AN EXPLORATORY STUDY OF INFORMATION EXCHANGE BETWEEN
STROKE SURVIVORS/CARERS AND HEALTH PROFESSIONALS

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SCHOOL OF NURSING, MIDWIFERY AND SOCIAL WORK
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ABSTRACT

Stroke is the primary cause of adult disability in the UK. Those who have experienced stroke have a higher risk of a subsequent stroke. Stroke recovery has physical, emotional and social dimensions and impacts on family caregivers as well as stroke survivors. Getting the right information at the right time is put forward as instrumental in supporting recovery and preventing further stroke. The research literature demonstrates persistent uncertainty about the best way to provide information to stroke survivors and carers in practice.

The aim of this study was to explore the processes, motivations and perceptions of the impact of information exchange between stroke survivors, carers and health professionals. A qualitative case study strategy was utilised for the study as this provided a flexible framework to incorporate multiple perspectives upon information exchange in the practice context. A single setting in, Salford, Greater Manchester, was used to study the phenomenon of information exchange from the perspectives of stroke survivors, carers and health professionals. Data collection included interviews with participants, observations of communication and documentary analysis. Data was analysed using the Framework analysis approach in order to compare and contrast perspectives across the different respondent groups and so develop study propositions to explain the data.

There was much common ground amongst respondents in the thematic categories identified from the data, but subtle differences in emphasis on different topics. The key findings from this research are in two areas. Firstly, the challenges of incorporating a self-management philosophy into information exchange post stroke are substantial. This is because patients experience a variable recovery trajectory and have insufficient contact time with the professionals who they perceive as valid information providers. Second, the research raises questions of what is meant by tailored information in practice: the timing of information was a critical issue for survivors and carers along with the desire for appropriate support to utilise information effectively.

These findings suggest a need to shift the focus of research from information provision to information exchange post stroke; to examine not the best way of providing information, but rather the best way of assessing individual need, and pacing provision tailored to these specific needs. This would require debate and consensus among the stroke community about the core underlying principles of information exchange, a reassessment of key time-points for sharing information and a re-examination of professionals ongoing development needs in communication skills to underpin this.
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Last, but not least, thanks to Mum and Dad for their practical love and support through yet another period of study.
AUTHOR BIOGRAPHY

Current work
I currently work as a Research Project Manager for Salford NHS providing project management to a National Institute for Health Research (NIHR) funded Programme Grant investigating primary care management of Irritable Bowel Syndrome.

Academic Qualifications
BSc (Hons) Nursing Studies (2.1)
1992 Kings College, University of London

MRes in Health and Social Care
2004 University of Salford

Research Experience
During my undergraduate degree I completed a small qualitative study of patient perceptions of psychiatric nursing care. This resulted in a single publication (Beech and Norman, 1995). I then worked clinically for eight years specialising in spinal injuries and neuroscience nursing. My interest in the role of information provision dates back to my clinical experience within these areas.

I moved into a mixed clinical and research role with the stroke team at Hope Hospital, Salford in January 2000. There I developed broad based research experience and skills:

- Assisting with acute stroke studies (recruiting, sample collection and processing)
- Co-ordination of patients in a multi-centre trial (recruitment, data collection involving 18 month follow up, liaison with contract research organisation)
- Leading a process evaluation of the Transient Ischaemic Attack (TIA) service (project design, securing funding, recruitment including consent, data collection and analysis across primary and secondary care and project management skills)

In the clinical part of this role I was involved with collating information resources and piloting a hand held patient discharge booklet. Experience during this time laid down the ideas that culminated in the study reported in this thesis.
During this time I completed my Masters of Research in Health and Social Care at the University of Salford. This was a three year part-time modular programme. Taught modules included ‘Research Appreciation and Change Management’, ‘Evidence Based Practice’, ‘Advanced Qualitative Methods’ and ‘Survey Design and Analysis with Advanced Secondary Analysis’. In the final year a supervised dissertation module was completed, for this I undertook a national survey of the practice of stroke physicians in the development of Transient Ischaemic Attack (TIA) Services. This resulted in a single publication (Beech et al., 2007).

During my PhD studies I have completed modules on Qualitative Research and Historical Research Methods. I also attended CAQDAS (Computer Assisted Qualitative Data Analysis and Software) training modules at the University of Surrey and an introduction to NVivo Software. I have attended internal seminars including a one day workshop on qualitative data analysis run by Methods@Manchester (research methods in the social sciences). I presented a methodology poster at the Royal College of Nursing research conference in 2008 (Beech, 2008) and attended the Service Delivery and Organisation Research conference in Liverpool in 2011.

My broad research interests include: patient/public perceptions of health services, communication/information sharing, and evaluation methods in healthcare.
CHAPTER ONE: INTRODUCTION

1.1 INTRODUCTION
This thesis presents an exploratory case study of views and behaviours relating to information exchange post stroke. Views and behaviours were examined amongst stroke survivors, family members/care givers and a mixed group of health professionals. The study was undertaken in order to try to offer insight and explanations for the challenges of providing appropriate and effective information in practice.

The aim of this introductory chapter is to provide context for the study. I will define stroke and its scope in order to locate the experiences recounted in this study within the broader spectrum of stroke experience. I will briefly overview the impact of stroke for individuals and society in terms of its prevalence, potential effects on the individual and economic costs. This overview provides context for the growing focus on stroke over the last fifteen years as ‘a preventable and treatable disease’ (National Institute for Health and Clinical Excellence, 2008, p4), rather than an inevitable consequence of ageing resulting in severe disability and/or death. This shifting perspective has been driven by the development of evidence relating to treatments such as thrombolysis and the organisation of specialist stroke unit care. In light of this, I will provide a brief overview of the development of stroke services in the UK to provide a policy background to the practice context in which information exchange takes place. Stroke services have and continue to undergo a lot of change and development moving from a ‘Cinderella’ service of old, within other specialities (general medicine, care of the elderly and neurology) to an established and distinct specialist service in their own right.

Also within this opening chapter, I will briefly discuss the growing emphasis on information provision in health care generally and within stroke care. Some of the challenges and uncertainties around information provision in stroke will be outlined in order to introduce briefly how the term ‘information exchange’ was conceived of in this study and why it was felt important to step back from an interventional study and explore the challenges of information provision in practice.
In closing this chapter, I will outline the thesis structure in order to orientate the reader to how material is presented.

1.2 DEFINING STROKE

Stroke is defined as:

“a clinical syndrome, of presumed vascular origin, typified by rapidly developing signs of focal or global disturbance of cerebral functions lasting more than 24 hours or leading to death”
(World Health Organisation, 1978 cited in Royal College of Physicians, 2008 p4)

‘Stroke’ is an historic term and unclear in its power of describing what stroke does to the body. More recently stroke has been described as a ‘brain attack’ (National Institute for Health and Clinical Excellence, 2008) making clear the location of its primary effects and encouraging the comparison with heart attack; highlighting their similar origins and processes as vascular diseases and encouraging the need for a similarly urgent response to both. A stroke happens when there is a loss of blood supply to part of the brain resulting in damage (cell death) of the affected brain tissue. There are two main forms of stroke, distinguished by the cause of the loss of blood flow. The most common form of stroke is referred to as Ischaemic stroke and results when a clot causes narrowing or blockage of blood vessels and accounts for 85% of all strokes (Department of Health, 2007a; National Audit Office, 2010). The second main form of stroke is referred to as Haemorrhagic stroke and results from a blood vessel bursting, this accounts for 15% of all strokes (Department of Health, 2007a; National Audit Office, 2010).

Within the clinical syndrome of stroke there are further sub-types. Transient ischaemic attack (TIA) describes the occurrence of stroke signs and symptoms that resolve within 24 hours. A non-disabling stroke describes stroke signs and symptoms that last more than 24 hours but resolve without residual disability (National Institute for Health and Clinical Excellence, 2008). There is debate amongst stroke specialists about the pertinence of maintaining distinct definitions based on duration of symptoms as many acute care requirements are the same and the desire is to get all symptom presentations treated with urgency (Royal College of Physicians, 2008). In the context of this thesis the descriptions are offered as a starting point to highlight the diversity of the stroke population and locate the study participants in relation to it. Subarachnoid haemorrhage (SAH) is
a specific form of Haemorrhagic stroke where the bleeding is into the subarachnoid space surrounding the brain, they account for approximately 5% of incident first strokes (Royal College of Physicians, 2008). These present differently at onset and require different management from neurosurgical teams.

Stroke survivors approached to participate in the present study were identified by their diagnosis with either an Ischaemic or Haemorrhagic stroke. Therefore, further discussion focuses on stroke not TIA or SAH.

1.3 THE IMPACT OF STROKE

Stroke is the leading cause of adult disability and the third most common cause of death in the UK, 11% of deaths in England are as a result of stroke (National Audit Office, 2005). Stroke incidence contributes to lower life expectancy in areas of deprivation compared to that of the whole population. Incidence and impact of stroke is higher in the North West of England than national averages (Drever, 2002).

In 2008-09 the direct care costs of stroke were estimated to be at least £3 billion per annum. Taking into account other associated costs of informal care and lost income, the wider economic cost is placed around £8 billion a year (National Audit Office, 2010). Indirect care costs include the impact on the health and lifestyle of friends and family who may take on a caring role for stroke survivors (Smith et al., 2004b). With an ageing population such costs present a pressing concern.

Each year approximately 110,000 people have a stroke (National Audit Office, 2010). For survivors, there is a 30-43% risk of a further stroke within five years (Mant et al, 2004 in Royal College of Physicians, 2008). Of those who have a stroke, approximately 25% die as a result. Of those that survive, approximately half require assistance with everyday activities. This represents around 300,000 people who live with a moderate to severe disability in England following a stroke (National Audit Office, 2010), and 900,000 stroke survivors in total (National Audit Office, 2005).

At an individual level, the personal impacts of stroke are variable depending on the location and extent of loss of blood flow in the brain. Problems encountered include:
• Loss of movement
• Loss of sensation
• Loss of co-ordination
• Impaired communication (understanding & expression)
• Loss of cognitive abilities
• Incontinence
• Visual disturbance

(Warlow, 2001)

This list of issues is not exhaustive and stroke sequelae by their impact on daily function may affect the ability to work and also impact on family relations (Smith et al., 2004b; National Audit Office, 2005).

Stroke risk factors are similar to those of other vascular diseases and include:

• High blood pressure
• Smoking
• High cholesterol
• Irregular heart rhythm (Atrial fibrillation)
• Diabetes
• Unhealthy diet and lifestyle
• High alcohol intake
• Previous or family history of stroke or TIA

(Warlow, 2001)

Stroke is more common as people get older and has traditionally been seen as a disease of the elderly, however, 25% of strokes occur in people less than 65 years of age and it can happen at any age. Certain ethnic groups are more likely to have a stroke, specifically people of African or Caribbean descent and men of South Asian descent. Stroke incidence is also higher in men than in women (National Audit Office, 2010). The range of potential risk factors and individual stroke impacts gives a flavour of the range of health professionals a stroke survivor may come in to contact with, including:

• Physicians (primary and secondary care of more than one speciality)
• Nurses (as above)
• Physiotherapists
• Occupational therapists
• Speech and Language therapists
• Psychologists
• Dieticians
• Social workers
• Orthoptists

This list is not exhaustive and length of contact time with different professionals is variable and occurs in both acute and community settings.

