know, a lot of people don't do anything. Y'know, it's really hard for them to get to town. Y'know, and that's the problem, and if I can do anything that I want to do then great. Because when I was in hospital the doctors thought I wasn't going to do anything." (Jeremy/S1).*

While acceptance for many is a stage reached at some time following a stroke, some participants showed a lack of acceptance even a few years after the stroke.

> *"I must feel selfish in a way I think, because y'know, because I've got a lot going for me, but I don't particularly want what I've got, I want old Mary, because I want to be that person that I was. And I thought y'know it would come easily year after year after year but it doesn't. I still want that person back still." (Mary/S1).*

Sandra, whose condition worsened after being discharged home, due to a fall that broke her hip, did not appear to reach any sort of acceptance.

> *"I died on the day I had the stroke." (Sandra/S2).*

It seems natural that it would be more difficult for Sandra, as for her the change was the biggest. She was going from being a fit and active woman, caring for her mother and her husband, to being virtually bed-ridden and in need of help with the most basic personal care.

Colin and Wallace both appear to quickly accept their situation, and adapt their lives to their new circumstances.

> *"You've got to if you want to keep going." (Colin/S2).*

Because they were both retired, and lived with supportive partners, they were not required to make big life changes due to their stroke, which may be why they were able to accept their situations quite quickly. Eva also seems accepting of her situation, possibly due to her long history of illness making her well practised at accepting limitations.

There appears to be a relationship between acceptance and participation. Firstly, an acceptance of the current situation can lead to solutions which ultimately benefit participation. Abid realised he would not be able to continue working as before, and so he sold half of his business to a younger man, and they then shared the workload in a way appropriate to Abid's abilities. In this way he continued to participate in his working life. Acceptance also seems to relate to participation in that acceptance precedes moving on, and moving on can mean finding new and more appropriate activities.

Acceptance is clearly an important milestone for many participants, and the following sub-theme will demonstrate how acceptance can assist with finding new participation. However, acceptance was not reached by all participants, and may depend on factors such as age and previous roles. How easy it is to reach acceptance appears to be related to the degree of role change experienced.

New participation

The final sub-theme of experience is 'new participation', referring to activities started post-stroke, which tended to have a positive impact and to be a result of gaining acceptance and developing coping strategies. There were many examples of this in source 1, but in source 2 only John and Eva appeared to have engaged in new sorts of participation. It may be that it takes longer than one year to reach this point. It could also be that the participants in source 1 were younger. For example April, Colin and Wallace seemed to have concentrated on participating in pre-stroke activities, even though they could only do these with assistance and to a lesser extent, and seemed satisfied with this.

John, who had entirely lost his old life as a publican found a new form of participation. He had a key moment in a counselling session when he realised he could spend the rest of his life miserable, or get out and do things. He found a new hobby which he could do despite his physical problems, crown green bowling, which led to a new circle of friends.

Eva starts thinking about more suitable activities she may be able to do as soon as she comes home from hospital, and by 12 months she has been able to start attending a stroke support group. We have already looked at John's transition from shock over his stroke, to acceptance, to taking up a new hobby of crown green bowling that becomes the focus of his life. Acceptance was a necessary precursor for taking up a new hobby.

> *"it's like, well I did go and see a, well it's not like, like for depression, I saw a doctor...just to have a chat, basically she said you can either sat there and be a*

> *cabbage, or you have got to accept what you have got and get on with your life again... I saw her about three times." (John/S1).*

In general, experiences of 'new participation' were positive, whereas experiences of returning to old participation could be disappointing. In both Elliot and Jeremy we can see that participating in new activities following stroke has been a positive experience, and for Elliot has given him an opportunity to feel like his old self.

> *"I felt really incredibly pleased that, I can't remember how I got involved in it. Someone said, do you want to go along to the houses of parliament? Erm, from Yorkshire, and a few other people around the UK, they were gonna talk to the MP's Lords. But we were getting a hotel free, and your wife can come with you, because she's a carer too, and your wife can come with you, dinner, I've never been there. And that was, I talked to the secretary of health, I can't remember her name, and my name got in it, and from that, erm, it's only happened twice. The BBC radio, which was the stroke survivors. The guy was saying well what does it matter, what happens? Erm, and dealing in some of the newspaper. They've been and gone, but I though, oh, that was part of me a little bit there. I can go along and it doesn't worry me, I haven't lost that bit, me as a nurse, you erm, pretend if you like, I've never been to the BBC before, and I got there and it's scary, and I thought, get on with it. And things like that are good." (Elliot/S1).*

In contrast when Elliot attempted to visit his previous place of work it was a very negative experience.

> *"...and I've tried going to where I used to work on the train, I've done that once, it was so incredibly scary, I would never do that again. It sounds, if you imagine, well you do, if you go on a train, now it's all electrical stuff, it tells you which platform at what time. And I'm trying to read it and it's disappeared. To get on the train, you want to stick down, and they don't have those little sticker things, it's little computer things now, you can sit here from...and I can't work it out, so I go and stand, I give up. You can't understand it. It's horrible." (Elliot/S1)*

New participation is likely to be chosen for its appropriateness to current abilities, and for Elliot and Jeremy this directly related to their experience as stroke survivors.

Summary

This chapter has described the key themes and sub-themes within the data. I have described the meaning of participation to stroke survivors, including the elements of 'being actively involved' and 'making meaningful choices'. I have explored the deeper meaning of participation to stroke survivors, 'being me', which describes the impact of participation on self-identity. This relationship is one of the reasons for the intense feelings of 'loss' experienced by stroke survivors. Other elements of the experience of participation are 'coping strategies', and 'acceptance'. Acceptance can lead stroke survivors to finding 'new participation', which appears to have a positive impact on the stroke survivors' sense of self. However, not all stroke survivors reach acceptance.

The next chapter will examine the longitudinal participants and how their experiences over the year following their stroke relate to the sub-themes of 'experience' presented in this chapter. This will enable the reader to see how the themes apply to individual stroke survivors, and enhance the understanding of the relationships between the themes, as well as explicating the temporal nature of the post-stroke experience.

Chapter 6: Case studies – Understanding Transitions

The six participants from the longitudinal cohort will be presented below as case studies. Providing case studies will help to highlight the process of change that the participants under-went following the stroke. It will also allow for me to show how the sub-themes relating to experience apply to specific participants in different ways.

Due to confidentiality issues, I have changed some details of the participants stories, which are not directly related to the stroke and its impact on participation. IPA is always the interpretation by the researcher, of the participants' interpretation of events. The stories I tell below are my interpretations of the stories that the participants told me, at three time points following stroke. Firstly, within a month of coming home from hospital or rehabilitation centre, and at six and twelve months later. The stories are based on the interview transcripts and observations made in my research diary.

The central aim of the longitudinal cohort interviews was to explore the experience of participation. Therefore, this chapter mainly refers to the sub-themes of 'experience': 'loss'; 'coping'; 'acceptance'; and 'new participation', although it does also touch upon sub-themes within 'meaning', particularly the 'being me', sub-theme, which is closely related to 'experience'.

I have included below the table showing the participant characteristics of the longitudinal cohort, which will now be discussed as individual case studies.

Source 2 participants							
Pseudonym	**Gender**	**Age at 1st interview**	**Communication difficulty**	**Language**	**Ethnic Origin**	**Marital status**	**Lives with**
April	Female	78	None	English	White British	Single	Alone
Colin	Male	68	None	English	White British	Married	Wife
Eva	Female	58	None	English	Black Jamaican	Divorced	Alone
John	Male	64	Mild dysarthria	English	White British	Widowed	Alone
Sandra	Female	69	None	English	White British	Married	Alone
Wallace	Male	81	None	English	White British	Married	Wife

Table 8: Source 2 participant characteristics

Colin – "...it's just one of those things."

Colin was sixty eight when he had his stroke. He was retired, and living at home with his wife. He had a stroke at home and while he and his wife did not understand what was happening, his daughter was there at the time, and realised it was a stroke. She called for an ambulance. Colin spent time on an acute stroke ward, and then a rehabilitation centre. He came home three months after his stroke.

I met Colin at home, with his wife. They were a working class couple living in pleasant semi detached home, which was warm and comfortable. Pictures of the grandchildren decorated the mantel piece. Colin's wife sat in at each interview, and often helped Colin to remember dates and the order of events, which he seemed to struggle with. Colin described himself as having been active prior to the stroke, enjoying darts and particularly golf. Despite a large extended family, family did not seem to have been a big part of his life, other than his wife.

The impact of the stroke had been left sided paralysis and dysarthria. By the time I met Colin at home, he was able to walk with a stick but not use his hand very much, and appeared to speak clearly, but he felt there was still some weakness and he sometimes dribbled food when eating.

Colin came across as rather stoical, and he explained that he did not readily express emotions. Occasionally in the interviews I had with him, he would refer to his wife and how much she had helped him since the stroke. He would not look at his wife at these times, and I got the impression that it was unusual for him to speak of such things. He never once complained about the disabilities he had due to the stroke, or expressed any sadness about it. This may be because his lack of emotion was part of his identity, and so to maintain his sense of 'being me', it was important to him to appear emotionally strong in this situation. His only complaint was about his adult children, who he felt disappointed in since he had come home, as they had not helped him as much as they had promised.

At the first interview he described life post stroke as *"...not 30% what it used to be, in terms of activities and that."* The thing that struck me during all my interviews with Colin was his acceptance of his physical disabilities. It appeared that after his time in the rehabilitation unit, he did not feel he had any control of gaining any more physical function. When I asked him at the first interview if he left the house, he referred to the aids that he was waiting for (including hand rails for the steps at the front door) which he hoped would help him to get out the house. It is meaningful that he immediately referred to this, rather than to any expected improvement in physical function. This can be seen as a type of emotional coping strategy. Colin received support from his wife, who had become his carer since he had been at home, and also from friends and neighbours. At the first interview he described how one friend would come every day to see if he was alright, or needed anything.

Typically, loss of participation is experienced less intensely by those at retirement age, as while all stroke survivors seem to experience losses, for these participants the loss most often relates more to hobbies than to work and family roles, which appear, unsurprisingly, to be more central to stroke survivor's sense of 'being me'. However, there are exceptions to this, as in the case of April, who despite being retired for many years, still identified strongly with her previous career as a midwife, and had continued this identity in having a caring role within her family. Exceptions such as these highlight the relationship between participation and 'changing roles'.

At the second interview, both Colin and his wife felt that nothing had changed in his physical condition, and also in the amount of participation that Colin could do. Again, they referred to external factors rather than personal factors to explain the lack of progress. The sub-theme 'coping' describes the many different coping strategies people use to adjust to their situation, and this could be an example of one sort of emotional coping strategy. Colin had been waiting for a leg brace to help his mobility, but this had been delayed due to a lack of communication between different departments at the hospital. Colin was reliant on friends to take him out, as his wife did not drive. Once again, this was all reported without any apparent sadness or distress. When I probed further into how he was coping emotionally with the change in his life, he said he had adapted to the new situation, *"you've got to if you want to keep going".* The sub-theme 'acceptance' describe how some participants come to accept their situation, which Colin seemed to be able to do quite quickly.

While he had managed a game of golf, he had not found any new activities to be involved in. 'Acceptance' can be a pre-cursor to finding 'new participation', but in Colin's case this did not seem to have happened. He did point to a pile of DVDs that he would be watching, and his wife raised a concern that he spent too much time watching TV and did not get enough exercise. As in the previous interview, the most emotion he showed was towards his wife, as he described how she helped him with his personal care, *"I might as well cut me throat if it weren't for her."* In some ways I found his apparent lack of embarrassment at being dependant on his wife at odds with his stoical masculine image. Combined with the other comments that suggested any further recovery would be due to external factors, this could be seen as part of an overall passive response to the post-stroke condition. It may also be that his appreciation of his wife, which he said had increased since the stroke, meant he wanted to give recognition to the role that she took.

At the third interview Colin reported that he had fallen, which had further set back his recovery. Despite this he felt his confidence had improved somewhat, although it was dependent on knowing that his wife was there to help. He had started taking short walks and had lost some weight. He also cited an example of having to walk to the bus stop because he had an appointment at the hospital and his friend was not able to take him. Previously he had described this walk as something that he could not do. He was looking forward to going golfing with a friend once the weather improves, which he was able to do if he used a golf buggy.

Reflecting on the level of participation that he was able to do, Colin felt he was a bit better. He elaborated by describing how friends came to take him out. Again, this indicates a passive attitude to life after the stroke. Colin has never referred to his own abilities or potential to improve, perhaps because he feels this is beyond his control. He seems content to live within the limits of how much others are able to help him. Throughout the interviews Colin has shown a remarkable level of acceptance of his situation, however, it may be that the passive nature of this acceptance has prevented him from finding new participation more appropriate to his abilities.

Viewing Colin's story in the light of the theme 'experience', which includes the sub-themes 'loss', 'coping', 'acceptance' and 'new participation', we can see that while Colin experienced some losses due to the impact of the stroke, they were not as intense as they may have been for someone younger and still working. His main coping strategy was to rely on his wife for assistance, whom he appreciated greatly, and they both appeared to use the strategy of looking for reasons in external factors, when progress in recovery was not as rapid and complete as they hoped. Colin managed to get back to a modified version of his old hobby, golf, by using a golf buggy, but did not engage in any new participation over the year. It may be that the passive nature of this acceptance has prevented him from finding new participation more appropriate to his abilities. It is also apparent from looking at the findings as a whole, that those participants with spouses as carers, are supported in returning to their old activities, and so the motivation to find new activities may be less.

John – “Not bad for a bloke on his own, who’s old.”

John had his stroke when he was sixty three, a few months before he was due to take early retirement from his job as a pub landlord. He had a stroke at home when he was alone, but realised what was happening because of an advertising campaign on television, and called the ambulance. He spent eight weeks in hospital, and was not able to return to his previous position as pub landlord, where he lived on the job. The stroke had affected his left arm, and his walking. He had recovered well, but still had some weakness and his left arm and walked with a limp. He had also had some dysarthria, which he was still conscious of when tired.

At my first interview with John, he was thin and frail looking, very emotional, and obviously still trying to come to terms with what had happened. I visited him at his home, which was a house he had bought in order to renovate it to live in after his retirement. On my first visit it was clean but not very welcoming, being quite sparsely decorated. John described repeatedly the shock he felt at going from being a busy man, working in the pub and working on his house, to being in hospital unable to walk. In comparison to Colin, who had experienced little role change, John’s role change due to the stroke was immense. He referred to others in the hospital, as being in a *“...worse state...”* than him, a coping strategy used by many participants, seemingly in order to put their own suffering into some kind of context.

John has two daughters, and had lost his wife to cancer just a few months before the stroke. He had nursed her until her death, and felt he was just beginning to move on when the stroke happened. He described the effect of the stroke as *"...me life got tipped upside down"*. The house he was now living in had been intended as their retirement home together, and he described being there alone as, *"..awful...absolutely devastating."* Not only had he and his wife planned to live there together, but the contrast between that and living above a busy pub was significant, and John felt very lonely. He saw one of his daughters fairly regularly but one not very often as she lived in a different city. He described his disappointment with *"..so called friends..",* as he saw very few of the people he knew from the pub since he had his stroke. The experiences that John described, and the way he described them, indicate an intense sense of loss, caused by the stroke but no doubt exacerbated by the loss of his wife a short time before. Again we can see that the theme 'loss' is not only related to the severity of the stroke, but also to the degree of 'changing roles' that the stroke survivor experiences.

John did not feel comfortable in the house on his own, as he felt afraid of falling and being alone. He had an alarm around his neck in case this should happen, but still felt uncomfortable. He described feeling a lot of fear, about having another stroke and having to stay in hospital. His physical recovery from the stroke had been good, and he had been advised that he could ultimately regain about 90% of his function, which is what he hoped for, including being able to drive again. He had found the emotional adjustment the most difficult aspect, as the stroke had happened shortly after losing his wife, and he had gone from a job where he was surrounded by people, to being completely alone. He also found it difficult to have to depend on others for help, having been independent previously. 'Independence' is an aspect of the 'meaning' of participation, as it can signify to people their ability to participate in their own life. It may also relate to the theme 'being me' linked to both sub-themes, 'how I see myself', and 'how others see me'. John saw himself as an independent person, and having to rely on others challenged this, as well as making him self-conscious with other people.

When I asked John about what his hopes were for the future, he said he wanted to be able to do up the garden. He reflected that prior to his stroke he had not looked after his health, as he drank and smoked. Since the stroke he had given up smoking, drank very little and was eating brown bread and other things recommended by the doctor. Despite John's struggles with some aspects of 'being me', this is an example of the way that 'how I see myself' can be challenged in a positive way. The doctor was pleased with his progress and John seemed to take comfort from this. This is another coping strategy employed by John, which was to follow the doctor's advice and rely upon their judgement.

When I telephoned John to arrange my second visit, he told me over the phone how well he was. When I arrived at the arranged time, he was out, and later explained he had forgotten my visit and gone out bowling. We rearranged the time and he was at his house for the next visit. As soon as John opened the door, I could see he had changed since the last visit. He had put on weight and looked fit and healthy, and was also animated and cheerful. During the interview John reflected on how *"It were too much to get used to all at once".* He had seen a psychiatrist a few times, who had given him the ultimatum of staying as he was, depressed and doing very little, or accepting what had happened and getting on with his life. He took this on board and the turning point had been when the Stroke Association gave him a list of activities that he could try. He attended a couple of stroke support groups that he did not feel comfortable at, as most of the attendees were older women, and tried crown green bowling. This seemed to have become the focus of his life, giving him a purpose and also a new set of friends. The encouragement John had received to find acceptance of his situation was clearly a turning point. In contrast to Colin's acceptance, John's acceptance had motivated him to find new participation which was suited to his post-stroke abilities.

He also explained how he had more confidence generally, and no longer used the alarm system that he had worn around his neck. His hand was nearly back to normal and although he walked with a limp he saw that as *"...something I have got to live with",* again indicating acceptance of his situation. He still used a board on the bath to help him get in and out, and felt it was better to be on the safe side with this, as he lived alone and did not want to risk falling. He had finished work on the house and garden, and was able to drive again.

He was getting used to living on his own, but still found long dark nights lonely and difficult. He had been on holiday, on a cruise, and was planning to go on another one. He had gone on holiday alone, which was in contrast to his life in the pub, being surrounded by people, but he reflected that in some ways he was on his own there, *"...because you couldn't really make friends with anybody really...and when you talk to everybody, you actually keep a* *certain distance you know."* In reflecting in such a way, John may have been attempting to create congruence between his pre and post-stroke roles, in an attempt to maintain 'being me'.

Despite John's general positivity, there were still things that he found difficult, *"I want to do everything I used to do, and I can't."*, and he mentioned feeling a hindrance to other people on holiday, who were mostly couples. In general though, he seemed very positive and optimistic. It seemed to help that he had now reached his official retirement age, and life was similar to what he might have expected at this time, if the stroke had not happened, also lessening the contrast in roles that he might feel. He seemed to have adopted the identity of an older man, which perhaps he did not have prior to his retirement. In this way John seems to have altered his self-identity somewhat, to suit his new situation, therefore lessening the challenge to 'being me' that having the stroke initially presented him with. He had continued with the healthy lifestyle he had adopted, not smoking and drinking very little. He also went to the gym regularly, as well as bowling at least three times a week. John mentioned that he was scared of having another stroke, and I think that following the doctors' instructions and doing everything he could to be healthy was a way of coping with this fear.

In my third interview with John, he reiterated a lot of what was said at second interview. He was still enjoying bowling, and felt his confidence was steadily growing. He had been on another holiday and this time single people had been specially catered for, so he had felt more comfortable being alone. This is another example of John's finding new participation suitable to his new situation. While he wished his wife was with him to share his retirement, he felt his life was better now than prior to the stroke. The stroke had made him try new things that he would not have done normally, and also encouraged him to give up drinking and smoking, which he did mostly because of being a pub landlord. It had also made him want to make the most of life, feeling before that he had been complacent. John seemed to value the medical opinion of his health, and took comfort in all his tests being clear and being discharged from the doctors, which he saw as a milestone.

John is unique among the participants in presenting an example of all the sub-themes of experience and the way they relate to each other. The first time I met John, his sense of loss was palpable, and easy to understand on hearing his description of his life prior to the stroke and how much had changed. By the second interview it was clear he had employed many ways of coping, including aids around the house, and following the doctor's advice on healthy living. In addition to this he had realised he had to reach acceptance of his situation. Throughout the second and third interviews it was clear that through a combination of coping strategies, and an attitude of acceptance, John had been able to build a new life for himself, which had involved identifying new participation which was appropriate to his post-stroke abilities. New participation seems to be dependent on acceptance, but does not necessarily follow from it, as in the case of Colin. The difference between Colin and John may be that as John did not have a spouse to support him and buffer some of the impact of the stroke, he was forced to take a more pro-active approach.

April – "I was an active young woman."

April was 78 years old and lived alone. She had never married and spent her life working as a midwife until her retirement. She had her stroke at home, and when she realised something was wrong she managed to call her sister in London who called an ambulance. The impact of the stroke was aphasia and mobility problems. By the time she came home after 6 weeks she had almost entirely recovered her language, and could walk with a stick.

I visited April at her home, which was a large semi-detached house. The garden was very overgrown, and the house very cluttered, to the extent that April had to clear a small space for me to sit down. However, it did not seem to be particularly unclean. April was very welcoming and gave me coffee and cake. She seemed to be very happy to have someone to speak with and also took an interest in me and my life. She was a very talkative person and it was occasionally a struggle to direct her to the topics that I wanted to cover.

Prior to the stroke April had been active, and had often travelled to London to care for sick family members. Despite April being one of the oldest participants, and having been retired for some time, she had still identified herself with her job as a midwife, and caring for family members seemed to be an extension of this. Because of this, April experienced quite an acute sense of role change. This is an example of how while the sub-theme 'changing roles' is often related to age, it cannot be simply explained by age at the time of stroke.

April described her stay in hospital as a time when she felt very determined, and put a lot of effort into being able to do the things she felt were essential. Her biggest fear was not being able to speak, and she was also determined to be able to go to the toilet. She described how, when everyone else on the ward was sleeping, she would be lying in bed repeating whatever words she could remember, trying to get her language back. We can see from this that April participated actively in her rehabilitation, and this relates to the sub-theme of meaning, ‘taking part’. Putting all her efforts into this can also be seen as a way of coping with the situation she found herself in.

At this point April was not able to go beyond her front gate, so could not do her shopping, but was working towards it, and was determined to be able to cook and clean, and this seemed to be associated with a deeper need to maintain her self-identity, *“...I want to be me again.”* This highlights the connection between participation and ‘being me’, inthat certain activities are needed to reinforce stroke survivors self-identity. She was also trying to increase her mobility by taking short walks outside, and increasing the length each day. April seemed to have very clear strategies for her recovery, which may have been due to her professional health background, and also reflects ‘being me’, specfically ‘how I see myself’.

April described her emotional reaction to the stroke *“...I could have just sat down and wept.”*, showing her experience of the feeling of loss, but also described how she had rallied herself, as she felt she had some time left to live and wanted to be useful in her life. However, she was not at that time able to have any sort of social life as she could not leave her home. She did not mention any friends or family coming to see her.

The second time I saw April she was not so positive. She seemed a little confused, and thought she might have had another small stroke the previous week. This had affected her eyesight. She also felt it might be the combination of medication she was taking, which she was uncomfortable with. The temporary blindness had scared her, but she had been to see the doctor and he had taken her blood pressure and told her that she was OK.

There seemed to have been a shift in April from planning strategies for recovery, to preparations for her future death, as she had started making a will and also wanted to sell a house that she no longer lived in. She described herself as lazy, and said that she sometimes could not be bothered to cook. This was quite a contrast to the determined lady

I had met previously. The loss of confidence may come from the disappointment April felt in her lack of recovery and being able to do the things that were central to her self-identity, 'being me'. Even in this altered state of mind, April was using active coping strategies in order to deal with the situation.

When asked about her progression over the last 6 months April explained that she had been *"...getting on alright",* she had stopped having people to help her with the cooking and cleaning, and using a special bus service in order to get out when she needed to.

Overall April had tried her best to get back to how things were prior to the stroke, but while she was managing, she felt things were very different to before, *"...you can say that once you've had a stroke that is the end of your old life and you come into a new life...you can try as much as you can to get back to the old life but you're never going to get back there I don't think."* At this point, approximately six months after coming home following the stroke, April appeared to have become truly aware of the loss she had experienced.

At my third interview with April, she was quite upset because of a break-in at her house, and it was difficult for her to focus on anything else. She felt that things had not improved much since I had last seen her. I noticed that the way she spoke about things changed, and seemed to indicate a growing acceptance of her situation, *"I try the best as I can, but you can only try."* She was just about managing the housework on her own but was looking for someone to come and help for a few hours a week. Prior to the stroke April had a caring role, and she continued to do what she could in this sense, by telephoning her sister twice a day to check on her, which may have been an attempt to preserve her sense of 'being me'. Overall I had the impression that April was beginning to accept her physical limitations, but was finding any sort of problems in life quite overwhelming.

Despite April's age, she still identified herself as an 'active young woman', and so unlike some of the other older participants, such as Wallace and Colin, the impact on her sense of 'being me' was quite acute. Throughout the time I visited April there were examples of how she tried to maintain her sense of self by continuing aspects of her old role, for example by helping other patients at the hospital. Like other participants, the full impact of the loss was not understood at the first interview, but by the third interview, when she had not recovered as she had hoped, she described what she saw as an overwhelming and permanent change from before her stroke. This led to an acceptance of her situation, although it was obviously not an easy thing to accept. April did not seem to have found any new forms of participation, but she did do some things, such as telephoning her sister daily to see how she was, indicating a desire to continue with her caring role as much as possible.

Eva – "I can't let them take away everything"

Eva was originally from Jamaica, and had lived in the UK since she was 18 years old. She was 58 years old when she had a stroke, which occurred while she was waiting for a blood test at the hospital. Eva had a number of long term conditions, including vertigo, epilepsy and something she described as "*weakness in my body"* which had meant that for most of her life she had been unable to work. Eva's life was clearly lived in the context of these conditions prior to the stroke, and rather than the stroke being life changing, it was one more condition in an ongoing pattern of illness and disability. This made it difficult to distinguish the impact of the stroke from the other conditions, but Eva described the stroke as quite mild, and while speech was initially affected she felt it had come back to normal. It did seem that the stroke had also limited Eva's mobility more, as prior to the stroke she had been attending a college course, which she could no longer do but hoped to get back to. Due to Eva's history of illness and disability, the stroke itself did not seem to have impacted much on her sense of 'being me'.

Eva had children and grandchildren who lived locally and visited her, and she had a weekly shopping trip with her daughter. However, she seemed to spend most of her time alone in her small, tidy home, and expressed concern about putting too much pressure on her family, who had jobs and families of their own. Throughout the year following the stroke Eva was mainly limited to the kitchen and living room, where her bed also was. While Eva was always friendly and polite, she also seemed shy and reserved, and it was difficult due to this to establish a good connection with her in the time period of the interview. I found she would open up more towards the end of the interview, when she seemed to relax a little bit more. In addition to her physical illnesses, Eva described how she struggled with depression and anxiety*, "sometime I feel so I have so much fear that my chest like it going to swell",* particularly she feared death, to the extent that she could not attend funerals.

'Independence' is an aspect of 'making personal choices,', a sub-theme of the meaning of participation. Despite her long term conditions and being largely housebound as she was unable to walk very far unaided, Eva tried to maintain her independence in her own way. She had carers who came in the afternoon and evenings, but in the mornings she tried to do what she could for herself, such as making the bed and mopping the floor. At the first interview she described how she was trying to increase her mobility by walking back and forth in the house.

The second time I visited Eva, she described herself as *"a lot better".* To an outsider, the changes were very minimal, but in the context of Eva's quite limited abilities, small changes made a big difference, for example she was able to manage the stairs better, which meant that she could manage her personal care more independently. She had also had a fall, which had broken the door but not caused her any serious injury, and she was quite bright and cheerful when telling me about this. She was planning on attending a stroke support group, and also hoping to return to college. Her optimism about the possibility of becoming involved in these activities is an example of the importance of the 'being actively involved' aspect of participation.

There had been a particular event that had an unexpected impact on Eva's general outlook. Her son also suffered from depression, and had been hospitalised due to this for a time. He was now out of hospital and regularly sat and talked about his problems with Eva. She described how having to take on her son's problems had put her own into perspective, *"that problem has dissolved mine a bit".* This also indicates that she has been able to fulfil another element of the 'being actively involved' sub-theme of participation, 'being needed, wanted and useful'. These small improvements in Eva's level of participation seemed to have affected a general increase in self esteem and well being. She described her depression and anxiety as a little bit better, and how she tried to control it.

By the third interview, Eva described ups and downs, and it seemed like she had not further improved since the last time I saw her. The lasting impact of the stroke which was clearly distinguishable from her other conditions was that she was less steady and kept falling and being unable to get up, which made her mobility very limited, and she was constantly scared of this happening. She had not yet been able to attend college but attended a stroke group every week. She enjoyed this and was not concerned that most of the other people attending were older then her. While some participants found it challenging to suddenly be identified with older, disabled people, Eva was perhaps more used to this environment because of her previous ill health. This relates to the 'how I see myself' element of 'being me'.

Eva did not seem to follow the loss, coping and acceptance trajectory of many of the participants, and this is most likely because prior to the stroke she already had multiple health problems, therefore the problems presented by the stroke were part of an ongoing life of illness and disability and did not signify a sudden change.
However, it was interesting to see how the themes relating to the meaning of participation applied to Eva, as her participation appeared to be quite limited. Despite this it was still possible to see evidence of the importance of making personal choices, and the difference in Eva's general when being when she felt able to take part, and be needed, wanted and useful.

Sandra – "I died on the day I had the stroke"

I visited Sandra at her home, where she lived alone, and was limited to a hospital style bed which was in the living room, and chair next to it. She had carers coming in throughout the day, to assist with personal care and housework. Sandra was 68 at the time of her stroke, and her life prior to the stroke had been very different. She had lived with her elderly mother, and been a carer for her, which she had not found particularly physically demanding. She also had a husband who was in a care home as he had dementia, and she visited him regularly. She described herself as fit and active, and would meet friends in town for a break from her caring responsibilities. Similarly to April, despite being over retirement age, Sandra had an active role caring for others, and so the stroke had meant a significant role change for her. However, she had previously had some health problems, including breast cancer, from which she had recovered well, and she had also had problems with her leg, which she had broken some years before and needed several operations on. It was while she was recovering from one of these operations in hospital, that she had the stroke.

Sandra had been having some rehabilitation at home, which she was progressing well with and had hopes for a good recovery, but she then fell and broke her hip, which caused a set-back in this process. The doctors had been unable to operate on the hip as they did not feel Sandra was well enough to cope with the operation, and at the first interview Sandra was unable to walk more than two steps. She was hoping to have the operation within the next two months.

Sandra had a brother who lived nearby, but she did not see him due to a fall out. She was very fond of her adult sons, who visited when they could, and also took her out, but both lived far away. She described how she was in regular phone contact with one son, who worked nights, so she was able to talk to him when she could not sleep.

The impact of the stroke of Sandra’s life was devastating. While her life prior to the stroke had various pressures, she felt she had everything under control, *“I enjoyed my life”.* The stroke changed everything. Her mother was now living in a care home, and she was unable to visit her and her husband. Even the cat had to be re-homed as she was unable to look after him. She described herself as very bitter about the stroke.

There was a particular circumstance that Sandra spoke about very passionately, which was that during her four months in hospital, she had been in a private room rather than on a ward. She had found this very difficult and the loneliness had made her very depressed. She felt the ward sister had purposely isolated her and been cruel to her, as she had begged her to put her on the ward, *“I will never forgive her for that”.* Although she felt physically well cared for in hospital, she found the loneliness unbearable. When Sandra spoke about the ward sister, she clearly had a valid complaint, but her hatred of this person was such that I wondered if she was transferring a lot of her emotion about the stroke into that one situation, as a type of emotional coping strategy.

Sandra was clearly very depressed about her situation, and fearful for her future. However, despite being extremely limited in her physical movement, she maintained some control over her situation. For example, she was on morphine due to pain in her leg, but had herself modified her dose so that she was not feeling too many side effects, *"it's me that should be able to tell them what it's like and what I need".* By exercising control in this way Sandra was maintaining the aspects of 'making personal choices': 'power to choose'; and 'independence' which form part of the meaning of participation.

Sadly, when I visited Sandra for the second interview, she had been told she was unable to have the operation she needed on her leg, as it was too risky, and had not been given any other options. Therefore she was stuck in the current situation of being immobile and in a lot of pain, and she described her feelings about this as *"dreadful".* The general sense I had from seeing Sandra was one of despair. She felt her life was over and there was no hope for her. She gained little pleasure from her current life, as she was unable even to move around her own home. She felt she had no control over anything, for example as she was reliant on carers to help her to go the toilet, so her 'power to choose' , another aspect of participation, was severely limited.

She still saw her sons when they were able to come, but did not see many old friends, and she thought this was because they felt embarrassed to see her in her current situation. Occasionally her son took her for lunch, but she described not really wanting to go as she did not feel she looked presentable. In this way the stroke had impacted both on 'how I see myself' and 'how others see me'. Despite being the same person, Sandra's friends found her image as a disabled woman hard to cope with, and Sandra herself felt embarrassed about her image when out of the house. The stroke had clearly challenged 'being me'.

At this time Sandra mentioned having to *"start again".* When I asked her what she meant by this, she explained that she needed to forget her old life and existence, as it was too painful for her to remember. However she did not know how to go about doing this. Even in the context of her extreme physical limitations, Sandra was aware of how things could have been worse if her speech had been affected. Having her speech and intellect enabled her to have some degree on control over her situation. Sandra's sense of loss regarding the stroke was very intense, understandably due to the severity of the stroke. However, she was aware that retaining her speech had given her the ability to participate by 'making personal choices', choices that she may not have been able to express had speech been affected by the stroke.

I was unable to contact Sandra for her third interview, although from calling at her house I was able to see that she was still living there. Sandra's stroke was the most severe of the participants, and as her ability to participate was so limited it is difficult to make many comparisons between her and the other participants. The most overwhelming aspect of Sandra's experience was the sense of loss, but it was also possible to see coping mechanisms within Sandra's story, both emotional ones, such as blaming the ward sister for her experience in hospitals, and practical ones, such as using her intellect and communication, both of which were unaffected by the stroke, to retain some control over her life. A central part of Sandra's loss, was the changing role from being a carer to her mother and husband, to herself needing the care. This completely undermined her feeling of being needed, wanted and useful, and also affected both how she saw herself, evident in her feeling embarrassed to leave the house, and how others saw her. Sandra maintained an element of participation through exercising her independence and power to choose, through the means of communication.

Wallace – "when you are that age, you accept things better"

I met Wallace at his home, on a quiet cul de sac where he lived with his wife, in an immaculate house. Both Wallace and his wife were very well presented, and both looked many years younger than they were. Wallace was 82 at the time of his stroke. They were extremely friendly and helpful. Wallace was obviously very reliant on his wife, who attended the interviews and would often prompt him. It was unclear whether this was a role that she had adopted since the stroke, or whether this was the natural relationship in their marriage, as Wallace was obviously a quieter and calmer personality than his wife.

Prior the stroke, Wallace had felt fit and well, and been active. The main impact of Wallace's stroke was an effect on his vision, and also his short term memory. He used to drive but despite having been declared as fit to drive since the stroke, he had not done, as he did not feel confident and was scared of causing an accident. He also enjoyed painting and drawing prior the stroke, but his vision had prevented him from taking this up again.

He found it difficult to distinguish the effect of the stroke on his short term memory, from the effects of normal ageing which had already caused a decline. However, there were some cognitive tasks, such as reading and doing cross-words that he had been unable to do since the stroke. His cognitive difficulties also affected day to day tasks, for example he described how he was able to dry the pots while his wife washed up, but he was unable to remember where they went, in order to put them away.

Despite the difficulties Wallace experienced following the stroke, he and his wife had a positive attitude to life, indicating their acceptance of the situation, for example, they were now using buses as Wallace was not confident enough to drive, and described the bus services as *"wonderful".* Similarly to Eva, who had long term health problems, Wallace's sense of loss regarding his difficulties following the stroke may have been lessened due to the fact that he had been experiencing some symptoms prior to the stroke, which he had attributed to normal ageing. It may also be that due to their advanced years, Wallace and his wife accepted the inevitability of some health problems, and saw it as part of the ageing process. This is in contrast to the initial response that April had to her difficulties. Despite being of a similar age, it took her longer for her to adjust to her difficulties. There is perhaps a contrast in 'how I see myself', between April, who saw herself as an active young woman, and Wallace, who saw himself as an older man in good health. Wallace's self-perception may have made it easier for him to accept his difficulties.

Wallace had a daughter who lived a couple of hours away, as well as grandchildren. They had recently visited and Wallace did not feel his relationships with his wider family had been affected by the stroke. He felt that he was fortunate to have very good friends and neighbours, who had been supportive since the stroke. This is also in contrast to April and Sandra, who roles within the family were changed by the stroke. Both Wallace and Colin's roles were unchanged, which may have made it easier to cope with the impact of the stroke.

During the first interview, Wallace described how he had not thought about the future much as he had just been concentrating on getting home. However, he was hoping to experience further improvements, and to take up drawing again, and also reading. He described himself as "*not a worrier*", and while he had experienced some depression in the acute stage of the stroke, now felt very positive.

By the second interview his eyesight had improved significantly, but his short term memory was still *"terrible"*. Other than that, Wallace felt physically fit, but frustrated at not being able to do the things he wanted to do. He had been able to return to reading books, but had not taken up driving or his artwork. He had also lost interest in gardening due to his colour blindness. His wife also had to get his clothes ready for him to wear because of this. Despite the difficulties Wallace did not feel that his intellect had changed.

He spoke in this interview about the support he received from his wife and that he felt she deserved recognition for it. Particularly in going out he needed his wife with him, as he was very confused and disorientated, and in social situations as he wasn't always able to recognise people he knew. Similarly to Colin, Wallace was very reliant on his wife, and having a supportive spouse may have acted as a buffer to some of the impact of the stroke, affecting their ability to cope.

By the third interview the situation had not changed. Generally, Wallace appeared to be quite accepting of the situation, even though he had not improved as much as he had hoped since coming out of hospital. When questioned about this, he put this down to his age, *"when you are that age, you accept things better"*, noting that, for example, had he been younger and working he would not have been able to return to work.

Despite considerable difficulties following the stroke, Wallace's sense of loss was minimal, possibly due to his age, and also the assistance of his wife. His wife was his main coping strategy, as she would help him with the things he found difficult, and through her he was able to continue with his old life and participation to some degree. He seemed very accepting of the situation, and attributed this to his age. He did not seem to have been motivated to find new forms of participation, and this may be because his wife was able to assist him in participating in the type of activities, such as visiting friends, that he would have done before the stroke. While there was some role change for Wallace, as he was not able to help around the house fixing things and so forth as he had done previously, the impact of the stroke on 'being me', seemed to be minimal, and this is probably connected to his acceptance of himself as an older person and the inevitability of illness and disability.

Unlike John, who had made a transition from seeing himself as a young man to an older man, Wallace had been a well older man, who now had some difficulties with memory and eye sight, which is less of a transition.

Summary and Comparison of case studies

In terms of their demographic characteristics the participants formed a heterogeneous sample, ranging in age from fifty eight to eighty one, and while half of the sample lived with spouses, the other half lived alone. Despite the differences in their circumstances, there are similarities in their experiences and meanings relating to participation, which can be expressed in the sub-themes of the theme ‘experience’: ‘loss’; ‘acceptance’; ‘coping’ and ‘new participation’. However, the relationship of the participants to the sub-themes varies, and is to some extent related to their age and marital status, as well as other factors.

Loss

Loss appeared to be directly related to the changing roles that were undergone by participants. Sandra, April and John seemed to experience the most acute sense of loss of participation following the stroke, whereas Wallace, Colin and April, while loss was an inevitable feature of their experience, seemed to experience it much less intensely. April was one of the oldest participants, but due to her self-perception and her caring role within the family, her sense of loss was much more than a younger participant, Eva, who had long term disabilities which meant that the stroke had not caused such a big change in her role.

Coping

All of the participants found a variety of ways of coping with their situation, including both emotional and practical coping strategies. Although the most effective coping strategies, which led to acceptance of the situation and ultimately new participation, were employed by John, even the participants who were least physically able, Sandra and Eva, had certain coping strategies to try and maintain some control over their situations. In Colin and John we can see the contrast between passive and active styles of coping, with Colin relying on his wife for support, and looking to external factors to explain his lack of progress, while John, with no-one to rely on, built a new life for himself based on his post-stroke abilities.