Despite this impact, for many years stroke had a relatively low priority in the NHS. Within the last fifteen years however, there have been developments in evidence based treatments and care for stroke and a growing movement to see these translated into practice effectively. The next section gives a brief overview of some of these key changes.

1.4 DEVELOPMENTS IN STROKE SERVICES

Since the late 1990’s, the Royal College of Physicians has worked to influence the development of comprehensive stroke services. This has been through a biannual audit process, the National Sentinel Stroke Audit (Rudd et al., 1999 in Royal College of Physicians, 2008), and a series of clinical guidelines on stroke (Intercollegiate Working Party for Stroke, 2000; Royal College of Physicians, 2004; Royal College of Physicians, 2008). The Department of Health did not initially feature stroke in its own right in policy initiatives, instead it featured in broader focussed service frameworks such as the National Service Frameworks (NSF) for Older People and Long Term Conditions (Department of Health, 2001; Department of Health, 2005). However, stroke was brought into focus by the document ‘Reducing brain damage: faster access to better stroke care’ produced by the National Audit Office (NAO) in 2005 (National Audit Office, 2005). This document highlighted the historically low priority of stroke in the NHS and the need to move, from a view of stroke as an inevitable event of ageing, towards a more equitable application of developments in stroke care. Examples of the type of evidence that contribute to building a case for the need to reorganise stroke services include evidence supporting the benefits of organised inpatient stroke care (Stroke Unit Trialists’ Collaboration, 1997; Indredavik et al., 1999) and evidence for the effectiveness of timely thrombolysis (Department of Health, 2006a). The NAO report of 2005 contributed to a Committee of Public Accounts hearing in 2006 that made recommendations to the Department of Health that
the costs of stroke could be reduced via re-organisation of current services (National Audit Office, 2010).

As a result, since the 2005 report there have been several initiatives to stimulate required re-organisation of services. A National Stroke Strategy was produced in 2007 providing markers for high-quality stroke care and potential actions and measures to achieve these over a ten year period. Funding and incentives were put in place to support implementation of the strategy. The National Stroke Strategy provides twenty quality markers for stroke care provision and these are drawn together in a ten point plan for action (Department of Health, 2007a).

**Figure 1: 20 Quality Markers of a good stroke service**

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<tr>
<th>QM1</th>
<th>Awareness raising</th>
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<tr>
<td>QM2</td>
<td>Managing risk</td>
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<td>QM3</td>
<td>Information, advice and support</td>
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<td>QM3</td>
<td>Involving individuals in developing services</td>
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<td>QM5</td>
<td>Assessment – referral to specialist (TIA minor stroke)</td>
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<td>QM6</td>
<td>Treatment</td>
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<td>QM7</td>
<td>Urgent response</td>
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<td>QM8</td>
<td>Assessment (Stroke)</td>
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<td>QM9</td>
<td>Treatment</td>
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<td>QM12</td>
<td>Seamless transfer of care</td>
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<td>QM13</td>
<td>Long-term care and support</td>
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<td>QM14</td>
<td>Assessment and review</td>
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<td>QM15</td>
<td>Participation in community life</td>
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<td>QM16</td>
<td>Return to work</td>
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<td>QM17</td>
<td>Networks to review and organise delivery of stroke services</td>
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<td>QM18</td>
<td>Leadership and skills</td>
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<td>Workforce review and development</td>
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<td>QM20</td>
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(Department of Health, 2007a)
The National Stroke Strategy (Department of Health, 2007a) marked a sea change in terms of the attention delivered to stroke and a real commitment to improving stroke management. Since the Stroke Strategy document there has also been a National Institute for Health and Clinical Excellence (NICE) guidance document on the early assessment and treatment of people who have had a stroke or transient ischaemic attack (National Institute for Health and Clinical Excellence, 2008), and a further guidance document is under development for stroke rehabilitation.

In 2010 the National Audit Office reported on progress in improving stroke care. They noted significant improvements in provision of acute hospital services but, that similar improvements had not yet been made in delivering more effective post-hospital support and in providing good information about available services to stroke survivors and carers (National Audit Office, 2010). An inherent challenge in tackling post-hospital support issues are barriers to joint working between the different agencies involved.

The purpose of this overview is to give contextual detail of the rapid developments in stroke care in comparison to years gone by. This and the scope of the potential changes place a high level of demand on health professionals involved in stroke care. There is a need for rapid growth of stroke expertise in several sectors of stroke care to underpin the aspirations of the policy documents outlined.
1.5 THE PERCEIVED IMPORTANCE OF INFORMATION PROVISION

Since the late 1990’s, building on the spirit of consumerism, there has been a drive for better informed patients with greater involvement in their healthcare and health services (Department of Health, 1997b; Department of Health, 1997a). Information is seen as pivotal to this agenda (Department of Health, 2006c). This will be discussed further with reference to stroke care in the literature review. Here it is discussed in brief in relation to the impacts of stroke already touched upon to provide a sense of why information provision (or exchange as it is considered in this study) was felt important to be studied in practice.

The significant impacts of stroke at individual and family level have been introduced already. Hence reducing both the incidence and impact of stroke is given high priority (National Audit Office, 2005; Department of Health, 2007a; National Audit Office, 2010).

Providing information is one aspect of reducing the incidence and impact of stroke. There is concern about how to provide effective public health information to prevent the incidence of first stroke (Department of Health, 2007a) however, this was not the concern of the study undertaken. Once a stroke has occurred there is also much interest about how best to provide information for survivors and carers, in order that they will engage in treatment and lifestyle change to reduce the risk of further stroke, and also to enable them to manage the diverse impacts of stroke on their lives and the various interactions with formal services it may demand (Royal College of Physicians, 2004; Department of Health, 2007a; Royal College of Physicians, 2008). This latter point is based on the belief that a more informed and engaged health service user will utilise services in a more cost effective fashion (Department of Health, 2006c). It is this type of post stroke information provision that was the focus of the present study. It can be seen that alongside concern for the individual’s situation post stroke, concerns about costs, risk management and efficiency may also be factors in professional and policy concern with providing information post stroke.

Concerns about information for individual stroke survivors and carers are far more personal with information being a potential tool to deal with the life changing experience of stroke. How useful a tool it can be however, is fraught with complications due to the variability of each unique stroke survivor and carer.
experience, communication issues, comprehension issues and emotional issues. A nurse writing about her own experience of surviving a stroke described it as follows:

“Stroke tyrannically redefines everything. When confronted by its terrible ultimatum, it would cause either the downfall or the rebirth of the survivor...It forces a person to either accept responsibility for their existence in a newly flawed body or sink into despair and utter personal destruction.”

(Lanza, 2006 p767)

Information for survivors and carers may be about working out how to be in a new life that they did not ask for. Information may be provided at a time when they are grieving for the life they knew before and this, in turn with other communication, cognitive and emotional sequelae experienced by stroke patients presents huge challenges to obtaining and using information post stroke (Niemeier and Burnett, 2001; Mukherjee et al., 2006). Brereton and Nolan (2002) document searching for knowledge to become familiar with the new post stroke world as a key feature of the ‘seeking’ activities undertaken by new carers to deal with the uncertainty and lack of confidence they feel in their new role. Currently most information is provided soon after the stroke yet the need for information as part of the ongoing process of living with the impact of stroke continues beyond a year post stroke (Hanger et al., 1998; Lanza, 2006).

Strokes happen without warning and may result in a majority of stroke survivors and their carers self-managing a long-term condition. This may require changing lifestyle behaviours, dealing with the social and emotional impacts of symptoms, managing disabilities and ongoing interaction with health and social care services over time. Accurate and timely information is argued to be a crucial tool for dealing with the challenges presented by stroke as a long-term condition (Royal College of Physicians, 2004). It was in this context that I chose to explore how and why information is sought and provided post stroke as the focus of my study.

In the context of my study I chose to use the term ‘information exchange’ as opposed to ‘information provision’. I did this because I felt that the term was broader and able to encompass and highlight the fact that I was interested in two-way communications around information provision post stroke. I wanted to examine how far two-way communication did occur because I was interested in
the ongoing report that patients and carers were dissatisfied with information they received (Healthcare Commission, 2005). I believed that much of what was written in policy or in relation to interventions around information was working from an assumed shared purpose or goal for information provision and I wanted to look at how well this was reflected in practice. Considering the definition of ‘to provide’ it means to:

- Make available for use, supply
- Equip or supply someone with something useful or necessary to them.

(Pearsall, 1998)

This definition implies some understanding of need. Such understanding would require effective two way communication to orientate the provider, in the context of this study the health professional, to the needs of stroke survivors and carers. Whilst survivors and carers may have overlapping information needs there will also be distinct areas of concern.

Taking this view starts to open up the complexity of information exchange in health care. It is more commonly termed information provision which belies this complexity implying a simpler act. Communication in health care is complex as everyday rules and boundaries are changed due to power dynamics that may influence effective two way communication (Scott and Thompson, 2003; Proot et al., 2007). The challenges of this complexity may reduce effectiveness, and therefore satisfaction with information provided as a result of communication exchanges. Satisfaction itself is a complex construct. Does it occur if the right information is given in response to an identified need, or even if this is the case can satisfaction still be elusive because the desired information may be unwelcome in its nature?

Therefore, I wanted to elicit accounts of communication around information provision and observe information provision to look at how much it was a two way exchange and thus able to be responsive to needs.

I came to the study with a broad view on information believing that if the everyday details are not dealt with effectively (that is where you are, who is dealing with you, what is happening to you and why) then this does not create the necessary conditions for more complex needs around facts or concerns to be
expressed and met. Also with stroke there is the underlying issue that the stroke itself impacts baseline abilities to communicate and process information (cognitive abilities). This is as a result of both the direct physical assault on the brain and also the emotional stress resulting from a sudden life changing event.

Information provision topics post stroke include:

- Where you are
- What has happened to you
- Who is dealing with you
- What is being done to you
- Why things are being done to you
- When things may happen to you
- What to expect
- What will happen in the future
- What will you need to get better
- Can you get better
- What you can do to get better
- How you may feel about what has happened
- Ways of coping with what has happened
- How to manage your condition
- How to manage risk factors
- Do I have to make changes
- How can I make changes

(Hafsteinsdottir et al., 2011)

In summary, there are many layers to the information that may be sought and given after stroke. Some are factual, some are more emotional and about concerns and coping and some relate to learning to manage an ongoing condition. Hence the term information exchange was used to acknowledge the aim of looking at information provision (the term more commonly used in literature and policy) more broadly. My aim was to explore information as part of interaction, to examine in practice the approach to interactions. I wished to examine whether these focused on activity concerned with a more routine imparting of facts and leaflets to patients or whether more two-way dialogue took place.
1.6 CONCLUSION

In this introductory chapter to the thesis, I have provided a definition of stroke and given a brief overview of its scope and impacts. I have placed the study participants stroke type within the broader spectrum described. Recent developments in stroke services have been summarised leading into a description of the perceived important role of information provision in stroke management and prevention. The choice to use the term ‘information exchange’ in the context of the study to focus on two way communications around seeking and providing information was presented.