Acceptance

The case studies illustrate how acceptance can take different forms, and serve different purposes. Both Colin and John achieved acceptance of their situation, in very different ways. Through accepting his changed physical abilities, John was able to select appropriate activities that he could enjoy. Colin also accepted his situation, but with his wife and friend's help in maintaining some of his former activities, was not motivated to find new activities. Wallace and Eva were also very accepting of their situations, in the context of their ages and abilities prior to the stroke. Acceptance was both a pre-cursor to coping, as in the case of John, and also a result of finding ways to cope, as in the case of April.

New participation

John was the only longitudinal participant who had found new participation with the year following stroke, but many of the participants from the other sources who were many years post-stroke had found new participation, which suggests that a year is generally too short a time period for this to happen within.

The longitudinal participants also provide valuable insights into the temporal nature of the post-stroke experience. For example we can see in many of the participants that the sense of loss is often not immediately realised, but is felt deeply after a period of living at home and undertaking rehabilitation, where full recovery may be hoped for and not achieved. We can see how positive, active coping strategies can lead to new participation, and acceptance is also a pre-cursor to new participation, but new participation does not necessarily follow. The role of the spouse seems to be significant here, as those participants, such as Wallace and Colin, with spouses who acted as carers, were supported in maintaining their old activities, even if in a modified form. The spousal relationship itself is also a form of participation. These factors may mean that the stroke survivor with a supportive spouse may feel less of a sense if loss, but also be less motivated to find new participation, which can be very positive, as in the cases of John and Elliot.

It is also possible to see in the case studies, the relationship between the experience of participation, and the sub-theme of the theme 'meaning', 'being me'. The loss of activities, such as the caring roles of Sandra and April, which were most central to their self-identity, were those most acutely experienced as loss. It is also possible to see a variety of ways in which 'how I see myself' and 'how others see me', interact with the experience of participation following the stroke. For example April's attempts to help other patients in the hospitals, and Sandra's self-consciousness about leaving the house when she did not like the way she looked.

Examining the longitudinal participants as case studies in relation to the findings, assists in not only capturing independent aspects of the participant's experiences, but also the inter-relations between the themes of loss, coping, acceptance and new participation, and the temporal nature of the post-stroke experience. Interpretive Phenomenological Analysis entails examining the findings in the light of other research in relevant areas. The discussion chapter will provide in explanation of this comparison, as well as an evaluation of the methods used.

Chapter 7: Discussion

The questions I aimed to answer by carrying out this study were:

What does participation mean to stroke survivors?

How do stroke survivors experience participation?

I used a qualitative methodology, and data from three sources, to successfully answer these questions. By using Interpretive Phenomenological Analysis, I have been able to bring together the multiplicity of the experiences of the participants, and outline certain features that capture the essence of the meaning of participation, and aspects that are central to the experience of participation. While the small sample size necessitates caution in assuming that these results can be applied to the wider population of stroke survivors, I am able to demonstrate the credibility of the research, and comparisons between the present study and other research in this area, also attest to its credibility. This chapter will provide an explanation of both of these points.

This chapter begins with a discussion of the findings from this study in relation to the research from the literature review, and I then appraise the research in regards to its contribution to the subject area, and particularly in the light of its original contribution. I also discuss the appropriateness of the research methodology in answering the research questions, and critically evaluate the methods used. I evaluate the quality of the research against the criteria previously discussed, before making suggestions for further research.

Summary of findings

Participation is a concept which is widely used in health rehabilitation including with stroke survivors, and assessing someone's level of participation can be essential to understanding the impact of a disability on a person's life, and tailoring support accordingly (Cardol, Jong et al. 2000). However, it is an ill defined concept and many argue that participation means something different to health professionals, than to stroke survivors themselves.

My findings showed that to the stroke survivors in my study, participation meant active involvement in activities, and making meaningful personal choices about what to participate in, and how to participate. 'Active involvement ', meant that that there was more to participation than simply being present, or doing. The stroke survivors needed to feel that they were 'taking part' and that they were 'needed, wanted and useful'. Making meaningful personal choices referred to the nature of the activities which constituted participation being unique to each individual, depending on the 'personal meaning' those activities had to them. The 'power to choose' was central to participation, as was 'independence'. The meaning of participation to some of my stroke survivors went further than just 'doing', to them it was about 'being'. What they did defined who they were, so when they lost the ability to participate in certain activities, this affected their self-identity. There were three elements to this: 'changing roles'; 'how I see myself'; and 'how others see me'. These three elements were interrelated. Changing roles was closely related to the experience of participation, particularly to the intensity of the loss experienced in regards to participation. A greater discrepancy between pre and post-stroke roles, led to a greater sense of loss. The way stroke survivors saw themselves, and how they felt others saw them, could both motivate and prevent participation.

Following a stroke, there were three main features that described the way the stroke survivors experienced participation: 'loss'; 'acceptance'; and 'coping'. Loss was felt on many levels, and the loss of participation led to a loss of sense of self, which links it to the 'being me' sub-theme of participation. Acceptance was a state that many reached and others were aware of as a goal, involving accepting their current situation and abilities, and being able to build on this. 'Coping' describes the many strategies used throughout the time following a stroke, to maintain participation at some level, and therefore a sense of self. Coping strategies were used by all the stroke survivors at all stages following the stroke, but acceptance was a precursor to particularly effective coping strategies, and ultimately moving on to find a new kind of participation, and a revised sense of self.

The meaning and experience of participation are clearly related, as the experience of participation is affected by what participation means to the individual, and the meaning of participation is affected by experiences. This link is most obviously observed between experience and the 'being me' sub-theme, but I have also described links between experience and other aspects of meaning, and this is particularly striking in the case studies.

Comparison of present findings to other relevant research

Impact of stroke and contextual factors

The themes related to meaning and participation were viewed within the context of the impact of stroke, and other contextual factors within the participants lives. These factors were outlined briefly, and echoed what had been found in previous research.

Post-stroke, the participants in the present study had problems in the areas of mobility, language and cognition. Many were unable to drive, as reported in studies by Edwards et al., (2006); White et al., (2012), and many reported less obvious but equally disabling issues such as tiredness and environmental sensitivity. Previous literature has attested to the disabling nature of these issues (Crosby et al., 2012, Gunnel et al., 2004). Social isolation was reported by some of the participants in the present study, as found by Northcott & Hilari (2011). As the literature review suggests, mediating factors played an important role in the impact that the stroke had on participant's lives, including support of family and friends.

All except one of the participants in the present study could have been described as moderately affected by stroke, in that they had long term problems because of the stroke that had a significant impact on their lives. For Sandra, the stroke had a more severe impact. She was the only stroke survivor who was completely immobile and reliant on others for personal care. Many of the themes related to Sandra less than to other participants, and it made me question whether the issues for people so severely affected may be too different to effectively study them within one cohort.

Meaning

The first question of this study was about the meaning of participation to stroke survivors. The present study looks at the concept of participation in terms of what it means to the individual. But how does this fit with wider definitions of the term? The Oxford English Dictionary defines participation as 'to take part' or 'to share in' (Pearsall & Hanks, 2010), which also indicates an active element, which suggests that the participants views are compatible with a lay-understanding of the term. Looking at the term from a health rehabilitation perspective, the ICF (World Health Organisation, 2001) defines participation as ‘involvement in a life situation’. This definition is very broad, and findings from the present study suggest that ‘involvement in a life situation’ may not always be participation, unless certain other factors are present, and these findings have been corroborated by the present study. There have been a small amount of qualitative studies seeking to explicate the meaning of participation, and my findings reiterate and encompass many of the factors previously attributed to participation.

Active involvement

This sub-theme describes the active nature of participation: simply being present is not enough to constitute participation, participation necessitates some sort of active involvement, for example for one participant this meant not only being asked to attend her sister-in-laws wedding but to contribute to the arrangements for the day. This has similarities to the value ‘being part of’, found in Hammel & Magasis, (2008) study about what participation means to disabled people. It would also encompass concepts such as ‘doing things for others’ (Haggstrom & Lund, 2008), ‘being engaged’ (Hjelle & Vik, 2011), ‘contributing and receiving resources from society’ (Mars et al., 2008). Barclay Goddard et al. (2012) participants also mentioned ‘being active’ as an element of participation.

Making meaningful choices

My study confirmed the findings of previous studies of participation (e.g. Barclay Goddard, et al., 2012), in illustrating the multiplicity of activities which may be considered participation to an individual. It was possible to categorise the activities that people considered to be participation into areas such as work, family and community, but each individual had a complex and very personal structure of activities that constituted participation for them. This suggests it is the meaning of the activity, rather than the activity itself, which distinguishes it as participation. For example, housework may be regarded as participation by someone for whom this has been an important part of their identity, whereas for someone else, this may simply be a task that needs to be done. It was emphasised by Lyon et al., (1997) that the quality, rather than the quantity of participation was what mattered to people with aphasia. This was reflected to some degree in the participants in the present study, as involvement in activities did not constitute participation in itself, without other factors being present. However, some participants, including

Jeremy, also mentioned the important of simply keeping busy with whatever they could, which helped them not to reflect too much on their pre-stroke life.

The theme ‘making meaningful choices’, has similarities to themes identified in previous studies including ‘meaningful engagement’ (Hammel & Magasi, 2008), and ‘meaningful activities’ which refer to the meaningfulness of the activity to the individual. One of my findings was related to the importance of meaningful private activities, as well as social activities, and these seemed particularly related to the sub-theme ‘being me’. For example, one of the focus group participants mentioned that being able to go fishing alone, was an important activity that he could no longer participate in. The literature around participation generally focuses more on the social aspects, but Hammel and Magasi (2008) also found that meaningful private activities were an important aspect of participation. The ‘power to choose’ was one element of the theme, ‘making meaningful choices’ and similar concepts are found in previous research, including ‘choice and control’ (Hammel & Magasi, 2008), ‘making decisions and exerting influence (Haggstrom & Lund, 2008). Dalemans et al., (2010) described how the meaningfulness of the activity was more important than the ‘doing’, and this was reflected in my findings. Using qualitative methods to explore participation has helped me and other researchers to move away from the emphasis on performance of tasks that much quantitative research on participation has been criticised for. However, my findings highlighted that performance of tasks was a factor in participation. For example, Mary and Sandra both talked about how they felt about not being able to perform everyday tasks such as cleaning. These tasks formed part of their roles prior to the stroke, and therefore have significance. Haggstrom & Lund, (2008), also found performing tasks to be a significant area of participation for people with acquired brain injury.

Certain aspects of my findings provided a different perspective to that found in the literature. For example, Mars et al. (2008) stated that for something to be social participation it had to be a positive experience. This was not particularly reflected in the present study, for example John provided an example of persisting with participation despite negative experiences, as he described the stigma of going on holiday as a single person. However, he had persisted despite this, and was already planning his next holiday.

The National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party, 2012) recommend that rehabilitation goals should be meaningful and relevant, suggesting that the meaningfulness of participation is already becoming recognised in evidence based practise. The emphasis on the importance of the personal meaning of participation adds to the argument of some researchers (Hammel & Magasi, 2008) that standardised measures of participation may not capture the full meaning of participation. The similarity of these themes to previous findings in studies looking at the meaning of participation in stroke survivors and others, adds strength to the credibility of this study. The themes in my findings seem to encompass various factors identified in previous studies, and to encapsulate them.

Being me

The theme 'being me' describes the relationship between participation and self-identity, by looking at three interrelated elements, the sub-themes, 'changing roles', 'how I see myself', and 'how others see me'. The latter two themes are both impacted by, and impact upon, participation. 'Changing roles' provides a link to loss of participation, which highlights the relationship between participation and self-identity. Clarke, (2003), while not specifically mentioning participation, touches upon many relevant issues in her discussion of how role and activities impact upon identity, and Robison et al. (2009) make a link between resuming valued activities post-stroke, and sense of self. A review of the literature by Salter et al., (2008), emphasised the way in which the stroke challenged the stroke survivors sense of self, and Lamb et al., (2008) found from their review of studies concerning the psychosocial spiritual aspects of stroke, the idea of 'connectedness', an important aspect of recovery which involved partaking in previously valued spiritual and religious activities. These can be seen as activities central to the stroke survivor's sense of self.

Doswell et al. (2000), found that in stroke survivors, recovery is measured by personal yardsticks, relating largely to congruence between pre and post-stroke life. There is substantial literature in the areas of illness, disability and stroke, around self-identity and roles, which has been summarised in the literature review, for example Murray & Harrison (2004), who also used Interpretive Phenomenological Analysis to look at the meaning and experience of being a stroke survivor and identified 'disrupted embodiment and the loss of self' as a major theme. However, the specific link with participation, which may provide insight into how this issue may be engaged within rehabilitation, has not been thoroughly explored.

Within the theme ‘being me’ were the sub-themes, ‘changing roles’, ‘how I see myself’, and ‘how others see me’. ‘Changing roles’ refers to the roles people have prior the stroke, such as ‘breadwinner’, ‘carer’, ‘father’, and how they change following the stroke. ‘How I see myself’ refers to the self image people have, which is both affected by stroke, and also affects people’s response to stroke. ‘How others see me’, refers to the way other perceive the stroke survivor, including expectations of family and friends, and also the stigma of disability. These three sub-themes are interrelated. They correspond with Personal Construct Theory (Kelly, 1955, cited in Brumfitt, 1999), which described the constructions which make up the core self as potentially containing the persons construction of themselves, the way they believe other people see them, and of the way they see their role in society (Brumfitt, 1999). The narrative approach to looking at the self in stroke survivors encourages us to think in terms of the persons ‘biography’, and how stroke survivors are able to weave the stroke into their life narrative in a way that maintains a sense of self. The participants in the present study John and April are both good examples of this. They both experienced a major disruption to their life roles, as John lost his job and his home, and April lost her role as a carer and a view of herself as an active young woman (despite being in her seventies). Over the year in which I interviewed them, they both adapted to their circumstances, partly by viewing themselves as ‘old’ which gave them a different context from which to view the impact of the stroke, making it more acceptable. This has similar implications to the findings in a study by (Kvigne & Kirkevold, 2003), which found that stroke survivors gradually came to accept the changed body as more familiar.

Role change

This sub-theme is central to the study, as it is forms an important connection between ‘Being me’, which refers to the definition of participation, and ‘Loss’, which refers to the experience of participation. The degree and quality of loss experienced appears to depend on the amount of role change that is caused by the inability to participate. Those stroke survivors who experienced most role change appeared to experience the most intense sense of loss, which went beyond a loss of participation to impact upon their sense of self, or ‘Being me’. The concepts of ‘biographical disruption’ (Ellis-Hill et al., 2008), and ‘biographical flow’ (Faircloth et al., 2004), are interesting to examine in the light of the my sub-theme ‘role change’. Biographical disruption suggests a fundamental change between pre and post stroke life, whereas biographical flow sees stroke as one element of an ongoing life. Both of these experiences were reflected in the participants in the present study, and which of these best described their experience depended on what degree of role change they had experienced due to the stroke, which often also depended upon age. Desrosiers et al., (2005) found that reduction in participation was also found as part of the process of normal ageing, although it may be more pronounced in stroke. The most significant role change tended to be experienced by the younger participants, although this was not true for all participants, and the exceptions suggest that rather than age itself, it is the extent of the change in role which affects the stroke survivor. For example we can compare Wallace and April who are of a similar age. Wallace experienced some change due to the stroke, but his life remained largely the same, as he was retired and living with his wife, with an extended family who would visit him. April however was single, had a more active life and would regularly travel to stay with family members who needed care. Therefore April had a more significant role change to adapt to. For the participants who were married the stroke also created changes within their relationships, for example Jeremy’s wife had become a carer for her husband who was once a successful and wealthy man. Studies by Eilertsen, Kirkevold, & Bjørk, (2013), Green & King, (2009) and Thompson & Ryan, (2009) have highlighted issues of changing gender roles and roles within relationships in stroke survivors, and Kitzmuller, Asplund, et al., (2012) found that changed roles impacts upon relationships. This was evident in the present study, for example Elliot explained how his relationships with his family had changed, and that his interaction with them had gone from being ‘the dad’, to ‘the grandad’. Haslam et al., (2008) found that maintaining group memberships can contribute to the continuation of social identity. We can see evidence for this in the participants of this study, for example Christina’s husband explained how their membership of the Freemasons had been helpful in maintaining Christina’s social life following the stroke, as it provided a known and safe environment in which to socialise in. Those participants who lived with partners were more likely to continue modified forms of previous participation, which Clarke, (2003) found could help preserve identity. However, my findings showed that while partners could help people to continue to participate in pre-stroke activities in a modified form, those without partners may be more likely to find new types of participation more appropriate to current abilities.

The most significant role change experienced by the participants in this study was experienced by those who were working prior to the stroke, and had subsequently been unable to work. John’s stroke had happened just a few months before his retirement was due, and this circumstance had its own implications. Initially there was a great sense of loss, as his original plans for retirement were disrupted by the stroke, but later, reaching his official retirement age seemed to help his adjustment to his renewed identity as an active older man. Lobeck et al. (2005) studied the experience of stroke specifically in men at the time of retirement, and found that the meaning of the two events was intertwined, and that the stroke could ultimately be reframed as a positive experience, as in the case of John.

How I see myself

In addition to role change, ‘being me’ was affected by ‘how I see myself’ and ‘how others see me’. This reflects the description of the relationship between self-concept and self-esteem described by (Brumfitt, 1999). Self esteem emerges from our self perception, influenced by the gap between our ideal self and our actual self. Belief about our personal effectiveness is an important aspect of self-esteem. There were many examples of this among the stroke survivors, especially those who worked prior to the stroke. Mary described how sad she felt that she could no longer do things such as tasks she would have done at work, that she would previously have been able to do easily. Abid described how his ‘power’ in work meetings was diminished because of his difficulty in finding the appropriate word.

There is discussion in the literature around whether aphasia can impact upon the persons’ ability to maintain a sense of self, as language may be central to this (e.g. Shotter, 1956, cited in Brumfitt, 1996). My findings did suggest that people with aphasia experienced loss in areas which people without aphasia did not, for example in the ability to share in humour, which may be more central to a sense of self than other losses. However, there was no suggestion within the findings that a sense of self was any less possible in someone with aphasia.

How others see me

Interactions with others also impact the way we see ourselves, and our self-concept is believed to be influenced by comparing ourselves to significant people in our lives (Brumfitt, 1999). Brumfitt, (1996), suggested that close personal relationships may play a significant part in maintaining sense of self in people with aphasia. A participant in the present study, Mary, provided an example of this, as her and her husband both explained how helpful it was when friends looked past the aphasia to respond to Mary as her old self. Conversely, members of Jeremy's extended family found it difficult to talk to him, and he distanced himself from these people, possibly because he found this threatening to his sense of self.

Summary

By comparing the findings of the present study to previous theories and studies in the relevant literature, we can see that the present study corroborates many previous findings, and offers new insights, particularly into the area of the relationship between participation and self-identity. Participation has become a concept of growing importance in stroke rehabilitation literature, but is ill defined. This research provides a detailed definition of participation from stroke survivors themselves, and not only this, emphasises the importance of participation through emphasising its relationship with roles, and therefore self-identity, in the sub-theme 'being me'.

Exploring the meaning of participation in stroke survivors had two purposes. Firstly to provide a firm foundation for looking at the experience of participation in stroke survivors, for which understanding the meaning of participation is essential. The findings from source one of the research in which the focus of the interviews was to explore the meaning, were influential in the development of sources 2 and 3. The second purpose of exploring the meaning of participation was to increase the understanding of the concept of participation for stroke survivors in the wider research context, which as explained above, has been achieved.

Experience

Loss

Quantitative studies of participation, which are particularly effective in measuring the impact of participation, suggest that stroke precipitates a loss of participation, even when the effects of normal ageing on participation are taken into account (Desrosiers et al., 2005). Qualitative studies also suggest a decrease in participation following a stroke (Dalemans et al., 2010), and a literature review by Mckevitt et al. (2004) emphasises the sense of loss experienced by stroke survivors.

Similarly, loss was evident in the participants in the present study. Many participants experienced a delayed sense of loss, as in the initial stages of the post-stroke experiences there may be hope for a full recovery. At around 6 months after returning home, when recovery was not as full or rapid as expected, the true nature of the loss was experienced. The degree of loss felt also depended on other external factors, for example, those with a supportive spouse tended to experience less of a sense of loss, as the spouse tended to act as a buffer and help the stroke survivor to maintain their previous activities, though often in a modified form. This experience is echoed in a review of studies appertaining to the psychosocial spiritual experience of stroke by Lamb et al., (2008). Their results suggested that as a sudden unexpected event, stroke is initially accompanied by shock, fear and confusion, and is ultimately perceived as a life altering event. The experience of loss following stroke has been compared to the bereavement process. Tanner & Gerstenberger, (1988) outlined the stages of grief experienced by people communicatively handicapped by stroke as: denial; frustration; depression; acceptance. While my findings to not necessarily support a stage model such as this, elements of each of these stages were present in the stroke survivors stories. Tanner & Gerstenberger, (1988) also identified ‘loss of self’ as one element of loss experienced by stroke survivors, which relates to the sub-theme ‘loss’ within the present study, in addition to the sub-theme, ‘being me’.

Ellis-Hill et al. (2000) developed their concept of self-body split, on the idea that there was a fundamental change between pre and post stroke life. While this has been challenged by other researchers (e.g. Faircloth et al., 2004) it was borne out for the majority of the participants in the present study, and seems to be related to the degree of role change experienced. It is clear from the present study that the loss experienced is more than simply a loss of function, but reflects a loss on a much deeper level. This is also reflected in the review by Salter et al., (2008), who identified loss of control, confidence and loss of self as part of the experience of living with a stroke.

Coping, acceptance and new participation

I have grouped the sub-themes ‘coping’, ‘acceptance’, and ‘new participation’ together in order to discuss them in the context of the literature, as while they are distinct sub-themes within my findings, they are not always clearly distinguished in other studies, and there is much overlap between then. The sub-theme ‘new participation’ could not be found within the literature, although it is mentioned briefly in some studies. Distinguishing between these different elements of the experience of participation offers insights into the temporal nature of the post-stroke experience, and the way in which different aspects of the experience interact with each other. For example, coping and acceptance are both reactions to the experience of loss. Coping is present in some form in all participants, whereas acceptance is not, but acceptance appears to precede particularly effective coping strategies which may lead to new participation.

Rochette et al., (2006) saw coping as a precursor to acceptance, as they found that their participants who used the coping strategy, ‘change how the situation is perceived’ were then able to reach acceptance. In the present study, acceptance is both a result of and a pre-cursor to developing coping strategies. Acceptance appeared to be a precursor to developing particularly effective coping strategies. However, many of my participants developed coping strategies without having reached acceptance, and there may be a two way relationship between acceptance and coping, where certain coping strategies are needed before acceptance is possible, and acceptance leads to further coping strategies. However, coping strategies of some sort were found in all participants, and in this way appear to be a necessity of post-stroke existence.

In a study specifically of stroke survivors, Popovich et al. (2007) identified coping strategies used by participants in the acute stage, including maintaining a positive attitude and asserting independence as much as possible. In my interviews with the participants of the present study, many gave examples of asserting their independence at this stage. For example April, who was determined to be able to get to the toilet by herself, and also Eva, who continued with this strategy throughout the year after her stroke. Eva had carers to help her around the house, but would try and do what little she could in order to retain some independence. However, ‘maintaining a positive attitude’ did not fit with the descriptions that my participants gave about the acute stage, which for them seemed to be characterised by shock and their focus was on survival and regaining physical function. It was later that such coping strategies were employed.

Ridder et al., (1997) identified three coping styles of people with chronic illness: balanced, allowing for positive coping strategies such as autonomy and acceptance; a militant attitude, which sees illness as an enemy to be fought; and a fatalistic attitude, where illness is perceived as the enemy which cannot be beaten, expressed in beliefs such as resignation and fatalism. It is not easy to fit the participants of this study into these categories, as many showed a combination of coping styles, which varied over time. It may be that coping styles also varied from day to day, depending on the mood of the stroke survivor and what circumstances they were in.

One of my findings was that carers and other people in general formed part of the stroke survivors’ coping strategies. Literature has highlighted that family and friends can both help and hinder the stroke survivor, and that the marital relationship can act as buffer for the impact of the stroke (Sumathipala et al., 2012). There is no doubt from my findings that a caring spouse can buffer perceived needs, as was illustrated by Colin and Wallace. Colin was particularly reliant on his wife for aspects of personal care, however, because he was able to remain in his home and his wife saw that life went on as normal, facilitating participation to some degree. The same can be seen in the case of Wallace, who maintained a social life with the support of his wife, who went with him everywhere and ensured that he was dressed appropriately, which was difficult for him due to colour blindness. In addition, the marital relationship is itself a form of participation, and those participants who were married did not tend to speak about loneliness in the same way as participants who lived alone.

However, contrasting these experience to that of John, it is also possible to see that while facilitating participation to some degree, a supportive spouse may not motivate the stroke survivor to find new participation more appropriate to their current abilities. John's wife had died prior to him having a stroke, and following the stroke he found himself completely alone. At first he was overwhelmed by the shock of what had happened, but by necessity he rebuilt his life, and by one year post-stroke had made more progress than Colin. This shows that while a spouse may act as a 'buffer' to the impact of the stroke, this may also have negative consequences as it may be less motivating for such stroke survivors to seek out new participation more suitable to their abilities, which as we see in the case of John and also Elliot, can be a very positive experience.

Johns story also fits with findings in the area of ageing research, which suggested that higher levels of participation in social and leisure activities, and replacement of relinquished roles were influential to well being (Longino & Kart, 1982) and that successful ageing was influenced by the selection of appropriate social and leisure activities (Adams et al., 2010). John lost his role as a pub landlord, due to his stroke. However, he took up a new hobby, crown green bowling, which appeared to act as replacement, not only in terms of activity but also in providing a social life.

Brands et al. (2012) use the word 'adaptation' to describe the process that stroke survivors go through after stroke, and this seems to encompass coping, acceptance and new participation. Comparing the process that the participants in the present study went through, to Brands et al's. (2012) description of the adaptation process in people with acquired brain injury, we can see several similarities. For example, when I interviewed the longitudinal participants six months after returning home, I could see that many had reached a point described by Brands et al. (2012), *"the patient begins to realize that the pre-morbid level of functioning is not going to be completely regained despite hard work" (p841),* and that the coping strategies had developed to not only include working to maximise physical function, but also accepting the loss of function, which Brands et al. (2012) suggested was necessary for adaptation to the impact of acquired brain injury. However, I would add to Brands et al's. (2012) description by including not only the loss of function but also the loss of role and self-identity, as part of the adaptation process that the stroke survivor needs to undertake, and that this may ultimately form a larger part of the loss experienced. This is also reflected in the results of a study by Nilsson et al. (1997), which suggested that a stroke seemed to challenge the whole of an individual's being. This has implications for the aims of rehabilitation following stroke, as it suggests that stroke survivors should be encouraged not only to maximise physical function and accept loss of physical ability, but also to maximise their participation in activities which contribute to their sense of self. This may involve looking at ways in which they can participate in similar activities in a different way to before stroke, and also providing emotional support for the possibly inevitable experience of the loss of activities which are central to their sense of self. It is also important to note how these activities will be unique to each individual, depending of their roles prior to the stroke and which activities were central to their sense of 'being me'.

Salter et al., (2008), also use the term 'adaptation', which they expand to include 'adaptation and reconciliation', which has similarities to the findings of my research. They describe the mastering of new skills and general adaptation to post-stroke life, with an emphasis on the meaningfulness of life to the individual. This corroborates my own findings of the importance of the stroke survivor engaging in activities which are central to their sense of self.

There were also examples in my participants of adapting long term goals because of functional losses, and the acceptance or otherwise of this. For example Wallace initially hoped to get back to his hobby of painting when his eyesight improved. However, by one year post-stroke he was still not able to see in colour, and explained that he wasn't really too concerned about painting anymore, as it made so much mess. This may be an example of the 'disengagement' that Brands et al., (2012) suggested was necessary to emotional acceptance of functional losses.

The distinction between emotional and practical coping strategies is apparent within the literature (Brands et al., 2012; Mattlin et al., 1990; Schüssler, 1992), and there were many examples of this among my participants. Often, emotional strategies developed following limited success with practical strategies, which formed part of process of reaching acceptance. For example, at my first interview with April, she described the many coping strategies she had used in hospital and was currently using at home, in order to maximise her physical independence. At that time she was walking a little further outside each day, in order to build her confidence. At the next interview, she had begun to talk more about how she was accepting the change in her life, which can be seen as an emotional strategy to cope with the disappointment of not making as much physical progress as she had hoped.

This also reflects what Rochette et al., (2006) suggested regarding ‘optimal participation’, which they saw as requiring a fit between expectations and reality. Similarly Fraas, (2011) reported that successful rehabilitation from a holistic point of view, would require acceptance of altered abilities. The participants in the present study demonstrated that acceptance could help to develop coping strategies leading to new and positive forms of participation, supporting this argument. John for example, found a new hobby that he could fully partake in despite a weak arm and leg, and through this found new friends. He also accepted himself as ‘old’ and embraced his status as a retired older man. From this viewpoint he could see himself as in relatively good health. John fits into one of the post-stroke patterns described by Kouwenhoven et al. (2011), 'finding a restored self'.

Acceptance of physical limitations was identified as a theme in O’Sullivan & Chard's, (2010) study on returning to leisure activities post stroke. During the year following stroke, the participants in the present study went through a journey of readjusting their expectations in the light of their post-stroke abilities. For example, April gradually accepted herself as an older person, rather than the active young woman she had considered herself before.

O’Sullivan & Chard, (2010) suggest that taking on new leisure activities could be a positive experience for stroke survivors. This was also apparent in the stroke survivors in this study, as there were many examples of people having positive experiences with new participation, in contrast to trying to return to previous activities which could be a source of frustration and disappointment.

Other literature

Some issues that were raised in the literature review, were not borne out in my own findings. For example, depression is known to affect around a third of stroke survivors (Lincoln & Guba, 1985; Wolfe, 2000) but it was mentioned very little by the participants in the present study. They spoke about other emotional problems such as anxiety and frustration, but the only participant with whom depression was a central topic was Eva, who had a history of depression prior to the stroke. This is not to say that depression was not an issue for this group. It may be that I directed the conversations in other directions, or that they were not comfortable to talk about that particular aspect of their experience. It may be simply that depression is not how they described their emotions. For example Sandra mentioned that she would prefer to be dead than in the situation she was in. This could be seen as indicating depression, but she did not mention depression, possibly because she saw these emotions as a normal reaction to her situation. This may be an indicator that Sandra was engaged in a grieving process, as Muller (1985, cited in (Brumfitt, 2000) describes the depression that is common in the early stages of stroke as being part of the grieving process.

Hilari, (2011) found that stroke survivors with aphasia participate less than those without. This did not appear to be the case with the participants in the present study, but this is likely to be because most of the participants who had aphasia were recruited from a group of patients known to the University for their willingness to participate in research. Therefore they may not be representative of the wider population. Sampling issues will be discussed further in the evaluation of the methods.

Ellis-Hill et al., (2008) discuss the goals of health professionals and participants with regards to stroke rehabilitation, which they suggest are often different. Some participants mentioned not getting enough help, but the goal discrepancy was not reported in the present study, and this may have been due to the longitudinal cohort having been recruited via the Stroke Associations' Family and Carer Support service, who identified stroke patients at acute stage, and supported them throughout their stay in hospital, and back home, for as long as needed. It was the Stroke Association who sign-posted John towards new activities that he could try, which were not exclusively for people with stroke. This led to a new hobby which opened up a new social life for him. Another example of the Stroke Associations' ongoing and patient centred involvement was with April. She spoke of a member of staff of the Stroke Association almost as a friend, and told me that when her house was broken into (a house that she rented out rather than lived in), he went with her for support to look around the house and helped her sort out what needed doing.

It is possible that the impact of the Stroke Association made the stroke survivor feel that their own goals were acknowledged by health professionals. However, because the matter of goal discrepancy was not very apparent in my interview, does not mean it was not an issue for some participants. Many of the Source 1 participants were many years after their rehabilitation, and goal setting in early rehabilitation did not form part of the discussion we had.

Applying findings to models within the literature

In the literature review, I described the biopsychosocial model, espoused within the ICF (World Health Organisation, 2001). It is interesting to compare the findings of the study to this model, which is facilitated by looking again at visual representation of this model (Figure 2).

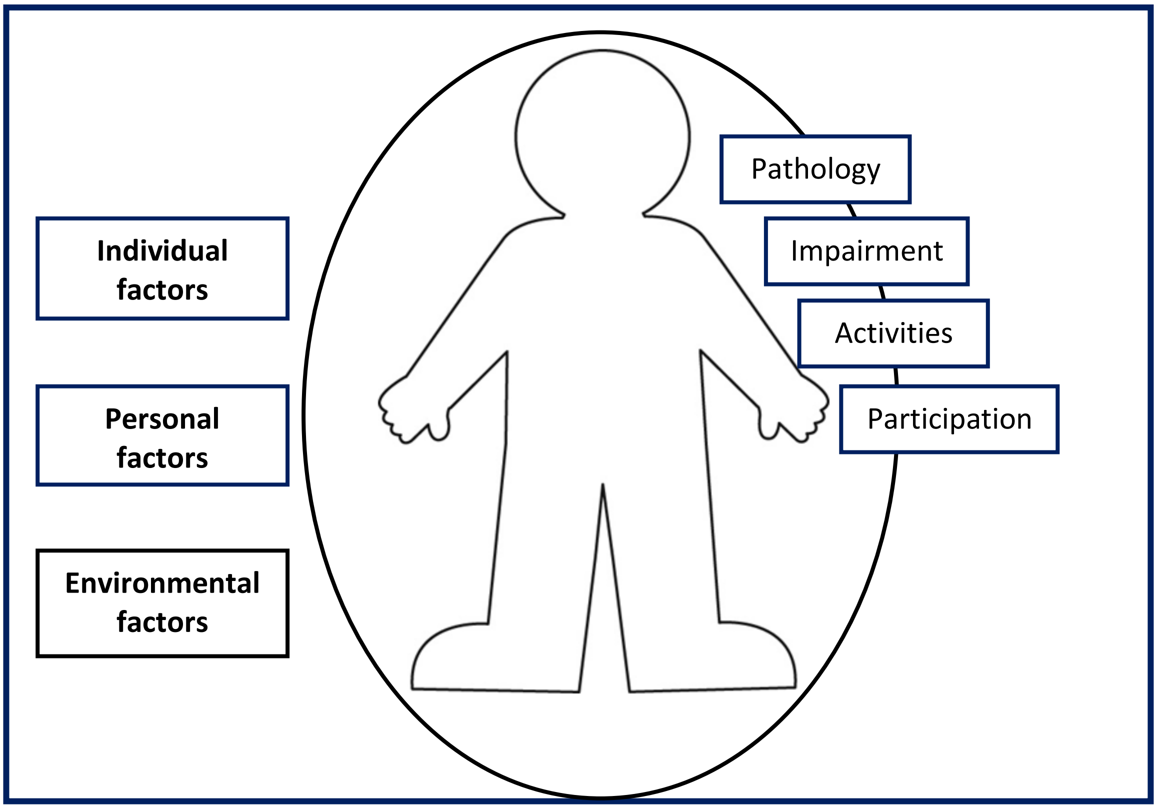

Figure 2: Representation of ICF view of illness and disability

The labelling of factors as individual, personal and environmental can be applied to the participants of the present study. If we take Wallace as an example, the individual factors which affected his participation were poor eyesight and problems with short term memory, both caused by stroke. The personal factors which affected his participation included his inability to drive since the stroke, which had a negative effect on his participation. The environmental factors which had an impact on participation were his relationship with his wife, and living in walking distance of some friends, both of which helped him to participate.

We can also apply the divisions between pathology and impairment, in that the stroke and its impact upon the brain is the pathology, and the impairments may include mobility problems, language problems, and cognitive problems. The activities and participation divisions are less easy to apply, as previous critiques of the ICF have suggested (Mars et al., 2008). The distinction between the terms 'activity' and participation' as used in the ICF , has been a topic of discussion in the literature (Badley, 2008). This was also discussed in my focus group, and the participants felt that choice was essential to the distinction. However, looking at the findings as a whole suggests that rather than being completely distinct from each other, certain activities may become participation in certain contexts, depending on the meaning they have for the individual, as discussed above. For example, prior to her stroke Mary saw eating as a form of participation, as she enjoyed food and would often make a social occasion out of eating, by having dinner parties. However, since the stroke, food had lost this meaning, and become merely an activity that she needed to do to survive.

The ICF (World Health Organisation, 2001) suggests using a comparison to a norm, a similar individual without a health problem, in order to identify problems. While this may work well for problems of function, to apply this to participation would be complicated. The present study suggests that the meaning of participation may change for the individual over time, as they readjust their perceptions to align with lost or changed roles and an altered sense of self. In addition to this, any sort of comparison is difficult due to the subjective nature of participation.

It is possible to relate aspects of the participants in the present study to each of the problems of post-stroke experience described by Kaufman, (1988). The 'discontinuity of life patterns', could be applied to all participants to some degree, but was most apparent in younger participants who were, for example, unable to return to work after stroke. Many of the participants in the present study experienced 'failure to return to normal', where expected recovery is never quite achieved. 'The defined self' could describe the experienced of John and April, mentioned above, and other participants, who went through a process of reconciling their experience of stroke with their life story. There are also similarities with Wood et als. (2010) post stroke goals, which they established by looking at the process of community integration following stroke: Gaining physical function; establishing independence; adjusting expectations; and getting back to real living.

We can specifically compare ‘establishing independence’ to the theme ‘coping’ in the present study, which describes how the stroke survivors learn to use coping strategies to manage the impact of the stroke. Adjusting expectations may be equivalent to my theme ‘acceptance’ and ‘getting back to real living’ may have similarities with ‘new participation’.

Summary

The contribution of my study to the understanding of the experience of participation in stroke survivors is significant considering the scarcity of research in this area. It is comparable to much of the research in the area of participation, but provides a unique insight into this particular population. The exploration of the meaning of participation to stroke survivors provides insights directly from stroke survivors, and expands upon current literature. The most significant and unique finding is that of the relationship between participation and ‘being me’, which suggests a link between the participation literature, the literature about the impact of stroke of self and identity, which has not yet been thoroughly explored in the literature. Looking at the experience of participation following stroke, and particularly the longitudinal cohort, has allowed me to highlight the temporal nature of the post-stroke experience, and to provide more detail than the current literature contains about how the experiences of loss, coping, acceptance and new participation, relate to each other.

Contribution of the present study to the wider research environment

My findings contribute to the wider research environment in the following ways:

- Presenting rich information which corroborates and elaborates on previous studies on the impact of participation.
- Providing an insight into the essence of participation in stroke survivors, significantly adding to this thinly researched area, and substantiating previous research aiming to elucidate the essence of participation.
- Providing an insight into the experience of participation by stroke survivors, which again supplements a sparsely researched area.
- Highlighting and exploring the relationship between loss of participation and self-identity issues in stroke survivors, offering new insights into an area that has been identified by previous research studies but not to my knowledge explored in depth.

Evaluation of methods

Interpretative Phenomenological Analysis

Interpretive Phenomenological Analysis was chosen as the most appropriate methodology by which to answer the research questions, which were about the meaning and experience of participation. The suitability of IPA for eliciting the essence of a phenomenon was particularly beneficial in answering the first question, about the meaning of participation, as is provided a way of gathering diverse data and amalgamating it into a coherent explanation without losing the depth and detail that is so valuable in qualitative research. In terms of exploring the experience of participation, IPA enabled me to go beyond the participants descriptions of their lives to explore the deeper psychological aspects of their experiences. Phenomenology, and in some cases IPA have been used in previous studies exploring issues such as self and identity. It may be that the aptness of this methodology for looking at such issues, is part of the reason why these issues emerged strongly from the interpretative analysis.

The potential weaknesses of IPA discussed in the methodology were the reliance on the participants to have sufficient linguistic ability to report on their experiences, and the ability of the researcher to leave aside their own perceptions in the analysis process. Both of these factors are discussed further throughout this chapter.

I departed from the standard IPA study in several ways, and this had implications for way that IPA was used. I will present each departure individually, describe its implications and evaluate its effectiveness.

Using a range of data collection methods

My first departure from classical IPA studies was to use a range of data collection methods, including focus groups and email interviews, whereas most IPA studies use semi-structured interviews. Smith & Osborn, (2008) recognise that the use of semi-structured interviews in most IPA studies is circumstantial, rather than being fundamental to the IPA process, and I feel that using multiple methods has strengthened this study. I will discuss more about triangulation later.