1.6.1 Plan of the Thesis

There are eight further chapters. Chapter two presents the literature, both policy and research, reviewed to inform the study and later interpret findings. Chapters three and four consider methodological choices and how these were applied in practice. Chapter five provides an introduction to the other results chapters. Reflections on data collection are offered and justification for the use of the different types of data in synthesising the results given. Chapter six draws upon interview, observation and documentary evidence to describe the activities and processes of information exchange. Chapter seven utilises interview accounts to compare and contrast reasons for and barriers to information exchange. Chapter eight again draws on interview data to look at perceived impacts of information exchange and how this affects views on information exchange activity. Chapter nine the discussion, draws together key issues from the results chapters. The strengths and limitations of the study are discussed. Finally the contribution of the thesis to knowledge, future research, policy, practice and education is summarised.
CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION
This chapter presents a review of policy and research literature on information provision, with a particular focus on information provision post stroke. The areas to be covered include policy drivers regarding information provision, the basis of professional rationales for information provision generally and the scope and trends of research literature on information provision post stroke.

Information provision is a topic with huge scope; therefore a purposeful decision was taken to keep a focus on literature pertaining to the practice context of stroke.

2.2 SEARCH STRATEGY
The aim of the narrative literature review presented in this thesis was to review the scope of the practice, policy and research literature relating to the provision of information to stroke survivors and carers by health professionals. The purpose was to look at the range of material available, its quality and the extent to which the material is able to guide practice in relation to information provision activity.

As described in my biography I had worked on information provision projects during my clinical practice in stroke, therefore some literature was collected prior to starting the current project. Hence, the literature reviewed during the course of the present study has been built up iteratively over a ten year period, using a variety of databases, via initially ADITUS and later OVID interfaces. However, two more formal phases of literature searching were undertaken for the purposes of the current study. The first was undertaken in late 2006 to early 2007 to inform study propositions, questions and design. The second was completed in March 2012 to capture further literature published during the course of the study, and to identify additional material in relation to theory and emerging issues relevant to themes identified during data analysis.

A basic key search term strategy was the starting point for database searches undertaken:
- Stroke (text word search)
- Cerebrovascular disease (explode)
3. Patient/carer information (text word search)
4. Patient/carer education (explode)
5. Communication (explode)
6. Searches were then combined with boolean operators in the following manner, ‘1 or 2’ and ‘3 or 4 or 5’.

These terms were chosen based on key terms from papers already in my possession at the start of the study and through discussion with librarian information specialists. The focus was on key terms to identify the population of interest and the intervention or activity of interest that is information provision/exchange. Search terms relating to comparators, outcomes and study designs were not used as the desire was to keep the search broad to retrieve a range of study types dealing with information provision/exchange post stroke (Centre for Reviews and Dissemination (CRD), 2009). This approach was taken because I was already familiar with the variability of study design and outcomes relating to information provision interventions, from reading of literature already in my possession (Forster et al., 2001). I therefore wished to maximise the scope of relevant material retrieved via searches. The terms presented above were adapted and refined within individual databases to find the best free text terms, Thesaurus Mesh Headings, synonyms and truncations to maximise retrieval of relevant articles in the database in question. Articles retrieved were restricted to those involving research on human subjects and those published in the English Language. Articles retrieved were reviewed for relevance focusing on post stroke, practice based information provision. The retrieval of papers already known to me along with new and relevant material defined a successful search strategy. Utilising the strategy described when searching MEDLINE using OVID from 1950 to 2007 retrieved just under 2000 references that were manually searched to retrieve key papers. The same search updated from 2007-2012 retrieved a further 125 papers for review. Review of these searches and other database search results produced 68 core papers that were appraised to inform the literature review. Two thirds of these papers were qualitative or descriptive in nature and a third reported trials or evaluations of interventions.

The databases accessed utilising the search strategy described were Medline, CINAHL, PsychINFO and ASSIA (Applied Social Sciences Index and Abstracts). These databases were searched as they encompassed literature from the various professional disciplines that may be involved in stroke care. Time frames
for the searches encompassed the earliest and latest searchable dates for each database, in order to maximise retrieval of material. Update searches carried out in 2012 were run from the last formal search point to the date of the current search. Later searches in 2012 also encompassed additional search terms relating to self-care, self-management of chronic disease, underpinning constructs of self-management and the process of recovery following stroke. This was done to help inform the discussion of the themes that had emerged from data analysis.

Additional searches were carried out using the same core terms via the Cochrane Database of Systematic reviews, Google and Google Scholar, to retrieve any additional relevant systematic reviews, policy documents, charity campaign materials and locally published reports respectively. Additional papers were also sourced by reviewing the reference lists of papers read and by recommendation of study supervisors.

The literature review undertaken was not conceived as a systematic review, the aim was to produce a narrative review appraising the scope of the literature pertaining to information provision/exchange after stroke. With this in mind a formal scoring system to appraise the quality of literature was not adopted. However, the principles of quality appraisal of literature advocated by the Critical Appraisal Skills Programme (CASP) in their published appraisal tools were utilised (Critical Appraisal Skills Programme (CASP), 2010). These tools encourage a focus on clarity of research question, appropriateness of methods, conduct of methods and quality and clarity of reporting, in order to assess the quality and relevance of a paper’s message for practice. These principles guided the evaluation of studies and papers identified during the course of the review.

Literature prior to 2007 underpinned the rationale and planning of the study. Later papers were examined for shifting trends in post stroke information provision and were compared and contrasted with views and experiences of study participants. As stated later searches also retrieved additional literature relating to underpinning principles of self-management (for example self-efficacy, coping and adaptation) and issues of stroke recovery. These papers are not dealt with in the main body of the literature review but drawn upon where relevant in the later discussion of results in chapter nine.
The next section will examine policy drivers for providing information and some of the benefits it is believed to offer, as a background to discussing information provision strategies in stroke.

2.3 THE ROLE OF INFORMATION PROVISION – POLICY AND GUIDANCE

There has been a drive since the late 1990’s, to build on consumerism, and have better informed patients with greater involvement in their healthcare and health services (Department of Health, 1997b; Department of Health, 1997a). Subsequent policy has built on this generically and for specific condition groups. Better information, better choices, better health: putting information at the centre of health (Department of Health, 2004) emphasised the role of high quality information in helping patients understand their health needs and make effective choices. A number of generic information strategies have been proposed for example copying letters to patients, information prescriptions and a patient information bank (Department of Health, 2004; Department of Health, 2005). The white paper ‘Our Health Our Care Our Say’ (Department of Health, 2006c) placed emphasis on communication and joined up care, service user involvement, support, facilitating independent fulfilled lives, greater choice about health and social care services and timely and appropriate information provision.

Of particular relevance to stroke, the need for effective information provision has been highlighted in the National Service Frameworks (NSF) for Older People and Long Term Conditions (Department of Health, 2001; Department of Health, 2005) and in the National Stroke Clinical Guidelines (Royal College of Physicians, 2004). The Stroke Association identified information provision as a priority for services with their campaign ‘Nobody told me…’ in 2006 (Stroke Association, 2006).

The NSF for Older People (Department of Health, 2001) recommends that advice is received by stroke survivors about managing the effects of the stroke on their lives and that required treatment and care is explained.

The NSF for Long Term Conditions (Department of Health, 2005) advises that:

- Information to make informed decisions should form part of integrated assessment and planning of health and social care needs
- Families and carers should receive information too, and
• Information provision should be part of an individual care plan agreed by the multidisciplinary team and social services.

The Long Term Conditions NSF advocates the crucial role of information provision in self-managing a long term condition and draws on recommendations in the document Better information, better choices, better health: putting information at the centre of health (Department of Health, 2004).

The National Stroke Guidelines (Royal College of Physicians, 2004) have a number of references to information provision highlighting deficiencies and potential solutions; however they acknowledge the weak evidence base for how information should be provided effectively. Statements made in these guidelines include the following:

• To be looked after by knowledgeable staff who understand the full range of patient/carer needs including communication and information needs
• The diagnosis and management plan is not always explained in a way that survivors and carers can understand and remember - written plans and information packs are suggested
• Patients and carers need to be offered relevant accessible information at each stage of their care and have access to contacts for further issues that may arise later
• Research demonstrates it is difficult to give information effectively and this failing is a common cause of complaints – information provision should be individualised, freely available in a number of formats, and education programmes should be offered to assist in adapting to new roles
• Carer information needs should be addressed promptly
• Verbal and written information should be provided including the reason for any medication, how and when it should be taken and possible side effects
• The opportunity to talk about the impact of stroke should be offered alongside information and advice
• Difficulty learning new information should be considered as part of cognitive assessment and compensatory techniques taught
• Provision of information is classed as an adaptive therapy
• Information about ongoing care and how to contact local statutory and voluntary agencies should be provided
• If a vehicle driver prior to their stroke an individual’s responsibilities post stroke should be made clear to them.

In 2006 the Stroke Association launched their “Nobody told me…“ campaign (Stroke Association, 2006). The aim of this was to bring attention to the importance of information for stroke survivors when discharged home. The risks of not receiving appropriate information were put forward and include: missing out on essential services, slower recovery, poorer outcomes and greater risk of further strokes due to not understanding preventive measures. Information was once again presented as helping survivors manage their condition effectively and preparing them to be involved in health decisions. Evidence driving the campaign came from three key sources: the Health Care Commission survey of stroke patients (Healthcare Commission, 2005), the National Sentinel Audit 2006 (Royal College of Physicians, 2007) and the Ipsos MORI study for the Stroke Association (Ipsos MORI, 2006). In the Healthcare Commission stroke survey only 55% of respondents said they understood the information they received in hospital. The sentinel audit highlighted that despite improvements in the number of stroke units displaying stroke literature information provision was still incomplete and many units lacked resources to fulfil information provision. For those who received care outside a stroke unit the situation was worse, with fewer than half being offered any literature about stroke. The Ipsos MORI poll for the stroke association emphasised the following:

- Survivors and families need more information, receiving this may aid recovery and emotional well-being
- Appropriate and timely written information is important but not a replacement for face to face discussion and explanation
- Information needs to be tailored
- Levels of information received fluctuate greatly throughout the country.

The “Nobody told me…“ campaign (Stroke Association, 2006) offered a checklist of what information survivors and families should receive at discharge and an action plan for this to be addressed. This checklist highlighted the following:

**Information needed:**

- Type of stroke, cause and treatment
• How to reduce future stroke risk
• Services available, eligibility and how these are accessed including a name and contact number – these include statutory and voluntary services, support services, financial services, how to make a complaint, peer group support and stroke association contact details.

To achieve this, it is recommended:
• That information provision is integrated into stroke services with commissioners and hospital staff clear about responsibilities
• Information provision should be individualised and part of the care plan
• Time should be made for questions and follow up of information provided and there should be access to someone to help survivors understand information both in hospital and in their own home
• Special communication needs must be addressed
• Cognitive, sensory and language deficits should be taken account of
• There should be a budget for materials and communication aids as well as funding to access someone to help survivors understand and use information
• An information strategy should be produced including an audit of current provision and consultation with survivors and carers about their experiences and what they would like.

The Stroke Association exhorted local commissioners to act strategically to ensure information provision for stroke survivors was an integral part of the care service. They suggested an audit of current provision, consultation with staff, stroke survivors and carers, a budget for materials and access to someone to facilitate understanding and use of information. They proposed that a member of staff should be tasked with implementation and liaison to achieve the goals laid out. This person should undertake the following:
• Collect appropriate information and ensure it is up to date
• Produce materials and packs for patients before discharge
• Ensure someone is available to help survivors and carers understand information
• Ensure that information is part of the care plan taking into account any cognitive and communication and sensory deficits.
Information provision issues in stroke progressed to feature in a series of government-led documents specific to stroke. In the document Improving Stroke Services: a guide for commissioners (Department of Health, 2006b) one of the key elements of a high quality stroke service was ensuring that stroke survivors and their carers were informed and empowered to take control of their care. In 2006 there was a shift to a more direct focus on stroke care by the Department of Health following the National Audit Office report ‘Reducing brain damage: faster access to better stroke care’ (National Audit Office, 2005). This was described in the thesis introduction in chapter one. A result of this was that a new national strategy for stroke went out to consultation (Department of Health, 2007b), emphasising the need for better information for stroke survivors and carers from the onset of their condition through to long term care. This was framed in the context of the choice agenda promoted in ‘Our Health Our Care Our Say’ (Department of Health, 2006c).

These campaigns and shifts in the focus placed on stroke care and the common reference to information provision within them, helped build a rationale for the current study and gain support for its conduct. Key elements to this were the broad aspirations of the claims made for the benefits of information provision along with a lack of clarity about how to achieve these in practice (Forster et al., 2001; Royal College of Physicians, 2004).

During the course of the study the National Stroke Strategy was published (Department of Health, 2007a), along with a first set of NICE clinical guidelines for stroke (National Institute for Health and Clinical Excellence, 2008) and a further update to the Royal College of Physicians Clinical Guidelines for Stroke (Royal College of Physicians, 2008). I will now draw out key references to information provision within these documents.

The 2007 National Stroke Strategy provided a vision for stroke prevention, treatment, care and support over the next ten years (Department of Health, 2007a). Information provision was a theme throughout the document but received particular focus in Chapter One in relation to raising awareness of prevention and a need to inform and involve the public more in stroke care and in Chapter Three discussing life after stroke. Information provision received specific reference in four of the twenty quality markers identified in this document:
• QM2 in relation to the effective assessment and management of vascular risk factors focusing on improving information and advice on lifestyle and treatment options
• QM3 providing information, advice and support through the stroke care pathway
• QM14 the need for review of stroke needs at six weeks post discharge, six months post stroke and annually thereafter thus improving access to information lifelong after stroke
• QM15 participation in community life where information was related to aiding emotional recovery after stroke.

The potentially important role of social care workers and voluntary care organisations in providing information was highlighted. Voluntary organisations specifically mentioned included the Stroke Association, Connect, Speakability and the Brain and Spine Foundation. The latter’s information access toolkit was referenced within the document but none of its content was specifically illustrated. Referring to this toolkit was the closest the stroke strategy came to offering specific operational guidance on the aims it presented for information provision. The Brain and Spine Foundation Information Access Toolkit is an online resource guide offering advice on verbal communication, developing information resources, auditing resources and the need to revisit information and top up material supplied overtime for individuals (http://www.brainandspine.org.uk/information/information_access_toolkit/index.html). However, in order to be comprehensive in its approach it does adopt a problem checklist approach to providing information that does not guide practitioners regarding more individual assessment of needs, readiness for information or facilitation of information use.

An overview of the topics/issues highlighted by the Stroke Strategy in relation to information provision is summarised below:

- Help for stroke survivors/carers to navigate the health system
- Changing needs overtime and the need for the right information at the right time
- Information to be tailored to individual requirements
- Flexible, easy access to written, diagrammatic, audio and web based information
• Provision of the means to signpost individuals back into services if needs change over time
• Information and support for families and carers
• A focus on staff skills/competencies for effective communication/information provision.

Whilst the need to tailor information to individuals’ needs was a key message in the Stroke Strategy little was said about how this could be achieved in practice, instead broad guidance was offered on how to review and monitor service provision including suggestions to:
• Review local policies and strategies for information provision
• Build stroke needs into existing information programmes
• Ensure services were adequately resourced to provide information
• Involve service users in developing services and tools
• Audit effectiveness of information provision.

The updated Royal College of Physicians Stroke Guidelines (Royal College of Physicians, 2008) said far less specifically about information provision than they had in their previous edition. This may reflect changes to the scope of the document (including TIA and SAH) and a different methodology employed in its preparation. This edition combined an evaluation of strength of evidence alongside a consensus approach amongst working group members to identify twenty-one top recommendations for stroke care. Also a recent update to the Cochrane review of information provision post stroke had presented persisting equivocal evidence about the best way of providing information to survivors and carers post stroke (Smith et al., 2008a).

Therefore within this edition of the guidelines information provision was referenced in relation to the following recommendations:
• Provision of educational programmes and information for patients and carers
• Patients and families to be provided with information and contact details for appropriate statutory and voluntary agencies
• Greater involvement of carers with patients consent and a greater focus on their needs
• To give all patients written information and advice on lifestyle changes to reduce the risk of stroke tailored to individual needs

• The need for specialist stroke services to have easy access to patient information, advice and support

• Detailed information provision on new medicines management for the prevention of stroke, taking into account individual competencies and deficits

• Recognition of individual, health professional and societal responsibilities in relation to lifestyle change - identifying shared responsibility of all professionals to raise and revisit this at points of contact

• Provision of information to help those experiencing depressed mood and anxiety

• Advice about assessing competence in relation to information provided in relation to decisions.

The NICE stroke guidelines (National Institute for Health and Clinical Excellence, 2008) focussed on the diagnosis and management of acute stroke and TIA. This document made the following references to information provision:

• The patient and family need continuing information and support

• Good communication should be supported by evidence based written information tailored to the person’s needs

• Information should be culturally appropriate and accessible in relation to communication disabilities and language spoken

• Information and support should also be targeted at families and carers.

In these later documents reviewed since the study started we see further high level guidance on aspirations with respect to information provision but this is not translated into specific practice guidance. This links to ongoing uncertainty about evidence to support specific information provision approaches in stroke that I will return to later in this chapter.

Policy makers and campaigners are concerned with information provision because of its ultimate promise. The potential it holds is that stroke survivors and carers should be well informed and better empowered to be effective service users in order to manage their health effectively and so reduce the risk of further vascular events. Information is proposed as a crucial tool for engaging effectively
in such self-management. However, how this is achieved effectively when survivors and carers concerns may be more immediately about how to make sense of their stroke and cope on a daily basis is not clear in policy. The next sections will consider some of the lessons learned from studies of information provision in other disease areas and then specifically in relation to stroke. The aim will be to highlight why an exploratory qualitative study was conducted in the present study.

2.4 BENEFITS OF INFORMATION PROVISION IN OTHER CONDITIONS

Information provision occurs across health services, settings and specialities. It is not unique to stroke services though there are some particular challenges in the stroke population if communication, sensory and cognitive impairments are present. Evidence supporting the potential benefits of information provision to aid self-management is available in other disease groups, such as asthma and arthritis (Partridge and Hill, 2000; Marks and Allegrante, 2005). Positive benefits that have been documented include improved ability to manage health and treatment, better psychological outcomes (for example anxiety and depression), reduced hospital admissions/unscheduled primary care visits, more appropriate medication use and improved quality of life through self-management (Caress, 2003). There is a significant amount of literature from other disease groups that could be used to guide and benchmark practice in stroke. However prior to data collection I did not wish to assume which comparisons may be most pertinent and considered reviews of self-management education to inform the study.

Caress (2003) reviews some of the complex issues that are entailed in providing information in health care. Providing information may not change knowledge if it is a passive process. Improved knowledge may not change other health outcomes depending on the desire, ability and resources available to patients and carers to utilise knowledge. Factors to consider include who is receiving and giving information, when and where is information being given, how is it provided and what formats are being used.

The positive benefits of self-management education outlined above drive policy directives on information provision. Such impacts however, are yet to be consistently seen with the stroke population which may be an artefact of poor theoretical underpinning of intervention design (Smith et al., 2004a; Redfern et al., 2006a), or a unique feature of this complex population. Jones (2006)
reviewed strategies used to enhance chronic disease self-management and how these may be applied to stroke. She notes that research in stroke self-management falls well behind that in other disease groups. The research done on interventions in stroke is heavily focused on education based strategies in the acute stages of care, despite stroke’s long term and complex sequelae and evidence of the development of coping strategies over time by stroke survivors (Rochette et al., 2006). Jones (2006) argues that development of future stroke information provision interventions needs to draw upon self-management research with other disease groups where interventions draw more on social cognition theory and self-efficacy theory (Lorig and Holman, 2003). Jones argues that how such lessons can be translated to the stroke population is a key subject for further study focusing on:

- Cost effective ways to equip individuals to cope with key transitions such as care transfers and discharge
- How the stroke population can undertake effective self-management in the long term
- Examining the role of professionals in this versus collaboration with lay supporters or other stroke survivors
- And the need for diverse methods to investigate the issues involved.

Therefore the present study sought to undertake underpinning work for this considering what are the activities, motivations and expectations around information provision currently for stroke survivors, carers and professionals. Examining what activity takes place in relation to information provision between health professionals and stroke survivors and carers is crucial empirical data to guide how professional health services may respond to the calls for improved information provision from the policy reviewed.

Key literature on information provision in stroke will now be presented to highlight some of the problems encountered in information provision post stroke already alluded to so far.

### 2.5 INFORMATION PROVISION POST STROKE

The need to improve information provision in stroke care has continued to be highlighted (Mold et al., 2003; National Audit Office, 2005; Stroke Association, 2006).
Stroke survivors and their carers have recounted dissatisfaction with information provision (Wellwood et al., 1994; O'Mahony et al., 1997; Hanger et al., 1998; Rodgers et al., 2001). This has been documented as persisting up to two years post stroke with information needs evolving over time. Concerns with the basic aspects of stroke diminish, fear of recurrence persists, questions regarding psychological consequences arise at six - twelve months and at two years questions regarding concentration, memory and continuing uncertainty about further recovery were asked (Hanger et al., 1998). Stroke survivor and carer feedback underpinning the stroke association campaign “Nobody told me…”, testifies that these issues remain a problem (Stroke Association, 2006).

Research has identified the types of information survivors and carers may want (Wiles et al., 1998). Wiles et al. (2007) documented information needs in a group of 31 stroke survivors and carers up to one year post stroke; they included recovery prospects, treatment and prognosis, practical caring tasks, social activities and community resources. These authors noted that it may not be possible to accurately meet all these information needs due to stroke recovery being unpredictable however; they suggested that individualised approaches to other needs could be developed. More recently Hafsteinsdottir et al. (2011) have produced a systematic review of research evaluating stroke patients’ and their caregivers’ educational needs. These authors searched mainstream medical and psychological databases up to January 2009 and generated twenty one studies for review. The studies reported a broad range of educational needs that were often reported as unmet. Educational needs identified spanned clinical care of stroke, prevention, treatment and functional recovery. Carers were found to particularly highlight needs in relation to lifting and handling, exercises, psychological changes and nutrition. Both patients and caregivers desired information tailored to their circumstances. Hafsteinsdottir et al.’s (2011) paper offers an encyclopaedic reference guide to potential topics to be covered in information provided post stroke. The paper calls for information and education initiatives to be related to recovery phases after stroke. As such the findings are offered as a platform for developing interventions for further research evaluation. The idea suggested by these authors that stroke recovery phases could guide information/education provision is a reasonable one that could contribute to tailoring information. However, with high variability in stroke recovery trajectories it is not unchallenging (Rochette et al., 2006; Taylor et al., 2011).
I would like to turn now to studies of information interventions and activity in stroke. First I will consider studies examined prior to the present study.