In their review of IPA studies within health psychology, Brocki & Wearden (2006) found four studies that had collected data via a focus group. The concerns cited regarding the use of focus groups, are that as IPA is intended to be an in depth analysis of personal experience, the focus group may not allow for the individual participants to express themselves as easily or in as much detail as an interview. These concerns are not relevant to the present study, as the members of the focus group had previously been interviewed via a qualitative interview, and so the focus group was added to the data already derived from these. However there were implications for the analysis process, as the type of data generated from the focus group was different to the data generated by the qualitative interviews. A focus group is not only an interaction between researcher and participant, but also between the research participants themselves. IPA is concerned with the way in which the participants 'interpret' the events that have happened to them. In a focus group, this process happens not only within the individual but between individuals, as through their shared experiences they come towards a shared understanding. In this case, the contribution to the overall analysis is similar to that of a qualitative interview, but the way that the ideas are developed is different.

IPA analysis looks at both what is said, and why it is said. In both a qualitative interview and a focus group, the researcher is not only interpreting the story of the participant, but asking questions as to why the participant is presenting themselves in this way. This element of the analysis is similar in focus groups to qualitative interviews, but is expanding to look not only at the interaction between the researcher and the participants, but between participants themselves. While the focus groups presented a different type of data to the interviews, IPA uses a series of steps to build up from analysing individual interviews, to understanding how these individual interviews compare to an ever increasing whole. These steps were followed in order to analyse the focus groups and while the procedure was more complex, it did not require extra analytical steps

However, the focus group analysis tended to use larger chunks of data than the qualitative interviews, where analysis was often on a sentence by sentence basis. In the focus group, participants went through a process of sharing and modifying each-other's ideas, and themselves presenting the conclusion of this interaction. These type of observations were noted in Step 2 of the analysis (initial noting of the transcript, making description, linguistic and contextual comments), and were then developed into themes or parts of themes.

The following extract from the focus group, with accompanying notes from the initial noting phase, demonstrates the three facets of analysis:

1. What the participants are saying
2. How the idea was developed within the group
3. What interactions between participants are of interest in themselves

Researcher:...so participation seems to have a social aspect. Do you agree with that? *C: Yes* *E: Yes it's a social thing participation isn't it?* *T: It is but then me, I like fishing, and I like doing that on my own, I like having time to think. I don't do that no more cos I have to go with someone and it's not the same.* *E: yes sometimes you want to do things on your own don't you and it's frustrating if you can't.* *T: so it's not always social.* *J: no, no...agree with that, no.* *Researcher: Ok so there's more it, this is interesting, more to it than being social, sometimes you might want to participate alone?* *T: yeah, yeah, I think that's quite important, that's like participating in your own life.* *(FG)*	1. Participation not only social but also a loved activity alone. 2. T starts by using himself as an example, rather than making a statement on every ones behalf. Once he has agreement from the group, he makes a more general statement. 3. E is the first to agree with T, after which J also states his agreement. J always wants back up from E. Is this because E is very active in the stroke community and J feels more secure with E's backup?

Table 9: Example of focus group coding

I would suggest that the nature of IPA, which looks not only at what is said, but how it is said, is particularly useful in analysing a focus group, where both the statements of participants, and the interaction between the participants, are of interest.

Brocki & Wearden (2006) also found two studies using email interviews, about which the authors had cited the advantages of email interviews in producing accounts that were frank and reflective. In my own use of email interviews, I found both advantages and disadvantages, which are discussed in later sections. In regards to using IPA analysis with email interviews, as with the focus group, IPA provides a flexible set of steps which I did not need to make any additions to in order to fully analyse the email interviews, although the data analysed had certain features which affected the analysis process. For example, as there was less interaction between the researchers and the participant, the email interviews were most often made up of several large chunks of text written by the participant, which needed to be broken down into separate units of meaning in order to be analysed. This is in contrast to face to face interviews, where a particular matter would be discussed and concluded between the researcher and the participant. The language used by participants in emails was often more formal than would be found in a face to face interview, and when interpreting the meaning of the interview, this had to be taken into account. The two extracts below, the first from an email interview, and the second from a face to face interview, show the contrast in the styles of language used, to give a similar message. It shows how email interviews give the opportunity for the participant to prepare an answer to a question, which may be more articulate and reflective than in a face to face interview, but may lack some of the raw emotion. Both extracts show the participants comparing themselves to other stroke survivors in order to assess their situation, which was a coping strategy used by many stroke survivors:

Email interview extract:

"A Stroke strikes a person in many different forms. In my case, I am fortunate in steadily regaining my speech but will never regain my former ability to play the piano. Others Stroke-people have little or no speech but retain all their physical capacities"

Face to face interview extract:

"Sandra: I mean I thank God every day that it didn't take my speech as it can do. I mean there was a lady in hospital in the Hallamshire, and they call it aphasia when it takes your speech...And she couldn't express anything on her face at all

Researcher: Oh gosh

Sandra: And that you know, that must have been terrible. And she had a beautiful singing voice and she kept that, strangely enough she could still sing"

IPA presents a set of general steps to guide the researcher through a process, and is not prescriptive, making it ideal for analysing data collected from a variety of sources. Following step 3 (developing emergent themes from initial notes), which is a level of abstraction away from the raw data, it was possible to draw on all sources simultaneously in searching for connections across themes, comparing individual cases to the whole, and looking for patterns between cases (steps 4, 5 and 6).

Using IPA with a longitudinal cohort

I could find no guidance in the literature regarding using IPA with a longitudinal cohort, nor any other studies that had undertaken this task. The longitudinal interviews were analysed initially as individual interviews using the steps outlined in the methods chapter. There were important aspects of the longitudinal data, which differed from the other data collected. Firstly, when themes were identified from a first interview, they were not only developed by the other data, but were also developed by subsequent interviews with the same participant. This meant that an understanding of change within a theme over time was possible. The second aspect was that the patterns which were created by the emergent themes were not only being compared between subjects, but also over time, which gave an insight into the ‘story’ of the participant as it developed, and enabled a comparison of the different trajectories of the stroke survivors lives. Without creating some additional tools by which to view these phenomena, there was a danger of them becoming lost within the wider data analysis.

Exploring the literature on qualitative analysis of longitudinal data enabled me to understand the basic principles of analysing longitudinal data, which I could then adapt to fit with my IPA approach. Molloy et al (2002), and Saldana (2003) suggest assembling in chronological order similarly coded passages, and Molloy et al (2002) suggest using tables as a way of organising this. Other qualitative longitudinal studies had used tables or similar tools to assist in the analysis process, for example (Eilertsen et al., 2013) used ‘flow charts’, to view change in their participants. Molloy et al (2002) describe this process, and encourage the longitudinal researchers to ‘ask questions’ of their data, in order to identify changes over time. Using the steps below, I developed tables for each longitudinal participant across each of the the themes.

1. The data related to each theme and sub-theme for a participant was gathered together.

2. A summary was created for each sub-theme, expressing the trajectory of the participant in regards to the sub-theme, throughout the three interviews. This involved me 'asking questions' of the data, and the resulting explanation was my own description of the participant's trajectory over the year.
3. This summary was entered into a table.
4. This process was repeated for each participant.

The resulting table showed the subthemes in the horizontal direction, and the longitudinal participants in the vertical direction. The vertical direction showed a summary for that sub-theme of each interview, and also a box 'reflections on change', allowing for a summary of change over time. The example shown below is part of the table for the theme 'Being me', showing one participant and two sub-themes.

	Participation is being me	**Participation is role change**
April 1	Initial stages of stroke could not walk or talk, felt like she was not herself. Talking was the most important thing. Still very much defines herself as a 'midwife', despite being retired. Wanting to be useful.	Can't help care for family members now, and misses this.
April 2	Being inactive and being active all your life is difficult.	Seems unable to cope with family issues now.
April 3	'I've always been independent' 'I can look after myself'. Is keen to emphasise how hard she previously worked.	Found family visit very stressful, but has enough food in the fridge in case anyone comes to stay. Rings sister twice daily.
Reflections on change	Immediately post-stroke seems to identify with the person she was before, especially her job as mid-wife, later reflects how much life has changed and doesn't seem to identify with old life so much.	Initially the change is that she can't physically care for family members as she used to. At 6 and 12 months she seems also unable to cope emotionally with her family.

Table 10: Example of longitudinal table

In order to further summarize the changes found, a table was made presenting the reflections on change for all sub-themes and all participants. The table below gives an example of two participants and two sub-themes:

	April	**Colin**
Impact		
Impact of stroke	Recovered ability to walk and talk. Condition has been exacerbated by possible repeat stroke.	Very little change over the year, and fall in bath was a set back.
Mediating factors	External factors throughout the year have caused stress which has not helped her recovery.	Very reliant on partner throughout. Fall in bath was a setback.

Table 11: Example of longitudinal summary table

Using tables to present the data enabled me to view aspects of the longitudinal data that may have not emerged through following the steps of IPA analysis alone. Being able to view the data in two directions, both between participants and over time, enhanced my understanding of the transitions experienced by the participants, and how their trajectories differed over time. Another tool not explicitly suggested within IPA, which was used throughout the analysis but was of particular use in the longitudinal interviews, was the keeping of memos. This concept was originally found in grounded theory, and the influence of grounded theory on the analysis process will be discussed in more detail later. I used memos with all data sources, as a way of noting the ideas regarding the development of themes and relationships between themes. Memos were particularly useful in relation to the longitudinal data, which was more complex, as they also allowed me to record the development of ideas about changes over time. For example, the memo below refers to the relevance of the concept of participation at different time points following stroke:

> *"Many people commented to the like that during the acute phase participation was not on their minds. Normally at this stage they were very busy with the rehab process, and dealing with the day to day aspects of feeling unwell, being newly disabled. They may not understand at this stage what their abilities will be when they are back in the real world, they may not even understand they have had a stroke. It is later, when most of the perceived potential for recovery has happened, that participation or lack of becomes an issue. There is no time limit for the acute stage, as it varies from person to person. But from my interviews it seems that 6 months is no time at all after a stroke, by a year many people are beginning to move on from the acute stage. Depression and confusion are key emotions at this time."*

It was also important to consider the most effective way of presenting the findings, in order to fully realise the value of the longitudinal data. Molloy et al (2002), describe the dilemma they faced in a study carried out on behalf of the Department for Work and Pensions:

> *"when longitudinal data is reported alongside cross-sectional data there are issues to be considered relating to how these two data sets are presented. A common approach is to interweave the two sets of data, placing the cross-sectional data alongside information gained from the longitudinal work. This allows discussion of the full range of views about a policy, combined with evidence as to the ways in which these may change over time and what causes this to happen...A particular challenge when reporting longitudinal evidence in this way, however, is to ensure sufficient attention is given to documenting and explaining changes over time"* (Molloy et al., 2002, p39).

As Molloy et al (2002) have suggested, presenting longitudinal data alongside other data mean that a discussion of the full range of issues is possible, and it was decided to present the findings from all sources together, including the longitudinal cohort, in order to be able to present each theme and sub-theme in its totality. However, this approach did not seem to fully emphasize the findings from the longitudinal data, and so an additional chapter was created, which presented the longitudinal participants as case studies, presenting their stories in such a way as to explicate the findings. These two approaches together are complimentary, and allow the reader to focus both on the themes themselves, as well as seeing how these themes relate to individual participants.

Number of participants

My second departure from traditional IPA studies was having an unusually high number participants (twenty three). Brocki & Wearden (2006) found studies using up to thirty participants, although the norm was to use a smaller number. They also found that those studies with larger sample sizes tended to present an in depth analysis of only a small number of cases. In the case of the present study, the large sample size is made up of three separate sources, and the participant numbers for the separate sources are more typical of IPA studies. Each of the sources provided a different and valuable perspective on the research questions. Having low numbers of participants allows the researcher to be able to analyse the data in the appropriate depth and detail. Because the three sources were carried out over the course of four years, I had ample time in which to analyse the data from each source in sufficient detail. However, assembling so much detailed data into a coherent whole was challenging, and this led to my third departure, using NVIVO for the storage and retrieval of data, which became necessary due to the volume of data. While hesitant at first, I ultimately found NVIVO useful in assisting me to perform the steps of IPA.

The influence of Grounded Theory on the data collection and analysis process

I have explained in previous chapters the influence of Grounded Theory on the design of the research, despite IPA being ultimately most influential to the design. I would now like to reflect upon how ideas taken from Grounded Theory were used throughout the analysis process. A method of *concurrant data analysis and collection* were used, whereby the analysis of previous interviews informed content of later interviews. *Theoretical sampling* was also employed to a a degree, in the iterative nature of the study. Each source was designed according to findings from the previous source. These two aspects of Grounded Theory are not found within normal IPA studies, where it is normal to collect a small amount of qualitative interviews, and analyse each, in the first instance, as an individual unit. However despite the concurrant data analysis and collection, in my analysis of the interviews I employed the IPA strategy of viewing each interview indivudually, before comparing to the whole.

Other aspects of Grounded Theory are no longer unique to that approach, but have become part of the broader understanding of qualitative research methods. What is called in Grounded Theory, *comparative analysis,* the constant comparing within and between categories to develop understanding, is also a central element of IPA particularly expressed in steps 4-6 (searching for connections across emergent themes, and looking for patterns across cases). The use of memos, which has also become a common practise outside of grounded theory, was the main way I used of noting relationships between themes, and expressing phenomena I found within the data which were too complex to be expressed within a single theme. I used the memo function in NVIVO, and the memos formed, in addition to my descriptions of themes and sub-themes, formed the basis for the reporting of the findings.

Summary

While I selected IPA as the most appropriate methodology for my research, I maintained an awareness that qualitative research is a complex process and requires the researcher to remain open and flexible to other approaches which may be beneficial is explicating the particular questions of the research, and the particular circumstances in which the research in taking place. For this reason, I made some significant diversions from what could be classed as a 'standard' IPA study, in order to best answer the research questions which I had proposed. These included the sources of data collection, using a longitudinal cohort and the extra methods used to analyse this data, the higher than normal participant numbers, and accompanying this, the use of NVIVO to assist with the data storage and retrieval, and taking elements of Grounded Theory and interweaving these with the steps of IPA. It is my conviction that the research should define the methods used and not vice versa, and therefore I feel it was appropriate to make modifications to the chosen methodology, in order to incorporate the developing needs of my study.

Including people from ethnic minorities in the research

Ethnics minorities are under-represented in research (Hussain-Gambles, 2004), and as the geographical area in which this research was conducted is multi-cultural, I aimed to make the research as inclusive as possible to people from ethnic minorities. As a white British person who has converted to Islam, I have connections with the local South Asian and Arab communities. While barriers still exist, such as language and cultural differences I have more contact with these communities than most people from my background. This contact is through attending mosques and other Islamic events, and the friendships that I have formed with other Muslims who come from these backgrounds. I also felt that as a visibly Muslim person I was more likely to engender a feeling of trust in people from these backgrounds, and an assumption of understanding of some issues, which may be overlooked by researchers without this experience. The Muslim community in Sheffield is diverse, as it is the world over. The most visible Muslim community here is the South-Asian community, and there are also strong Yemeni and Somali communities, as well as other Arab and African origin people. While many have been born and brought up in the UK and speak English as a first language, many of the older generations, or newer immigrants, have Punjabi/Urdu or Arabic as a first language.

I had all research material translated into Arabic and Urdu (Punjabi is a spoken language and literate Punjabi speakers would read and write Urdu), as well as trained community representatives to assist with the process, so that I would be able to recruit some people from these backgrounds to my study. I used my contacts in the community to recruit stroke survivors and carers from these communities to Source 1.

Wendler, et al., (2006), found that while rates of participation in research differed significantly between minorities and non-minorities, actual consent rates, that is, those who agreed after having been invited to take part in research, showed small differences. This suggests that there is no difference in willingness to partake in research between minorities and non-minorities. However, some of my experiences while trying to recruit people from ethnic minorities suggested that their may be some unwillingness among ethnic minority groups to partake in research. When I was using my contacts in order to try and recruit, several people who were from ethnic minority backgrounds suggested that I would struggle to recruit people from their communities to the research. Several reasons were given for this. Firstly that there is a general belief that these things are ‘a waste of time’, secondly that there may be suspicions and fears around giving personal information, perhaps based on immigration issues, and thirdly, that in the countries of origin of many people from ethnic minorities, there is not a culture of speaking about health and healthcare.

Out of twenty three participants, one was Caucasian of German origin and four were from ethnic minority backgrounds. Of these, three were South Asian and recruited as a result of my strategies, and one was Black Jamaican and recruited through the Stroke Association.

Of the three South Asian participants, one was a friend who was a carer for her father who had a stroke (Maryam), one was a friends Uncle (Abid) and one (Nur) was recruited through attending a Muslim women’s health group, arranged via an organisation (Roshni) in which a friend works. Maryams first language was English, Abid had English as a second language but did not need and translator, and only Nur did not speak English fluently and required translated materials and a translator.

Census data shows that 9% of Sheffield’s population are from non-White ethnic backgrounds (Office for National Statistics, 2001), and around 21% of the participants in the present study were from non-British ethnic backgrounds. While the numbers are satisfactory, the experience of trying to recruit from ethnic minority groups has helped me to understand why such groups may be under-represented in research. Through my University contacts I had access to a bank of potential participants, who were willing, articulate and reliable. They were also all white. Conversely, in order to recruit ethnic minorities I was reliant on the good will of people from these communities (volunteers) who translated my materials, translated during interviews and helped me to find participants. To access the first group, I would make a simple phone call and arrange a meeting, to access the second, I may have to go to a community centre, try and find a time when a translator would come with me, explain my research through a translator, then arrange a meeting with anyone who was a suitable participant, which meant finding a time suitable for the participant, me and a translator. I would then need to have the interview translated. For me the cost was in time, for other researchers, there would also be a financial cost involved. The amount of resources that are spent on preparation and training, compared to the amount of actual participants could be discouraging. For example, I did not have the opportunity to use the materials that were translated into Arabic, and the Arabic speaking community representative did not have the opportunity to use the research skills that she had acquired.

Including people with aphasia in the research

One third of people will have communication difficulties following a stroke (Department of Health, 2009). Approximately 30% of the participants in the present study had some degree of Aphasia, suggesting that people with Aphasia were appropriately represented in the research. Five of these participants were in Source 1, and two in Source 3. There were no participants with aphasia in Source 2.

Four of the participants with aphasia in Source 1 were articulate and able to navigate the consent procedure and also take part in an interview without any difficulty. However, despite their abilities these are not people who would have described themselves as only mildly affected by aphasia. This is encouraging as it suggests that with the right support aphasic people can partake in research. One participant (Christina) was more severely affected and needed significant help in order to consent, and also requested her husband to be with her in the interview. She attended the focus group without her husband. I attempted to manage the focus group in such a way as to give her the time and space to speak, and provide simplified summaries of the conversation for her. The other members of the focus group, two of whom knew her already on a social level, also tried to support her to contribute. However, her contribution to the focus group was very limited. Also, when presenting the findings, it was easy to let Christina's voice get lost among other, more articulate speakers. Although Christina's contribution to my overall understanding of the themes was significant, it was difficult to hear Christina's 'story' in the same way the stories of other participants came across. Other methods may have helped Christina to contribute more, such as methods based on the use of pictures.

There were no participants with aphasia in Source 2. I was reliant on Family and Carer Support team members at the Stroke Association as a first contact with the stroke survivors, in the acute stage of stroke. In this sense, the team members can be seen as the 'gate-keepers' through which I had access to participants. I had discussed with the team what my recruitment criteria were, and encouraged them regularly to help me to recruit stroke survivors even if they felt they would have difficulty with the research, as long as the stroke survivor was willing. However I feel that there may have been some selection of participants by the team. For example on one of my visits to the office a member of the team said of one potential participant, 'you'll like this one, she's a talker', which made me reflect that perhaps others who were not 'talkers' were not passed on to me. This is understandable, and also may reflect a desire to protect the stroke survivors who they were trying to help. I may have been able to have more control over these decisions had I asked for records to be kept of how many stroke survivors had been seen, how many had been asked about the research, and how many had given consent to be contacted. However, when working with a busy team, there is a balance to be struck in order to maintain a positive relationship.

Using email interviews was obviously going to present a barrier for some people with aphasia. As by this stage people with aphasia were already well represented in the research, I felt that the benefits of email interviews in potentially including less mobile stroke survivors, outweighed the disadvantages. There was also a chance that certain people with aphasia who were able to use email, may feel more comfortable with this method, as they were able to answer the questions in their own time, and modify their answers before sending them to me. Two of the five participants were people with aphasia. One of these participants was hesitant about partaking in the research, as she doubted that she would be able to navigate the process. However, I provided encouragement and reassured her that I was interested in what she was saying, and not how it was said. She did consent and managed the interview process without difficulty.

Sampling

Smith et al. (2009) recommend purposive sampling strategies to recruit homogenous samples. However, restricting the target population for this study, for example, according to age or type of stroke, was not deemed to be feasible as this would be too restrictive to recruitment in the timescale available.

The diversity of the participants, in terms of gender, ethnic background and age, offered the benefit of a variety of experiences and perspectives with which to view the research questions and in this study the methods of IPA worked well in bringing together the experiences of a diverse range of participants. The sample size allowed me to reach saturation point in my data collection, which is an indicator of rigour in qualitative research.

A small sample size is essential in qualitative research in order to achieve the depth of analysis required, but means that it is not possible to generalise from the experiences of the participants in this research to all stroke survivors. However, qualitative research is judged by other appropriate criteria. These factors will be discussed later in relation to quality.

The age ranges of the participants in each source were:

Age ranges for each source	
Source 1	48-68 (carers 16-68)
Source 2	58-81
Source 3	45-63

Table 12: Age ranges for each source

We can see that the participants in Source 1 and 3 were young stroke survivors, most of them being under retirement age. Given the sources of recruitment this suggests that younger stroke survivors are more likely to be in contact with support groups and with other stroke survivors. It is important to consider the impact of the sample recruited on the accounts obtained as this has implications for the transferability of the findings. Thirteen of the seventeen stroke survivors were under the age of sixty five, and this is likely to have affected the findings, as the impact of stroke has different implications for people of working age. This may mean that the findings are less applicable to older stroke survivors.

Some of the participants were people who had developed a general interest in stroke support and research. Their interviews tended to be very eloquent and informed, and appeared to be the result of years of expressing their views on the subject, whereas other participants gave less eloquent but possibly more personal accounts.

Recruiting and maintaining participants

Some issues with recruiting participants have been discussed above in reference to participants from ethnic minority backgrounds and participants with aphasia. In source 2, participants were interviewed within a month of returning home from hospital or rehabilitation centre, and followed up at six and twelve months. All participants were interviewed three times, except for Sandra. I was unable to contact Sandra for her twelve month interview. After leaving two phone messages, and calling at her home once, I felt it unethical to continue to try to contact her.

Semi-structured interviews

Smith et al. (2009) describe qualitative research interviews as a *"conversation, with a purpose" (p57)*, the purpose of which is informed by the research questions. I approached the interviews by trying to get an understanding of the 'story' of the participant, and used the interview schedule as a prompt to ensure the that all the relevant issues were covered. The flexibility of the semi-structured interview worked in interviewing people with aphasia, as I could reword questions which were not understood, and the participants had the space in which to help me understand their message. The flexibility of the semi-structured interview also allowed for me to interview a non-English speaker with the help of a translator, who translated directly between me and participant. Although this data cannot to be said to be equivalent to a direct conversations between researcher and participant, I feel it is better that this participants voice was heard, than not.

In Source 1 interviews, I asked the participants directly about the meaning of participation. For some aphasic participants, they were unable to answer the question immediately, and I rephrased it in various different ways in order for them to understand what I meant. Even for the non-aphasic participants, participation was not a word that they used or thought about, although they were able to define it having given it some thought.

An interview is essentially a verbal report of the subject being discussed, and it is possible that participants do not want to reveal certain things to an interviewer, or that they paint a certain portrait of themselves. To some extent, IPA works with this, as it is essentially the researcher's interpretation of the participants' interpretation of events. However, the use of other methods such as observation, would allow the researcher a more real insight into the participant's lives. The longitudinal cohort countered this issue to a certain extent, as it enabled me to view the progress of the participants, and showed the difference between what people said and what they did. Interviewing both the participant and the carer also gave more than one window into the same reality. This was particularly noticeable in the interviews with Tony and his daughter Rosemary. Tony felt that his children were not very helpful since the stroke, and did not really realise the extent of his disabilities. However, Rosemary described caring for her father as an experience that had changed her life, and made her grow up. While these accounts seem contradictory, neither Tony or his daughter were being dishonest, rather they show that the same situation can be viewed differently by different people.

Many interviews took place with the stroke survivor's carer in the same room, and some of them made contributions to the interview. I did not attempt to prevent this, as I wanted the environment to be as comfortable and natural as possible for the stroke survivor. Some participants with aphasia relied on their carers to help them to explain things, others who had memory problems since the stroke asked them to help report the ordering of events after the stroke. However, the presence of carers could have inhibited the interview to some extent, especially in discussing topics in which the carer might be implicated, for example, changes in relationships.

Focus group

The focus group was used as a way of feeding back the findings to participants in order to further the development of the analysis. The focus group setting worked as an advantage in that within the focus group, interaction was not only between me and the participants, but between the participants themselves. This gave them the opportunity to compare and contrast their experiences, and it was interesting to note that the participants asked questions of each other that I would not have thought to ask. The opportunity to see my interpretation of the findings from the participants view point was invaluable, and highlighted areas where I may have been influenced by my own preconceptions, or by literature I had read. For example, the focus group highlighted that participation in loved activities alone, was as important as the social element of participation. I had not seen this in my analysis of the interviews, but following the focus group, I reanalysed in the light of this, and found things that I had missed.

The dynamics within the focus group were occasionally difficult to manage. Of the four participants attending, three already knew each other, which meant that the other participant was coming into a situation where he was the only stranger. Thankfully the other participants welcomed him, and he contributed throughout the session. Out of the three participants who knew each other prior to the group, two of them had been friends for some years. One of these two often referred to matters that only the two of them would be aware of, which appeared to annoy the other one. As previously mentioned, one of the participants (known to two of the others) was severely aphasic, and it was difficult for her to contribute to the same extent as the others.

Longitudinal cohort

Most of the issues relating the longitudinal cohort have been covered in the section of semi-structured interviews. Seeing the participants at more than one point post-stroke provided the opportunity to see their progression over the first year following stroke. This added a very important dimension to the findings which would not have come from retrospective interviews alone. The weakness of this method is that one year may be too short a time period in which to view participation following a stroke. However, time constraints would not allow me to follow up participants any further than one year.

The longitudinal cohort, while consisting of a series of semi-structured interviews, provided an opportunity to develop a connection and understanding with the interviewees which differed from that which could be achieved during a single interview. Seeing the participant at three time points, and in addition to this, several phone calls in order to make appointments, allowed for a greater empathy with the participant. Seeing the participant more than once also allowed me to understand the participant's perspective, and take this into account in later interviews. For example, I tended to use the language used by the participants to refer to something they had mentions in a previous interview, as in the example below:

> ***Researcher****: I think last time, last time you'd said to me you know life's not 50 per cent what it was, you know in terms of what you can go out and do.*
>
> ***Participants wife****: Do. Aye, yeah. It int is it.*
>
> ***Participant****: No, it is. It's a big, it's a big change.*

Using the same language as the participant helps to show empathy and shows your understanding as a researcher for the participant's situation, therefore providing a degree of continuity with the interviews and potentially allowing for a deeper understanding between the participant and the researcher.

Analysing the longitudinal cohort within an Interpretative Phenomenological Analysis framework was challenging, and I incorporated the use of tables into the analysis, in order to gain as much as possible from the longitudinal data, as has been discussed in detail in a previous section. This helped to view change over time, which was essential in understanding the progress of the participants over the year following stroke.

Email interviews

Conducting email interviews with stroke survivors was an exploratory exercise, and to my knowledge this is the first study which has conducted email interviews with stroke survivors, although studies using email interviews have been carried out with people with communication difficulties (e.g. Egan, Chenoweth, & McAuliffe, 2006; Ison, 2009). This gave me the opportunity to add to an already rich data set, by elaborating on certain points which were of significance within the analysis. Because of the format, and also because of the purpose of the interviews, the interview questions were more rigid than in the semi-structured interviews. The advantage of this was that it gave me a chance to explore specific elements of the stroke survivors experience. It also gave me contact with people who may not have come to be involved in stroke research otherwise. The medium of writing also has the advantage that the stroke survivor could take as much time as needed to prepare their replies. The disadvantage was that using set questions may have discouraged stroke survivors from expressing what was most important to them about the experience, although some questions were general enough to allow this to some extent.

It was challenging to manage the interaction of the email interviews without face to face contact. Some of the participants wrote very short answers in response to my first questions. This is normal in an interview situation, however, with face to face contact it is easier to build up rapport with the participant, whereas over email this is a longer process, and I did not achieve it with as much success as I might have done face to face. Ison (2009), emphasised the importance in email interviews of making people feel listened to and that their experience in valued, and I was conscious in my replies to acknowledge what they had said in the previous email, whether or not it was of interest from a research perspective, and provide encouragement for them to elaborate.

Triangulation

Triangulation of methods was used in order to enable a deeper understanding of the issues than would have been possible with just one research method. The findings were definitely enhanced by the various methods used, which provided different perspectives on the same issues. Each method had its own strength, for example while the longitudinal interviews showed change over time, the email interviews allowed for thoughtful reflection.

Value of information from carers

Carers were interviewed in their own right, rather than being recruited in order to obtain proxy information on the stroke survivor. However, their insights into the stroke survivors situations have been used to enhance the findings. I originally intended to look at the impact of stroke of the carers participation, as well as the stroke survivor themselves. It became clear that this would not be possible in the scope of this project. However, the information collected from carers of stroke survivors who were participants offered useful insights into the stroke survivors lives. Interviews were also carried out with carers when the stroke survivor was not a participant, but it is their reflections on the meaning of participation, rather than experience, which are drawn upon in the findings.

Information from carers, in combination with information from stroke survivors themselves, was very valuable, and given more time and resources, it would have been useful to include them in Sources 2 and 3. However, time and also the requirement of IPA to focus on a small number of participants, meant that I chose to focus on stroke survivors in these sources. I feel that the analysis has been enhanced by having data from carers. However, it is important that the voices of the stroke survivors are the focus of the analysis, and I have written the description of the interpretive analysis to reflect this.

Analysis

Qualitative analysis gives a central role to the researcher, and an inherent feature of IPA is the double hermeneutic, meaning events are interpreted firstly by the participant and then by the researcher. Therefore my interpretation of the data must be seen as only one possible interpretation. The area of self-identity came through strongly in my analysis, and it might be that events in my own life, which have challenged by own self-identity, made me primed to recognise this in the accounts of other people. In order to check the credibility of my analysis, a sample of three interviews were reviewed by a fellow researcher, who checked the analysis. This process confirmed that my analysis of the data was logical, and the suggestions made helped to develop the themes. The development of the analysis was regularly reviewed with my supervisors, in order to minimise the potential for misinterpretation or over-identification with the data.

IPA relies to a certain extent on the narrative skills of the participants and for this reason, the contribution of some participants to the interpretative analysis is greater, and I was unable to include equal contributions from participants in presenting the results of the analysis. This was not a divide between the aphasic and non-aphasic participants, in fact, some of the aphasic participants, for example Elliot and Mary, were amongst the most eloquent and their interviews the longest. Some participants just found it easier, or were more willing to express themselves than others, and this meant that a greater level of interpretation was required when considering the views those who were less expressive.

There is an element of power in interpreting the words of others, and the discrepancies between the amount of detail in the accounts given by the participants made me more conscious of this position. The ‘bracketing off’ method prior to analysing each interview helped me to step away from my perspective and become more in tune with the participants perspective. There was also an iterative element to the research, which enabled me to check my understanding with the participants. In Source 1, this was the focus group, which enabled me to present my tentative themes to the participants, which they then helped me to develop further. In Source 2, I saw the participants three times in total, which enabled me to check my understanding of the previous interview with them, in the second and third interview. In Source 3, the email interview gave me the opportunity to clarify certain points, and for the participant to see in writing how I had interpreted their previous answers to questions. Further clarification could have been sought from all participants by consulting with them regarding the final themes. The themes were not always discrete categories as represented and participants did not relate to them all in a consistent or universal way. I have done my best to represent this diversity within the description of the analysis.

Reflexivity

Throughout this study I have endeavoured to practise reflexivity, that is, to reflect upon my own position in relation to the research, and the effects that this may have on this research, in order that I can understand and limit the impact of this on the findings.

As a reflexive researcher, I acknowledge my personal beliefs, which were explained in relation to the research in the methods chapter. These beliefs affected my choice of methodology and method. This study was iterative and emergent, and therefore the developing design was a result of the reflexive process. I recognise my role at all stages of the research and that the accounts heard will be influenced by the questions asked; the interaction between the participant and I during the interview; as well as the interpretations made during the analysis.

In doing this it is necessary to reflect upon who I am, and how the participants may have perceived me. As a 35 year old female, I feel I am non-threatening and probably typical of the health professionals that a stroke survivor may see in the time following their stroke. While I have an English name and am Caucasian, I am also visibly identifiable as a Muslim, because of the way that I dress. I have never encountered any difficulties with this, in either a clinical or a research setting, and it is easy for me to dismiss this as ‘not an issue’.

However, on further reflection, it is probably because I am so used to dealing with peoples' reactions that I don't notice it anymore. It is also important for me to acknowledge that I may not be aware of the impact this has on people.

With all of the participants, except the email participants, I spoke to them on the telephone, giving my name, before meeting them in person. This may have set up an expectation about the type of person they may meet. It is very normal for people who have spoken to me on the telephone to look slightly surprised when they meet me in person, and this was the case with most participants. On reflection, I believe that I subconsciously made an effort in the way I spoke and by reference to particular things, to identify myself as culturally similar to my interviewees, to overcome any barriers that may have been created by my appearance. I experienced no negative reactions from participants because of my faith, although two of the participants commented upon it: April, who told me about her work in a predominately Muslim area of Sheffield, which had made her feel positively about Islam; and David, who politely asked at the end of the interview if he could ask me some questions about being Muslim, which I was happy for him to do. While I saw no evidence that my being Muslim had any impact upon the interviews, a researcher must always accept that their interviewees perceptions of them may influence how much, and what they reveal about themselves.

Not only does the researcher impact upon the research through their interaction with the participants, but they also bring to the research their own professional and other influences, which impact upon the way they interact with the research topic, the participants, and the data. As a qualified speech therapist I feel I approached the research topic from a particular angle. This was a conscious decision in that I wanted my research to be something that could not only be of interest in academic forum, but also be of interest and potentially useful for health professionals and patients. In addition to this conscious decision, I believe that my training as a health professional may have influenced the way I perceived the participants. The position of my thesis within the wider CLAHRC environment also influenced the decisions I made about the design of the research. As CLAHRC is designed to form a bridge between research and clinical practise, and this is an aim I consider to be very important, I was conscious throughout the research process of the potential practical applications of my research. I believe that these influences had a positive impact on the my research, as being from a health professional background I can sympathise with both the academic and clinical aspects of the research, and my work on previous large scale research projects within the NHS has also given me insight into the practical application of academic ideas.

I attempted to manage my own influence on the findings by reflecting on my personal feelings about each interview in memo form, before undertaking analysis of each interview. I found that this helped me to move beyond my preconceptions and move closer to the experience of the participant. However, I believe that the themes that emerged from the data were influenced by my own life experiences, both in relation to stroke and in other more personal aspects. Warren, (2002) recognised the influence of the researchers own biographical position in the findings of qualitative research, in that a researcher may see aspects of themselves in their participants' stories. This was balanced by discussions with my supervisors and a fellow researcher who looked over my analysis, and also by discussion and consultation with participants, such as in the focus group.

Just as the participants may have been changed by the interview process, and being prompted to think about certain aspects of life, I was also changed by the research process. Throughout the period of this study, I have been growing and maturing as a researcher, and also as a person, through hearing and seeing the stroke survivors, and learning from their stories.

Quality evaluation

The following table was presented in the methodology chapter, and here provides the opportunity to assess this study by the standards defined as appropriate for judging qualitative research (Lincoln & Guba, 1985; Pope & Mays, 1996; Tracey, 2010; Yardley, 2000).

Sensitivity to context/credibility *Does the researcher show extended engagement with the subject matter/sensitivity to context?*	The literature review chapter shows my knowledge of the subject area, and sections in the methodology and methods chapters contain evidence of my understanding of the context of the research.
Credibility *Has the researcher reflected on their*	I have explained the use of reflexivity within IPA research in the methodology chapter and given examples of how I used

role in research?	reflexivity in carrying out this study in the methods chapter. I have also reflected on my role in the research in the discussion chapter.
Transparency and Coherence/Dependability *Is there a fit between the research questions, the philosophical perspective and the method?*	The research paradigm, methodology and methods were selected as the most appropriate with which to answer the research questions, and the reasoning for these choices can be found in the methodology and methods chapters.
Transparency and Coherence/Dependability *Is there an audit trail of the research process?*	The methods for the recruitment of participants, the gathering of data, and the analysis are clearly set out in the methods chapter.
Credibility *Has triangulation been used?*	This study uses 3 sources, each with a different method of data collection, in order to view the research questions from multiple perspectives. This has been discussed in the methods chapter.
Credibility *Has the researcher tried to ascertain whether participants recognise the findings to be true to their experiences?*	Each of the sources contained an iterative element, giving the participants an opportunity to influence the development of the findings, as discussed in the methods and discussion chapter.
Credibility *Is the data collection and analysis complete?*	Data collection is complete (one participant from source 2 was unable to be followed up at twelve months) and has been analysed according to the steps outlined in the methods chapter. Data collection reached saturation point. Details of data collection and analysis are explained in the methods chapter.
Transparency and coherence *Is there clarity of presentation of the analysis?*	The findings chapter clearly presents and defines the themes and sub-themes which form the interpretative analysis.
Dependability *Has the researcher shown attention to negative cases?*	Within the findings chapter I have endeavoured to represent the cases that do not fit typically within the themes.
Transferability	The interpretive analysis presented in the findings chapter

Does the analysis reach a level of abstraction?	goes beyond description and suggests relationships between themes, and therefore may be applicable to others in similar situations.
Impact and importance *Does the research contribute to, and advance knowledge?*	I have demonstrated in the discussion chapter that my research contributes to the knowledge of stroke and participation and also offers an original contribution by exploring the relationship between participation and self-identity.
Impact and importance *Does the researcher make well founded and plausible claims about the significance of findings?*	I make suggestions as to the impact and importance of this study in the discussion chapter, based on my knowledge of the subject area.

Table 13: Quality in qualitative research applied to this study

Implications and recommendations

Although this research is based on the views of a small number of stroke survivors and carers, it has highlighted several areas which have implications for people working with stroke survivors, and also suggests areas for future research. As it cannot be assumed that the findings are generalisable, the following suggestions are made tentatively and may not be applicable for all situations.

For people working with stroke survivors

- The single-most important factor to have emerged from the analysis is the fact that each stroke survivor has a unique experience of participation, and what is said to be participation for one stroke survivor is different for another. Therefore, it is likely that individualised approaches to rehabilitation will best assist stroke survivors to participate in a way appropriate to their own needs and preferences.
- Assessing someone's level of participation can be essential to understanding the impact of a disability on a person's life, and tailoring support accordingly (Cardol, Jong et al. 2000). However, my study links with previous qualitative work around participation, to suggest that measurement instruments based on a predefined list of activities are unlikely to reflect the individual stroke survivors perceptions of participation. This study identified features of the essence of participation, which

underlie the subjective meaning it has for the individual. Other studies have identified similar features. This suggests the potential for using the concept of participation in a way which may be beneficial for people working with stroke survivors. A more appropriate approach would be to address skills and deficits, emotional and social needs, and create joint goals between the stroke survivor and the person working with the stroke survivor

- Some feel that a weakness within the ICF (World Health Organisation, 2001) is that activities and participation are not clearly distinguished (Mars et al., 2008). It is generally recognised that for the successful application of the ICF (World Health Organisation, 2001)a distinction between these components needs to be made. This research may provide insight into how the two components can be distinguished, particularly that choice and meaning may be central to the distinction.
- This study highlights the process of adjustment that follows a stroke, and provides examples of more and less successful outcomes. It may be possible for people working with stroke survivors to take some lessons from these descriptions and encourage stroke survivors to engage in successful strategies for reaching satisfactory participation.
- Loss emerged from the analysis as forming a significant part of the experience of being a stroke survivor. While this study neither suggested nor contradicted the relevance of applying grief and bereavement theories to stroke survivors, it suggests that people working with people with stroke survivors need to be aware of the sense of loss that the stroke survivor is likely to be experiencing. Further to this, the extent of loss may be related to the degree of role change experienced by the stroke survivor. Both maximising opportunities for meaningful participation, and helping the stroke survivor to adjust their expectations through acceptance, may ease the feelings of loss.