Forster et al.(2001) undertook a Cochrane review of information provision studies for stroke patients and their caregivers, considering types of intervention and their impact. The review only found nine completed trials and eight ongoing studies suitable to review. The interventions included leaflets, booklets, manuals and lectures. Primary outcomes focused upon in studies were knowledge about stroke and services, impact on health and more specifically impact on mood. Of the nine complete trials three evaluated a programme of lectures and the remainder the provision of information in the form of leaflets, booklets or packs. The results of the review were limited due to the high variability in trial quality and the wide ranging outcome measures used that made useful comparison and synthesis across studies difficult. Some evidence was seen that information combined with education improved knowledge and was more effective than information alone. Information provision alone had no effect on mood, perceived health status or quality of life for survivors and carers. Where satisfaction was used as an outcome in two trials no difference was found between groups. The review concluded that the general effectiveness of information provision could not be confirmed. The review identified problems in trial design, for example lack of blinding, poor comparability of groups and attrition in participant numbers for follow up. The incorporation of patient/carer views before trial design was rare. The key messages of the review were the need for interventions that moved beyond the simple provision of information without supportive strategies, that were better informed by patient /carer preferences and were underpinned by ‘greater clarity……about the aims and expectations of information provision’ (Forster et al., 2001 p10). This latter point was fundamental to the rationale for the present study.

Searches carried out in preparation for the present study identified some further trials of interventions completed since this initial Cochrane review. These examined more tailored strategies and strategies combining information with other support. Trial quality was improving but in terms of improving the collective evidence for information provision post stroke the position was still equivocal due to the variability in intervention styles, outcome measures and therefore results. I will briefly describe the studies in question to demonstrate this variability.
Clark et al. (2003) looked at providing an information pack along with three visits from a social worker trained in family counselling for survivors and carers. At 6 months this resulted in improved family functioning with associated improved functional and social patient outcomes. However there were no effects on depression, anxiety, mastery or health status.

Smith et al. (2004a) investigated the provision of an information manual and fortnightly education meetings with the multidisciplinary team for stroke survivors and carers. This resulted in reduced patient anxiety at three and six months post stroke but no significant change in other outcomes of knowledge, handicap, function, social function and satisfaction, though there were trends in favour of the intervention.

Hoffmann et al. (2007b) examined the effects of a computer generated tailored written education package for patients following stroke. This intervention improved satisfaction with information received but had no effect on knowledge, self efficacy, depression or perceived health status.

Maasland et al. (2007) tested an individualised multimedia computer programme for health education with patients with a recent minor stroke or Transient Ischaemic Attack (TIA). No lasting effect was seen on patient knowledge of risk factors and prevention of TIA or minor stroke.

Lowe et al. (2007) assessed the impact of CareFile, an individualised information booklet on patient’s knowledge and satisfaction level post stroke. A significant improvement was seen in knowledge and recognition of risk factors for stroke following the intervention however there were no differences between the groups regarding satisfaction with information received.

Visser-Meily et al. (2005) undertook a systematic review of intervention studies for caregivers of stroke survivors. It is difficult to tease out the role of information in the studies reviewed as four broad types of support programmes were studied. These were: providing specialist services, (psycho) education, counselling and social support by peers. Most of the studies actually focused on both the caregivers and the patient despite the focus of the review. The review was not able to confirm the efficacy of any one approach though there was a positive trend in outcomes for counselling interventions. The authors point to a need to
support active problem solving approaches and promote support seeking behaviour within carers. They advocate that carer interventions should focus on their individual needs and not those of the patient.

There have also been studies of interventions with carers separately and success has been demonstrated in American studies developing an information needs checklist (Bakas et al., 2002) and offering information in conjunction with problem solving strategies via telephone follow up (Grant et al., 2002).

The position at the start of the present study was that approaches and results remained variable and this was under trial conditions. Reports on actual practice also raised concerns. Knight et al. (2006) conducted an observational study of how health information was provided to stroke patients in an acute stroke unit setting. Seven stroke patients were observed and then interviewed. Looking at all participants’ observation data, 56% of observed interaction time between health professionals and participants was spent without any communication and only 18% of communication time was spent providing health information. Other data from the study confirmed that patients desired information similar to that reported elsewhere in the literature. They did not all receive this information, not one topic was consistently covered, the amount and quality of information varied and provision was erratic and unplanned. This study underlines the importance of striving to examine what actually happens in practice via observation as well as what is reported in relation to information provision. The aim of combining such approaches is the provision of contextual data about what facilitates and prevents information provision in practice in order to inform strategic plans for improving information provision.

Hoffmann et al. (2007a) surveyed twenty stroke team health professionals regarding their use of and perspectives on written education materials. Most participants (70%) provided materials, but only to 25% or fewer patients on their case load. Twenty five per cent of professionals reported never providing written materials to stroke patients. When materials were provided it was usually close to or at the time of discharge and few participants reported that written materials should be provided more frequently or later post discharge. Occupational therapists, social workers and speech and language therapists were thought to be most likely to provide written information though there was uncertainty about who in the team did provide information. The study highlights the need for
improved communication and documentation within teams regarding information provided and also raises issues around the capacity amongst staff to screen for information needs and provide high quality information. The paper identifies the need to research why health professionals provide written information and how they may do this more effectively. Once again this fitted with the aspirations of the present study.

Ongoing equivocal results in trials of information interventions, and concerns raised in studies of actual practice provided clear support for the present study’s plan to examine actual practice as well as reported experiences of information exchange. The aim was to consider behaviours, motivations and expectations of the different parties involved in information exchange after stroke.

2.6 GAPS IDENTIFIED IN THE STROKE LITERATURE AT THE START OF THE STUDY (2007)

Effective information provision and how to respond to the expressed dissatisfaction with information provision/communication remained elusive (Murray et al., 2003a; Murray et al., 2003b; Anderson and Marlett, 2004; Garrett and Cowdell, 2005).

Interventions designed to respond to unmet information needs were largely focused within specialist acute stroke services. Some success in attaining increased knowledge had been seen in the stroke literature, but with highly variable interventions and variable study design consensus on the true impact and effectiveness of information provision remained elusive (Forster et al., 2001). Forster et al. (2001) highlighted the need to focus on what is required by stroke survivors and carers and to clarify the aims and expectations of information provision to better underpin future study design.

Stroke survivor/carer information needs are variable due to the broad ranging impacts of initial stroke disability and the development of information requirements over time as the implications of the stroke event unfold. Therefore the focus on studying information provision acutely seen in the literature needed to shift. There was a need to look at the role of General Practitioners (GPs) and primary care staff as well. The GP team is often perceived as the main consistent point of contact for all patients post stroke as the period of specialist rehabilitation is relatively short compared to the ongoing process of self-
management and adaptation (Rochette et al., 2006). The GP role in ongoing stroke care whilst acknowledged in the literature as important was undeveloped (Bisset et al., 1997; Hare et al., 2006).

These identified gaps in the stroke literature on information provision highlighted the need for better understanding of the phenomenon of information exchange in practice post stroke. Taking a step back from further interventional work in order to examine the actual practice of information exchange in depth was felt to be necessary to fully inform future developments to improve information provision post stroke. Therefore the aims of the present study are now addressed.

2.7 STUDY AIDS

The key concerns identified from practice and the literature at the outset of this study included the following:

- Accurate timely information provision is promoted as a key tool in involving the public in health care and management of their own health concerns
- In stroke care there are persisting reports of inadequate information provision post stroke
- Specific interventions tested to address this problem may improve survivor/carer knowledge base but have little impact on behaviour and satisfaction
- Many studies looking at the issues around this topic address it from one key informant’s perspective and there is little attention to the role of primary care staff in carrying forward information provision for the stroke survivor care group.

Therefore, for the purposes of study design this was synthesised into the following study aim and questions.

Study aim:
To explore views and behaviours about information seeking and provision activity during stroke recovery

Questions:
1. How do survivors & carers obtain information post stroke?
2. When do survivors & carers obtain information post stroke?
3. Why do they want information post stroke?
4. How do they use information post stroke?
5. How do health professionals deliver information post stroke?
6. When do health professionals deliver information post stroke?
7. Why do they give information post stroke?
8. How do they document information provision post stroke?
9. How is the impact of receiving good or poor information perceived/judged by the recipient and provider?
10. Are there opportunities for improving information provision?

Completion of this study hoped to provide specific local empirical evidence to inform how evidence and resources for information provision (Joule, 2006) could be put in place to provide a responsive service. Any practice change recommendations could then be the subject of further evaluation.

Trends in the stroke information provision literature during the course of the present study are now discussed.

2.8 DEVELOPMENTS IN STROKE INFORMATION PROVISION LITERATURE (2008 – MARCH 2012)

Updated Cochrane Review
Forster et al.’s 2001 Cochrane review was updated in 2008 (Smith et al., 2008a). Once again this sought to assess the effectiveness of information provision strategies in improving outcomes for stroke patients and/or their identified carers. The review process identified seventeen trials involving 1773 patients and 1058 carers. This review excluded one of the trials assessed in the earlier review; the other eight were included along with another nine new studies. Trials were selected where information provision was a prime focus intended to improve outcome, but where it did not form part of a more complex rehabilitation intervention. The latter point was the main reason for trial exclusion followed by lack of a random allocation procedure, information provision not being the evaluated intervention, use of a mixed population where stroke data could not be extracted and the lack of a suitable control group. The authors still noted that issues with trial design including: randomisation, lack of blinding for outcome assessment, small sample sizes, variable degrees of power and variable outcome measures still limited the ability to synthesise results.
Smith et al. (2008a) focussed on the primary outcomes of knowledge and mood and categorised interventions into active and passive groups. A passive intervention involved the passive receipt of information with no subsequent plan for systematic follow up and reinforcement. Active interventions involved the engagement of recipients with information provided and a subsequent agreed plan for clarification and/or reinforcement. Eight passive intervention trials were reviewed; these interventions included three trials of generic information booklets and leaflets and five studies of tailored booklets, leaflets, clinical summaries and a multimedia package. Nine active intervention trials were reviewed; these interventions included four lecture programmes and five multi-component interventions. These more active strategies were variable involving instruction, skill practice, the use of recovery plans, ongoing contact with a named contact, workbooks and a greater emphasis on coping strategies. Most interventions were still delivered early in recovery; with eight trials delivered prior to discharge, three around or soon after discharge and four at varying time points up to three years post stroke. From the meta-analysis they were able to conduct, the authors identify that information provision interventions can improve patient and carer knowledge of stroke, aspects of satisfaction and result in a decrease in patient depression scores (though not at a level of clinical significance). There was no strong evidence of effect on other outcomes. Further analysis demonstrated that more active interventions had a greater effect in improving patient mood. Placing this in a self-management context this would make sense as more active strategies are likely to impact the underpinning principle of self-management approaches that is self-efficacy (Lorig and Holman, 2003). Unfortunately, these authors still concluded that the best way to provide information post stroke remained unclear. However, their identification of the positive impact of greater active patient/carer involvement and planned follow up/clarification/reinforcement represents a step forward in terms of linking stroke information provision strategies more clearly to self-management principles. Smith et al. (2008a) identify the need for:

1. Education of stroke health professionals in more active information provision approaches
2. Further development of active information strategies to generate a widely applicable (generaliseable) active intervention for testing in large scale trials
3. Development of a reliable, valid stroke knowledge outcome measure
4. Debate about the most appropriate outcome domains for information interventions

I would agree with points one and four and the directive for pursuing more active approaches. However, generating a single generaliseable approach (point two) is extremely challenging in a variable population such as stroke. This is developed further in the discussion of the present study’s results in chapter nine.