For research

- The present study has revealed a number of salient findings that point towards several lines of enquiry for future research. This study was successful in answering the research questions, and saw the emergence of the topic of self-identity related to participation, which was not identified prior to the research but became apparent from the analysis itself. The link between participation and self-identity in stroke survivors brings together aspects of previous research in this area, but there needs to be more work looking at this specific relationship.

- This success of this study in achieving its aims suggests that Phenomenology and more specifically IPA, are appropriate approaches for others who would embark on similar work. The successful inclusion of people with aphasia in this research, provides evidence to suggest the future research with stroke survivors should not contain blanket exclusion criteria for people with aphasia. The people with aphasia were able to consent with the help of a specially designed consent procedure, and were able to contribute significantly to the study.

Summary

This chapter has reviewed the findings of the present study in the context of previous research, and also evaluated the methodological basis for the research, and the methods used to answer the research questions. I have demonstrated that the methods used have effectively answered the research questions, and described how my research both reiterates findings in previous studies, and offers new insights into this area. The quality of the research has been judged according to criteria suitable for assessing the quality of qualitative research, and on the basis of my findings I have made suggestions about clinical implications and also suggested future research directions.

Chapter 8: Conclusion

This study aimed to explore the meaning and experience of participation to stroke survivors, specifically to answer the research questions:

What does the term 'participation' mean to stroke survivors?

How do stroke survivors experience participation?

These questions were answered within a qualitative paradigm, using Interpretative Phenomenological Analysis as a methodology, also drawing upon concepts found within grounded theory. The findings came from three sources: retrospective interviews with stroke survivors more than one year post stroke and their carers and a follow up focus group with stroke survivors; interviews with a longitudinal cohort of stroke survivors over the first year following stroke; and email interviews with stroke survivors more than one year post stroke. The research design was iterative, as the design of each source was influenced by the findings from the previous source, and the study was designed to be accessible to people with communication problems and people from ethnic minorities.

The findings chapter described the key themes and sub-themes within the data, and the discussion chapter discussed the findings in relation to the literature review. The two central themes were 'meaning and 'experience'. 'Meaning' included the sub-themes 'being actively involved', 'making meaningful choices' and 'being me', and these have been described in detail including the categories within them. 'Being actively involved' and 'making meaningful choices' reiterated and encompassed concepts already found within qualitative participation literature. 'Being me' described the relationship between self-identity, role and participation, and while these have been previously explored in relation to stroke, this study is unique in linking that to participation. This relationship between participation and self-identity is one of the reasons for the intense feelings of 'loss' experienced by stroke survivors, which was one sub-theme of 'experience'. Other elements of the experience of participation are 'acceptance', 'coping' and 'new participation'. 'Loss' and 'coping' were experienced by all the stroke survivors to varying degrees. However, acceptance, which was not seen in all stroke survivors, seemed to be a precursor to particularly effective ‘coping’ strategies which could lead to ‘new participation’.

The findings were compared to relevant literature in the discussion chapter, and it was demonstrated that the findings are supported by the literature, as well as adding to the literature in this area, in regards to the meaning and experience of participation, and suggested a link between participation and self-identity, which has not previously been explored in the literature.

The discussion chapter also evaluated the methodological basis for the research, and the methods used to answer the research questions. I have demonstrated that the methods were effective in answering the research questions, and the quality of the research has been judged according to criteria suitable for assessing the quality of qualitative research. The strengths of this study included triangulation, and the iterative design which enabled the participants to influence the research design and analysis, both of which increase the credibility of the research. Limitations of the study included the reliance on the linguistic abilities of the participants, which meant that some participants were heard more than others, and the small number of participants, which, although appropriate to the methodology, limits the potential of the findings to be generalised.

Despite the study limitations, I was able to make suggestions as to the implications of this study for people working with stroke survivors, and possible future research directions. The most significant clinical implication is that each stroke survivor has a unique experience of participation, and what is said to be participation for one stroke survivor is different for another. Therefore, it is likely that individualised approaches to rehabilitation will best assist stroke survivors to participate in a way appropriate to their own needs and preferences. The most significant suggestions for future research is to explore further the link between participation and self-identity in stroke survivors, as while both participation and self-identity are already discussed in relation to stroke within the literature, the link between participation and self-identity in relation to stroke has not yet been explored.

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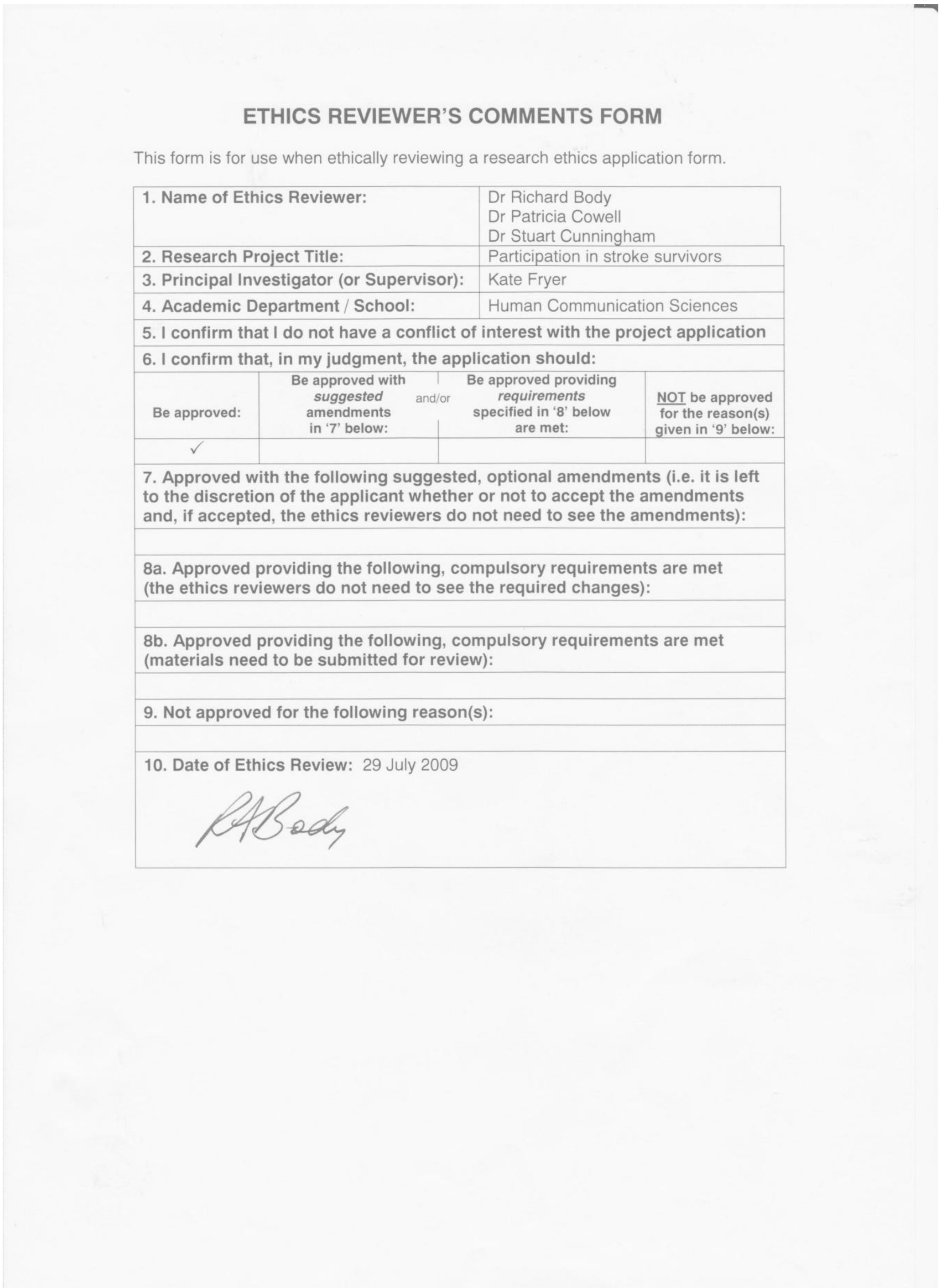
Appendices

Appendix 1 - Ethical Approval Documents

1.1-Source 1



ETHICS REVIEWER'S COMMENTS FORM

This form is for use when ethically reviewing a research ethics application form.

1. Name of Ethics Reviewer:	Dr Richard Body Dr Patricia Cowell Dr Stuart Cunningham
2. Research Project Title:	Participation in stroke survivors
3. Principal Investigator (or Supervisor):	Kate Fryer
4. Academic Department / School:	Human Communication Sciences

5. I confirm that I do not have a conflict of interest with the project application

6. I confirm that, in my judgment, the application should:

Be approved:	Be approved with *suggested* amendments in '7' below:	and/or	Be approved providing *requirements* specified in '8' below are met:	NOT be approved for the reason(s) given in '9' below:
✓				

7. Approved with the following suggested, optional amendments (i.e. it is left to the discretion of the applicant whether or not to accept the amendments and, if accepted, the ethics reviewers do not need to see the amendments):

8a. Approved providing the following, compulsory requirements are met (the ethics reviewers do not need to see the required changes):

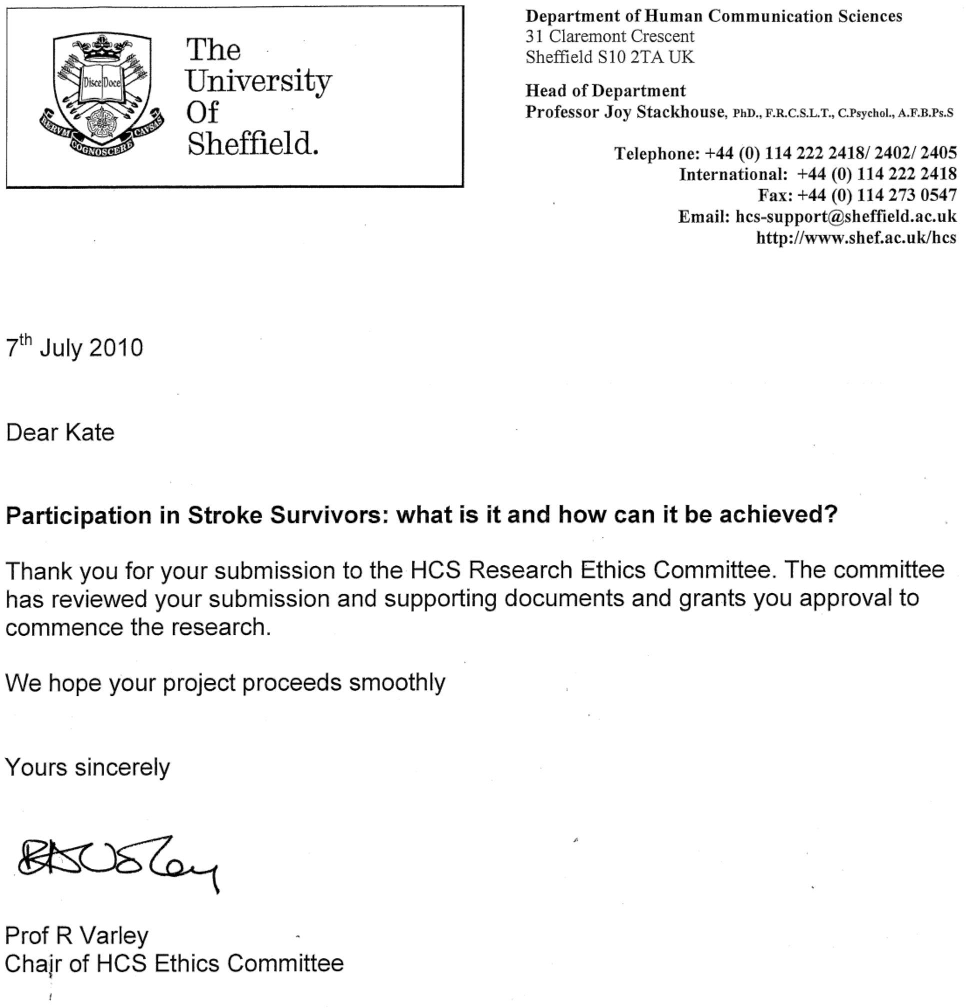
8b. Approved providing the following, compulsory requirements are met (materials need to be submitted for review):

9. Not approved for the following reason(s):

10. Date of Ethics Review: 29 July 2009

RABody

1.2-Source 2



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Professor Joy Stackhouse, PhD., F.R.C.S.L.T., C.Psychol., A.F.B.Ps.S

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7th July 2010

Dear Kate

Participation in Stroke Survivors: what is it and how can it be achieved?

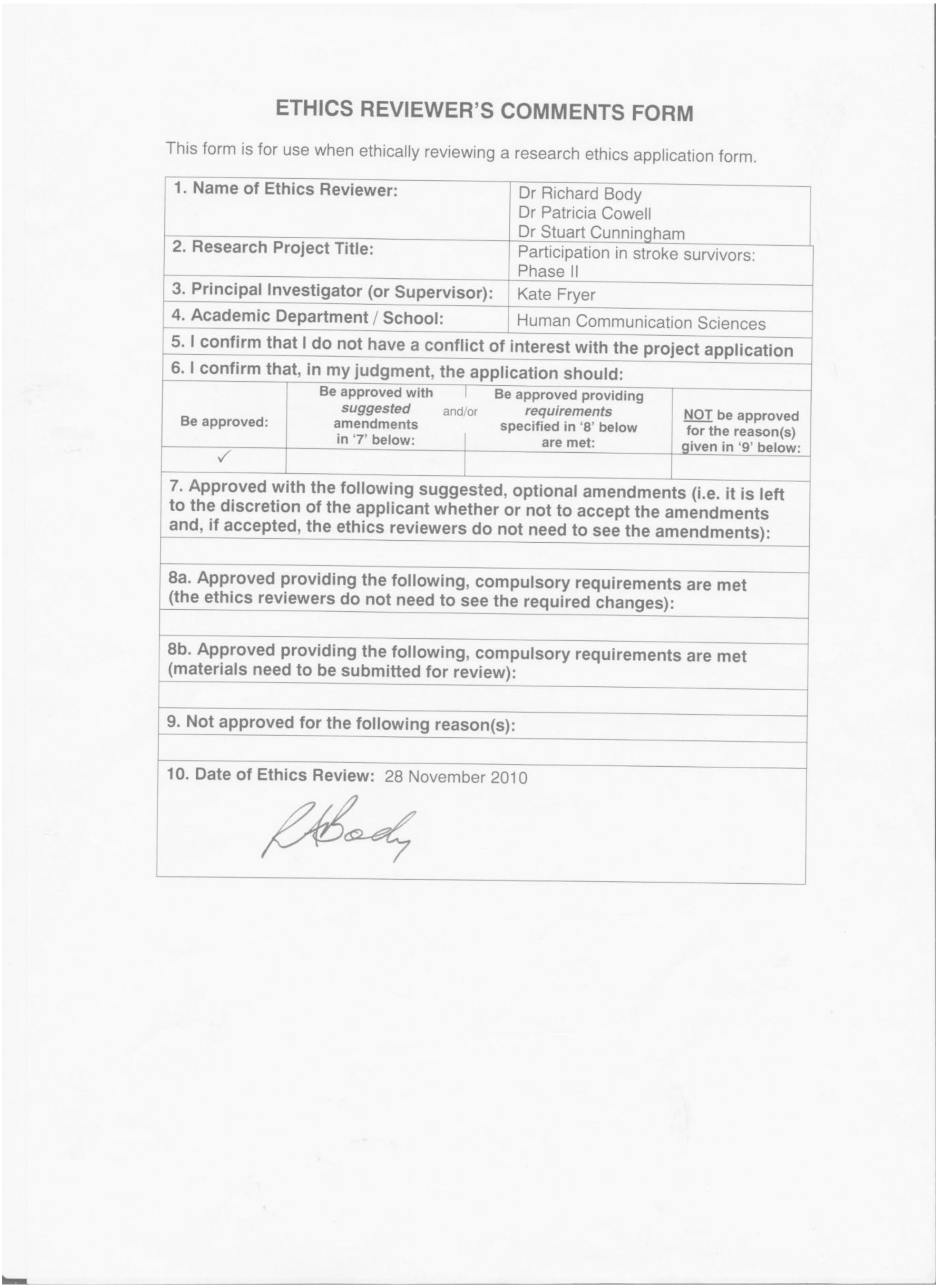
Thank you for your submission to the HCS Research Ethics Committee. The committee has reviewed your submission and supporting documents and grants you approval to commence the research.

We hope your project proceeds smoothly

Yours sincerely

Prof R Varley
Chair of HCS Ethics Committee

1.3-Source 3



ETHICS REVIEWER'S COMMENTS FORM

This form is for use when ethically reviewing a research ethics application form.

1. Name of Ethics Reviewer:	Dr Richard Body Dr Patricia Cowell Dr Stuart Cunningham
2. Research Project Title:	Participation in stroke survivors: Phase II
3. Principal Investigator (or Supervisor):	Kate Fryer
4. Academic Department / School:	Human Communication Sciences

5. I confirm that I do not have a conflict of interest with the project application

6. I confirm that, in my judgment, the application should:

Be approved:	Be approved with *suggested* amendments in '7' below:	and/or Be approved providing *requirements* specified in '8' below are met:	NOT be approved for the reason(s) given in '9' below:
✓			

7. Approved with the following suggested, optional amendments (i.e. it is left to the discretion of the applicant whether or not to accept the amendments and, if accepted, the ethics reviewers do not need to see the amendments):

8a. Approved providing the following, compulsory requirements are met (the ethics reviewers do not need to see the required changes):

8b. Approved providing the following, compulsory requirements are met (materials need to be submitted for review):

9. Not approved for the following reason(s):

10. Date of Ethics Review: 28 November 2010

RBody

Appendix 2 – Recruitment Materials

2.1-Source 1

2.1.1-Community representatives recruitment poster

Arabic/Urdu/Punjabi speakers wanted

Asalam u alikum

- Do you speak and understand any of the above languages fluently?
- Are you in Sheffield in the Autumn?
- Would you be willing to help me with my research in exchange for training in focus groups/interviews by an experienced researcher?

I am an experienced researcher doing a PhD looking at participation in stroke patients.

I want to include ethnic minorities in my research, in order that local services may be better equipped in future to serve our communities.

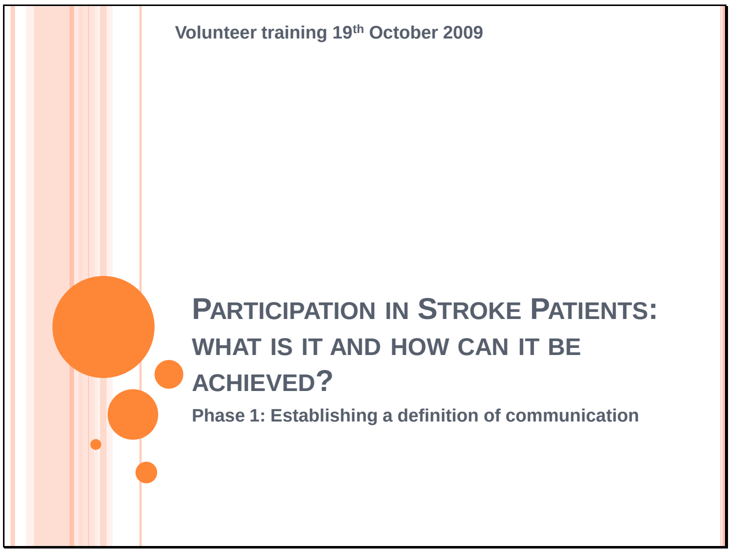
If you are willing to help out, I can offer in return, training in focus groups/interviews. Good for the CV!

If interested please contact Kate:

fryerkate@hotmail.com

2.1.2-Power-point presentation for community representative training

Slide 1

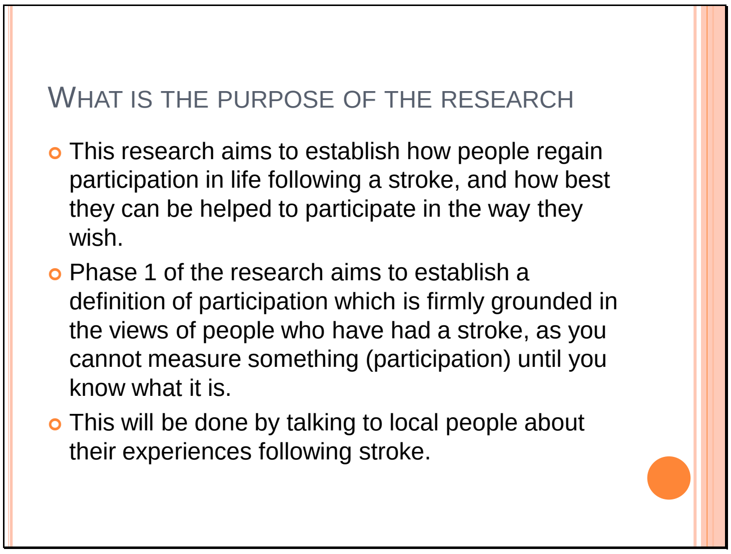


Volunteer training 19th October 2009

PARTICIPATION IN STROKE PATIENTS: WHAT IS IT AND HOW CAN IT BE ACHIEVED?

Phase 1: Establishing a definition of communication

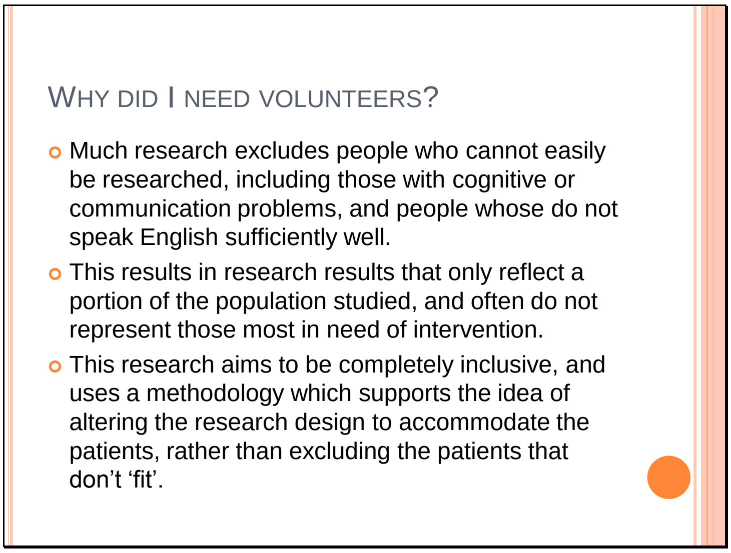
Slide 2



WHAT IS THE PURPOSE OF THE RESEARCH

- This research aims to establish how people regain participation in life following a stroke, and how best they can be helped to participate in the way they wish.
- Phase 1 of the research aims to establish a definition of participation which is firmly grounded in the views of people who have had a stroke, as you cannot measure something (participation) until you know what it is.
- This will be done by talking to local people about their experiences following stroke.

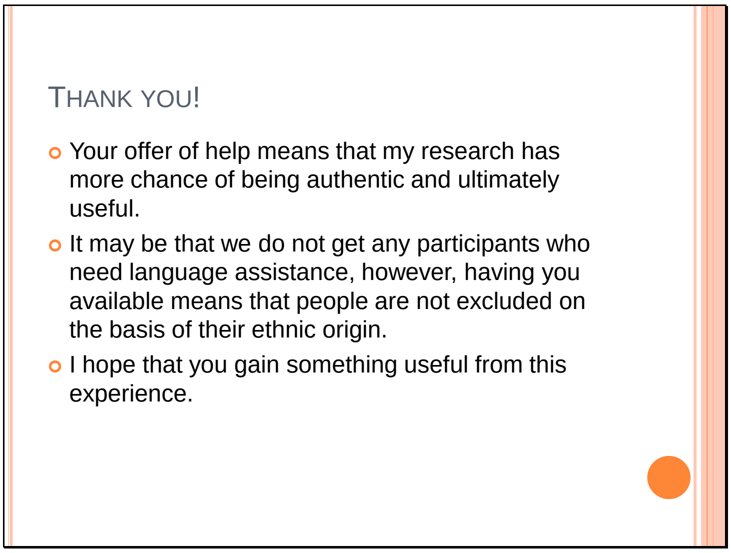
Slide 3



WHY DID I NEED VOLUNTEERS?

- Much research excludes people who cannot easily be researched, including those with cognitive or communication problems, and people whose do not speak English sufficiently well.
- This results in research results that only reflect a portion of the population studied, and often do not represent those most in need of intervention.
- This research aims to be completely inclusive, and uses a methodology which supports the idea of altering the research design to accommodate the patients, rather than excluding the patients that don't 'fit'.

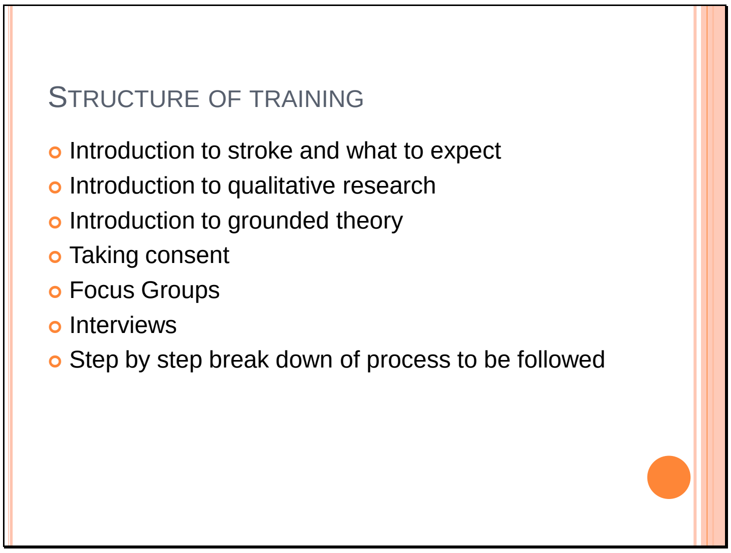
Slide 4



THANK YOU!

- Your offer of help means that my research has more chance of being authentic and ultimately useful.
- It may be that we do not get any participants who need language assistance, however, having you available means that people are not excluded on the basis of their ethnic origin.
- I hope that you gain something useful from this experience.

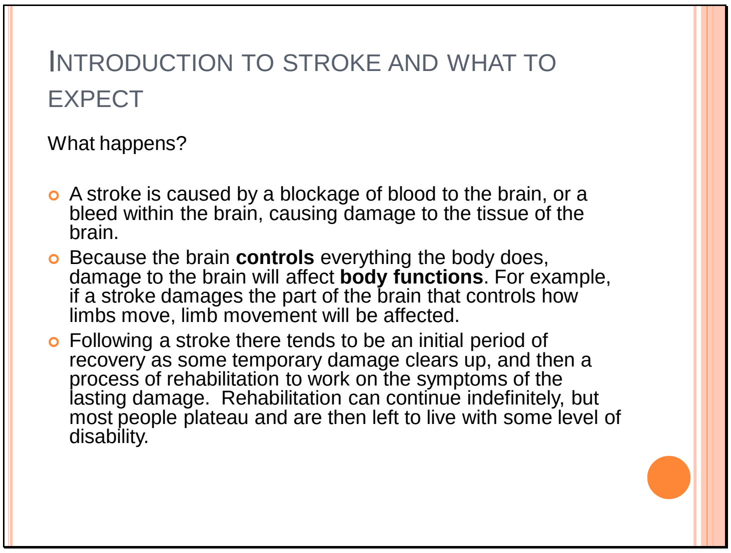
Slide 5



STRUCTURE OF TRAINING

- Introduction to stroke and what to expect
- Introduction to qualitative research
- Introduction to grounded theory
- Taking consent
- Focus Groups
- Interviews
- Step by step break down of process to be followed

Slide 6

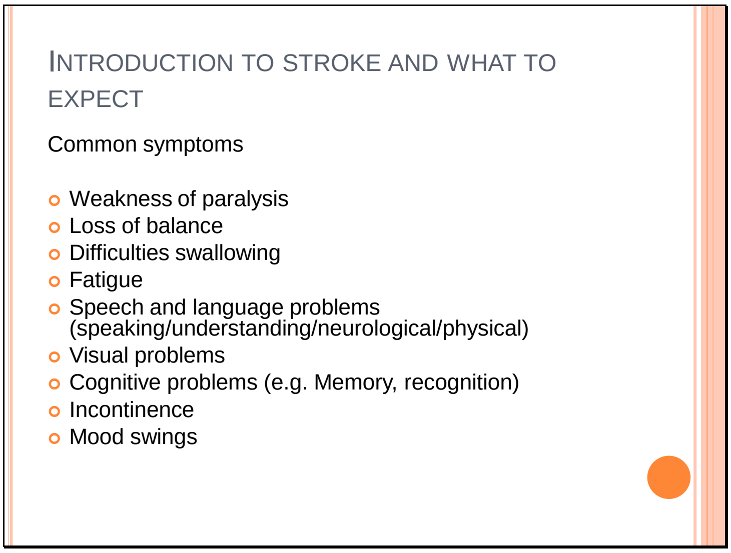


INTRODUCTION TO STROKE AND WHAT TO EXPECT

What happens?

- A stroke is caused by a blockage of blood to the brain, or a bleed within the brain, causing damage to the tissue of the brain.
- Because the brain **controls** everything the body does, damage to the brain will affect **body functions**. For example, if a stroke damages the part of the brain that controls how limbs move, limb movement will be affected.
- Following a stroke there tends to be an initial period of recovery as some temporary damage clears up, and then a process of rehabilitation to work on the symptoms of the lasting damage. Rehabilitation can continue indefinitely, but most people plateau and are then left to live with some level of disability.

Slide 7

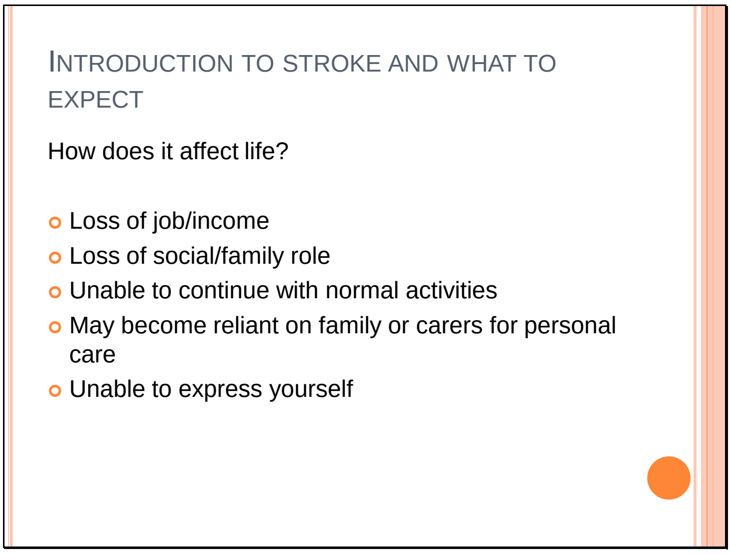


INTRODUCTION TO STROKE AND WHAT TO EXPECT

Common symptoms

- Weakness of paralysis
- Loss of balance
- Difficulties swallowing
- Fatigue
- Speech and language problems (speaking/understanding/neurological/physical)
- Visual problems
- Cognitive problems (e.g. Memory, recognition)
- Incontinence
- Mood swings

Slide 8

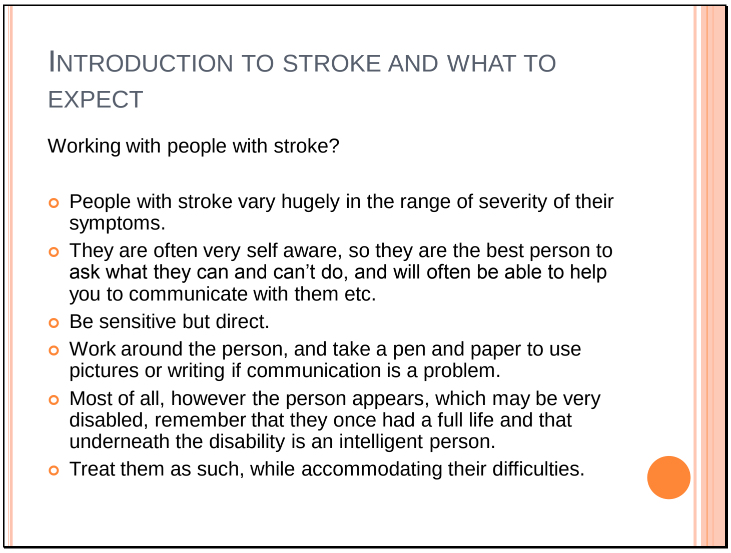


INTRODUCTION TO STROKE AND WHAT TO EXPECT

How does it affect life?

- Loss of job/income
- Loss of social/family role
- Unable to continue with normal activities
- May become reliant on family or carers for personal care
- Unable to express yourself

Slide 9

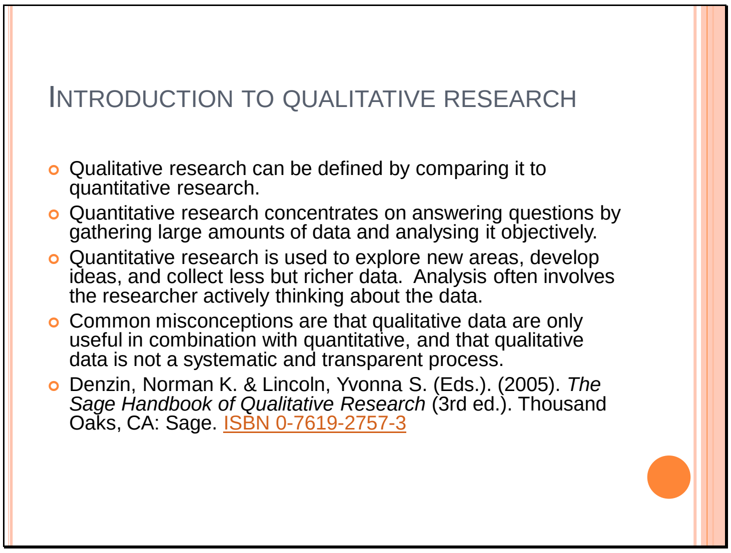


INTRODUCTION TO STROKE AND WHAT TO EXPECT

Working with people with stroke?

- People with stroke vary hugely in the range of severity of their symptoms.
- They are often very self aware, so they are the best person to ask what they can and can’t do, and will often be able to help you to communicate with them etc.
- Be sensitive but direct.
- Work around the person, and take a pen and paper to use pictures or writing if communication is a problem.
- Most of all, however the person appears, which may be very disabled, remember that they once had a full life and that underneath the disability is an intelligent person.
- Treat them as such, while accommodating their difficulties.

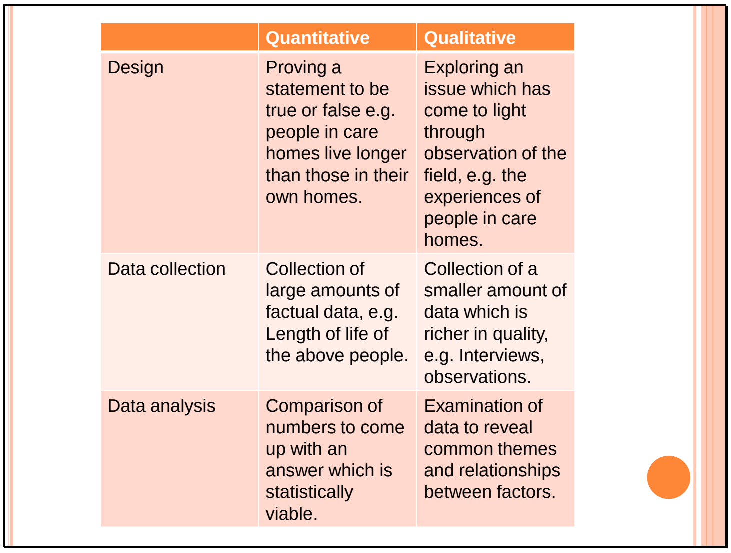
Slide 10



INTRODUCTION TO QUALITATIVE RESEARCH

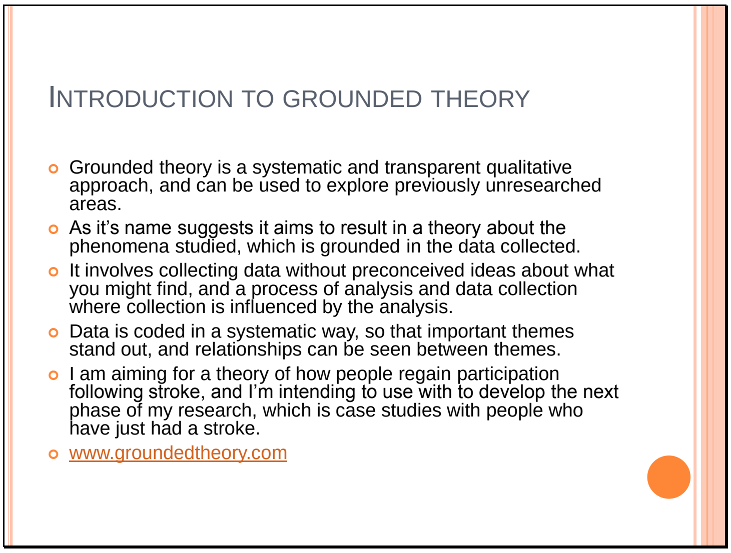
- Qualitative research can be defined by comparing it to quantitative research.
- Quantitative research concentrates on answering questions by gathering large amounts of data and analysing it objectively.
- Quantitative research is used to explore new areas, develop ideas, and collect less but richer data. Analysis often involves the researcher actively thinking about the data.
- Common misconceptions are that qualitative data are only useful in combination with quantitative, and that qualitative data is not a systematic and transparent process.
- Denzin, Norman K. & Lincoln, Yvonna S. (Eds.). (2005). *The Sage Handbook of Qualitative Research* (3rd ed.). Thousand Oaks, CA: Sage. ISBN 0-7619-2757-3

Slide 11



	Quantitative	Qualitative
Design	Proving a statement to be true or false e.g. people in care homes live longer than those in their own homes.	Exploring an issue which has come to light through observation of the field, e.g. the experiences of people in care homes.
Data collection	Collection of large amounts of factual data, e.g. Length of life of the above people.	Collection of a smaller amount of data which is richer in quality, e.g. Interviews, observations.
Data analysis	Comparison of numbers to come up with an answer which is statistically viable.	Examination of data to reveal common themes and relationships between factors.

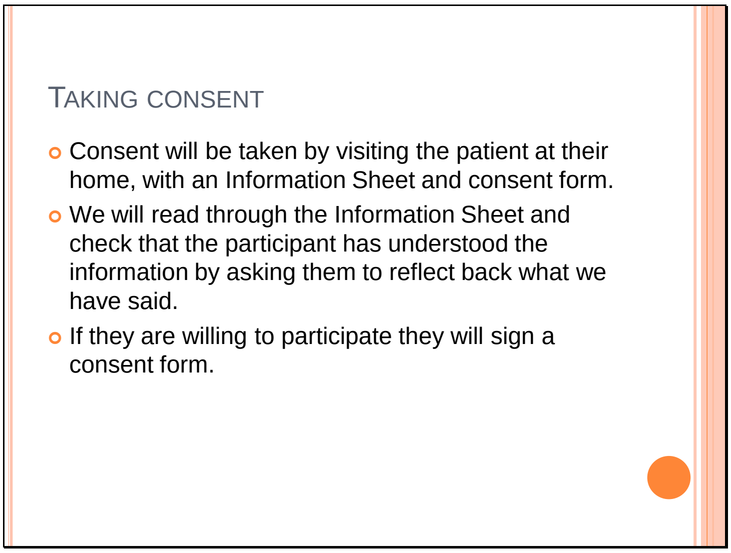
Slide 12



INTRODUCTION TO GROUNDED THEORY

- Grounded theory is a systematic and transparent qualitative approach, and can be used to explore previously unresearched areas.
- As it's name suggests it aims to result in a theory about the phenomena studied, which is grounded in the data collected.
- It involves collecting data without preconceived ideas about what you might find, and a process of analysis and data collection where collection is influenced by the analysis.
- Data is coded in a systematic way, so that important themes stand out, and relationships can be seen between themes.
- I am aiming for a theory of how people regain participation following stroke, and I'm intending to use with to develop the next phase of my research, which is case studies with people who have just had a stroke.
- www.groundedtheory.com

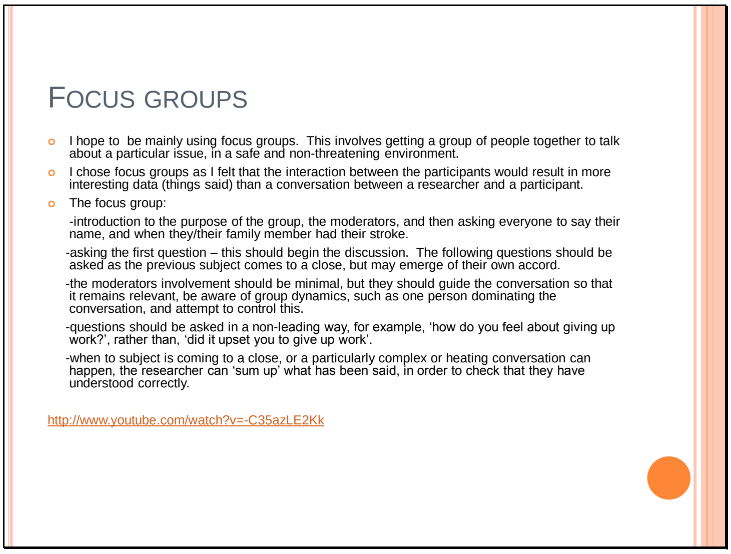
Slide 13



TAKING CONSENT

- Consent will be taken by visiting the patient at their home, with an Information Sheet and consent form.
- We will read through the Information Sheet and check that the participant has understood the information by asking them to reflect back what we have said.
- If they are willing to participate they will sign a consent form.