Trends in other types of studies

Studies of and relating to information provision post stroke, have been ongoing during the present study. They are variable in design and focus, and therefore limited in their ability to address the issues identified above from Smith et al.’s review (2008a). I will focus on three specific papers of note later but first will give a summary of other work.

Studies include two review papers, one of expressed learning needs of patients and carers (discussed earlier in this chapter) (Hafsteinsdottir et al., 2011); the second a review of health education in patients with a recent stroke or TIA (Maasland et al., 2011). Maasland et al. (2011) reiterate messages from earlier authors (Jones, 2006; Smith et al., 2008a); that health education is less developed in stroke care and methods used unproven. They contrast this with more positive effects seen in coronary artery disease. They call for further large trials in stroke with long follow up and testing individualised, repetitive and active methods to engage stroke patients and their relatives in health promoting behaviours to reduce disability and help prevent further stroke.

The focus of other literature has been variable and includes: studies describing patient and carer experiences after stroke (Cameron and Gignac, 2008; Pringle et al., 2008; Greenwood et al., 2009; Reed et al., 2010); studies describing health professional practice (Alaszewski et al., 2008; Eames et al., 2008; Hedberg et al., 2008; Hoffmann and Cochrane, 2009; Eames et al., 2010; Gustafsson et al., 2010; Menard et al., 2011); studies describing preferences for mode of delivery of information (Eames et al., 2011a; Eames et al., 2011b); studies describing development of tools and interventions (Allison et al., 2008; Redfern et al., 2008; Stonecypher, 2009; Joice et al., 2010); studies describing small scale pilots of interventions (Byers et al., 2010; Neubert et al., 2011) and studies describing larger trials of interventions (Kendall et al., 2007; Battersby et
al., 2009; Joubert et al., 2009; McManus et al., 2009; Rochette et al., 2010; Wolfe et al., 2010).

Progress can be seen through these papers in terms of more studies describing actual experiences of survivors, carers and health professionals in practice in order to inform development of improved information provision strategies. Also, the reporting of the actual development of tools aids in later evaluation of results seen with these and also opens up debate in the stroke community about the drivers of these developments and their fit with reported experiences elsewhere in the literature. Findings were compared and contrasted with those of the present study to inform the discussion presented in chapter nine.

Another trend seen in the studies published since the start of my study is to evaluate more tailored approaches, this responds to one of the recommendations of policy and systematic review. However, other recommendations relating to the degree of active engagement of survivors and carers and the length of follow up is often unclear in studies reported. This along with few larger well powered studies and persisting variability in outcomes will continue to make meta-synthesis challenging. Hence, the present study remains relevant with the potential to contribute to the debate about aims and expectations of information exchange that can in turn inform consistent high quality study design.

In seeking to tailor interventions many studies have focussed particularly on information relating to secondary prevention of further strokes (Joubert et al., 2009; Wolfe et al., 2010). This is a more predictable and tightly bound aspect of post stroke information that lends itself more to consistent intervention design and also answers public health concerns regarding stroke so this is understandable. However, as stroke affects so many aspects of life for individuals a limitation of this approach is that other more pressing concerns of patients/carers may be overlooked. Such concerns may be moderating factors in how well patients and carers engage with such interventions and thus impact on the results of such studies.

Before closing this chapter I would like to discuss three specific studies that draw out key issues for discussion of results later in the thesis. The three studies chosen are all completed trials, involving at least one hundred participants but
with varying approaches demonstrating different outcomes. The studies highlighted are an approach specifically framed in terms of self-management (Kendall et al., 2007); a paper highlighting a model of shared care (Joubert et al., 2009) and a larger scale risk factor management study (Wolfe et al., 2010).

Kendall et al. (2007) conducted a randomised controlled trial of a recognised chronic disease self-management course. They recruited one hundred first time stroke survivors soon after discharge from inpatient rehabilitation. Participants were randomly allocated to either attend the self-management course or just receive standard post discharge rehabilitation. Outcomes that were evaluated included family role functioning, activities of daily living, self-care, productivity, mood, social participation and self-efficacy. In this study the intervention did not result in changes to self-efficacy, mood or social participation. In terms of family role function, activities of daily living, self-care and productivity, both groups reached similar end point outcomes but the intervention group had demonstrated improvements in measures through the twelve months of follow up carried out. The authors were surprised by the lack of impact on self-efficacy as they had expected this to be central to the intervention. Lack of impact on this could be attributed to features of the course design and delivery. They conclude that despite this the self-management approach appeared to help avoid rapid decline in some aspects of well-being. Therefore the intervention was described as protective rather than fundamentally changing outcome. This study is notable because it is the most overt testing of self-management principles in stroke I have discovered. A need to shift to this type of focus was raised by Jones (2006). Also it is a study that focuses on wide psychosocial skill expansion rather than just stroke prevention and risk management. The difficulty impacting trial outcomes raises questions for improving intervention design and also the need to evaluate process measures as well as endpoint outcomes. It raises the question of whether improving the process of recovery is an acceptable goal even if the end point outcome is unchanged?

Joubert et al. (2009) piloted a trial of an integrated care programme for the reduction of secondary stroke. Recruitment occurred within the hospital setting, 186 patients were recruited and randomly allocated to receive the intervention or standard care. The intervention entailed providing education, advice and support to both the patient and their GP. This role was undertaken by a hospital based co-ordinator within the stroke service. The model successfully modified a variety
of vascular risk factors, reduced disability, improved recall of advice and maintained quality of life in the intervention group compared to the controls. Some caution needs to be exercised with these results due to features of the trial design. However, what is notable in this work was that as well as targeting key problem areas in secondary prevention management (knowledge of both patients and GPs) it also offered a high level of contact and support. The support included arranging all GP follow up visits (five over the course of the year), phoning to remind patients of visits and again to follow up on outcomes of visits. Depression was also screened for so this could be responded to. This study makes no direct links to self-management principles, however the support offered could well have impacted upon self-efficacy principles that underpin this (Lorig and Holman, 2003).

The final study picked out for comment was the largest trial of a tailored information intervention for risk factor management that I found entitled ‘Stop Stroke’ (Wolfe et al., 2010). The development of the tool used in this study was reported in the literature (Redfern et al., 2008). This work drew upon the literature and quantitative and qualitative development work to identify current practice in and barriers to secondary prevention following stroke. The authors followed phase I – III of the Medical Research Council (MRC) framework for developing and evaluating complex interventions (Campbell et al., 2000). The intervention developed utilised the local stroke register to produce individualised written information packages, “Keeping Well Plans”, about risk factors and stroke prevention that were then mailed to patients and GPs. The trial of this was a cluster randomised controlled trial involving 523 consecutive incident stroke survivors. Packs were received ten weeks post stroke and followed up by a researcher at five months and eight months post stroke. Follow up points were used to collect data on changes to risk factors and management so modified plans could be generated and sent out again. Discussion of risk factors and support with changes was not evidently part of these follow up visits. The trial’s primary outcomes were management of key risk factors at one year using treatment with an antihypertensive, treatment with an antiplatelet and smoking cessation as the measured outcomes. No improvement was seen in risk factor management. The authors identified the need for further evidence about how behaviour could be effectively modified in order that further trials of tailored information in relation to risk factor management might produce clinical benefit.
The authors were disappointed with these results having employed high quality strategies in intervention and trial design, to try and tackle common criticisms of the poor theoretical underpinnings of studies. However in seeking to target risk factor management they may have privileged medical concerns over personal concerns of survivors. Also choosing to rely on a written intervention they did not make links to theory underpinning self-management approaches that may facilitate actual change in behaviour over time. These are issues that will be picked up later in the discussion of the present study’s findings. The authors suggested the following reasons for lack of impact:

- Unanticipated improvements in usual care
- Lack of power in the intervention to influence GP and patient self-management
- That impact was on process rather than outcome
- That barriers to change for individuals may not have been addressed
- Choice of outcome whilst originally influenced by guidelines may not have been sensitive to change
- Unanticipated changes in practice resulted in an underpowered study to detect change
- Complexity of this type of intervention with the stroke population.

These are all valid issues identified by the authors, and their lack of success in changing outcomes highlights the challenges encountered in developing complex, multifaceted interventions such as those involving information provision. Experiences such as those of Wolfe et al. (2010) have been reflected in an update to the MRC guidance on evaluating complex interventions that discusses the use of a wider range of methods in developing and evaluating these types of interventions (Craig et al., 2008).

Reviewing the scope of the information provision literature, there are issues with both the volume and quality of papers, and therefore the credibility of the evidence they present to guide practice. Qualitative papers predominate in the literature identified but they do not all address information provision as a distinct topic. However, studies of the stroke experience often highlight within their accounts the need for more information as part of managing stroke as a long term condition. Qualitative works may highlight perceived information needs and deficits but they have not articulated issues around how such needs may be met.
Whilst less in number, quantitative papers have focused specifically on trialling information based or linked interventions and there have been two attempts at systematic review of such studies. However, problems identified within this literature include: problems with conceptual clarity of interventions (about the nature, the purpose of, the intended outcomes of and the mode of effect of information based interventions), problems with sample size, randomisation and power in study design. This makes for difficult interpretation of studies, either in isolation or together as part of a systematic review. It is therefore difficult to guide practice and define best practice based on evidence. Without clarity about the makeup and purpose of information based interventions and their likely outcomes, we are left with a heterogeneous research literature which makes meaningful comparison and interpretation of results challenging. We are not comparing like with like and not clarifying what works when and for whom. Is it information in its own right, or in combination with other forms of support and interaction, and in this context what role does information itself play. Reviewing the literature to date demonstrates that we know information can improve knowledge and if delivered actively or with some means of emotional support can improve some outcomes (Forster et al., 2001; Smith et al., 2008a; Maasland et al., 2011). However, this does not translate in to clarity in practice about the aims of providing information, how information is provided or how this may translate in to meaningful action for stroke survivors and their families.

2.9 CONCLUSION

This chapter has provided an overview of the policy context driving the desire for improving information provision in post stroke care. The outcomes that are hoped for by providing information have been discussed. The lack of consensus achieved in trials of information provision interventions post stroke has been highlighted. The need to look not just at information provision in acute specialist care but in primary care has also been raised. The identification of these deficits and challenges in the literature underpinned the presentation of the main aim and questions of the present study. The study’s aim was to explore the expectations, motivations and actions relating to information provision post stroke from the perspectives of stroke survivors, carers and professionals examining these up to two years post stroke. This was considered important to produce empirical data to strategically guide service developments. Trends in the post stroke information provision literature since commencement of the study have also been discussed in preparation for discussion of the present study’s
results later in the thesis. The next two chapters will present the justification and application of the chosen methods for the present study.
CHAPTER THREE: METHODOLOGY

3.1 INTRODUCTION
This chapter describes how and why the methodological strategy of case study was chosen to meet the study aims and objectives. Following a presentation of the rationale for selecting case study strategy I will go on to describe the type of case study undertaken, the definition of the case in this study and the choice of setting for the case study. The chapter closes by considering the strengths and weaknesses of choosing a case study approach. This will provide the context for description in the next chapter of how the strategy was applied and made operational in the practice of data collection and analysis.