Slide 14



FOCUS GROUPS

- I hope to be mainly using focus groups. This involves getting a group of people together to talk about a particular issue, in a safe and non-threatening environment.
- I chose focus groups as I felt that the interaction between the participants would result in more interesting data (things said) than a conversation between a researcher and a participant.
- The focus group:

  -introduction to the purpose of the group, the moderators, and then asking everyone to say their name, and when they/their family member had their stroke.

  -asking the first question – this should begin the discussion. The following questions should be asked as the previous subject comes to a close, but may emerge of their own accord.

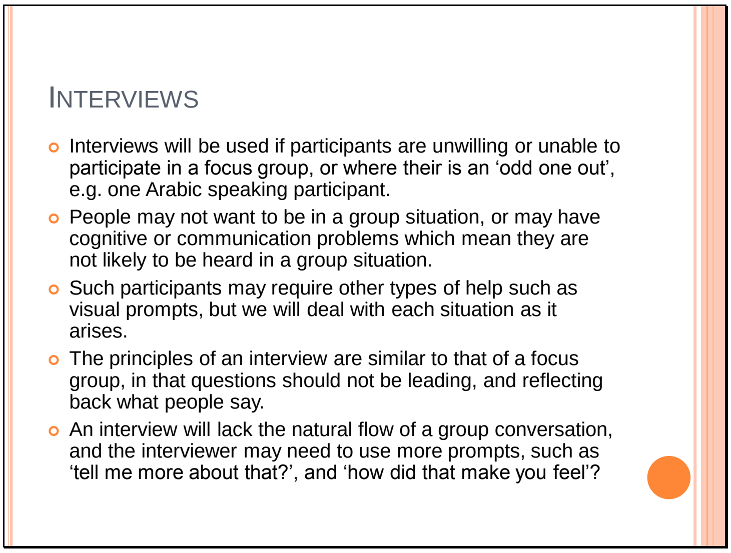
  -the moderators involvement should be minimal, but they should guide the conversation so that it remains relevant, be aware of group dynamics, such as one person dominating the conversation, and attempt to control this.

  -questions should be asked in a non-leading way, for example, ‘how do you feel about giving up work?’, rather than, ‘did it upset you to give up work’.

  -when to subject is coming to a close, or a particularly complex or heating conversation can happen, the researcher can ‘sum up’ what has been said, in order to check that they have understood correctly.

http://www.youtube.com/watch?v=-C35azLE2Kk

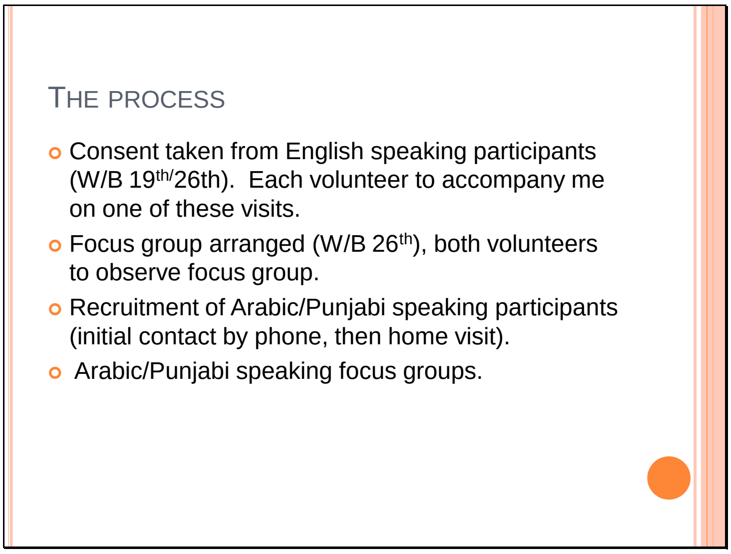
Slide 15



INTERVIEWS

- Interviews will be used if participants are unwilling or unable to participate in a focus group, or where their is an ‘odd one out’, e.g. one Arabic speaking participant.
- People may not want to be in a group situation, or may have cognitive or communication problems which mean they are not likely to be heard in a group situation.
- Such participants may require other types of help such as visual prompts, but we will deal with each situation as it arises.
- The principles of an interview are similar to that of a focus group, in that questions should not be leading, and reflecting back what people say.
- An interview will lack the natural flow of a group conversation, and the interviewer may need to use more prompts, such as ‘tell me more about that?’, and ‘how did that make you feel’?

Slide 16



THE PROCESS

- Consent taken from English speaking participants (W/B 19th/26th). Each volunteer to accompany me on one of these visits.
- Focus group arranged (W/B 26th), both volunteers to observe focus group.
- Recruitment of Arabic/Punjabi speaking participants (initial contact by phone, then home visit).
- Arabic/Punjabi speaking focus groups.

Slide 17

THANK YOU

Any questions?

2.2-Source 2

2.2.1-Letter to The Stroke Association

The
University
Of
Sheffield.

8th June 2009

Dear colleagues,

Thank you for allowing me the time to speak to you about my research on participation in stroke patients. I wanted to provide you with some background about myself and my research, prior to our meeting.

I have worked in health related research for approximately 8 years. I began working with heavy drinkers, and then moved into the area of elderly rehabilitation. During this time I had contact with many Speech and Language Therapists, and decided to return to education and train in this myself. I completed this in 2007. I have since been working as a research SLT.

I was given the opportunity to undertake a Phd in the area of stroke and participation. This was a great opportunity to work with a familiar client group, and develop my personal research interests.

The purpose of my PhD is to establish what participation means to people who are living with the consequences of stroke, and how they can be helped to reach their full potential in this regard. I have a particular interest in those patients who are often harder to reach for therapy and research purposes, including lower socio-economic groups, ethnic minorities and those with cognitive and communication problems.

I was delighted to discover that The Stroke Association had just launched their Family and Carer Support Services in the Sheffield area, as I understand the Stroke Association to be at the cutting edge of Stroke Care, incorporating a person centred approach.

I would be very grateful if you could tell me more about your service, and the way it works in Sheffield. It is my sincere hope that we can find a way to work together, which would be mutually beneficial, and this is what I would like to discuss when we meet.

If you have any questions in the mean time please email me on hcp08kf@sheffield.ac.uk.

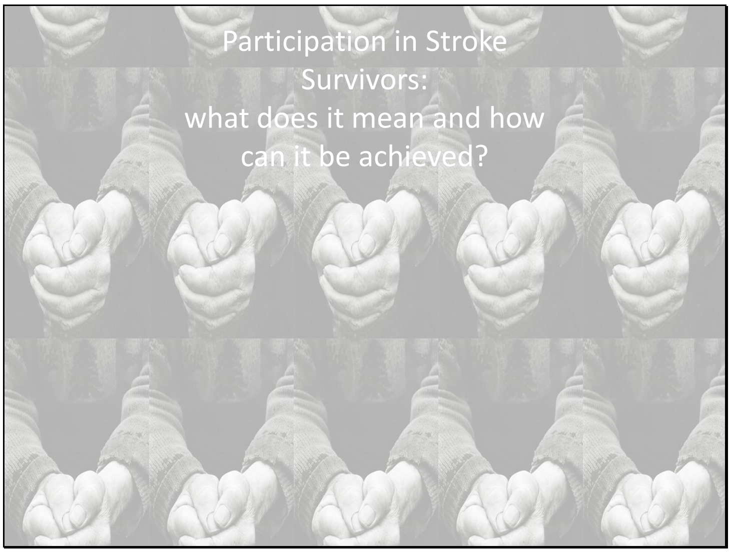
Many thanks.

Yours sincerely

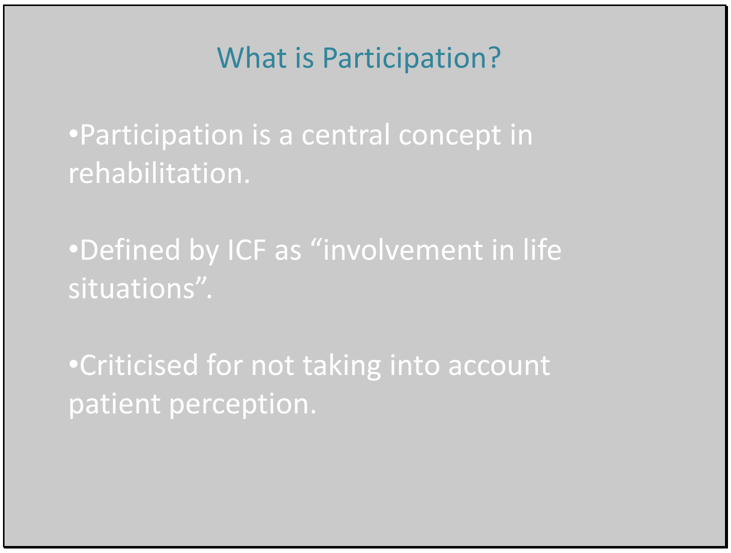
Kate Fryer

2.2.2-Power-point presentation for The Stroke Association

Slide 1



Participation in Stroke Survivors:
what does it mean and how can it be achieved?



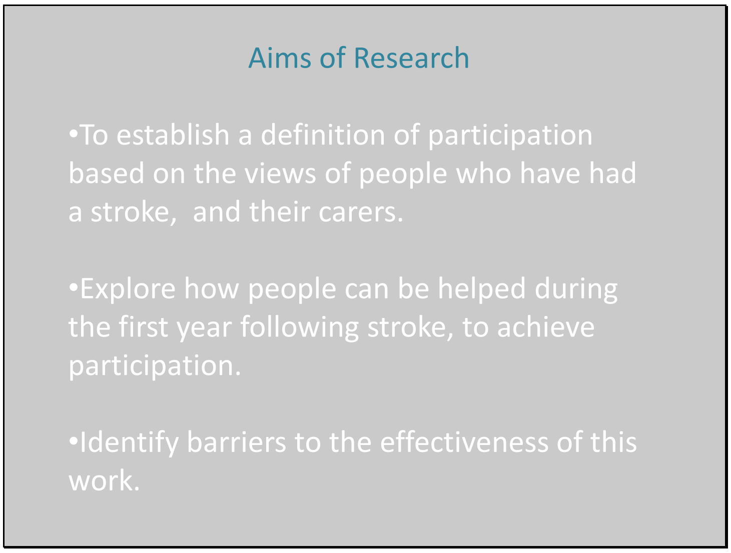
What is Participation?

•Participation is a central concept in rehabilitation.

•Defined by ICF as “involvement in life situations”.

•Criticised for not taking into account patient perception.

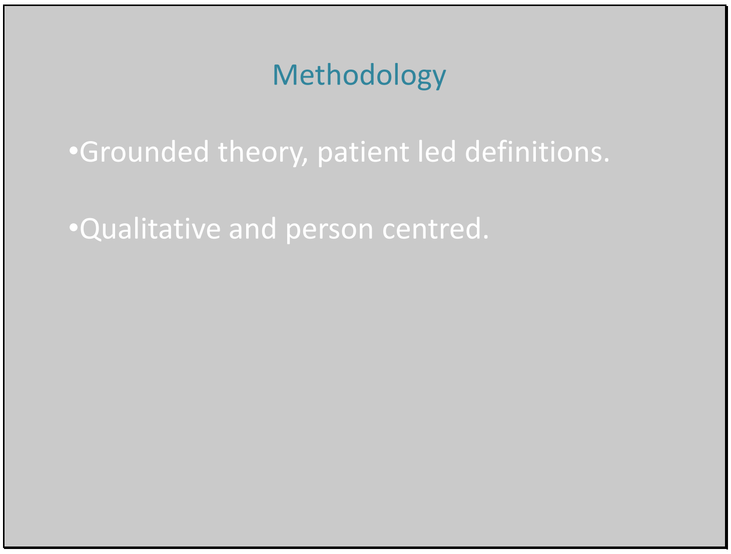
Slide 3



Aims of Research

- To establish a definition of participation based on the views of people who have had a stroke, and their carers.
- Explore how people can be helped during the first year following stroke, to achieve participation.
- Identify barriers to the effectiveness of this work.

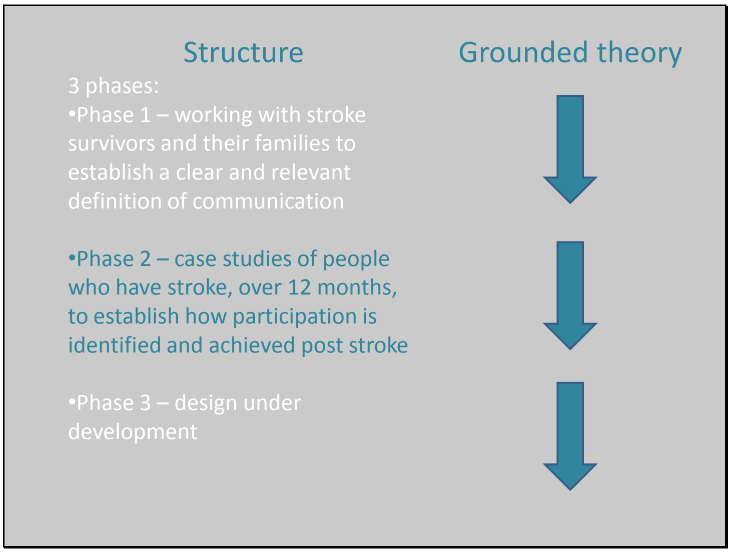
Slide 4



Methodology

- Grounded theory, patient led definitions.
- Qualitative and person centred.

Slide 5



Structure

3 phases:

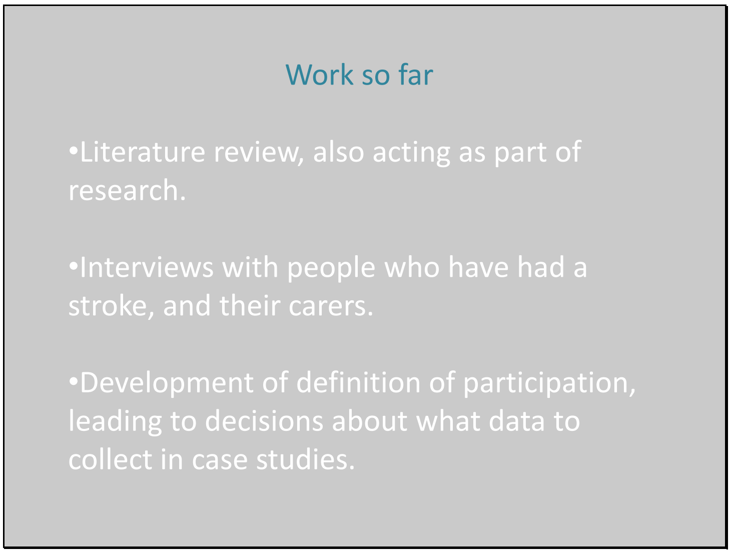
- Phase 1 – working with stroke survivors and their families to establish a clear and relevant definition of communication

- Phase 2 – case studies of people who have stroke, over 12 months, to establish how participation is identified and achieved post stroke

- Phase 3 – design under development

Grounded theory

Slide 6



Work so far

- Literature review, also acting as part of research.

- Interviews with people who have had a stroke, and their carers.

- Development of definition of participation, leading to decisions about what data to collect in case studies.

Slide 7

Thank you

2.3-Source 3

Content of email to forums

Dear all,

I am a PhD student from Sheffield University, and I am doing research into how people participate in life, following a stroke. I am looking for volunteers to do some email interviews with me.

This would involve you initially telling me about your experiences, and I would then ask further questions about what you had written.

The emails would be completely confidential.

It is my hope that this work may contribute to health professionals understanding of people who have had a stroke, and how they can be helped to cope with the long term implications of having a stroke.

If you would be willing to take part, please could you email me on:

hcp08kf@sheffield.ac.uk

and I will send you more information about the project.

Many thanks

Yours sincerely

Kate Fryer

Appendix 3 - Screening tools, information sheets and consent forms

3.1-Source 1

3.1.1-Cognitive Screen

Cognitive Screen

1. What year is it?	Correct 0 points Incorrect 4 points
2. What month is it?	Correct 0 points Incorrect 3 points
3. Instruct patient to remember the following address - John Smith, 28, London Road, Luton	
4. About what time is it? (within the hour)	Correct 0 points Incorrect 3 points
5. Count backwards from 20-1.	Correct 0 points 1 error 2 points 2+ errors 4 points
6. Say the months of the year in reverse.	Correct 0 points 1 error 2 points 2+ errors 4 points
7. Repeat address.	Correct 0 points 1 error 2 points 2 errors 4 points 3 errors 6 points 4 errors 8 points All wrong 10 points

0-7 = normal

8+ significant

3.1.2-Information sheet

Information Sheet

Participation in Stroke Survivors: What does it mean and how can it be achieved?

You are being invited to take part in research.

Please read the information below.

Ask questions.

Then decide if you would like to take part.

What is the project's purpose?

Participation is seen as important by health professionals.

But what is it?

What do people who have had stroke think it is?

Why have I been chosen?

You or your family member contacted me because you saw my poster.

Do I have to take part?

You don’t have to take part.

You can withdraw at any time.

What will happen to me if I take part?

You will be asked to take part in a group discussion, or just have a conversation with me.

I will ask some questions, and you can tell me anything you like.

This will be about what participation means to you, since your stroke.

This will take place within the next 3 months.

I will record it onto a tape.

tape dispenser
C90
j-me.

No-one except the research team will listen to the tape.

tape dispenser
C90
j-me.

What do I have to do?

You just need to tell me what you think.

What are the possible disadvantages and risks of taking part?

There are no risks associated with you taking part.

What are the possible benefits of taking part?

Your opinions will be heard.

I hope this research will help health professionals to help people like you in future.

What happens if the research study stops earlier than expected?

You will be told that the research is no longer taking place.

What if something goes wrong?

If you are unhappy with anything you can contact my supervisor:

Professor Shelagh Brumfitt, Department of Human Communications Sciences
The University of Sheffield
31 Claremont Crescent
Sheffield
S10 2TA

Tel: +44 (0) 114 222 2406
Fax: +44 (0) 114 273 0547
email : s.m.brumfitt@sheffield.ac.uk

And if you are still not happy you can contact the University's Registrar and Secretary:

Dr David Fletcher
The University of Sheffield
Western Bank
Sheffield
S10 2TN

Will my taking part in this project be kept confidential?

Your details will be kept in a locked filing cabinet.

Anything you say will be anonymous.

What will you be asking me and why?

I want your opinions and experiences.

Your Ideas Matter
I Want My Say

What will happen to the results of the research project?

The results will be written up in my thesis.

They may be used in other publications.

I will write them up for you and the other participants, so you can see what you all said.

Who is organising and funding the research?

This research is funded by the Department of Health.

Who has ethically reviewed the project?

This project had been ethically reviewed by Sheffield University Research Ethics Committee.

Contact for further information

For further information please contact me:

Kate Fryer
18 Claremont Crescent
Human Communications Sciences
University of Sheffield

Sheffield S10 2TA
0114 2222452

hcp08kf@sheffield.ac.uk

You will be given a copy of this form, and a signed consent form to keep.

Thank you for your time.

3.1.3-Information sheet Arabic

Information Sheet

صفحة العلمومات

Participation in Stroke Survivors: What does it mean and how can it be achieved?

مُشاركة المرضى النّاجين مِن السّكتة الدّماغيّة: ما معنى هذا، و كيف بالإمكان تحقيقه؟

You are being invited to take part in research.

ندعوكُم لِلمُشاركة في البحث.

Please read the information below.

رجاءً اقرأْ المعلومات أدناه.

Ask questions.

اسأَل ما تَشاء

Then decide if you would like to take part.

ثُمَّ قَرِّر إن كُنتَ تُريد المُشاركة أم لا.

What is the project's purpose?

ما هي الغاية مِن المَشروع؟

Participation is seen as important by health professionals.

يُعتَبر الإشتراك مُهِم جِدّاً بالنِّسبة للأخِصّائيين في الصِّحة.

But what is it?

ولكن ما هي؟

What do people who have had stroke think it is?

ماهي اعتِقادات الأشخاص المُصابين عن السَّكتة الدَّماغية؟

Why have I been chosen?

لِماذا اختاروني؟

You or your family member contacted me because you saw my poster.

أنتَ أو أحد أفراد أُسرَتُك اتَّصلوا بي عندما شاهدوا اعلاني في المنشور.

Do I have to take part?

هل يَجب عليَّ أن أشتَرك؟

You don’t have to take part.

لا أنتَ غير مُجبَر على الإشتراك.

You can withdraw at any time.

يُمكِنُكَ الإنسحاب في أي وقت.

What will happen to me if I take part?

ماذا سَيَحدث لي إذا شاركتُ في البحث؟

You will be asked to take part in a group discussion, or just have a conversation with me.

سَنَطلُب مِن عِندَكَ أن تُشارك في الحَديث مَعَ مجموعة من المُشاركين أو التَّحَدُّث معي فقَط.

I will ask some questions, and you can tell me anything you like.

سوفَ أسأَلُكَ بعض الأسئلة، و تَستَطيع أن تُحَدِّثُني عن أي شيءٍ تُحِب.

This will be about what participation means to you, since your stroke.

وهذا سَيكون حَول ما هو مَفهوم الإشتراك لَديكَ، مُنذُ أن أُصِبتَ
بالسّكتة الدّماغيّة.

This will take place within the next 3 months.

سَيَبدأُ هذا البحث خلال الثّلاثة أشهر القادمة.

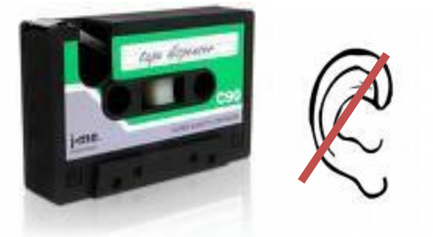
I will record it onto a tape.

وَ سأقومُ بِتَسجيل المُحادثة.

tape dispenser
C90
j-me

No-one except the research team will listen to the tape.

ليسَ هناك مَن سَيَسمع الشَّريط، أنا فقط التي سَأستَمع إليه.



What do I have to do?

ماذا يَجِبُ عليَّ أن أفعَل؟

You just need to tell me what you think.

فقط أن تَقولَ لِي ما هُوَ اعتِقادُكَ؟

What are the possible disadvantages and risks of taking part?

ما هي العُيوب والخُطورة المُمكِن حُدوثها في حالة الإشتراك؟

There are no risks associated with you taking part.

ليسَ هُناكَ أي خطورة في الإشتراك.

What are the possible benefits of taking part?

ماهي المنافع الممكن حُصولها في حالة الإشتراك؟

Your opinions will be heard.

سَنَستَمعُ إلى رأْيُكَ.

I hope this research will help health professionals to help people like you in future.

آمل أن يُساعِد هذا البحث الأخصّائيين في الصّحة في تقديم المُساعدات للمصابين مثلُكَ في المستقبل.

What happens if the research study stops earlier than expected?

ما يحدث لو أنَّ البحث تَوَقَّف قبل الوقت المُتَوقّع؟

You will be told that the research is no longer taking place.

سَنقومُ باعلامِكَ عن تَوقف البحث.

What if something goes wrong?

ماذا لو حدثَ شيء خَطأ؟

If you are unhappy with anything you can contact my supervisor:

لو كُنتَ غير راضي عن أي شيء ، يمكِنكَ الإتصال بِمشرفي:

Professor Shelagh Brumfitt,

Department of Human Communications Sciences

The University of Sheffield

31 Claremont Crescent Tel: +44 (0) 114 222 2406

Sheffield Fax: +44 (0) 114 273 054

S10 2TA email : s.m.brumfitt@sheffield.ac.uk

And if you are still not happy you can contact the University's Registrar and Secretary:

وإن كُنتَ لا تزال غير راضي يُمكِنُكَ الإتصال بِسكرتير أو أمين سجل الجامعة:

Dr David Fletcher

The University of Sheffield
Western Bank
Sheffield
S10 2TN

Will my taking part in this project be kept confidential?

هل سَتكون مُشاركتي في هذا المشروع خصوصيّة؟

Your details will be kept in a locked filing cabinet.

سَنَحتَفظُ بمعلوماتِك في ملفات سريّة.

Anything you say will be anonymous.

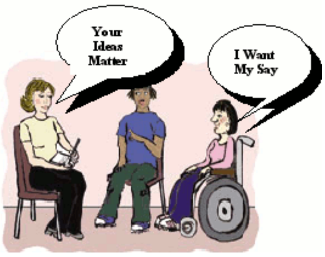
وكل شيء تَقولهُ سَكون مجهول الإسم.

What will you be asking me and why?

ماذا سَتسألوني و لماذا

I want your opinions and experiences.

أريد أن أستَمعُ إلى رأيُك و تجرُبَتك.


Your Ideas Matter
I Want My Say

What will happen to the results of the research project?

ماذا سيحدث لنتائج مشروع البحث؟

The results will be written up in my thesis.

سأكتُب النّتائج في رسالتي العلمية.

They may be used in other publications.

وربُما سَتُستعمل في منشورات أخرى.

I will write them up for you and the other participants,

so you can see what you all said.

سأكتب لك و لبقية المشاركين لكي تقرأو ما قلتم في المحادثة.

Who is organising and funding the research?

من الّذي سيقوم بتنظيم و تمويل البحث؟

This research is funded by the Department of Health.

هذا البحث مدعوم مِن قبل إدارة الصِّحة.

DH Department of Health

Who has ethically reviewed the project?

من قام بِمراجعة هذا المشروع من النّاحية الأخلاقية؟

This project had been ethically reviewed by Sheffield University Research Ethics Committee.

قام بمراجعة هذا المشروع من الناحية الأخلاقية، جمعية البحوث الأخلاقية

في جامعة شيفيلد.

The University Of Sheffield.

Contact for further information

الإتصال لمزيد من المعلومات

For further information please contact me:

لمزيد من المعلومات يُرجى الإتصال بي:

Kate Fryer

18 Claremont Crescent

Human Communications Sciences

University of Sheffield

Sheffield S10 2TA

0114 2222452

hcp08kf@sheffield.ac.uk

You will be given a copy of this form, and a signed consent form to keep.

سنقوم بتزويدك بصورة من هذا الإستمارة وأيضاً استمارة افادة الموافقة الموقع عليها.

Thank you for your time.

شكراً على اعطائنا من وقتك.

3.1.4-Information Sheet Urdu

Information Sheet

معلومات شیٹ

Participation in Stroke Survivors: What does it mean and how can it be achieved?

اسٹروک زندہ بچ جانے والوں میں شرکت: کیا اس کا مطلب یہ ہے کہ یہ کس طرح حاصل کیا جا سکتا ہے؟

You are being invited to take part in research.

تم تحقیق میں حصہ لینے کے لئے مدعو کیا جا رہا ہے.

Please read the information below.

معلومات ذیل میں ملاحظہ کریں

Ask questions.

سوال پوچھیں

Then decide if you would like to take part.

تو یہ فیصلہ اگر آپ حصہ لینے کے لئے چاہتے ہیں

What is the project’s purpose?

منصوبے کا مقصد کیا ہے؟

Participation is seen as important by health professionals.

شرکت صحت کے ماہرین کی طرف سے

اہم کے طور پر دیکھا جاتا ہے.

But what is it?لیکن یہ کیا ہے؟

What do people who have had stroke think it is?

لوگ ہیں جو فالج ہو چکے ہیں کیا خیال

ہے کہ یہ کیا ہے؟

Why have I been chosen?

میں کیوں منتخب کیا گیا؟

You or your family member contacted me because you saw my poster. آپ یا آپ کے خاندان کے رکن نے مجھ سے رابطہ کیا کیونکہ تم نے میری پوسٹر دیکھا.

Do I have to take part? کیا میں حصہ لینے کے لئے ہے؟

You don’t have to take part.

آپ کو حصہ لینے کی ضرورت نہیں ہے.

You can withdraw at any time.

آپ کسی بھی وقت واپس لے سکتے ہیں.

What will happen to me if I take part?

مجھے کیا ہو اگر میں حصہ لیں گے؟

You will be asked to take part in a group discussion, or just have a conversation with me.

آپ کو ایک گروپ کی بحث میں حصہ لینے، یا صرف میرے ساتھ ایک بات چیت کہا جائے گا.

I will ask some questions, and you can tell me anything you like. میں کچھ سوال پوچھنا ہے، اور تم مجھے کچھ بتا سکتے ہیں جو آپ کو پسند کریں گے

This will be about what participation means to you, since your stroke. یہ آپ کے دل کے دورے کے بعد تم کیا شرکت کرنے کا مطلب ہوگا.

This will take place within the next 3 months.

اس سے اگلے 3 ماہ کے اندر اندر جگہ لے جائے گا.

I will record it onto a tape.

میں یہ ایک ٹیپ پر ریکارڈ کریں گے

No-one outside the research team will listen to the tape.

ریسرچ ٹیم سے باہر نہیں ایک ٹیپ
سننے گا.

What do I have to do?

مجھے کیا کرنا ہے؟

You just need to tell me what you think. آپ بس
مجھے بتاو کیا آپ کو لگتا ہے کہ ضرورت ہے.

What are the possible disadvantages and risks of taking part?

ممکن حصہ لینے کے نقصانات اور خطرات کیا ہیں؟

There are no risks associated with you taking part.

کوئی تمہیں حصہ لینے کے ساتھ منسلک خطرات ہیں

What are the possible benefits of taking part?

حصہ لینے کے ممکنہ فوائد کیا ہیں؟

Your opinions will be heard.

آپ کی رائے کو سنا رکھا جائے گا.

I hope this research will help health professionals to help people like you in future.

مجھے امید ہے کہ اس تحقیق سے صحت کے ماہرین آپ کی طرح مستقبل میں لوگوں کی مدد کرنے میں مدد ملے گی.

What happens if the research study stops earlier than expected? اگر تحقیق مطالعہ پہلے توقع سے زیادہ بند ہو جاتا ہے تو کیا ہوتا ہے؟

You will be told that the research is no longer taking place.

تم کہ تحقیق اب کوئی جگہ نہیں لے جا رہا ہے سے کہا جائے گا.

What if something goes wrong? کیا ہوگا اگر کچھ غلط ہو جاتا ہے؟

If you are unhappy with anything you can contact my supervisor:

اگر آپ کو کسی چیز سے خوش نہیں ہیں تو آپ کو اپنے سپروائزر سے رابطہ کر سکتے ہیں:

Professor Shelagh Brumfitt,

Department of Human Communications Sciences

The University of Sheffield

31 Claremont Crescent Tel: +44 (0) 114 222 2406

Sheffield Fax: +44 (0) 114 273 0547

S10 2TA email
: s.m.brumfitt@sheffield.ac.uk

And if you are still not happy you can contact the University's Registrar and Secretary:

اور اگر آپ پھر بھی خوش نہیں ہیں تو آپ یونیورسٹی کے رجسٹرار اور سیکرٹری سے رابطہ کر سکتے ہیں:

Dr David Fletcher

The University of Sheffield
Western Bank
Sheffield
S10 2TN

Will my taking part in this project be kept confidential?

اس منصوبے میں حصہ لینے خفیہ رکھا جائے گا؟

Your details will be kept in a locked filing cabinet.

آپ کی تفصیلات مقفل فائلنگ کابینہ میں رکھا جائے گا.

Anything you say will be anonymous.

بھی آپ کا کہنا ہے کہ گمنام ہو جائے گا.

What will you be asking me and why?

تم مجھ سے کیا اور کیوں رکھا جائے گا پوچھ رہے ہو؟

I want your opinions and experiences.

میں آپ کی آراء اور تجربات کی ضرورت ہے.

Your Ideas Matter
I Want My Say

What will happen to the results of the research project?تحقیق منصوبے کے نتائج کا کیا ہو گا؟

The results will be written up in my thesis.

نتائج اپنے مقالہ کے وزٹرز کا ریکارڈ رکھا جائے گا رکھا جائے گا.

They may be used in other publications.

انہوں نے دوسرے اشاعت میں استعمال کیا جا سکتا ہے.

Who is organising and funding the research?

کون منظم ہے اور تحقیقی فنڈنگ؟

This research is funded by the Department of Health.

DH Department of Health

یہ تحقیق کی طرف سے فنڈز فراہم کررہی ہے

Who has ethically reviewed the project?

کون منصوبے کا جائزہ لیا ہے؟

This project had been ethically reviewed by Sheffield University Research Ethics Committee. یہ منصوبہ تھا کیا گیا ہے کی طرف سے جائزہ

The
University
Of
Sheffield.

Contact for further information

مزید معلومات کے لیے رابطہ

For further information please contact me:

مزید معلومات کے لیے براہ مہربانی مجھ سے رابطہ کریں:

Kate Fryer

18 Claremont Crescent

Human Communications Sciences

University of Sheffield

Sheffield S10 2TA

0114 2222452

hcp08kf@sheffield.ac.uk

You will be given a copy of this form, and a signed consent form to keep.

آپ اس فارم کی ایک کاپی، اور ایک دستخط شدہ اجازت کے رکھنے کے لئے کرنے کے لئے اس فارم کو دیا جائے گا.

Thank you for your time.

آپ کے وقت کا شکریہ.

3.1.5-Consent Form

Consent Form

Participation in Stroke Survivors:

What does it mean and how can it be achieved?

Name of Researcher: Kate Fryer

Participant Identification Number for this project:

Please initial box

1. I confirm that I have read and understand the information sheet/letter (delete as applicable) dated *[insert date]* for the above project and have had the opportunity to ask questions.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. *Insert contact number here of lead researcher/member of research team (as appropriate).*

☐

3. I understand that my responses will be anonymised before analysis.
   I give permission for members of the research team to have access to my anonymised responses.

✓

☐

4. I understand that audio recordings will be made and I give permission for members of the research team to listen to these recordings.

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☐

5. I agree to take part in the above research project.

✓

☐

Name of Participant Date Signature

(*or legal representative*)

Name of person taking consent Date Signature

(*if different from lead researcher*)

To be signed and dated in presence of the participant

Lead Researcher Date Signature

To be signed and dated in presence of the participant

If participant has significant cognitive/communication problems:

Name of carer Date Signature

To be signed and dated in presence of the participant

Copies:

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy for the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.

3.1.6-Consent Form Arabic

Consent Form

استمارة إفادة الموافق

Participation in Stroke Survivors:

What does it mean and how can it be achieved?

مُشاركة المرضى النّاجين مِن السّكتة الدّماغيّة: ما معنى هذا، و كيف بالإمكان تحقيقه

Name of Researcher: **Kate Fryer** كيت فراير

Participant Identification Number for this project:

رقم هوية المشارك لهذا المشروع

Please initial box

رجاءً وقع اسمك في المربع

6. I confirm that I have read and understand the information sheet/letter (delete as applicable) dated *[insert date]* for the above project and have had the opportunity to ask questions.

1.أُأَكِّدُ بأنّي قرأتُ و فهمتُ صفحة/رسالة المعلومات المؤرّخة

(   ) للمشروع أعلاه وكانت لديَّ الفُرصة للسؤآل.

☐

7. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. *Insert contact number here of lead researcher/member of research team (as appropriate).*

2.أفهم بأنّ مشاركتي تَطوُّعاً وعندي الحريّة في الإنسحاب من المشاركة في أي وقت أشاء ومن دون أن أعطي أي سبب. رجاءً أدخل رقم اتصال الباحث/أو عضو فريق البحث. (   )

☐

8. I understand that my responses will be anonymised before analysis. I give permission for members of the research team to have access to my anonymised responses.

3.أفهَمُ بأنَّ أجوبتي ستكون مجهولة الهوية قبل التحليل. وأقدم الموافقة لأعضاء فرقة البحث للإطلاع على الأجوبة المجهولة الهوية.

☐

9. I understand that audio recordings will be made and I give permission for members of the research team to listen to these recordings.

أفهمُ بأنَّ المحادثة ستُسَجَّل على شَريط وأُوافق على أن يَستَمعُ أعضاء فَريق البحث لهذا التَّسجيل.

☐

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5. I agree to take part in the above research project.

4.أوافق على أن أشترك في مشروع البحث أعلاه.

☐

Name of Participant Date Signature

(*or legal representative*)

Name of person taking consent Date Signature

(*if different from lead researcher*)

To be signed and dated in presence of the participant

Lead Researcher Date Signature

To be signed and dated in presence of the participant

If participant has significant cognitive/communication problems:

Name of carer Date Signature

To be signed and dated in presence of the participant

Copies:

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy for the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.

اسم المشارك التّاريخ التَّوقيع
(أو الممثل الشرعي)

اسم الشخص الّذي سيأخذ التّاريخ التَّوقيع
إفادة الموافقة(إن كان غير الباحث)
يجب التوقيع و كتابة التّاريخ في حضور المُشارك

الباحث التّاريخ التَّوقيع
يجب التوقيع وكتابة التّاريخ في حضور المشارك
إذا كان المشارك يعاني من مشكلة في الفهم أو في تبادل المعلومات

اسم الشخص المسؤول على عنايته التّاريخ التَّوقيع
يجب التوقيع وكتابة التّاريخ في حضور المشارك
نُسَخ:

بعد أن يوقَّع على هذه من قبل كل الجهات المشاركة، يستلم المشارك نُسخة موقَّعة و مؤَرَّخة من استمارة إفادة المشارك، مع رسالة أو صحيفة معلومات أو أي معلومات أُخرى تُعطى للمشاركين. يجبُ أن تُحفَظ نُسخة موقّعة و مؤَرَّخة من استمارة إفادة المُشارك في السِجل الرَّئيسي للمشروع، ويجب أن تُحفظ في مكانٍ أمين.

3.1.7-Consent Form Urdu

Consent Form

رضامندی فارم

Participation in Stroke Survivors:

What does it mean and how can it be achieved?

اسٹروک زندہ بچ جانے والوں میں شرکت:

کیا اور اسے کس طرح حاصل کیا جا سکتا ہے کیا مطلب ہے؟

Name of Researcher: **Kate Fryer** محقق کے نام

Participant Identification Number for this project:

اس منصوبہ کے لئے شریک شناختی نمبر:

Please initial box

براہ مہربانی ابتدائی باکس

1. I confirm that I have read and understand the information sheet/letter (delete as applicable) dated *[insert date]* for the above project and have had the opportunity to ask questions.

میں تصدیق کرتا ہوں کہ میں نے معلومات کی شیٹ / خط پڑھ اور سمجھ

(قابل اطلاق کے طور پر حذف) مندرجہ بالا منصوبہ کے لئے تاریخ [ڈالیں تاریخ] ہے اور تھا

کو سوال کرنے کا موقع ہے.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. *Insert contact number here of lead researcher/member of research team (as appropriate).*

میں سمجھتا ہوں کہ میری شرکت رضاکارانہ ہے اور یہ کہ میں واپس لینے کے لئے آزاد ہوں
کسی بھی وجہ سے دینے کے بغیر کسی بھی وقت. قیادت کے یہاں تعداد سے رابطہ داخل
محقق / رکن تحقیقی ٹیم کے (مناسب طور پر).

☐

3. I understand that my responses will be anonymised before analysis. I give permission for members of the research team to have access to my anonymised responses.

میں سمجھتا ہوں کہ میرے جوابات تجزیہ سے پہلے رکھا جائے گا.
میں ریسرچ ٹیم کے ارکان کے لئے اجازت دے کو رسائی حاصل ہے

☐

میرے جوابات.

4. I understand that audio recordings will be made and I give permission for members of the research team to listen to these recordings.

میں سمجھتا ہوں کہ آڈیو ریکارڈنگ اور کیا جائے گا اور میں تحقیقی ٹیم کے اراکین کے لئے کی

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☐

اجازت دیتے ہیں ان کی ریکارڈنگ سننے کے لئے.

5. I agree to take part in the above research project.
میں نے مندرجہ بالا تحقیق کے منصوبے میں حصہ لینے کے لئے اتفاق کرتا ہوں

☐

______________________	_______________	___________________
Name of Participant	Date	Signature
شرکا کے نام	تاریخ	دستخط
(or legal representative)		

_______________________	_______________	___________________
Name of person taking consent	Date	Signature
شخص کے نام کی رضامندی لے		
(*if different from lead researcher*)		

To be signed and dated in presence of the participant

Lead Researcher ______________________	Date ______________	Signature ___________________
محقق لیڈ		

To be signed and dated in presence of the participant

If participant has significant cognitive/communication problems:

اگر شریک اہم علمی / مواصلات مسائل ہیں:

Name of carer ______________________ Date ______________________ Signature ______________________

نگراں نام

To be signed and dated in presence of the participant

Copies:
نقول:

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy for the signed and dated consent form should be placed in the project’s main record (e.g. a site file), which must be kept in a secure location.

جب ایک بار ایسا کیا گیا ہے تمام جماعتوں کی طرف سے دستخط کئے گئے شریک پر دستخط کئے اور ء شریک منظوری فارم پر خط / پہلے سے لکھے ہوئے شیٹ سکرپٹ / معلومات اور کسی دوسرے تحریری شرکاء سے فراہم کردہ معلومات کی ایک نقل حاصل کرنا چاہئے. پر دستخط کئے اور ء رضامندی فارم کے لئے ایک کاپی منصوبے کی سب سے اہم ریکارڈ (مثال کے طور پر ایک ویب سائٹ فائل)، جس میں ایک محفوظ مقام پر رکھنا چاہیے میں رکھا جانا چاہئے.

3.2-Source 2

3.2.1-Communication Screen

Communication screening test to assist with provision of project information in an accessible form

Pre-screen check:

Can the client see?

Does the client wear glasses?

Does the client wear a hearing aid? Left ear Right ear Both

Verbal comprehension:

Yes/no questions *(indicates how reliable the client's responses to questions are)*

Are you in hospital?		Is your name...?	
Are you a man?		Have you got green hair?	
Are you sitting in a chair?		Is January in the summer?	

Comprehension level:

1 key word	2 key words
Close your **eyes**	Touch your **head** then your **knee**
Point to the **ceiling**	Point to the **chair** and the **window**
Show me the... (1/3 objects)	Put the **pen** in the **cup** (spoon, pen, cup, box)

3 key words	4 key words
Point to the **ceiling**, **floor** and **window**	Touch your **left knee** with **two fingers**
Put the **spoon** and the **watch** in the **box** (spoon, watch pen, cup, box)	Put the **watch** in the **box** and the **pen** in the **cup**

Complex: tap each shoulder twice with two fingers keeping your eyes closed

Verbal expression:

Conversation

Tick any of the following that apply:

Complete meaningful sentences	Word finding difficulties
Use of key words only	Struggling to produce words physically

Sentences with no meaning (jargon)	Slurred speech (dysarthria)
Unusual answers/not keeping to topic	Difficulty using language to reason

Reading comprehension

Ask the client to find the object which matches each written word (point to the word for the client to read but don't say it aloud. NB cover up the rest of this page to avoid distraction)

Cup Pillow Watch

Ask the client to carry out the written instructions below:

Point to the window

Close your eyes then touch your nose

Put the watch and the pen in the cup

Ask the client to read the following paragraph:

Mary and Bill went to the theatre to watch the Sound of Music. In the interval Bill had an ice-

cream and Mary had a cup of tea. They took a taxi home at 11.30 pm.

Yes/no questions:

Did Mary and Bill go to the cinema?

Did they watch the Sound of Music?

Did Mary have a glass of lemonade?

Did they catch the bus home?

Did they go home before midnight?

Written expression: *Ask the client to 1) write their name and*

2) answers to your questions

Summary: circle those that apply

Level of verbal comprehension (number of key words): 0 1 2 3 4 every day conversation

Level of verbal expression:	No difficulty	Word finding difficulties
	Poor sentence formulation	Limited meaningful speech
	Reduced speech intelligibility (slurred speech)	Incorrect speech sounds (dyspraxic errors)

Ability to read: None single words 2-3 key words in sentence paragraphs

Ability to write:

Communication strategies to consider in ensuring comprehension of patient information

Select the ones that match the patient’s communicative ability.

To assist understanding	To assist expression
Point/show what you are talking about	Offer pictures to point to
Speak slowly and clearly	Write useful words to point to
Use pictures to help convey your message	Offer note pad and pen
Use short simple sentences , emphasising the most important word	Encourage patient to gesture
Gesture/mime what you are going to do	If finding the correct word is difficult, encourage description of the object/event
Leave simple written explanations, highlighting key words/ideas	Encourage slow speech with exaggerated mouth movements

Form of information to provide:

Written and verbal comprehension level	**Project Information style**
Able to read full sentences in a paragraph	PIS 1 – standard format
Able to read 3 key words in a sentence	PIS 2 – Short sentences, key words highlighted, picture support
Able to read 1-2 key words and have understanding of spoken words at 2 key word level	PIS 3 – presentation of information in small chunks supported by pictures on power point. To be presented by therapist with addition of spoken explanations of each point
Verbal and written understanding both less than 2 key words	Show video of someone using the computer and power point with only single key words and pictures. As unable to include all information in this format, if the patient is happy with the general concept of the project, the carer will be given the full info sheet PIS1 and asked to provide carer declaration.

3.2.2-Information Sheet 1

Patient Information Sheet

1. Study Title

Participation in **Stroke** Survivors: what does it mean and how can it be achieved?

2. Invitation

You are being invited to take part in a **research study** to look at **how people participate in life following a stroke**. Before you decide it is important for you to understand why it is being done and what it will involve. **Please read** the following information, and **discuss** with family, friends or carers if you wish. **Ask** if there is anything unclear or you would like more information. Take time to **decide** whether to take part.

Thank you for reading this.

3. What is the purpose of this study?

It is important that people who have had a stroke are able to **participate in activities that they enjoy**. I want to find out:

What is important to people who have had a stroke?

How they participate in the months following the stroke?

How the Stroke Association can help participation?

I would like to speak to you in the months following your stroke, to find out these things.

4. Why have I been chosen?

You have been chosen because you had a **stroke**, and have received help from the **Stroke Association**.

5. Do I have to take part?

It is up to you whether or not to take part. If you decide to take part you will be given this form to keep and asked to sign a **consent form.**

You can **withdraw** at any time without giving a reason.

If you decide not to take part, or withdraw, it **does not affect you rights** to use the Stroke Association or any other services.

6. What will happen to me if I take part?

If you decide to take part, I will visit you shortly to **interview you and ask you some questions.** I will then collect the same information at **6 and 12 months** later.

You will be visited 3 times. The visit could take up to 2 hours. If that is too long I can make 2 shorter visits.

7. What else do I have to do?

This is all you have to do, the research does not affect anything else in your life.

8. What are the side effects of taking part?

There are no expected side effects. Your health will be the priority at all times.

9. What are the possible benefits of taking part?

Your views will be heard, and may contribute to an improvement in the service provided by the Stroke Association, and contribute to health professionals understanding of the needs of people who have had a stroke.

10. What happens when the research study stops?

This will not affect any of the services you use.

11. What if something goes wrong?

This project does not have any special risks. However, if you wish to **complain** about any aspect of the way you have been approached or treated during the course of the study, please contact:

Professor Shelagh Brumfitt
Department of Human Communications Sciences
The University of Sheffield
31
Claremont Crescent

Sheffield

S10 2TA

email : s.m.brumfitt@sheffield.ac.uk
Tel: +44 (0) 114 222 2406
Fax: +44 (0) 114 273 0547

And if you are still not happy you can contact the University's Registrar and Secretary:

Dr David Fletcher
The University of Sheffield
Western Bank
Sheffield, S10 2TN

Will my taking part be kept confidential?

All information collected in the course of the research will be **anonymised.**

What will happen to the results of this research study?

The results will be written up into a **PhD**, and probably also in **other publications**.
They will also be used by the **Stroke Association** to improve the service provided.

Who is organising and funding the research?

This research is funded by the **Department of Health.**

Contact for further information:

Kate Fryer
18 Claremont Crescent
Human Communications Sciences

University of Sheffield
Sheffield S10 2TA

0114 2222452

hcp08kf@sheffield.ac.uk

Thank you for taking part in this study. You will be asked to sign a consent form, and can keep this form for your records.

3.2.3-Information Sheet 2

The
University
Of
Sheffield.

The STROKE Association

Patient Information Sheet

1. Study Title

Participation in **Stroke** Survivors: what does it mean and how can it be achieved?

2. Invitation

You are being invited to take part in a **research study** to look at **how people participate in life following a stroke**. Before you decide it is important for you to understand why it is being done and what it will involve. **Please read** the following information, and **discuss** with family, friends or carers if you wish. **Ask** if there is anything unclear or you would like more information. Take time to **decide** whether to take part.

Thank you for reading this.

3. What is the purpose of this study?

It is important that people who have had a stroke are able to **participate in activities that they enjoy**. I want to find out:

What is important to people who have had a stroke?

How they participate in the months following the stroke?

How the Stroke Association can help participation?

I would like to speak to you in the months following your stroke, to find out these things.

4. Why have I been chosen?

You have been chosen because you had a **stroke**, and have received help from the **Stroke Association**.

5. Do I have to take part?

It is up to you whether or not to take part. If you decide to take part you will be given this form to keep and asked to sign a **consent form.**

You can **withdraw** at any time without giving a reason.

If you decide not to take part, or withdraw, it **does not affect you rights** to use the Stroke Association or any other services.

6. What will happen to me if I take part?

If you decide to take part, I will visit you shortly to **interview you and ask you some questions.** I will then collect the same information at **6 and 12 months** later.

You will be visited 3 times. The visit could take up to 2 hours. If that is too long I can make 2 shorter visits.

7. What else do I have to do?

This is all you have to do, the research does not affect anything else in your life.

8. What are the side effects of taking part?

There are no expected side effects. Your health will be the priority at all times.

9. What are the possible benefits of taking part?

Your views will be heard, and may contribute to an improvement in the service provided by the Stroke Association, and contribute to health professionals understanding of the needs of people who have had a stroke.

10. What happens when the research study stops?

This will not affect any of the services you use.

11. What if something goes wrong?

This project does not have any special risks. However, if you wish to **complain** about any aspect of the way you have been approached or treated during the course of the study, please contact:

Professor Shelagh Brumfitt

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31 Claremont Crescent
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email : s.m.brumfitt@sheffield.ac.uk
Tel: +44 (0) 114 222 2406
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And if you are still not happy you can contact the University's Registrar and Secretary:

Dr David Fletcher
The University of Sheffield
Western Bank
Sheffield, S10 2TN

Will my taking part be kept confidential?

All information collected in the course of the research will be **anonymised.**

What will happen to the results of this research study?

The results will be written up into a **PhD**, and probably also in **other publications**.
They will also be used by the **Stroke Association** to improve the service provided.

Who is organising and funding the research?

This research is funded by the **Department of Health.**

Contact for further information:

Kate Fryer
18 Claremont Crescent
Human Communications Sciences
University of Sheffield
Sheffield S10 2TA

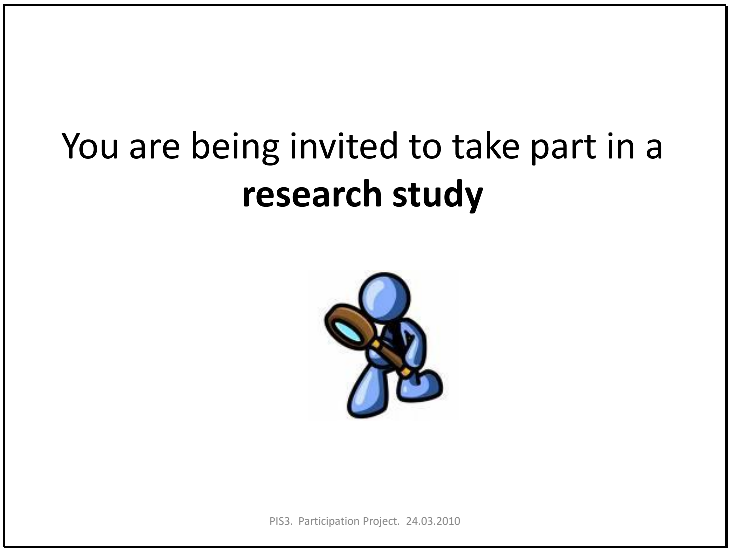
0114 2222452

hcp08kf@sheffield.ac.uk

Thank you for taking part in this study. You will be asked to sign a consent form, and can keep this form for your records.

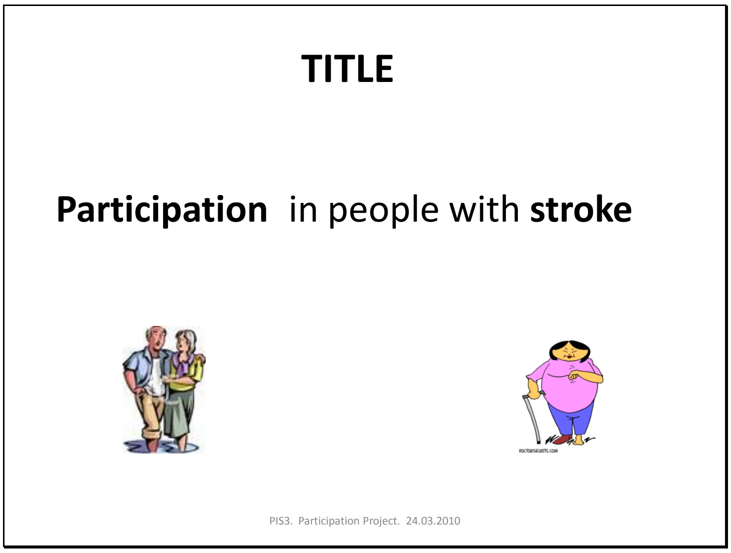
3.2.4-Information Sheet 3

Slide 1



You are being invited to take part in a **research study**

Slide 2



TITLE

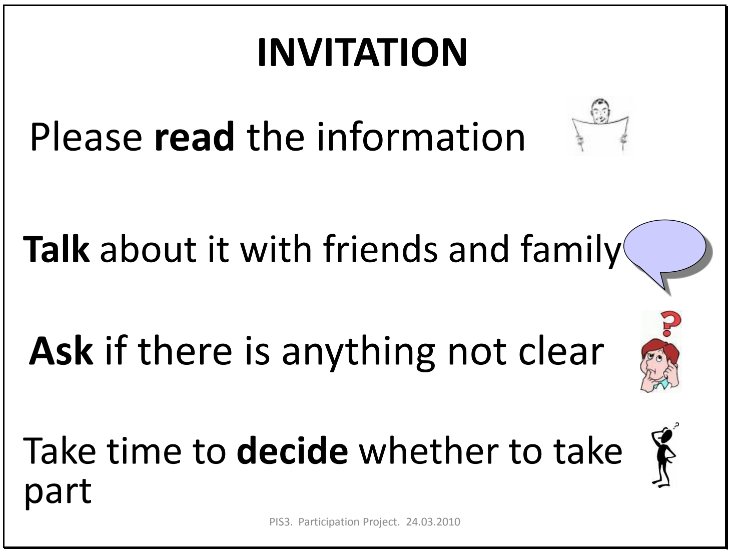
Participation in people with **stroke**

Slide 3

What does it mean?

How can it be achieved?

PIS3. Participation Project. 24.03.2010



INVITATION

Please **read** the information

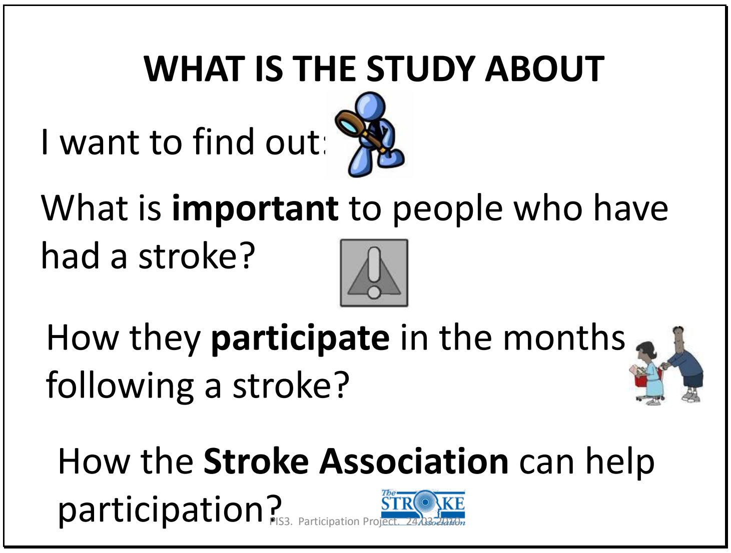
Talk about it with friends and family

Ask if there is anything not clear

Take time to **decide** whether to take part

PIS3. Participation Project. 24.03.2010

Slide 5



WHAT IS THE STUDY ABOUT

I want to find out:

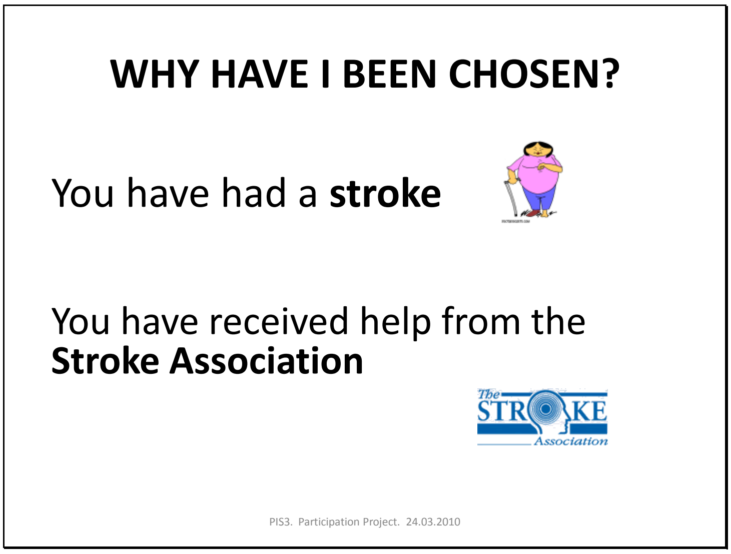
What is **important** to people who have had a stroke?

How they **participate** in the months following a stroke?

How the **Stroke Association** can help participation?

PIS3. Participation Project. 24.03.2010

Slide 6



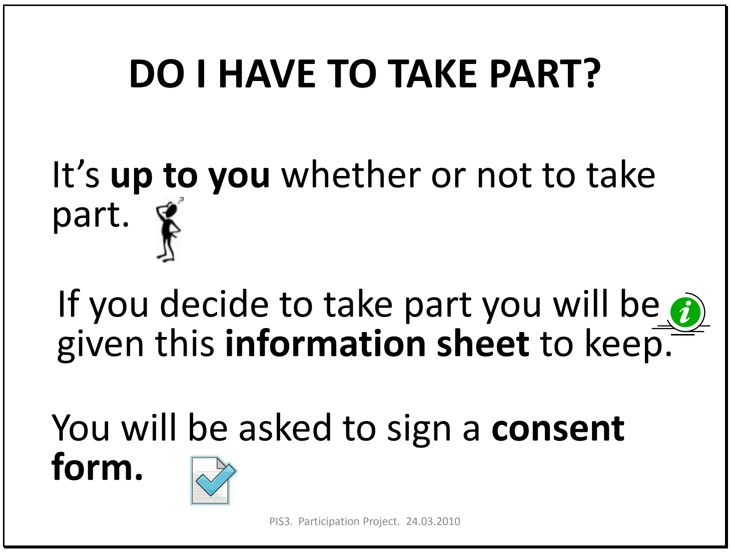
WHY HAVE I BEEN CHOSEN?

You have had a **stroke**

You have received help from the **Stroke Association**

PIS3. Participation Project. 24.03.2010

Slide 7



DO I HAVE TO TAKE PART?

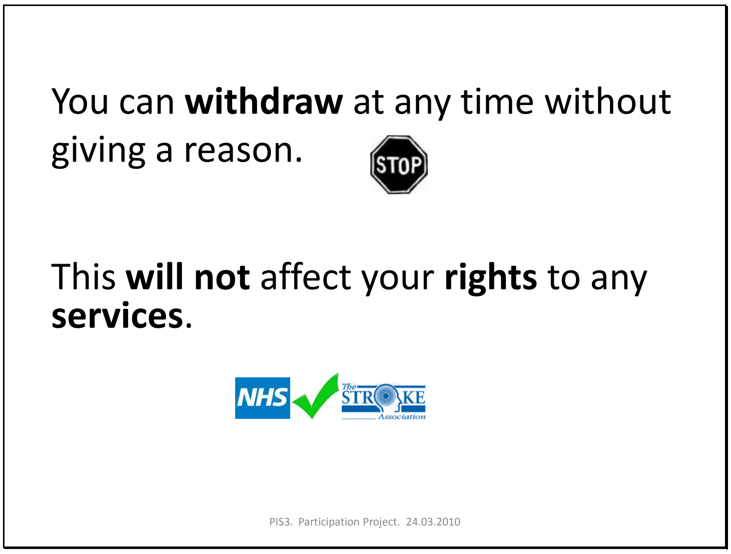
It’s **up to you** whether or not to take part.

If you decide to take part you will be given this **information sheet** to keep.

You will be asked to sign a **consent form.**

PIS3. Participation Project. 24.03.2010

Slide 8



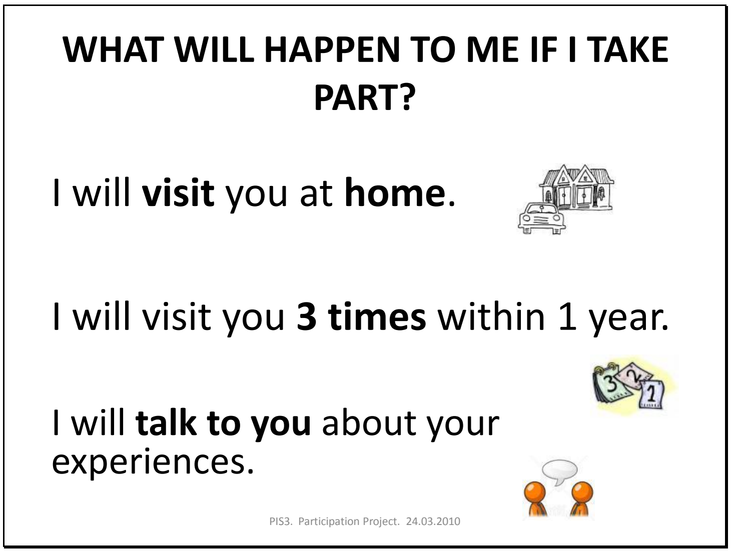
You can **withdraw** at any time without giving a reason.

This **will not** affect your **rights** to any **services**.

STOP
NHS
The STROKE Association

PIS3. Participation Project. 24.03.2010

Slide 9



WHAT WILL HAPPEN TO ME IF I TAKE PART?

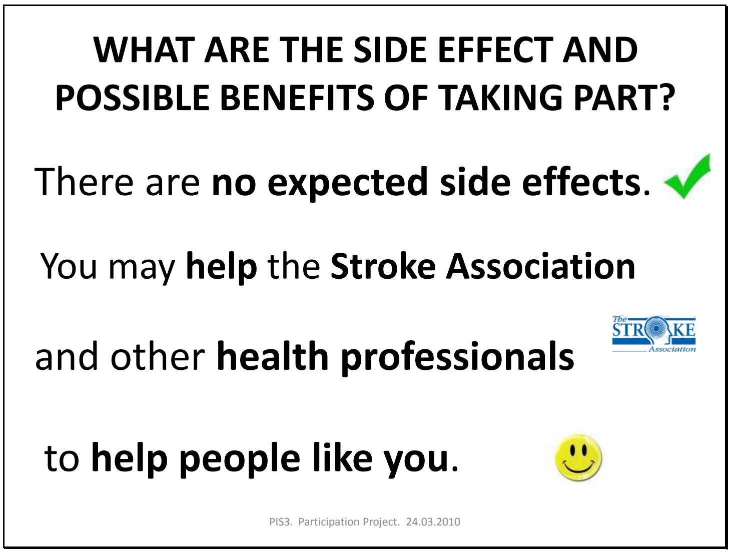
I will **visit** you at **home**.

I will visit you **3 times** within 1 year.

I will **talk to you** about your experiences.

PIS3. Participation Project. 24.03.2010

Slide 10



WHAT ARE THE SIDE EFFECT AND POSSIBLE BENEFITS OF TAKING PART?

There are **no expected side effects**. ✓

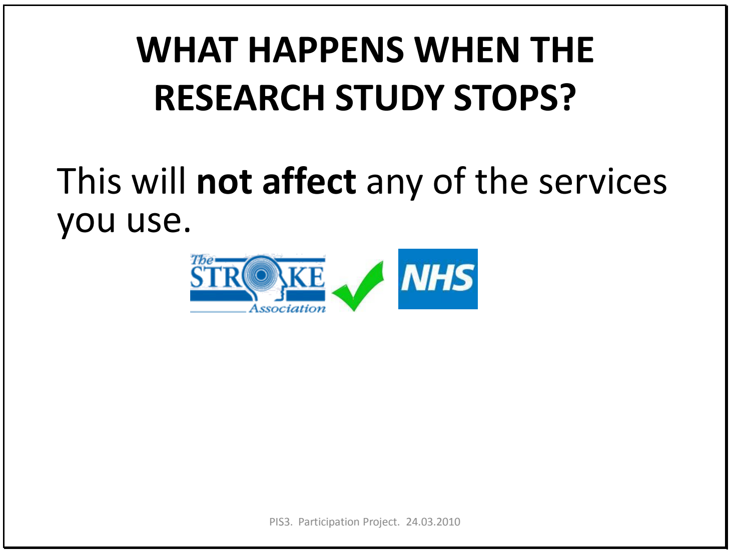
You may **help** the **Stroke Association**

and other **health professionals**

to **help people like you**.

PIS3. Participation Project. 24.03.2010

Slide 11



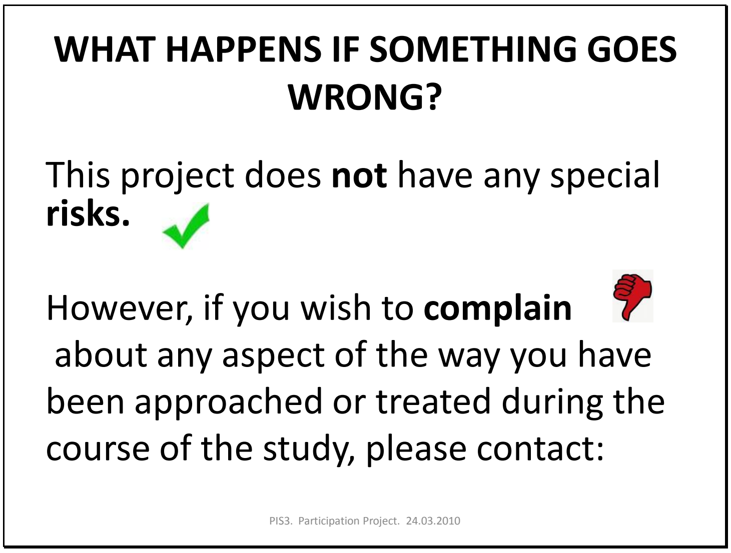
WHAT HAPPENS WHEN THE RESEARCH STUDY STOPS?

This will **not affect** any of the services you use.

The STROKE Association ✓ NHS

PIS3. Participation Project. 24.03.2010

Slide 12



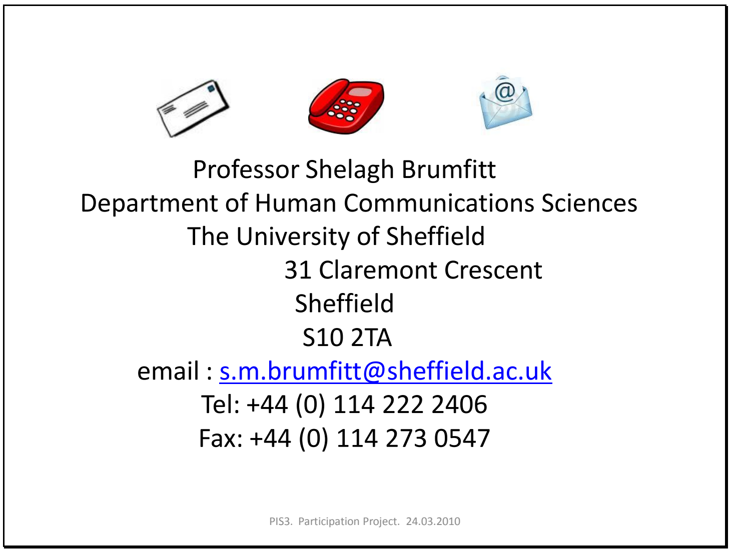
WHAT HAPPENS IF SOMETHING GOES WRONG?

This project does **not** have any special **risks.** ✓

However, if you wish to **complain** 👎 about any aspect of the way you have been approached or treated during the course of the study, please contact:

PIS3. Participation Project. 24.03.2010

Slide 13



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Fax: +44 (0) 114 273 0547

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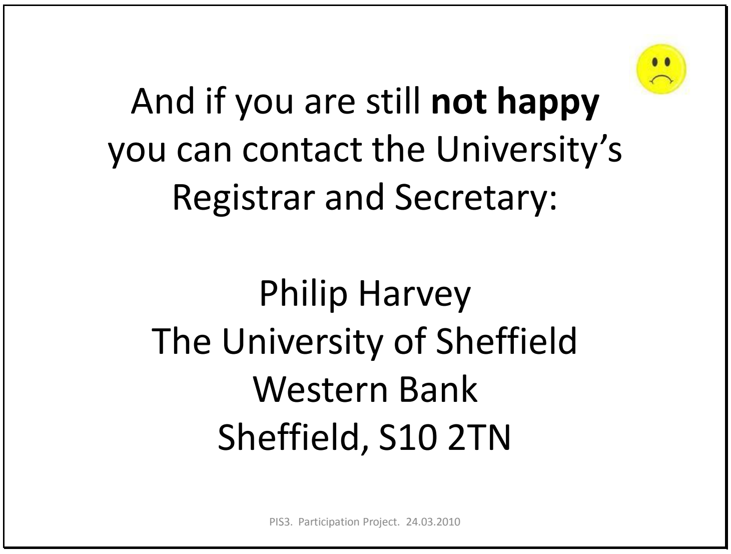
Slide 14



And if you are still **not happy**
you can contact the University's
Registrar and Secretary:

Philip Harvey
The University of Sheffield
Western Bank
Sheffield, S10 2TN

PIS3. Participation Project. 24.03.2010

Slide 15

WILL MY TAKING PART BE KEPT CONFIDENTIAL?

All information collected during the research will be **anonymised.**

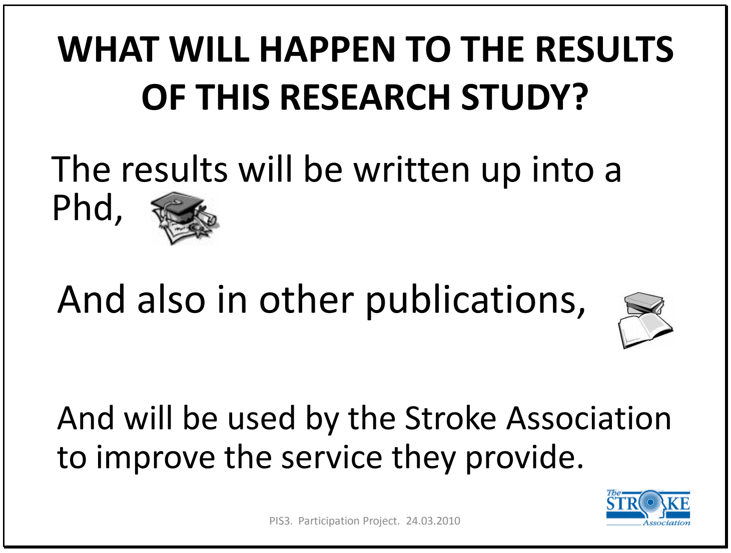
Joe Bloggs

↓

PN1234

PIS3. Participation Project. 24.03.2010

Slide 16



WHAT WILL HAPPEN TO THE RESULTS OF THIS RESEARCH STUDY?

The results will be written up into a Phd,

And also in other publications,

And will be used by the Stroke Association to improve the service they provide.

PIS3. Participation Project. 24.03.2010

Slide 17

WHO IS ORGANISING AND FUNDING THE RESEARCH?

The research is funded by the **Department of Health.**
CLARHC (NIHR)

For further information contact:
Kate Fryer
hcp08kf@sheffield.ac.uk
07954 138255

PIS3. Participation Project. 24.03.2010

Slide 18

THANK YOU

PIS3. Participation Project. 24.03.2010

3.2.5-Consent Form

The University Of Sheffield.

The STROKE Association

Patient Consent Form

Participation in Stroke Survivors: what does it mean and how can it be achieved?

Please **read** the statements and **initial** the boxes.

1. I have **read** and **understood** the **information** sheet for the above study. ☐

2. I have had the **opportunity** to ask **questions**. ☐

3. I understand that my participation is **voluntary** and that I am free to **withdraw** at any time without my medical care or legal rights being affected. ☐

4. I understand that audio **recordings** will be made and I give permission for members of the research team to listen to

☐

these recordings. They will be destroyed following the completion of the study.

5. ✓ I agree to take part in the above study. ☐

Please sign below

Patient

Name:

Date:

Signature

Researcher

Name:

Date:

Signature

3.3-Source 3

3.3.1-Information Sheet

The
University
Of
Sheffield.

NHS
National Institute for
Health Research

Patient Information Sheet

1. Study Title

Participation in **Stroke** Survivors:

DOCTORSECRETS.COM

What does is mean and how can it be achieved?

2. Invitation

You are being invited to take part in a **research study** to look at how people **participate** following a **stroke**.

Before you decide it is **important** for you to **understand** why it is being done and **what it will involve**.

Please read the following **information.**

Discuss with **friends, relatives** and others.

Ask if there is anything **not clear**

or you would like more information.

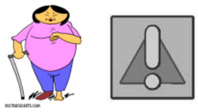
Take time to **decide** whether to take part.

3. What is the purpose of this study?

It is important that people who have had a **stroke** are able to **participate** in activities that they **enjoy**.

I want to find out:

What is **important** to **people** who have had a **stroke**?



What affects **how** they **participate** following the stroke?

I would like to **speak to you** about this.

4. Why have I been asked?

You have been asked because you had a **stroke**

5. Do I have to take part?

It is **up to you** whether or not to take part.

If you decide to take you will be asked to email your consent**.**

You can **withdraw** at any time without giving a reason.

If you decide not to take part, or withdraw, it **does not affect** you **rights** to use the **internet forum** or any other **services**.

6. What will happen to me if I take part?

I will **email you** and ask you to tell me about your experiences.

When you reply, I will **ask you** some more **questions** based on your responses.

I will let you know when I have all the information I need.

You can stop the email contact at any time.

7. What else do I have to do?

There is **nothing else** you have to do.

The research **does not affect** anything else in your life.

8. What are the side effects of taking part?

There are **no** expected **side effects.** ✓

9. What are the possible benefits of taking part?

Your views will be heard.

You may contribute to an **improvement** in the services for people who have had a stroke in the **future**.

You may contribute to health professionals **understanding** of the **needs** of people who have had a **stroke.**

10. What happens when the research study stops?

This will **not affect** any of the **services** you use.

11. What if something goes wrong?

This project does **not** have any special **risks**. ✓

However, if you wish to **complain** 👎 about any aspect of the way you have been approached or treated during the course of the study, please contact:

Professor Shelagh Brumfitt
Department of Human Communications Sciences
The University of Sheffield
31 Claremont Crescent
Sheffield
S10 2TA
email : s.m.brumfitt@sheffield.ac.uk
Tel: +44 (0) 114 222 2406
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And if you are still not happy you can contact the University's Registrar and Secretary:

Philip Harvey
The University of Sheffield
Western Bank
Sheffield, S10 2TN

Will my taking part be kept confidential?

Yes.

I will **take out** of your emails any **information** you could be **identified** by.

I will print them off and **delete** the original **email**.

What will happen to the results of this research study?

The results will be written up into a **PhD thesis**

and also in **other publications**.

Who is organising and funding the research?

This research is funded by the **Department of Health.**

CLAHRC (NIHR).

Contact for further information:

Kate Fryer
18 Claremont Crescent
Human Communications Sciences
University of Sheffield
Sheffield S10 2TA

0114 2222452

hcp08kf@sheffield.ac.uk

Thank you for taking part in this study. You will be asked to sign a consent form, and can keep this form for your records.

3.3.2-Email and consent paragraph

Dear (participant),

Thank you for your reply, I'm delighted that you want to take part in my study. I've attached an information sheet which briefly explains the research. You can email any questions you have based on this.

Once you feel satisfied that you understand what is involved, and if you are happy to take part, you need to send me an email containing the following paragraph:

“I have read the information sheet and have had the opportunity to ask questions. I understand that taking part in the study is voluntary and I can withdraw at any time with no negative side effects. My responses confirm my ongoing consent”.

Once I get that, I can email you the questions I would like to ask. I may also ask further questions based on your responses if you are happy to continue.

Best wishes

Kate Fryer

Appendix 4 - Data collection and analysis

4.1.1-Source 1 interview transcription

Abid

Kate: so can you just start by telling me a little bit about when you had your stroke and what happened around that time?

Abid: well, thing is it happened about 2.30 in the afternoon, and I was perfectly OK, and I went to the mosque and said my dhuhr [midday] prayer, and er it was 2 oclock, and I, we finished the prayer at quarter past 2, I came back, opened the office and ordered a sandwich, from the corner shop, and I was sitting downstairs with friends and it happened...and I was confused yeah, I tried to...but I couldn't talk. And there were three friends, and they said, y'know that is Abid is joking, I'm the sort of person you know I never shut up, so they thought, y'know I was joking. And things went on and I was very confused and then they realised. And one of them was a doctor, and he said y'know, Ok, call the ambulance. Somethings wrong, yeah. And first of all the thing is, they thought the ambulance will take pretty long time and one of my friends he took me to the [hospital], the nearest one, yeah, and they called the ambulance, and took me to the [hospital]. And I was senses, I knew what is happening y'know. I was quite in senses, yeah.

Kate: so you knew what was going on?

Abid: yeah, thing was I couldn't talk, and the main thing is y'know, the doctor in [local area] who saw me he's my GP, but he couldn't recognise me, he couldn't because I don't see him very often. And I see doctors, 2, 3, 4 years, I was registered with them and later on y'know I came after that treatment, to find out yeah, and he called the ambulance, and took me to [hospital], and they did so many x-rays, and erm basically, basically, I don't know, I was there for 45 minutes, and I had a bit of money in my pocket and they took it and rung my wife, so I was fully aware of what was happening, yeah, but they drove me to the [hospital] later on and they found I'd had a minor stroke and they said, 'you're lucky your shall make within 3 hours' and it is a treatment, drugs, well that's what they said, yeah, that sometimes if you reach there after 3 hours, basically the thing might run out but it depends on the seriousness of the stroke, yeah, yeah. That's what I thought, they did not say that it's a minor stroke or very heavy stroke, but I couldn't still I couldn't talk for a day for a night. And in the morning my wife was telling me that 'say something say something' and the first word I said 'alhamdulillah' (all praise be to Allah), Alhamdulillah, Alhamdulillah, and it was a repetition, yeah, repetition...yeah, and then I was, got a lot of visitors and I was telling them, Alhamdulillah I'm fine, but still speech was a big problem for so many days.

Kate: how long were you in hospital for?

Abid: 9 days

Kate: and how long ago was the stroke?

Abid: sorry?

Kate: how ,long ago was the stroke, was it years ago, or months, or...

Abid: what do you mean by?

Kate: er, when did it happen?

Abid: it happened on the 26th of May this year. And I was home on the 9th of June. 26th of May 2.30, yeah, and I was in for 9 days. Yeah for 9 days.

Kate: and did you have speech therapy for your language problems?

Abid: yeah, they were very very helpful people and I wrote them a letter and said they look after me very well, and speech therapy lady was coming from for 3 months.