3.2 REVISITING STUDY AIMS
The key concerns identified from practice and the literature at the outset of this study included the following:

- Accurate timely information provision is promoted as a key tool in involving the public in health care and management of their own health concerns
- In stroke care there are persisting reports of inadequate information provision post stroke
- Specific interventions tested to address this problem may improve survivor/carer knowledge base but have little impact on behaviour and satisfaction
- Many studies looking at the issues around this topic address it from one key informant’s perspective and there is little attention to the role of primary care staff in carrying forward information provision for the stroke survivor care group.

These points informed the study aim which was:

To explore views and behaviours about information seeking and provision activity during stroke recovery

Specific research questions driving the exploration were:

1. How do survivors & carers obtain information post stroke?
2. When do survivors & carers obtain information post stroke?
3. Why do they want information post stroke?
4. How do they use information post stroke?
5. How do health professionals deliver information post stroke?
6. When do health professionals deliver information post stroke?
7. Why do they give information post stroke?
8. How do they document information provision post stroke?
9. How is the impact of receiving good or poor information perceived/judged by the recipient and provider?
10. Are there opportunities for improving information provision?

With this overarching aim and these questions in mind it was evident that a strategy was required that offered flexibility to consider a number of perspectives simultaneously and to do this with sensitivity to the practice/policy context in which these viewpoints are held and in which actions are taken. The desire was to adopt an approach that could address the interplay between context, beliefs and actions.

3.3 POTENTIAL METHODOLOGICAL APPROACHES CONSIDERED

Early in the planning of the study I decided not to take a quantitative or positivistic approach. I rejected an interventional approach to the study using a pragmatic randomised controlled trial of some form of intervention. This was based on the observation within the literature that this had been attempted on a number of occasions with varying styles of intervention and with mixed results. These studies have not clarified the position regarding effective information provision. I would argue that these studies have missed out a crucial stage in investigation and this may be a part of the reason their results are so mixed. Traditional intervention studies have been designed with the perspective and motivation of health professionals paramount. Intervention content may have been informed by topics identified by stroke survivors and carers but mode of delivery has been decided by professionals and there has been no attempt to clarify the expectations of all parties about information provision. Is there a shared understanding of what information provision can achieve or provide for individuals? Intervention studies have treated information like a pill or treatment that can be delivered, but without overt discussion or consensus on the desired and likely outcome of interventions.
I wanted to explore in more detail information provision as it happens currently in clinical practice and from multiple perspectives. The next strategy rejected was the option of a quantitative survey. Whilst this would have allowed the views of large numbers of respondents to be elicited it would not provide the depth of data desired. Similarly to an interventional approach there would be too rapid a move toward data reduction in deciding the questions to ask via this method and the formats for reply that would be offered for ease of response and analysis. In addition a weakness of the survey approach is self report bias that is the answers/accounts provided may not truly reflect actual practice. A survey would not provide the level of detail required about the processes and motivations involved in information demand and provision. It would not allow for an exchange between researcher and respondent to elicit core assumptions, beliefs and values.

I wanted to take the exploration of the phenomenon of information provision back to a more fundamental level with the opportunity to question and probe individuals beliefs and practices and to compare this with evidence of actual practice. The decision therefore was to adopt an interpretive approach undertaking a naturalistic, qualitative, field study to investigate the phenomenon of information provision in action. This was true to the purpose of the study to explore and describe the phenomenon of information exchange post stroke in a particular context, not to generate causal explanations.

An interpretive approach can describe a number of approaches to research. Interpretivism is often used almost synonymously with constructivism, but they are broad labels for related families of methodological and philosophical persuasions (Schwandt, 1998). Guba and Lincoln (1998) present constructivism as one paradigm choice that can inform the research process. Paradigms are belief systems or viewpoints that describe different views about the nature of being (ontology), the nature of knowledge that can be discovered or revealed (epistemology) and therefore inform how this knowledge can be discovered (methodology). Guba and Lincoln (1998) argue the importance of being clear about ones paradigm view and subsequent epistemological position as this informs choices made about specific strategies and methods of data collection. The term constructivism embraces a range of specific positions but central features of these include:

- A move from ontological realism to ontological relativism
• Relativism refers to reality in the form of multiple, mentally constructed realities particularly of socially and experientially based phenomena, parts of constructions may be shared and they are dynamic not fixed
• Results are produced from the interaction of researcher and researched
• This is achieved through processes of interpretation comparing and contrasting positions in order to produce ‘a consensus construction’ or a new more forward thinking position.

(Guba and Lincoln, 1998)

Reasons I chose this approach for my study are:
• The process of reconstruction aims to improve understanding based on multiple experiences
• The knowledge produced seeks consensus drawn from acknowledging individual constructions
• It allows for full acknowledgement of my experience as a practitioner.

(derived from Guba and Lincoln (1998))

I therefore took a broadly constructivist view however, this was not an extreme relativist one where reality appears so ephemeral as to be beyond any meaningful apprehension. My view or approach to my work was to acknowledge personal meanings and constructions of the phenomenon under study, information provision/exchange. This is important as information provision has a strong social element due to the interpersonal element of information exchange in practice and through the social context of political drivers around information provision. The aim throughout the study was to articulate personal meanings and constructions around information exchange from different perspectives, to allow comparison and to contrast them with a view to seeing where some consensus could be achieved and where divergence occurs. I believed this type of knowledge would be a basis for directing more individually sensitive/responsive practice. A constructivist approach is appropriate as information exchange is a complex social phenomenon and to be successful I would propose requires the mutual communication and negotiation of intentions, motivations and knowledge in order to reach a shared understanding that may form the basis for a satisfactory exchange of information.
Within the broad framework of a constructionist perspective for the study, a number of specific research strategies were considered.

Phenomenology considers the existential experience of a phenomenon from the perspective of those experiencing it. There are a number of approaches, a key feature is the use of hermeneutics to deepen understanding and focus on the individual experience (Crotty, 1996). This approach may have allowed access to the perspectives of key stakeholders however the phenomenological approach was rejected due to its particular emphasis on individual experience. I did not want to examine specifically the existential experience of stroke that is, 'what it is to be a stroke survivor or carer, but rather the processes involved in the practice of obtaining/providing information as part of stroke recovery. I wanted to consider contextual details of how this activity of information provision is negotiated in clinical care, what guides it and how it is recorded. These broader elements were beyond the scope of a phenomenological study.

Grounded theory uses qualitative methods to explore phenomena in their natural context and offers systematic guidance to undertake analysis of data to derive theory from actual data (Glaser and Strauss, 1967). Grounded theory met some needs of the study as it would have facilitated the study of information provision in the context of communication between individuals and provided a framework for analysis grounded in the data. However, it was rejected as the proposed study is an exploratory one with a diverse population. Building a theory of information provision was not an aim of the study and was unrealistic at the starting point. Instead the study aimed to improve understanding of the phenomenon of information provision post stroke with a view to developing a conceptual framework or model that may stimulate discussion of policy and offer guidance to practitioners. Theoretical sampling, sampling based on the issues arising from data as it is collected, would not have been feasible in the timeframe of the study with the different groups (lay and professional) involved. In addition grounded theory’s focus on interaction can lose a sense of the wider political and social context and I wanted to preserve and factor this into the analysis (Denscombe, 2003).

Ethnography is a research strategy based on the work of anthropologists used to describe peoples or cultures (Denscombe, 2003). This was considered as a potential strategic option as data collection methods from this discipline allow the
study of a phenomenon or experience from a number of perspectives such as: self report (interview), observable action (observation) and recorded action (documentary analysis). However, with this approach there is usually a heavy emphasis on observation data and a broader interest in the general experience of the culture/group under study rather than a focus on a specific aspect of the experience or a practical problem/issue like information provision. As such, an ethnographic approach did not provide a sufficiently focused strategy to study the area of interest and so was rejected.

Case study research offered a strategy for combining methods to look at a complex phenomenon in its natural setting/context. Case study strategies offer flexibility and adaptability to different settings and world views or paradigms as they have been applied in varied practice based settings often to study how things actually work in practice and to aid our understanding of the relationship between policy, theory and practice (Simons, 2009). Denscombe (2003) summarises the key characteristics of case study research as focusing on:

- Depth rather than breadth of study
- The particular rather than the general
- Relationships and processes rather than outcomes and end-products
- A holistic view over isolated factors
- The natural setting rather than an artificial situation
- Using multiple sources and methods rather than one approach.

These characteristics fitted the study needs as no particular type of data collection or focus would be privileged over others. Case study allowed the study of information exchange in its contemporary practice context in order to examine the influence of this on information exchange. Case study provided flexible use of multiple data collection methods and through this the opportunity to explore public and private accounts of information exchange in action from different key perspectives. Case study has been presented as the research of how and why questions (Yin, 2003) and allows the context specific, in depth, multifaceted study of a specific phenomenon, in the case of this study information exchange between stroke survivors and carers and health professionals. Hence the decision was taken that case study offered the best fit to address the aim and questions identified for the study.
Having decided on a case study strategy I then considered the forms it may take in order to plan its actual application in the study.

3.4 THE CHOSEN RESEARCH STRATEGY OF CASE STUDY

The research strategy of case study has a long history in health service research (Yin, 2003). This is unsurprising as it represents a very flexible research strategy which supports the use of multiple data collection methods to examine complex real life phenomenon in context (Yin, 2003). Many practice based research questions demand such an approach as they cannot be oversimplified. Zucker (2001) highlights its potential to contribute to the development of patient sensitive interventions. Examples of the use of the case study strategy in nursing research include: the evaluation of the care of the terminally ill in the community (Bergen, 1992), the role of community nurses as case managers (Bergen and While, 2000), to describe the experience and meaning of living with coronary heart disease over time (Zucker, 2001) and to study decision making practices with health visitors (Appleton, 2002).

For a number of reasons case study is subject to misunderstanding and criticism. It is not often introduced in introductory research teaching and texts therefore despite its increasing popularity many researchers and consumers of research are naïve as to its nature and purpose (Bergen and While, 2000). The term case study in medical and educational spheres has a different meaning entirely which is the in-depth study and presentation of a single instance of something for illustrative purposes.

Case study as a research strategy may take a number of forms to study a predefined phenomenon, in detail and in context in order to improve understanding of the phenomenon. Different proponents of case study strategy present apparently variable forms of the strategy using different language to describe these forms and offering different degrees of prescription about their conduct. This can therefore make case studies difficult to undertake for the first time and difficult to evaluate from the research consumers point of view (Atkins and Sampson, 2002). In healthcare particularly, the very flexibility of case study that is its strength may appear to be a weakness to an audience used to appraising evidence against pre-set criteria. As a result it is important to make clear the particular approach taken to case study for a particular piece of
research and the terms that will be used and what they will mean and present a rationale for the choices taken (Bergen and While, 2000; Appleton, 2002).