Kate: at home?

Abid: yeah yeah at home and she said y'know, ok, and there's no point for me to come. But another lady was coming for how I was coping with the life because I did not...while I was there my leg and arm was very weak, but within 14 days I was perfectly OK, and I was er, sort of at home and I didn't want to depend anybody else so I was having a bath and shower and things no problem, and so I was very very careful at the shower and no problem , but in the hospital, they really look after me and because I was in there, and they were saying 'you could have a shower' but I am telling them that my wife is coming for the shower. But they were very very very helpful. They were very very very very helpful, staff and the nurses, and the male and the female staff they were magnificent. Yeah.

Kate: and how do you feel your speech is now?

Abid: sigh. I'm still struggling. I do feel the effects and I hope it will be 100% but what the doctors say is that 100% is not possible. But I very hope to Allah and I pray to Allah, I'm a strong believer, and I'm a strong believer of Allah and speech is, the health is from Allah, and he has given me the speech problem and he will return it back. Yes, I think so inshAllah. But, do you fully understand what I say?

Kate: completely yeah.

Abid: don't you think so, I struggle to speak or...

Kate: your speech is very good and it's easy to understand, but because I'm used to seeing people like I can tell that there's some words that you're struggling to find, that's what's coming across, but I can understand you perfectly. I'm gonna read back what you've said to check I've understood you correctly. Erm, so you had the stroke on the 26th of May, and that was at 2.30 and you'd just come back from praying at the mosque and got yourself a sandwich and you were downstairs with your friends when it happened. And you became quite confused and you couldn't talk. They initially thought that you were joking, and then they realised and took you to the hospital where they called and ambulance. And all this time you were in your senses, you were aware of what was going on, but you couldn't talk at all. You were in hospital for 9 days and the first word you said was Alhamdulillah, and then you had repetition of that word quite a lot, and you felt that you were physically fine after just a few days, but the speech remained a bit of an issue. So you had 2 or 3 months of someone coming to see you at home about your speech, and they felt that they had done their job, so you don't feel that your speech is quite 100% yet but your hoping that it will be.

So changing direction slightly now, I want you to think about the word participation, and if you can tell me what that means to you?

Abid: the thing is that y'know I'm a, I was thinking about my office all the time basically, because it took me 25 years to build the practise, and er to basically y'know I'm married to my office, I work very very hard and I was thinking that if you stay at home for a long time, the clients sort of they think that you are very very ill and they should go somewhere else. I was thinking that line, but I wanted to come back to office, yeah, as quickly as possible, and after 2 months yeah, I was sort of, I was thinking that I should go to office, and do not, in office, don't do any work, I should be present. And at the same time I was thinking that I should have a partner, because I was sole trader, I was running this business on my own, yeah, I was thinking I should have a partner to carry on this business. And I was quite fond, a very good friend of mines son, and I sold 50% of the business to him, for some money, yeah, and since that I sort of come here into the office in the afternoon and he comes in the morning and I come the afternoon, but basically I don't do any work, but I can work, it's er, because I can work yet, and if it comes to the worst, I was taking so many jobs home and I will do work, not very very hard, but basically y'know I am working yes.

Kate: so you're keeping at it yeah. So you quite quickly came to a solution about your working life and got that sorted yeah.

Abid: at the moment i'm very active in the sense, and in the business my job is to get the business because I know a lot of people for the last 25 years, so my job is to get the business, and his job is to get it done. And I always help him as well yeah.

Kate: so is work for you part of participation? Is it something you see as participating in life, being able to work?

Abid: yeah, yeah. Active participation yeah, because basically you know I sold 50% of the business, and basically we do all the jobs before January 2010, all the jobs to be done before that date, and both my partner and I should be very very active.

Kate: and what else do you see as being participation in your life, other than work. What does the word participation make you think of?

Abid: well to be very honest y'know, my social life was very very, I was very very active, and I was counsellor in the central ward for 2 years, and I'm still candidate for the election in May, and I go around, once, 2 or 3 times to meet people and to make sure that they will vote for me, and I'm doing the leafleting at the moment. My car is full of leaflets, yes, and I do it sort of once or twice in a week. But basically your life, my family, I've got 4 daughters and my family in the sense that, they don't know, they don't want me to do any participation, active participation in the politics, because they think it's y'know, they think y'know, I don't feel well health wise and they are worried for me. But sometimes I listen to them and sometimes I don't listen to them, but I used to stay until friends until 11 or 12 o'clock nightime, but at the moment if I stay out too late they get worried, so I get home before 8 or 9 O'clock yeah.

Kate: so you're inside the house a lot earlier?

Abid: yea yeah. But I still think if I physically I'm all right and my speech comes back then I will be I want to be involved in politics, and active yeah.

Kate: So you've mentioned work and you've mentioned your political activities, is there anything else that you think of as being participation, part of your life.

Abid: no, office, social life with friends and the politics yeah. We have no time apart from that and the day is very short and yeah, yeah.

Kate: And you've mentioned one thing which is that your family now worry about you and you have to be home earlier, is there any other changes since before your stroke to your participation?

Abid: I'm still active yeah. It was 2 months I didn't do any work, and my political friends, they were thinking about it that is Abid a candidate for the central ward, I was thinking that I would come back in a few months time yeah.

Kate: I'll just go through the last bits you've told me to check I've understood you right, ok? So where did I get up to, ah yeah, you were telling me about work, so you were immediately after the stroke you were thinking about the business and how you were going to handle that side of things, and it had taken 25 years to build up the practise so obviously that's very important, and you were married to your office you said, so you thought if you stayed at home for a long time your clients would think you were will and they'd go somewhere else. Erm, so you felt it was very important that you came back to the office, so after 2 months you decided to come back, erm, not necessarily to work but to have a presense there, erm, so your solution to that was to sell half of the business to a friends son, so you could carry on. Erm, so now you come in in the afternoon and he comes in in the morning, and you bring in the business, he does the work and you help him. Ok, so you're still very active in the business, erm, and you see work very much as participating, that's quite important to you, erm, you also have a very active social life and are counsellor for the central ward, is that right?

Abid: for 2 years yeah.

Kate: and a candidate for the elections. So you go to meet people, get them to vote for you and that kind of thing. So you have family, you have 4 daughters, and they are a bit worried about you, that you're not very well and you're not well enough to be involved in politics, and that kind of thing, so sometimes you listen to them and sometimes you don't. But you said one change was that you perhaps don't stay out as late as you used to. Is that, do you feel tired more easily or anything like that?

Abid: No, cos they get worried, and 2 daughters are married, one is in Birmingham and one is in Manchester. There are 2 daughters at home, so they always need me, and if I'm late I worry for them.

Kate: so you're now in the house a lot earlier, so you said that in your life really your participation is work, politics and socialising. And that's all you have time for. And family I presume is a...

Abid: I can't ignore the family y'know, I take them out once or twice, no no, whenever they want it y'know, I take them to [unclear] or restaurant. So the family comes first, yeah basically.

Kate: so basically you're still very active since your stroke and you're optimistic that the difficulties you still have will be resolved and you'll be back to normal really. And it was just 2 months when you didn't do any work and you were deliberating, and you were planning to be fully back and engaged in life. I just want now to divide the world up into 3 things. So thinking about, I'm gonna write 3 words down. So I first want to ask you about how, about these factors and if there are things that help or hinder your ability to participate. So by personal I mean feelings and emotions personal to you because of your stroke, so what other people have mentioned might not be the same for you because if the severity, is being frightened to go out and that sort of thing.

Abid: well to be very honest it's something y'know that affected me quite a lot (fear). Some people they told me it can be, you can get the attack again and it worried me and er all the time in the sense. I'm strong believer and I believe in Allah, I trust in Allah, but it's always in my mind, yeah, and er yeah, that's something to be very honest that's affected me quite a lot.

Kate: and how's that affected your life?

Abid: well I try to ignore it, most of the time I try to ignore it and try to forget about it, to be very honest, and if I think, sometimes I think about it, and basically you know I think about the family. So Basically I was very active and sort of, I didn't tell you at the very beginning, I came here in 1967, and I have been living here for the last 42 years, and this is the first time that I've been to hospital.

Kate: oh really, gosh, so you were very healthy.

Abid: and I was thinking y'know it's perhaps a warning, y'know the time is very near, and basically I'm 60 years old, and I had a good life, and so if the time has come to go and I will leave here and it's room for somebody else yeah.

Kate: But is' definitely been on your mind then...

Abid: yeah, it's in my mind yeah

Kate: and thinking now about situation and what I mean by situation is the fact if you having had a stroke and the impact that's had which for you is in your language, how that helped and hindered your participation. Has that has an impact?

Abid: yes basically y'know, sometime, if I had a meeting, I take somebody else, I take my partner, I used to go myself and my speech was fluent and I, because if you are accountant, if you, your power to convince the other person reduced tremendously, so you can't think very quickly. You need to be kind of , and you can't bring the proper word, it's very much affected. I think twice before I speak, yeah. And sometimes I can't get a word and it will come after 2 minutes, after 1 minute after 30 seconds, it will come and I get tired, basically from thinking of the word.

Kate: so you tale somebody with you as sort of a back up so if you're struggling, yeah yeah.

Abid: and after half an hour, 30 minutes, I really get tired then and can't carry on a meeting.

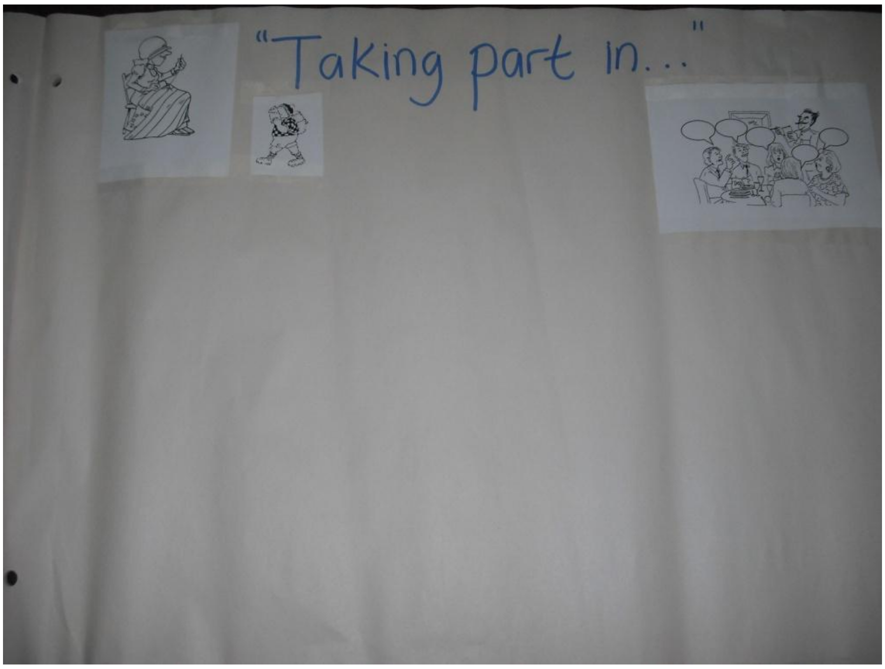
Kate: And in terms of the environment, I'm thinking about things, again I'll give you examples from other people that might not be the same for you, but a lot of people that had stroke find that when they go out the amount of information sort of in the environment, they find quite overwhelming, it makes them feel quite ill, y'know that there's too much going on and they can't sort through it in their brain and things like that. And another aspect of the environment would be, someone in a wheel chair comes across a flight of stairs, so is there anything since you've had the stroke in the environment that you think that's a barrier.

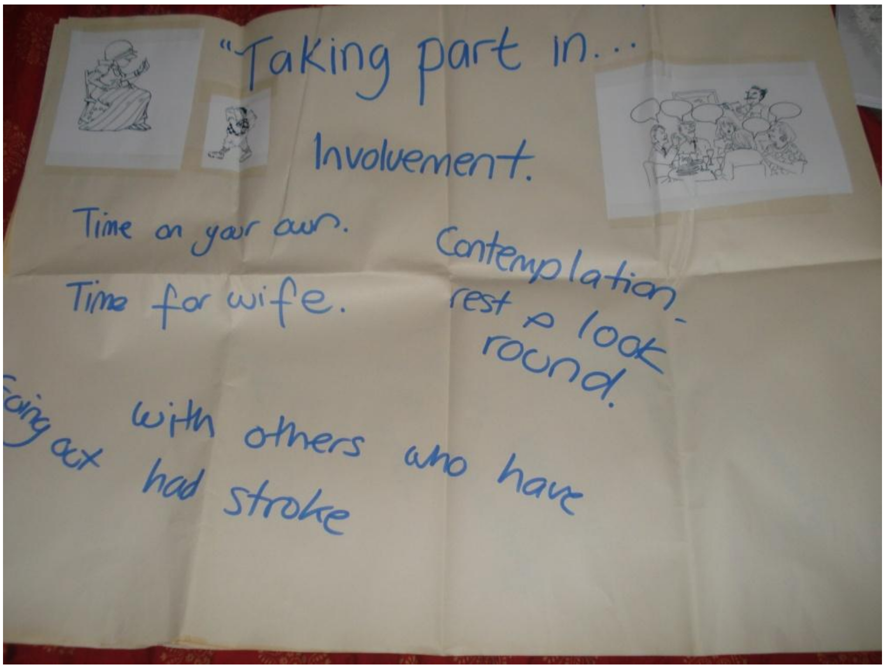
Abid: no no it's not, the thing is, I've gone quite low, I used to speak quite a lot, and I always add something to the conversation, to friends, and if there is debate, and I will always pass of questions and I basically ... I can't speak

Kate: and how do you feel about that?

Abid: well I don't know to be very honest, I feel slated and slighted, you know but I think at the passage of time the brain can work, and with the passage of time the brain will actively work and I don't get tired and my speech will come back, but if it doesn't Alhamdulillah. I can't do anything about it. But I think it is er, since it happened...it's a problem, speech problem in the brain yeah.

4.1.2-Source 1 focus group photos





"Taking part in...

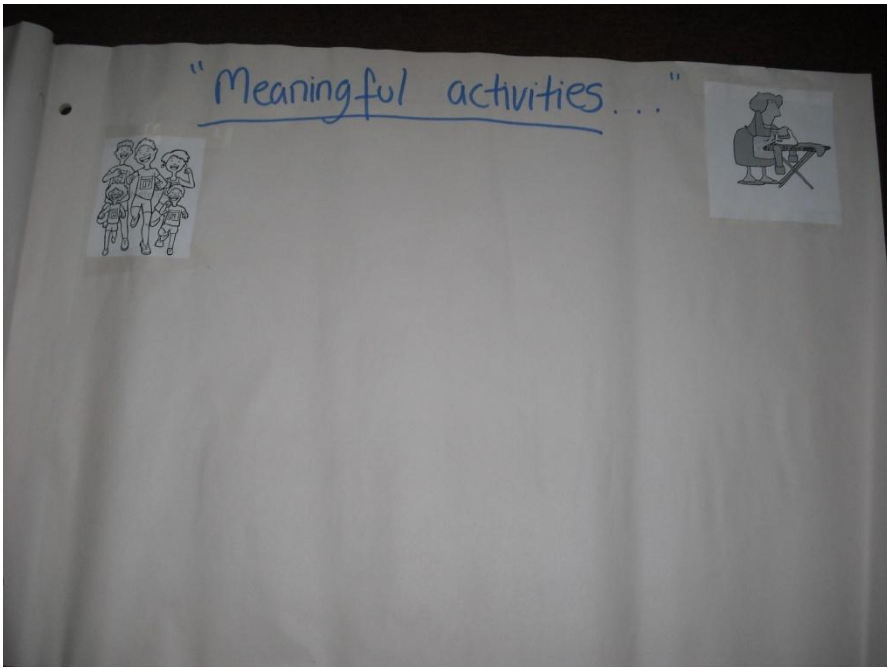
Involvement.

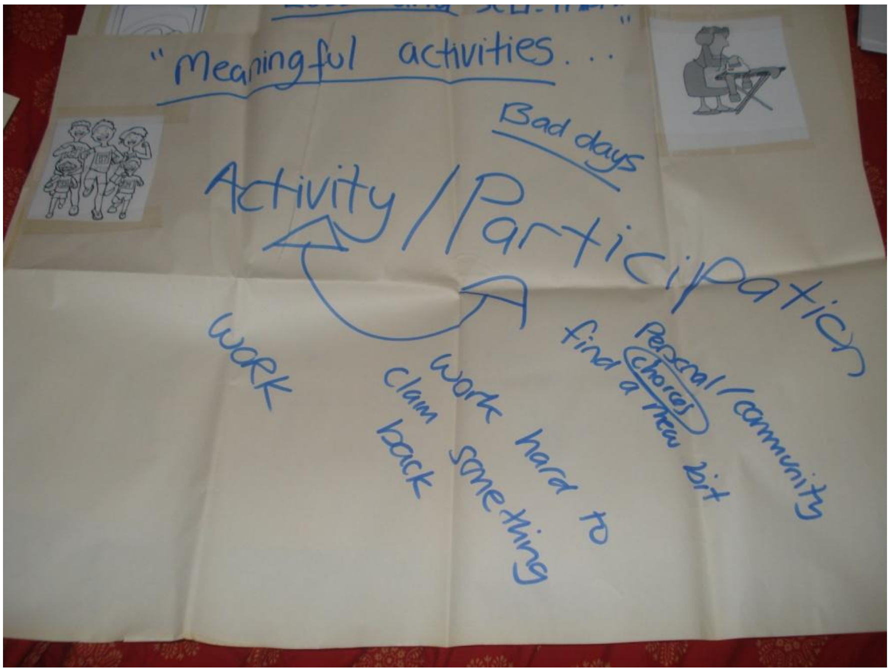
Time on your own.

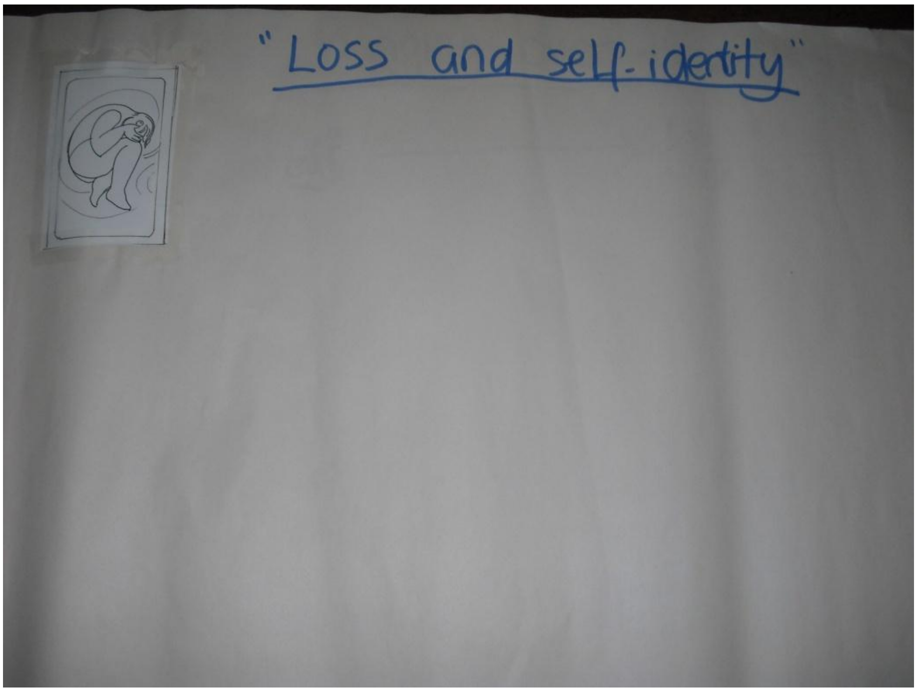
Time for wife.

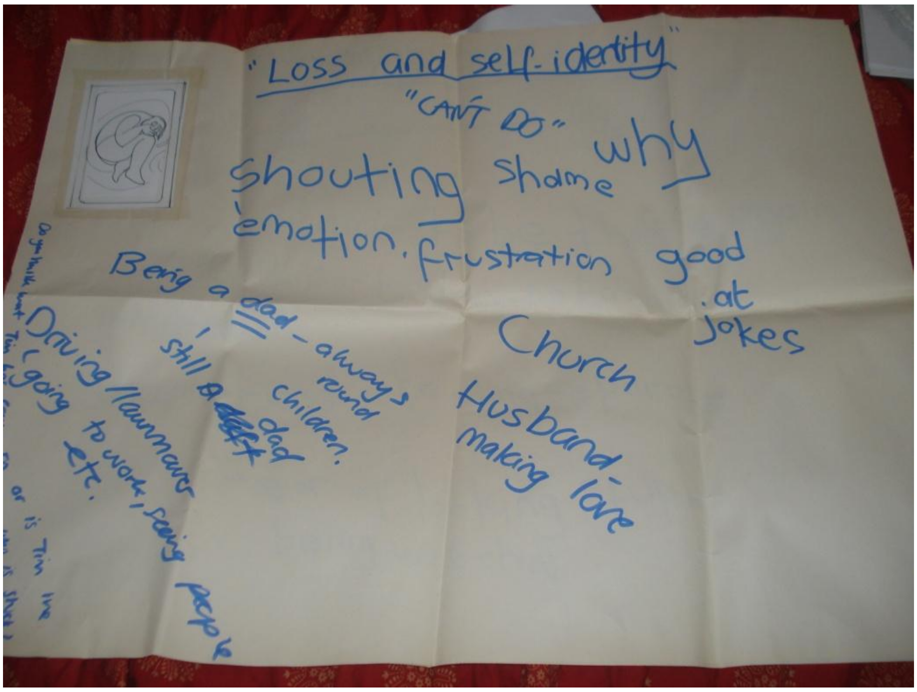
Contemplation-
rest & look
round.

oing out with others who have
had stroke

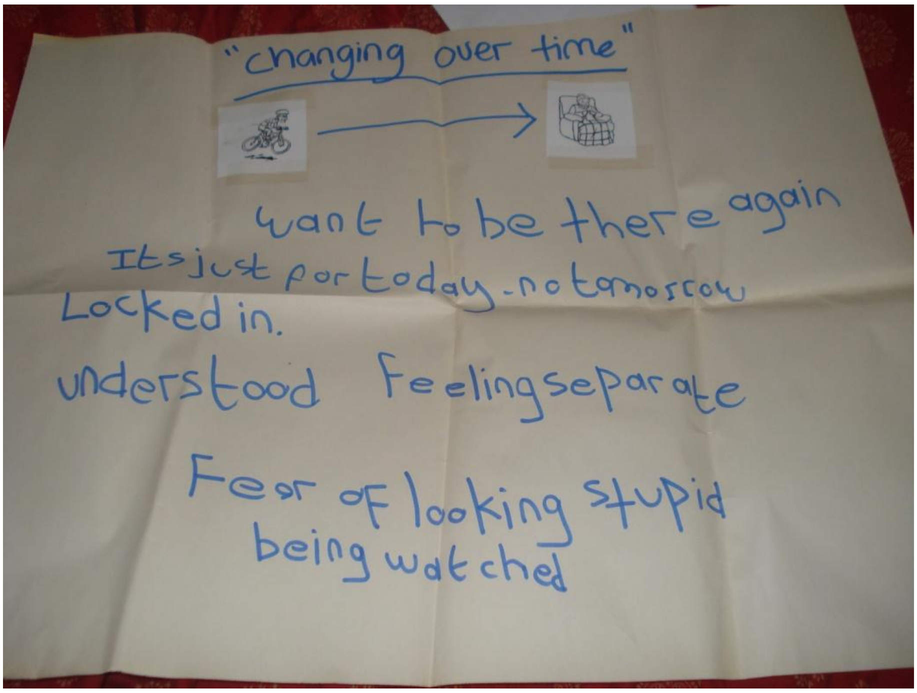

"Meaningful activities..."


"Meaningful activities..."
Bad days
Activity/Participation
Work
work hard to claim back something
find a new bit
Personal/community
chores


"Loss and self-identity"


"Loss and self-identity"
"CAN'T DO"
shouting
shame
why
emotion, frustration
good at jokes
Being a dad - always round children.
still a ~~[illegible]~~ dad
Church
Husband - making love
Driving /lawnmower
(going to work, seeing people etc.
Do you think what
or is Tim the

"changing over time"



"changing over time"

want to be there again

Its just for today - no tomorrow

Locked in.

understood Feeling separate

Fear of looking stupid

being watched

4.2-Source 2 interview transcription

Wallace

1: so last time I saw you, was about 6 months ago and you were

2: oh was it <laughter>

1: yeah <laughter>

1: you had your stroke and you were quite recently back at home I think at that stage

2: yeah yeah

1: and I think the problems you were having back then was that your eye sights was affected, wasn't it

2: yes yeah

1: and your short term-memory

2: yes

1: which is the same as what you are saying now isn't it

2: yeah yeah

1: yeah

2: me eye sight seems to have improved a bit

1: oh that's good

1: yeah so that's stabilised now but the short-term memory is still

2: is still a bit of a problem

1: yeah

2: me long term memory is absolutely <overlapping conversation> <laughter>

1: yeah that's usually the way it is, is in it <laughter>

2: yeah yeah

1: do you think your short-term memory has improved since you first had the stroke or

2: oh I think uh <pause> a bit I think

1: hmmm but still finding it quite a struggle

1: so in what ways does that affect you then, on a sort of day to day way

2: well I can't remember where <laughter>

2: My [wife] might say to me so and so, you know

1: yeah

2: can you, it’s somewhere, and within a few minutes, I will probably have forgotten

1: yeah

2: but that could be a <pause> lack of concentration sometimes on my part

1: hmmm, hmm

2: you know you can’t put it down to anything

1: but it’s defiantly a change, you know from how you were before

2: what before I had the stroke

1: before the stroke yeah

2: um yeah but as I say physically, I feel quite quite fit

1: oh that’s good

2: all I am now is frustrated really

1: hmmm

2: because I can’t drive

1: oh okay

1: what’s stopping you from driving?

2: well initially it was me eyes, you know

1: yeah

2: and then now I couldn’t really, I could get into the car and start it and what not, I’ve no problem with that

2: It’s finding me way, and where to go <laughter>

1: uhh yeah

2: which would be a hazard to both me and other people, you know <laughter>

1: yeah yeah, so you just don’t feel it’s the right thing to

2: I don’t think it’s the right thing to do actually

1: yeah yeah

2: I have never had an accident or anything and I would hate to have one, you know

1: yeah of course

2: and be the cause of hurting anybody else

1: ohhh yeah

1: and there were other things you mentioned, that you enjoyed that you weren't doing when I last spoke to you, including your art I think

2: oh yeah

2: well no, I I haven't done any actually

1: hmmm

2: because um I can't, um, apart from red and green

1: hmmm

2: I can't tell colours <laughter>

1: alright okay!

1: That's another problem with your eye sights

2: yeah

1: yeah yeah

2: I'll be able to tell traffic lights <laughter>

1: yeah <laughter>

1: well that's something

2: <laughter>

2: but if it comes to things like, [wife] really has to get me clothes ready to dress me

1: yeah

1: because I can't tell you know, when it comes to cream, white, I can't, can't tell

1: right

1: so you might end up looking a bit like, patched together <laughter>

2: yeah yeah, and I have got a pair of shoes that, two pair of shoes, a black pair and a brown pair

1: hmmm

2: and they are exactly the same

1: hmmm

2: I could have a brown one on, and a black one <laughter>

1: <laughter>

1: so yeah that's a bit limiting then, the art work, yeah

2: to a certain degree yeah

1: yeah yeah

1: is that something you would like to get back to

2: no, quite honestly I am not bothered

1: you’re just not bothered, no

2: no no

2: Its having some where to do it that’s not <pause> been in the way

1: yeah

2: and also it can be, you can be a bit messy doing it

1: yeah

2: I’d rather not put anything else on [wife], she’s got a enough to do

1: ahhh yeah

2: without, you know

1: you feel it might create more work sort of thing

2: yeah yeah, I don’t want to do that

1: awww

2: she’s looking after me [wife]

1: is she, that’s nice

2: yeah, and she ought to have some compensation for it

1: yeah yeah

2: I mean nobody has ever said to us, do we want any

1: help

2: help, financial assistant

1: since the stroke

2: pardon

1: since the stroke you mean

2: yeah

1: there are things you can look into on that front

2: yeah

1: you should make sure that you, to see if you are entailed to anything

2: yeah

2: we don’t know where to go

1: hmmm

2: we have never had to, I mean we have never

1: yeah you not been a position before to any

2: so many people seem to get it

1: hmmm

2: but nobody has ever mentioned anything to us at all about it

1: because if it wasn’t for [wife], you would need assistance

2: I would need somebody to, yeah

1: are you still, do you still have contact with the stroke association and those people

2: um [wife] will probably know, I can’t remember

1: yeah I will ask her, because I think they would be good people to ask

2: hmm

1: just in terms of where you would go to find out about that

2: that’s right yeah

2: because I think, you know she needs a bit of financial help

1: hmm

2: you know even if it’s just <pause> as a token <laughter>

1: yeah just a recognition, yeah yeah

2: yeah

2: and people say things, you know they say oh so and so gets this, gets that and the other

1: hmmm

2: and nobody has ever approached the subject with us

1: that’s interesting is in it, I think sometimes they look at a situation and

[wife] (3) enters the room

1: we are just talking about financial situation, and really if it wasn’t for you, you would need some kind of help

3: oh he has no idea when bills come in or anything, you know he did them all

1: hmmm

3: i never did anything like that but

1: hmmm

3: of course when he was in hospital I had to start then

3: not that I didn’t know how but I never dealt with things like gas, electricity, direct debt you know

1: hmm

3: you know we don’t have to worry about things like that

3: you know I just never bothered, he did it and that was that

1: yeah

2: I mean I have got

3: he won’t know now

2: credit and debit cards

1: hmmm

2: every number was there, I didn’t write them down, I just remembered them

1: hmmm

2: so if I wanted use Mark and Spencers or me bank card to get some money or what ever

1: you would just know

2: it will be there, but it’s gone

3: but not now <laughter>

2: fortunately it’s a joint account, so [wife]

1: yeah so you can both do it

3: no no we are alright

2: yeah

1: hmmm

1: but we were just wondering whether there is things you might be entitled to you know

3: well yeah, [neightbour] that only lives across road, she had this letter one day, and she says oh I’ve got another £25, have you got it

3: and he went what for

3: and it’s if the temperature goes below so and so, and you get £25 you see

1: alright

3: she said did you get yours last year?

3: because you know he was 80, and she has turned 80 she thought he got it

1: hmmm

3: so she gave me this phone number and I rang them

3: and they said are you on any benefits

3: I went no

3: are you on anything

3: he says oh you can’t have it then

1: that seems to be the thing, if you are not on anything you can’t get anything

3: yeah yeah I don’t understand it

3: but she says, I mean she’s a widow, I don’t know whether that makes any difference

1: hmmm, yeah

3: but she says she’s not on any benefits

3: so I really don’t know

2: I can’t understand it

1: no

3: and then, oh I know, she says try age concern

1: hmmm

3: so I rang them and I said can I make an appointment to come and see you because they are in town

3: and she says yes, what’s it about, and she said the same thing, if you’re not on any benefits you can’t claim it <laughs>

1: hmmm

3: so um, she says I am sorry, and you know we chatted and she says I can’t do anything for you

1: hmmm

3: and then she said try um, which I haven’t rung

2: citizen’s advice bureau

3: citizen’s advice

1: yeah they’re good

3: yeah you would think age concern would know more

3: anyway she just said no if you are not on any benefits

1: right

3: and that’s it

1: um are you still in contact with the stroke association, and the people from there,

3: well no no no, they don’t come, they came you know for few months

2: <overlapping conversation>

1: yeah

3: they didn’t say, I mean she didn’t say you could claim for anything

2: no no, nobody has ever approached the subject with us at all

2: which seems to be a bit unfair

1: yeah

3: one thing she did was give me her number, and if you wanted any jobs doing, proper work men you know what I mean, in their own trade and they would do it cheaper than normal

1: yeah

3: so we needed our new

2: security light

3: security light went in the back

1: yeah

3: he never came, he said he would, but he never came

1: aww that’s <overlapping conversation>

3: you can’t whinge can you, you know <laughs>

3: we, we haven’t got it done

2: so you know, its things like that

2: I mean, we’ve had pluming jobs done haven’t we, but

3: yeah but I think he wanted, they wanted bigger jobs

3: you see it was already wired; it just needed the old one taken off, and the new one putting on

1: hmmm, um

2: I mean probably, if I hadn’t had a stroke, I, I could have sorted that out meself

1: yeah

2: but

3: anyway

1: but this is the point isn’t it

2: yeah I can’t

3: they gave me this number, it was for all trades, not just electricians, you know

1: umm yeah

2: you see I I can’t, if I look up, I go dizzy

3: he gets a bit dizzy <overlapping conversation>

1: ahh

2: so you know it limits me activities to a certain degree

1: yeah you don’t do DIY and

2: I can’t do jobs that I could do before

1: yeah yeah, yeah

2: an so it’s <indistinct> 13.20

2: reward less <laughter>

1: Yeah <laughter>

1: and the other things were like reading books and things, you weren’t really managing last time, and cross words, have you got back to that?

2: oh I have, have read some books, I am reading some books

2: and I read certain things in the news papers, but not, because news print is rather difficult to read at best of times you know

1: yeah it’s small and

2: yeah

2: but I can read headlines, you know in the news papers

1: yeah that’s good

2: I can see people better

1: hmm

2: I mean last time you came, I didn’t think I could you know see your features

1: right okay

2: but I can now you know

1: ahh okay, good <laughs>

2: which is a good sign

1: yeah, things have improved

1: what about um, I think when I spoke to you before you didn’t feel that your relationship with you family had changed really since the stroke, um you’ve got some grand children and they come when they come and

2: yeah when when me daughter, well they live out of Sheffield you see

1: yeah

2: so, but we’ve seen them once or twice when they’ve come for Christmas, you know

1: oh lovely that’s nice

2: me daughter, she’s having chemo at the moment

1: ahh

2: but she came, she’s got a big Toyota 4X4, living in the country virtually <laughs>

1: hmm, right oh lovely

2: they came and fetched us

1: oh lovely

2: you know and we had a few days there

1: oh that’s nice

2: but then again, when I was there, I was a bit disorientated

1: hmm

2: you know out of me comfort zone to a certain degree

1: hmm

2: but I I was, the way I feel now, If went I would be better you know

1: yeah a couple of months

1: so you still feeling improvements

2: I am feeling improvements you know, both physically and mentally

1: that’s good, because last time I saw you, I think at that stage you were saying to me you weren’t really thinking too far ahead because you were quite recently at home and you were just sort of getting through day to day really

2: yeah

1: so do you think now that’s changed a little bit and you

2: yeah I feel, I feel I've improved a bit

1: yeah

2: I know I wasn't interested in anything when I first came out <laughs>

1: hmm

2: hospital is just a <indistinct> <laughs>

1: yeah <laughs>

2: because there is nothing worse than been stuck in hospital and

1: no

2: probably people who haven't got the same interest or intellects if I am, I might be a bit snobby <laughs>

1: yeah no, I know what you mean <laughs>

2: not that I am a genius or anything <laughs>

1: it's just been with similar people isn't it

2: that's right ...yeah it's a bit, a bit soul destroying to a certain degree <laughs>

: It is, yeah, there is only so many magazines you can read and

2: that's right yeah yeah

1: definitely

2: well when I was in hospital you see, I couldn't, I couldn't even read you know

1: oh gosh yeah

2: because I couldn't see <laughs>

1: aww

1: so means of entertainment were

2: well I was listening to other peoples, very often, conversations <laughs>

1: ohh yeah

1: oh dear, yeah just glad to be home

1: I will just go through what you have told me so far, just to check I have understood everything right

1: so since I saw you six months ago, you feel you have improved

2: I feel, oh yeah yeah

1: yeah

2: occasionally I feel a bit ..... when I am out, but I am better than I was **(18.00)**

1: hmm, hmm

2: hello Margret

2: she can’t hear me

1: she’s cleaning away

1: and physically you feel quite

2: physically

1: quite good

2: I feel quite, not bad at all

1: yeah yeah

2: you know obviously I couldn’t do things that i could do before

1: yeah

2: I can’t look up; if I look up I become dizzy

1: hmmm

2: so you know <laughs>

1: so yeah it limits you to a certain degree

2: I can’t do jobs about the house like

1: do you think um, do you think, because you seem quite accepting of the fact that things have changed a bit physically, do you think that’s because of your age

1: that with age you expect a certain, expect things to alter slightly, do you feel you can accept it or is it, is that your personality or

2: oh I don’t know

1: <laughs>

2: that’s a difficult

1: question

2: question that

2: I mean alright so I am what, 81 am I, I think

1: hmm

2: um I suppose it’s getting on a bit isn’t it <laughs>

1: <laughs>

2: but I don’t feel, I haven’t got, I don’t think I’ve got an average 81 years olds health

1: no

2: Margret will tell you whether I have or not

1: <laughs>

1: I am asking because from the people I have seen

2: yeah

1: sometime people who have had strokes are less, um, I don’t know quite how to put it, are less, less kind of angry and depressed about what’s happened than some of the younger people

2: alright

1: and quite often it’s perhaps because the stroke has happened while they have still been working or something like that, so it’s more of a change maybe

2: I think, yeah, I mean I would have never been able to go back and do me job

1: no no

2: you know if I had been working

1: whereas you were retried anyway so

2: I was retired anyway in any case

1: yeah

2: I was, I mean I was 80 you know

1: yeah yeah

2: so, you probably when you are that age, you accept things better

1: hmm

2: I don’t know first time I have been 80 <laughs>

1: well yeah <laughs> first time you have been 80 and first time you have had a stroke, yeah

2: well I did, I did, yeah because I had a slight one on me 80th in 2009

1: alright okay

2: when I, Margaret

3: yes

2: didn’t I had a slight stroke when we were at [daughters] when I was 80

3: yes, yeah that was the first one you had, yes yeah

1: hmmm

2: when we were in [town]

3: yes yeah, they took him into hospital, they only kept him overnight

1: hmm, umm

3: and then came home

1: hmm

3: then he had to go to the [hospital], and have a thing on his neck and then everything was alright

1: hmm, yeah

3: and that was it, so

1: and then it was, it followed

3: yeah yeah

2: and then this one I had

1: hmm so at the moment frustration is really the thing, that’s, with the memory <overlapping conversation>

2: it it is, in so much that, even though i can see much better than I I could and what not

2: um I can’t remember and

1: hmm

3: don’t even know where he is when he is on a bus

2: oh when I am on a bus, I am hopeless

3: he is no idea where he is

1: disorientated sort of thing

2: yes

3: yeah no idea

2: you see I could get into me car, start it up and everything

1: hmm

2: but I wouldn’t know which way to go

3: no no

1: hmm

2: would I?

3: no he wouldn’t, he is only really this last year, this year that he is really know where we live as you came, we come up door and he went we are here, we are here

3: but he didn’t, if I would have walked past, he would have walked past, he wouldn’t have know, would you

1: hmmm

2: yeah

3: but he does now

2: but now in any case I can see numbers on the houses

1: yeah

3: yes

2: but I couldn’t see that before

3: no no

1: right right

2: you know when I first

3: it’s also, well when [woman] from stroke when she came, she said he can see

3: hospital when he had his eyes test, she said he could see, but it’s part of his brain that’s telling him what he can see

1: yeah I see

3: that’s it isn’t it, yes yes

2: yeah

3: and he can’t tell, somebody will speak to him, and he will often say ‘oh i don’t know who it is’ you know

1: hmm can’t put the two things together sort of thing

2: yeah

3: no no

1: hmm

3: but then sometimes you hear a voice and you know straight away who that person is

2: yeah yeah I know I know by their voice

3: he says oh I know who that is

2: and to a certain degree when you meet somebody in the street, you are quite close to them aren’t you

1: hmm

3: yes and you can’t always tell then can you

2: if they are away you know, I am better

1: ahh okay that’s interesting

2: yeah I am better

3: yes yes

3: and it was his left hand side that affected his eye, his eye sight

1: hmm um

2: yeah

1: that’s interesting

2: but I I don’t think I have quite lost me marbles yet<laughs>

3: nooo not yet

1: you certainly don’t seem like it <laughs>

3: oh you’ve got about years

3: but then as you get older your short term memory does begin to go

1: yeah defiantly

2: yeah

3: normally doesn’t it, it just means going to get worse <laughs>

1: yeah yeah

2: that’s most frustrating thing about it <overlapping conversation>

3: yeah

1: hmm

3: a lot of people when they go back to, when you were a child and things like that <overlapping conversation>

1: yeah

2: oh yeah

2: and me, I don’t think me intellects

3: oh no no

2: has changed has it

3: no no

1: yeah

2: and you know I watch...and things like that (24.51)

1: hmmm

3: right from the beginning he knew the answers, and then I think how did he know that you know

1: hmm

3: how can he remember that, and he would say the answers before they did you know, when it came up he knew, yeah

1: yeah <laughs>

3: so thats not gone

1: a very different part of the brain

2: yeah

3: yes yes, it’s a weird thing your brain isn’t it really

1: i mean my grandmother, the same maybe, she’s is 90 and her short-term memory is awful

1: i mean she just asks the same question over and over again

3: over again yes

1: if you get her talking about, looking at some old photos, the stories and the names and, its all there you know

3: yes

2: yeah

3: yes and during the wars, i always remember that, and things like that

1: yeah

3: oh yeah

1: it’s amazing

2: that’s what’s caused my stroke actually

1: what

2: the war

3: the war

2: yeah

3: give over <laughs>

2: it is and that flaming cellar grate that hit me on the head

3: <laughs>

1: <laughs>

1: all these years later <laughter>

2: <laughs>

2: i was in, you know the night of the blitz

1: right

2: i was in a cellar and a cellar grate came, got blown throw and it hit me on the back of the head

1: really, oh gosh

3: and what did it do, smash, it got blown <overlapping conversation>

2: oh the day before, the Wednesday night, the Wednesday, the blitz was on the Thursday

2: i had me first piano lesson

1: yeah

2: the Thursday the night of the blitz, the piano was shattered <laughs>

1: aww

3: <laughs>

2: and I never had another one

1: aww so you still can’t play the piano

2: no <laughs>

3: you would think somebody was thinking right, wouldn’t you

1: yeah <laughs>

2: and i would have loved to have played the piano

1: aww

2: because I love music

1: aww

3: never mind, never mind

1: still time <laughs>

3: houses are not made now for piano

1: no

1: you would need a big bay, well you’ve got a little bay window haven’t you

3: yeah but they are not big enough are they for a

2: no

1: aww

2: anyway that's by the way <laughs>

1: <laughs>

2: that's all in the past

1: so um, so the reading and that you have got back into, which is nice because last time you

2: oh yeah I have read a few book

3: yes yes, I thought I am gonna start him with a book, I mean it took him a him a while to read anything, it was like a child you know

2: yes

1: hmm

3: because she, when she came from this, she tried him with, with things to make things square

1: ahh

3: but that didn't, he couldn't do it, and he put his finger on, and she says oh no that's it, he did it his own way

1: yeah

3: and he was alright, but slowly, anyway I got him a book and you read it didn't you

2: oh yeah

3: it was

2: Clarissa Dickson Wright's autobiography

1: ohh

3: and she's had a very colourful colourful so I thought he will enjoy that, which he did

1: <Laughs>

2: yeah

3: and then he has gone on from there, and he keep, give him another one to read and he is, so he is doing quite well really

1: ohh that's, that's really good then

2: yeah

3: yeah

1: okay

2: at the moment I am reading Damon Runyon short stories

1: ohh

3: oh yeah I was sorting some books out, and I found some books upstairs and i thought oh we got some many books in this house, and I thought oh I bet he will enjoy reading that

2: what guys and dolls is based on

1: ohh alright okay

3: yeah things like that, very funny

2: very funny short stories

1: yeah hmm

3: yeah so I gave him that to read

2: yeah

3: so he has started that, haven’t you

2: yeah <laughs>

1: hmm, that’s nice

3: I mean you have read it once years and years ago

2: oh yeah

3: in fact I have forgotten we have got it <laughs>

1: yeah, nice to go back to things sometimes isn’t it

3: yes, oh dear

2: i have read it before, we bought it actually

1: ahh

3: anyway, that’s, so yeah he is reading alright

2: yeah

1: that’s good then, yeah

3: yeah

1: I mean I think before you might have said that you were just, you felt perhaps a little bit down <overlapping conversation>

2: yeah I feel quite, I feel happier than I did, um you know

1: yeah, yeah

2: um but I I think, its social, you want some social discourse with people you know with same interests and what not you know

1: hmm

2: I think that’s the main thing

1: hmm

1: do you think you are missing that one at the moment?

2: um no because we go out quite a lot and we, we meet people you know

1: hmm yeah

2: but i think that <coughs> excuse me

2: you know, i think that would be for anybody really

1: yeah I see

2: in my opinion

1: so that’s social contact and

2: yeah, I think I think if you were sat on your own

1: hmm

2: with nothing or nobody to talk to, oh it would be terrible

1: hmm um

1: so what’s your, where do you socialise and that kind of thing

2: well we have quite a few friends you know

1: hmm

2: I mean, are you there [wife]?

2: oh she’s gone

1: <laughs>

2: I mean we, went across the road I think it was Saturday night

1: hmm

2: and had a game of cards, now that I can see, you know

1: hmm

2: I am I am slow, slower than I was

1: umm

2: but I enjoy a game of new market and you know

1: hmm

2: but our friends understand that I am not as quick as

1: yeah yeah

2: and me thought process aren’t quite as quick as they used to be <laughs>

1: yeah yeah and it doesn’t really matter, I suppose if you were a bit slower and then <overlapping conversation>

2: <laughs>

2: no no and you know and I think that’s you know, that’s something that everybody needs

2: you know social intercourse of some description

1: hmm, yeah

2: but that’s that why I didn’t you know, like it in hospital you know

1: umm

2: because you, you want people with the same, I mean I am not interested in football

1: right yeah, that’s a big topic of conversation I suppose between men

2: yeah, but I will watch rugby all day you know <laughs>

1: <laughs> yeah

2: things like that you see, you have got to have people with the same interest to a certain degree, you know

1: yeah, oh defiantly, defiantly

2: well that’s my opinion anyway

1: yeah

2: for what it’s worth <laughs>

1: yeah I think you are right

1: so I mean, are you able to answer this do you think, that, or do you not feel that this very relevant to you really, this depression, depression question

2: um

1: because it’s fine if you don’t want to answer it

2: I don’t, well, are you there [wife]

3: you what, hmm

2: am I depresses?

3: occasionally yes, yeah

2: I, I

3: it gets him down because he can’t remember

1: hmm

3: but I mean not not

1: probably depressed

3: no no no no

3: he gets just a bit low and then

1: would you rather not say its depression, because that’s sort of a different thing

3: yeah, no no its not, no

2: no no

2: no because I will have a joke with anybody, wont I

1: yeah

3: yeah yeah, no he just gets, gets frustrated

1: yeah

2: i just get frustrated

3: and then I will say oh what’s the matter, then he will say oh I am just fed up I can’t do this and I can’t do that you know, but no no

1: hmm

3: but no no it’s not depression

2: its frustration isn’t it, I wont

3: frustration

3: I mean we go out as much as we can, don’t we

2: yeah

1: hmm

2: sometimes its hard work to go out isn’t it you know, well

3: well I have to get his clothes out, because he is no idea, his colour has gone a lot

1: yeah he was saying yeah

3: yes

3: he will say what colour trousers are these, are these, no of course they are not, they are whatever they are you know

1: yeah

2: at least they fit <laughs>

3: <laughs>

1: <laughs>

3: but no no, a lot of colours have gone haven’t they, so that’s part of it

2: yeah

3: it’s funny that isn’t it

2: yeah green and red are alright

1: that’s funny because when people are colour blind they are the ones that get confused

3: yes yes, me father was colour blind

2: I can tell green and red

1: hmm

2: but when it comes to

3: bright

2: light brown

3: yes

2: as I said shoes

3: yes, ‘are these black or are they brown’

2: because I’ve got <overlapping conversation>

3: they are similar style aren’t they?

1: hmm

2: well they are virtually; I think they are same aren’t they

3: yes, yeah

2: and um, i think they are same make

3: yeah they are so they, but they are a bit

2: a bit lighter

3: yeah so

2: I could have a black one on and a brown one on <laughs>

1: and you wouldn’t know <laughs>

3: well he would if he did it himself <laughs>

1: good job you’ve got your wife to

3: oh dear <laughs>

2: that will be a talking point, wont it

1: yeah it will <all laugh>

1: so it’s a bit of an effort to go out and this, but you sort of keep on, keep on at it

3: yes, oh yes, yes

3: oh yeah he likes to go out

3: we went, we went on, you know the thingy gardens that built at the bottom

1: hmm

3: well a friend of mine

3: the one across the road, she’s a member, because she goes to bingo and things like that

1: hmm

3: and we went on Friday night, and we had a fish and chip meal and

1: oh

3: it was absolutely, the fish was absolutely gorgeous

2: yeah

3: anyway we went out there and her daughter, because it was her daughter’s birthday the next day

1: hmm

3: so that was quite nice, and there were one or two people that, that don’t live there but had gone in, you can go in and

1: hmm

2: you can, I mean you can, it’s not very expensive is it

3: I can’t remember, because [daughter] says I am paying because it were her birthday <laughs>

2: you can be

3: oh its £25

1: hmm

3: yes yes

2: which is not bad

3: and he enjoyed that you know

1: hmm

3: and then Saturday night, we went across there, we had some friends, and we played cards

1: hmm

3: every so often so we, because he can play cards

1: hmm, yeah he was saying

3: he can play cards, cant ya

2: dominos

1: hmm

3: yeah yeah things like that

1: umm

1: so you have got the thought process, that’s

3: yeah yes

2: me thought process is a, um is quite, well

3: yeah he can play cards

3: and we haven’t played for a long time because our friend has not been very well, so we haven’t played for a while

1: umm

3: but it went fine

2: yeah

3: we only played a simple game, what did we play?

2: did I win?

1: <laughs>

3: no I won

2: oh I were playing you Margret

3: we played for a penny, a penny a pot <laughs>

1: yeah <laughs>

3: we not big gamblers

2: oh no we are not Las Vegas <overlapping conversation>

3: no no not quite, not quite

3: so we have a good laugh

1: hmm

3: so you know, oh we went to the ballet the other Sunday

1: ohh

3: that was nice

2: oh yeah

3: it was in city hall

1: ohh

3: Moscow

3: no Siberia

2: Siberian state valley

3: yeah we have seen

2: they are very good

3: oh I have enjoyed that, it were lovely, it was the sleeping beauty

1: oh that’s good

3: we enjoyed that, didn’t we?

2: yeah

1: that’s nice

2: even though, I could see it alright

3: oh yeah we had good seats as well

2: we had good seats, but I I couldn’t quite follow it

1: hmm

2: but the music makes up for it in any case

1: yeah sort of, just enjoying it

2: yes

3: yeah yeah oh it was lovely, beautiful customs

2: it was great

1: aww

2: because my first love is opera actually

1: oh hmm

2: but Margret likes bally

3: I like both

2: I know you like both

1: do you get many operas in Sheffield or

3: um not for a while no no

2: no we used to

3: no I can’t remember the last time one came

2: no I cant

3: its a few years since we went to the arena and saw: Madame Butterfly

1: ohh

2: oh its is yeah

3: didn’t we

2: yeah yeah

3: but we have not been to one since

2: we never went to <overlapping conversation>

2: some time ago to see ... <indistinct>

3: no not in Sheffield, you get the ballet

1: yeah

3: at the city hall some times

1: yeeah

3: but no no you don’t

1: hmm

3: but no

2: <indistinct> <all laugh>

2: I I just be careful, you know

1: yeah

2: I think [wife] is more fearful

1: umm, huh

2: than, than I am of things

1: hmm

3: <wife returns> they ring, he is going to hospital tomorrow and they fetch him in a car

1: alright

3: but they always check the day before, you know to see if he is still going

1: yeah

3: so I said yes <laughs>

2: yeah

3: but you have to be ready for 8 o clock

1: oh gosh that's early

3: oh yeah, well, it's getting a bit longer between times he is going

3: and it was about nearly 8.10 when they came, he was stood ready, and he went 'they are here' 'they are here' <laughs>

1: yeah yeah

3: so you have got to be

1: on the ball

3: yes yes

2: yeah, but then again

3: it's coming back that takes a long time sometimes

2: it's coming back

1: right

3: he didn't get back till about 12 o clock mid day, you know its a long

3: he were shattered when he came back, although he had done nothing

2: yeah

1: just sat waiting

2: I didn't know you could get so tried doing nothing <laughs>

1: I think that's when <overlapping conversation>

3: yeah <laughs>

1: yeah

3: sometimes it's a quicker than that

2: yeah

3: it just depends, just depends

1: yeah yeah

3: I wish they would hurry up and change it to our doctor and then to the nurse

1: yeah

3: but they haven't done yet

3: it's for his Warfarine

1: alright okay

2: yeah

3: it's because he is taken Warfarin

1: that seems like it's something that could be done a bit more locally, couldn't it

3: well this is it, she, at the hospital, she came out and she says oh it will only be for a few weeks, but it's been since June, you know

1: oh gosh, that's a long time

3: I don't know when, I did mention it to the doctor when we saw last week

2: yeah, is it about once a month I go

3: yes yes yeah

3: so they just give a date, they don't tell him, a letter comes the next day

1: hmm

3: I don't know, and he is still been on the same 3mg a day

1: hmm

3: so I don't know why it's taken a long time, but anyway, I don't matter

2: hmm

3: they will sort him out

2: i had to go to have me blood taken, last Friday was it

3: oh yes that was up at the doctors, yes yeah

1: hmm

2: yeah

2: haven't got results

3: she said she'd ring in

3: she's lovely, our doctor

2: hmm

3: and I started going to her, and then she wanted to see [participant] to assess him

1: hmm

3: and he did quite well, she asked him quite a lot of question

1: hmm

3: there were only that you didn’t know, I can’t think what it was

2: no

3: it was the actually day, was it the day we had gone, he knew what year it was and all that sort of thing

3: there was just one

2: oh yeah its things like that, I don’t know what day it is

3: day it is

3: no often he will say ‘what day is it today’

1: right

2: yeah

3: and I say well what was it yesterday, and I will try and get him to work it out

1: yeah

2: yeah

1: what as in Monday, Tuesday, Wednesday, or as in the dates

3: no the actual day

1: the day

3: well he might not know the date

2: the date as well you know

3: yes yes

1: you do have less structure to your week, don’t you, of you are not working

3: well yes yes, you do

2: it all goes into one

1: hmm

3: everybody says that when they retire

3: you wake up and think I wonder what day it is today <laughs>

1: yeah <laughs>

3: but yeah when you work you know, don’t you

1: yeah

2: yeah

3: you know it’s the weekends or whatever

2: I didn’t have that trouble when I retired

1: hmm

3: no not really

2: I knew what day, everything

1: hmm

2: you know

1: hmm

3: oh but you weren’t quite 60, were you, so

2: when I retired, no

1: hmm

2: and I have been retired a long time

3: hmm yes you have

1: yeah

3: but no, he does, he does think oh what day is it <laughs>

1: hmm, umm

3: you have to make yourself think

1: yeah yeah

3: oh dear

1: okay well I think that’s all of my questions, just to get an impression really

3: yeah

1: how life is and <laughs>

3: yes yes, if it helps you

2: well <overlapping conversation>

4.3-Source 3

Email interview

Andrew

Email 1

1. How old were you when you had your stroke?

2. How long ago was your stroke?

3. Has your stroke impacted on your everyday life?

4. If so, how?

5. Has your stroke had an effect on your roles in life?

6. Has stroke affected the way you see yourself?

7. Do you think being male has made any difference to the way the

stroke has affected you?

8. Has your age made any difference to how the stroke has affected you?

Reply 1

1. *How old were you when you had your stroke?*

I was 43 years old

2. *How long ago was your stroke?*

It was in August 2010, so 21 months ago.

3. *Has your stroke impacted on your everyday life?*

Yes

4. *If so, how?*

I am now unable to:

Drive;

Dress myself fully – can’t cope with buttons, zips or tie laces.

Type with two hands;

Eat with both a knife and fork;

Run;

Perform most bilateral tasks;

Concentrate for an extended period of time upon mental tasks.

5. *Has your stroke had an effect on your roles in life?*

Yes: was previously a self-employed consultant running my own company– not being able to drive took me from family breadwinner to an unemployed person, heavily dependent on others. I am now struggling with running the company and am being threatened with criminal proceedings, incredulously.

6. *Has stroke affected the way you see yourself?*

Yes; I now feel I am a vulnerable adult who is a burden on family/society.

7. *Do you think being male has made any difference to the way the*

stroke has affected you?

Yes, in some ways – you feel you need to appear to be a strong, virile person but appear and feel quite the opposite. I think I would be less impulsive were I not male. That impulsiveness helped my recovery.

8. *Has your age made any difference to how the stroke has affected you?*

I think so – I was initially half-paralysed but have since made a very good recovery – surpassing all predictions. I have high hopes and dreams for a full recovery because I am relatively young. It is hard sometimes not to give in to depression and wonder if I am disabled/impaired for the remainder of my life. It feels terribly unfair – but chronic illness doesn’t know what fair means. I was attempting suicide 6 months after stroke because I believed my recovery was over – it is believing that with my age I can make an excellent recovery that keeps me going.

I hope these answers help!

Email 2

Hi [participant], many thanks for your open and candid response.

If it's OK I'd like to ask a few more questions based on your last

responses:

1) Could you tell me more about the change from your previous role as

breadwinner to the situation you are in now? For example what does

this mean for you day to day, and has it impacted on your

relationships with family and friends?

2) You describe yourself as feeling 'vulnerable' and 'a burden', what

is it exactly about your situation that makes you feel this way?

3) I was very interested i what you said about your 'impulsiveness'

helping your recovery. Can you give any examples?

Reply 2

1) *Could you tell me more about the change from your previous role as*

breadwinner to the situation you are in now? For example what does

this mean for you day to day, and has it impacted on your

relationships with family and friends?

My situation is completely different now. My marriage has ended after my wife became emotionally abusive, controlling and violent. I am not currently working but am actively seeking work - it's a tough time to be looking.

2) You describe yourself as feeling 'vulnerable' and 'a burden', what is it exactly about your situation that makes you feel this way?

I feel vulnerable in that: (i) I was a tall, strong, fit man with physical presence but now limp and feel vulnerable when faced with groups of teenagers mocking my limping (eg calling me " wooden-leg"; (ii) I feel emotionally vulnerable and avoid confrontation; (iii) I have lost confidence - I am not as cognitively sharp as I once was, worry my speech is not clear.

I feel I am both a financial and physical burden on my aging parents who are now my carers and who have taken me in after my marriage collapsed.

I remain positive for the future, am seeking new relationships, am making slow progress in finding work and continue to improve slowly.

3) I was very interested in what you said about your 'impulsiveness'

helping your recovery. Can you give any examples?

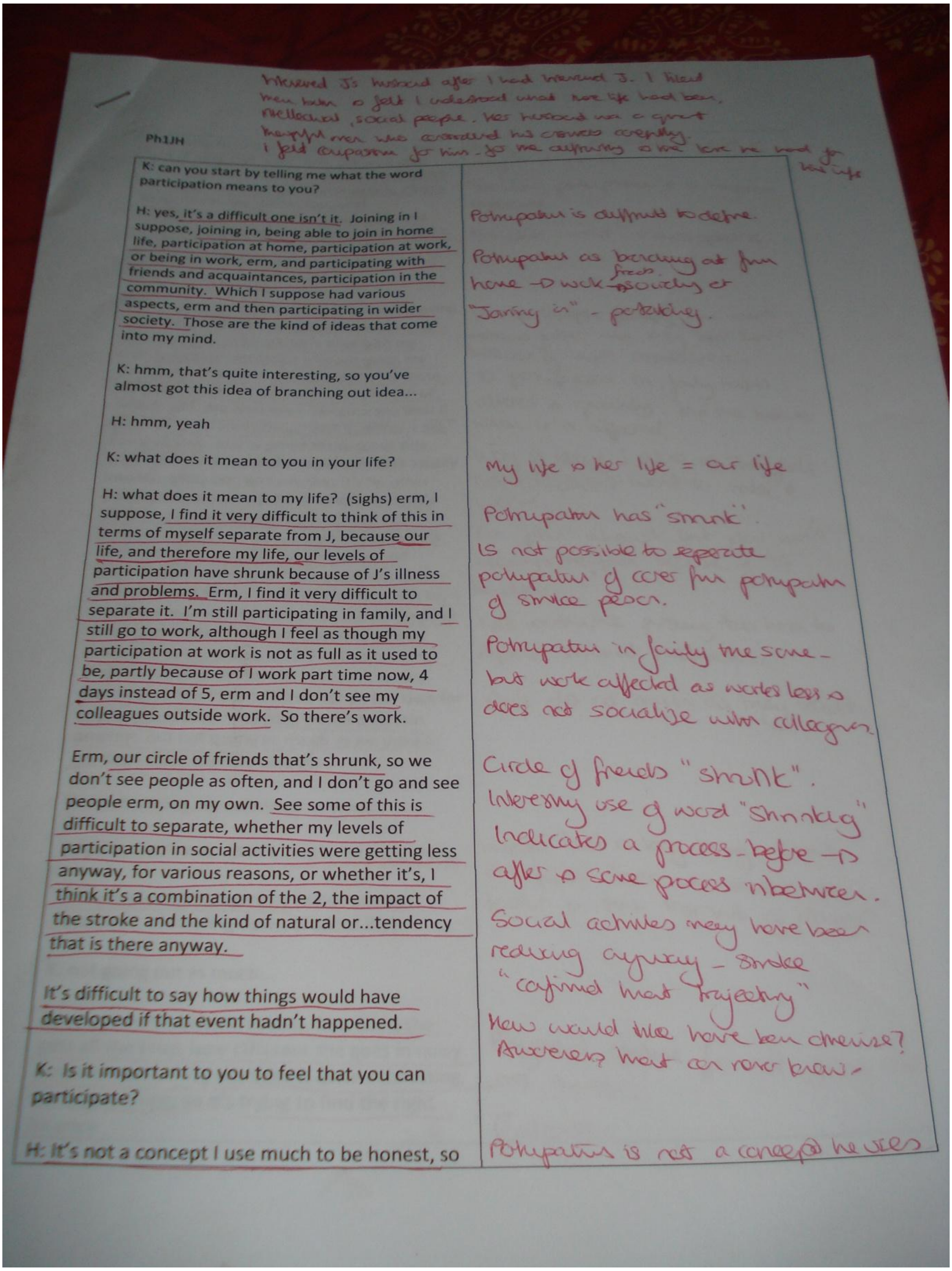
In rehabilitation, I was urged not to walk unaided but would walk hundreds of metres in my hospital room to improve my walking. I first walked up steps outside the hospital in the pouring rain. I was literally like "Andy" off Little Britain - in the wheelchair one second, walking around the next, when out of sight. I would stand at the window and wave at my family arriving to visit, when I could only just stand. I am very mobile now - I've been to London and travelled on the underground during rush-hour, can walk outside on country lanes, walk up ladders. I'm convinced that refusal to be disabled helped me. I was described as the fastest recovering adult the rehabilitation centre had seeen. Men with right Hemisphere strokes are known to be at the highest risk of falls because of their impulsiveness, I believe.

I hope these answers are useful to you, again - this research is very interesting and important. The psychological impact of stroke is poorly understood and little-tackled, in my experience. You sometimes feel like a walnut that "life has taken a sledgehammer to". I requires considerable self-will to remain positive about it.

4.4-Analysis

4.4.1-IPA steps

Step 2

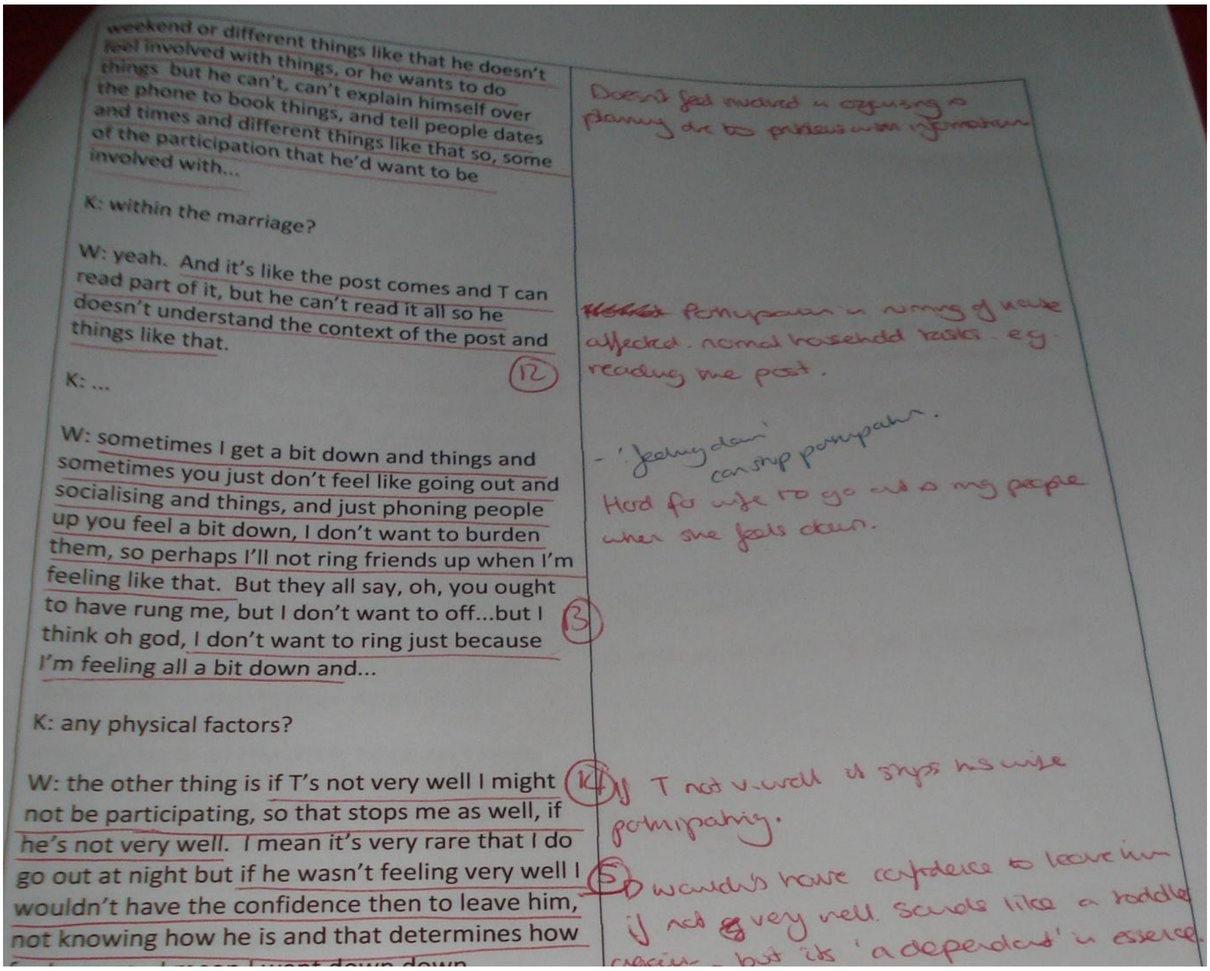


Interviewed J's husband after I had interviewed J. I liked them both & felt I understood what their life had been, intellectual, social people. Her husband was a great thoughtful man who considered his answers carefully. I felt compassion for him - for the difficulty & the love he had for his wife

Ph1JH

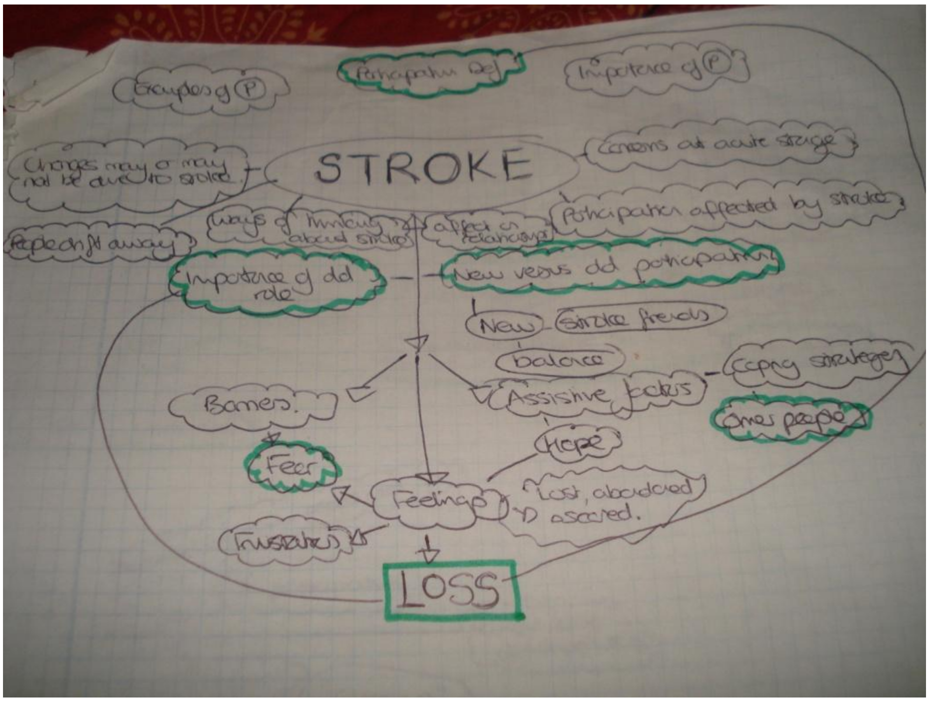
K: can you start by telling me what the word participation means to you?	
H: yes, it's a difficult one isn't it. Joining in I suppose, joining in, being able to join in home life, participation at home, participation at work, or being in work, erm, and participating with friends and acquaintances, participation in the community. Which I suppose had various aspects, erm and then participating in wider society. Those are the kind of ideas that come into my mind.	Participation is difficult to define. Participation as branching out from home → work → friends socially etc "Joining in" - potentially.
K: hmm, that's quite interesting, so you've almost got this idea of branching out idea...	
H: hmm, yeah	
K: what does it mean to you in your life?	
H: what does it mean to my life? (sighs) erm, I suppose, I find it very difficult to think of this in terms of myself separate from J, because our life, and therefore my life, our levels of participation have shrunk because of J's illness and problems. Erm, I find it very difficult to separate it. I'm still participating in family, and I still go to work, although I feel as though my participation at work is not as full as it used to be, partly because of I work part time now, 4 days instead of 5, erm and I don't see my colleagues outside work. So there's work.	My life → her life = our life Participation has "shrunk". Is not possible to separate participation of carer from participation of stroke person. Participation in family the same - but work affected as works less & does not socialise with colleagues.
Erm, our circle of friends that's shrunk, so we don't see people as often, and I don't go and see people erm, on my own. See some of this is difficult to separate, whether my levels of participation in social activities were getting less anyway, for various reasons, or whether it's, I think it's a combination of the 2, the impact of the stroke and the kind of natural or...tendency that is there anyway.	Circle of friends "shrunk". Interesting use of word "shrinking" Indicates a process - before → after & some process in between. Social activities may have been reducing anyway - stroke "confirmed that trajectory"
It's difficult to say how things would have developed if that event hadn't happened.	How would life have been otherwise? Awareness that can never know -
K: Is it important to you to feel that you can participate?	
H: It's not a concept I use much to be honest, so	Participation is not a concept he uses

Step 3 – Developing emergent themes

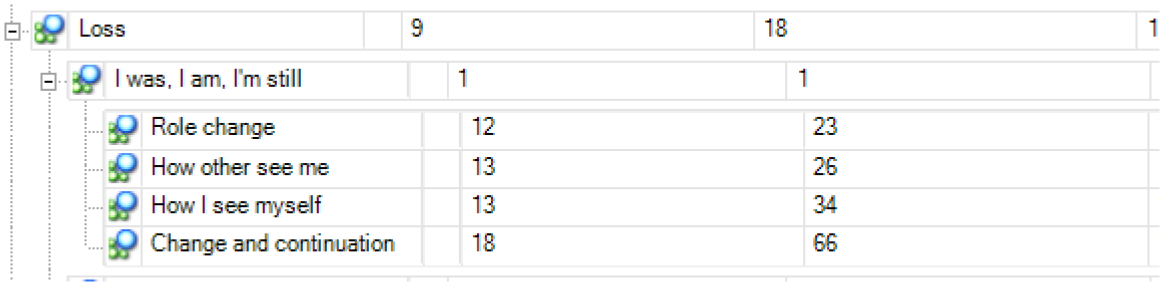


weekend or different things like that he doesn't feel involved with things, or he wants to do things but he can't, can't explain himself over the phone to book things, and tell people dates and times and different things like that so, some of the participation that he'd want to be involved with...	Doesn't feel involved in organising & planning due to problems with information
K: within the marriage?	
W: yeah. And it's like the post comes and T can read part of it, but he can't read it all so he doesn't understand the context of the post and things like that. ⑫	Participation in running of house affected. normal household tasks. e.g. reading the post.
K: ...	
W: sometimes I get a bit down and things and sometimes you just don't feel like going out and socialising and things, and just phoning people up you feel a bit down, I don't want to burden them, so perhaps I'll not ring friends up when I'm feeling like that. But they all say, oh, you ought to have rung me, but I don't want to off...but I think oh god, I don't want to ring just because I'm feeling all a bit down and... ⑬	- 'feeling down' can stop participation. Hard for wife to go out & ring people when she feels down.
K: any physical factors?	
W: the other thing is if T's not very well I might not be participating, so that stops me as well, if he's not very well. I mean it's very rare that I do go out at night but if he wasn't feeling very well I wouldn't have the confidence then to leave him, not knowing how he is and that determines how	⑭ If T not v. well it stops his wife participating. ⑮ wouldn't have confidence to leave him if not very well. Sounds like a toddler again – but it's 'a dependent' in essence.

Step 4 – Searching for connections across themes

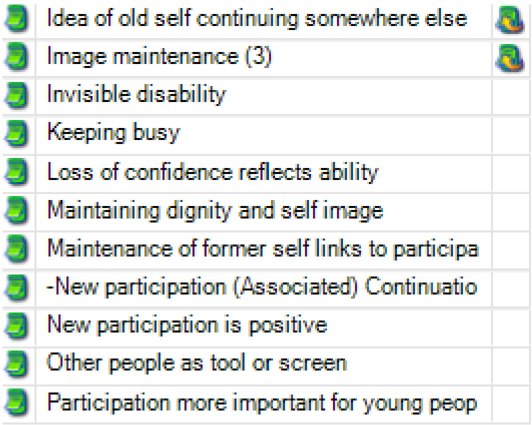

Examples of (P)
Participation def
Importance of (P)
STROKE
Concerns at acute stage
Changes may or may not be due to stroke.
Participation affected by stroke
People drift away
Ways of thinking about stroke
affect on relationships
Importance of old role
New versus old participation
New
Stroke friends
balance
Coping strategies
Assistive factors
Other people
Barriers.
Hope
Fear
Feelings
Lost, abandoned & scared.
Frustration
LOSS

4.4.2-NVIVO tree node example



Loss	9	18	1
I was, I am, I'm still	1	1	
Role change	12	23	
How other see me	13	26	
How I see myself	13	34	
Change and continuation	18	66	

NVIVO memo list example



- Idea of old self continuing somewhere else
- Image maintenance (3)
- Invisible disability
- Keeping busy
- Loss of confidence reflects ability
- Maintaining dignity and self image
- Maintenance of former self links to participa
- -New participation (Associated) Continuatio
- New participation is positive
- Other people as tool or screen
- Participation more important for young peop

4.4.3-Matrix of themes for longitudinal cohort

	April	**Colin**	**Eva**	**John**	**Sandra**	**Wallace**
Impact						
Impact of stroke	Recovered ability to walk and talk. Condition has been exacerbated by possible repeat stroke.	Very little change over the year, and fall in bath was a set back.	Sees improvements at 6 months and seems to feel more positive, but by 12 months things have not improved any further.	Recovered well from stroke, but hand and leg still affected by end of first year.	Stroke led to a fall which compounded impact of stroke.	Eyesight improved over time but memory problems remained the same.
Mediating factors	External factors throughout the year have caused stress which has not helped her recovery.	Very reliant on partner throughout. Fall in bath was a setback.	Steady over year, has other conditions.	Use of aids gradually reduces over the year. Signposting by stroke association to bowling is turning point.	Fall compounds problems.	Reliant on wife throughout.
Impact on participation	Between first interview and 6 months April had become able to get out of the house and had done some sewing, but had not been able to return to former participation.	Participation is affected, but by 6 months is able to participate in things he wants to do with the help of partner and friends. This is the same at 12 months.	Impact on participation remains stable throughout the year.	Was not able to go back to former life as pub landlord, but has adapted to his new circumstances over the year.	No change, and by 6 months has lost hope completely of getting back to anything like her former life.	Small improvements in participation but does not do everything he did before.

I was, I am, I'm still						
Participation is role change	Initially the change is that she can't physically care for family members as she used to. At 6 and 12 months she seems also unable to cope emotionally with her family.	Was retired pre stroke so no change there. Relationship with wife has changed as he is now very reliant on her.	As suffered with health before her role has not changed. However, her son becoming ill changed her role as she then had someone to worry about and help.	John was formerly defined by his role as publican, so losing this had a big impact. He found a replacement activity by 6 months, and by 12 months he had reached the point when he would have been retired and took on the persona of 'retired person'.	Role completely changed from before stroke, no change in first 6 months.	No change in role so doesn't seem to have affected sense of self.
Participation is how others see me	Doesn't have enough contact with people to be very aware of this.	Because he is interacting mainly with family and friends he may be sheltered from others views of him.	Not mentioned, because is mostly in house?	Has felt stigma at all times throughout year but has carried on trying to participate.	No change.	No change.
Participation is how I see myself	In first interview identifies self as a very useful helpful person, but 6 months she describes herself as 'lazy'. By 12 months she sees herself in a more positive light, but this is defined more by her internal character traits.	He come across as quite a traditional man, and has a stoical outlook. Sees himself as strong emotionally.	No change.	At 6 months he seems to be attempting to come to terms with new identity, jokingly describing himself as old, but by 12 months he compares himself favourably to others of his age.	Focus moved more from reflecting on who she was before, to looking at current circumstances and future.	No change.

Change and continuation	At first interview in trying to maintain her independence, at 6 months she reflects on the need to accept that stroke is the end of your old life. By 12 months she has found ways to think positively about this.	Is able to continue with the life he had before in a limited way with the help of wife and friends.	Using audio books has enabled her to continue an activity she enjoyed before.	Life has completely changed, although he reflects that being alone is not so much different to before, when he was always around people but alone in a different sense.	By 6 months she feels she needs to forget the past as no hope of regaining any aspects of former life.	Has not returned to all former activities but is able to do many things he used to with help of wife and friends.
Moving on						
Acceptance	At first April was determined to recover, but as time goes on she accepts that she will not be the same again. By 1 year she accepts what she has and does her best.	Colins' attitude seems to remain constant over the year, and was to accept the situation he was in.	The stroke seems to be just part of a long history if illnesses and her attitude to this does not seem to change over time. She does mention at 12 months feeling down as she can't do what she wants to do, which may reflect disappointment that earlier hopes at improvement have not been realised.	Between the first interview and 6 months there is a big change in that John accepts what has happened and finds ways to move on. Reaching his official retirement age seems to enable him to relax into his new lifestyle by 12 months.	Sandra was not able to accept her condition, and at 6 months had lost hope of improvement.	Acceptance of situation seems to remain stable over the year.
Coping strategies	Just after the stroke coping strategies were around recovery, and at 6 months were	Main coping strategy has been to use aids around the house. At 6 months when little physical	Fairly constant throughout, though she later limits her attempts at independence due to	At each stage John seems to use 3 different types of coping strategies: Practical, using aids	Sandra uses intellect to have some control over her life, and copes by watching television and	Stayed the same.

	concerned with managing at home. At 12 months coping strategies are also managing at home and also emotional strategies to come to terms with situation.	progress had been made, he and his wife referred to problems with the health system, possibly trying to externalise the reasons for lack of change.	a fear of falling.	in the house which he limits by 6 months, and going on a cruise to avoid dark nights. Emotional, comparing himself to others. And trusting opinions of health professionals to believe he is healthy.	reading. No change at 6 months.	
Post-stroke participation	Did not appear to have engaged in any new participation and concern was mainly with previous activities.	Does not appear to have engaged in new participation, is engaging is his old activities in a more limited way, with the help of his wife and friends.	Immediately after stroke she is thinking about different activities she could do, and by 12 months is well enough to start attending a stroke group.	At the first interview John explained how the stroke had forced him to give up his old lifestyle. By 6 months he had found a new hobby to throw himself into, and by 12 months reflects that life is better due to the stroke, which made him change his lifestyle.	There was no opportunity for participation, but at 6 months, with no hope of recovery, she talked about forgetting the past and starting again.	Stayed the same.