In the planning of this study the two main proponents of case study research and their approaches were considered these are Robert Yin (2003) and Robert Stake (1995).

Yin (2003) presents case study as the strategy of choice when research questions include ‘how’ or ‘why’ inquiries; when there is little control over events and when the focus is on a contemporary phenomenon in its real-life context.

“A case study is an empirical inquiry that
• Investigates a contemporary phenomenon within its real life context, especially when
• The boundaries between phenomenon and context are not clearly evident.”

(Yin, 2003 p13)

He identifies three types of case study exploratory, descriptive and explanatory. The three types of case study described by Yin can take different forms: single case studies and multiple case studies and these in turn can be holistic or embedded. This typology results in four design models: single, multiple, single embedded and multiple embedded. Whether a study is holistic or embedded depends on the unit(s) of analysis relating to the case to be studied. Yin (2003) proposes that case study can use quantitative or qualitative methods though it is not to be classed as a qualitative research approach. Yin (2003) advocates for common ground between qualitative and quantitative research rather than a divisive split on the basis of philosophical beliefs. He would seem open to an inclusive and pluralistic view of strategies provided these fit questions and purpose. This appropriateness of fit and concern for quality of design and conduct of case study is a key feature of Yin’s work. More than other case study authors he endeavours to make the hard task of case study easier by offering a set of procedures. He sees procedure as a key tool in defending common criticisms of case study as lacking rigour. However, he uses many definitively positivist terms to define his mechanisms of study quality control. These include construct validity, internal validity (explanatory studies only), external validity and reliability. Yin (2003) does not claim that his approach is definitive or static but offers it as a starting point for good design, he emphasises the need for logical
and clear design over and above any allegiance to a specific research paradigm. He identifies five components of design as important:

- Study questions
- Study propositions if any
- Study units of analysis
- Logic linking data to propositions
- Criteria for interpreting findings

Study questions are a universal research term. Propositions are statements that could be seen as akin to hypotheses, they direct attention to what the study is concerned with or interested in. Their purpose is to direct the attention towards what should be investigated within the scope of the study. Exploratory studies may not have propositions but should still have a rationale and sense of direction. The unit of analysis relates to defining what the case is and the elements of it to be studied. The case, or primary unit of analysis, can be an individual, an ‘event’ or an ‘entity’ less defined than an individual. Examples would include decisions, programmes, an implementation process or an organisational change. Some of these phenomena present challenges for study as their boundaries may be unclear, Yin is more flexible than other authors such as Stake about how clearly bounded or defined the ‘case’ for study should be. Initial definition of the case/unit(s) of analysis derives from study questions and areas of concern for the study. I will go on to address the specifics of this in relation to my study later in this chapter.

Stake (1995) describes case study as the study of particularity and complexity to improve understanding of activity within context. Stake’s background is educational research and in contrast to Yin he places case study firmly in an interpretive paradigm drawing on ‘naturalistic, holistic, ethnographic, phenomenological and biographical research methods’ (p xi). Stake (1995) is far looser in his prescription of how to carry out case study advocating choosing from a range of methods to suit the operational circumstances for the study. In contrast to Yin, Stake has a rather more rigid view of what may be a ‘case’ for study and is concerned with its boundaries, and that it is a ‘specific, a complex, functioning thing’ (p 2).

Similarly to Yin (2003), Stake (1995) offers a typology of case studies:
• Intrinsic - this is when a single case is studied just to learn about the case
• Instrumental - when there is a problem or question to study and options regarding cases to illuminate this
• Collective - as per an instrumental case study but several cases are studied in a co-ordinated fashion to illuminate the problem.

In considering the “boundedness” of the case, Stake sees the case as linked to the setting for study. Stake takes a pragmatic view of case/setting selection suggesting the following are considered:
• Maximising what can be learnt
• Timing and access
• The balance between uniqueness of the case and context, though the case does not have to be typical to maximise learning.

The latter point links to the fact that the generalisations made in case studies are naturalistic and theoretical to improve understanding not to predict population behaviours or results. Stake emphasises self-awareness and interpretive skill throughout case study design and conduct, presenting broad principles of qualitative analysis rather than specific guidance for this activity. That said he also states the importance of discipline and a well thought through plan for the study. He believes this to be led by the development of good research questions that will guide the study’s conceptual plan but allow flexibility and responsiveness to context and data collected. He suggests using issues to build up concepts and questions for the study, even goal statements or hypotheses can be put forward as long as a healthy curiosity is maintained so these may be refuted or refined as the study progresses. In principle looking at these two case study proponents’ descriptions alongside one another there is much common ground and some of the difference is linked to language and the affiliations this implies.

Yin (2003) and Stake’s (1995) approaches are sometimes presented as in opposition to each other and ascribed to be from different paradigms, Yin positivist/post-positivist and Stake interpretive/constructivist (Appleton, 2002). These are reasonable interpretations based on each author’s presentation of their approach. However, what Yin and Stake both advocate is the primacy of:
• Clarity of research questions
• Appropriateness and utility of methods to answer these
• The flexibility of the method to facilitate this process in a number of forms
• The need to present the process and findings in a manner most accessible to its intended audience.

Therefore the case study I chose to undertake was driven by the research questions defined earlier including an emphasis on the how and why of information exchange in action in clinical practice. I had decided to utilise qualitative data collection and analysis techniques as the aim was to improve understanding of information exchange in action post stroke as part of an exploratory study. Yin’s comfort with a fairly loosely bounded or defined ‘case’ for study particularly in exploratory studies, but provision of a clear and crisp structure for study design fitted with the requirements for drawing together a study plan that would be understandable and accessible to research approvals bodies within the health care setting and to healthcare practitioners with an interest in the study. Yin’s descriptors of type of case study and structure of case study were considered to be more accessible and able to aid the understanding of the study design. This was both from my own perspective as a novice researcher and from the point of view of participants and consumers of the research both during the conduct of the study and upon presentation of results on completion. Therefore, whilst keeping in mind the common principles shared across case study approaches, I decided to draw predominantly on Yin’s typology of case studies and guidance in order to help me in the design my study.

3.5 ARTICULATING THE CASE AND TYPE OF CASE STUDY UNDERTAKEN
The study’s overall aim and study questions were presented at the beginning of this chapter and the study questions were important in directing the sources and types of data to be collected. There was a primary concern with the how, when and why of information exchange post stroke in practice. Hence I was interested in different layers of data. First, in the accounts of the parties involved patients, families and health professionals; second in observing interactions between the parties to witness actual behaviour to consider this alongside accounts of this behaviour and finally with records of information provision to see how these may or may not support the process.

As I was undertaking an exploratory study Yin (2003) would not stipulate that study propositions were absolutely necessary as long as the focus of the study
was clear. However, I did develop propositions in order to articulate the study focus and some of my concerns around information exchange post stroke coming in to the study. The propositions were derived from my own clinical experience and literature reviewed in planning the study. The propositions were:

1. The aims of information provision/exchange are unclear in everyday practice
2. Where aims in information provision/exchange are unclear mismatches in communication are therefore likely making it difficult to provide effective tailored information to individuals.
3. Communication around information may not always be a two way process making it challenging to clarify/agree aims.
4. It is unclear at present how information can be tailored effectively in practice.

I was therefore seeking to uncover shared and divergent expectations, motivations and meanings around information provision post stroke in order that any consensus or lack of it might inform future practice in this area. It was these propositions alongside the study aim and questions that directed the data to be collected; this is discussed further in the next chapter.

Having examined Yin's typology of case studies my design emerged as an exploratory case study using a single embedded case study model after Yin (2003).

Figure 3 shows a schematic representation of the study design to illustrate how the case was conceptualised and how different data collection elements were seen to contribute to the study of the case that was defined as information exchange between stroke survivors/carers and health professionals in the chosen setting.
The case or phenomenon under study was information exchange between stroke survivors/carers and health professionals. This is a complex and highly variable case and the design was chosen to allow its study in depth in one setting Salford.

I made the choice of one geographical location/setting in order to examine how in one healthcare setting staff may respond to the highly variable information needs of different stroke survivors and carers. I wanted to understand more about the variability at individual level (patient, carer and professional) because I think it is important to have insight into this prior to exploring how the organisation of different health care settings may further impact on this and be another factor influencing how information needs are met. This rationale was accepted as the study went through the approvals process. However, if concerns had been raised about the use of a single setting by management teams or ethics, then this decision would have been reviewed. This would have entailed considering the option to study more than one setting using smaller numbers of comparable individual respondents in each setting.

I designed the case study as an embedded design (after Yin (2003)) as I considered the survivors, carers, staff and documents recruited and collected
during the study as units of analysis. These units of analysis were used to illuminate the primary unit of analysis the 'case' rather than being seen as 'cases' in their own right. Several units of analysis that is several individual survivors and carers at different points in their recovery post stroke, their documents and health professionals involved in their care contributed to data. These embedded units of analysis were used to aid understanding of the practice of information exchange in the chosen setting. The specific methods for data collection included key informant interviews, participant observation and documentary analysis and these are described further in the next chapter.

3.6 CHOICE OF STUDY SETTING AND ACCESS
The location I chose for the study was the Salford Health Economy. Salford was chosen as I was employed as a researcher at the time by Salford PCT. My employment therefore, afforded me the opportunity to negotiate the study as a funded piece of work as part of my role at the time. I had previously worked in stroke services in Salford therefore had contacts to facilitate access to these specialist services. This was an important part of the decision process as access is a key issue when undertaking practice based research (Burgess, 1984). The proposal for the study was based on my knowledge of the local stroke population and services gained from my previous employment as a research practitioner in stroke. On the basis of the proposal, Salford PCT financially invested in the project in terms of my salaried time and a further lump sum to support study expenses. Therefore Salford was chosen partly on pragmatic grounds as my previous work provided a level of local knowledge and contacts that facilitated access to study sites and participants.

However, it was also a fertile health economy to recruit suitable respondents for a stroke study as Salford in common with the North West region has an above average incidence of stroke (Drever, 2002). There were 4,000 stroke survivors registered with Salford general practices in March 2006 prior to starting the study (e-mail communication from informatics department Salford PCT). In 2006 the stroke service reported seeing approximately 450 new stroke patients per year of whom 300 survived the acute phase (defined as 1 week post onset of stroke (Langhorne and Duncan, 2001)). Taking into account further mortality over a two year period post stroke, the time period of interest in this study, 500 stroke survivors up to two years post stroke were predicted to be available within the
health economy (verbal communication S.Cross Stroke Specialist nurse July 2007). This afforded confidence that recruitment would be feasible.

I also proposed that Salford was a good choice of setting for the study as it had a well developed stroke service providing the key features of a stroke service as defined by the Royal College of Physicians (Royal College of Physicians, 2004) At the time this study was proposed and started the services provided in Salford included:

- A 10 bedded acute stroke unit (ASU).
- A 18 bedded rehabilitation unit.
- A multidisciplinary rehabilitation team.
- A neurovascular assessment clinic.
- Three follow up out-patient clinics following discharge from both wards. Follow up offered was time limited; a lifetime review service was not offered.
- There were four consultants (making up approximately equivalent to one whole time equivalent consultant) and one specialist nurse in post. The number of consultants was one unusual feature but reflected the research commitments of the lead clinician and the demands of providing a thrombolysis service via the ASU. The unit was research active.
- There was little stroke specialist outreach into primary/community services. Community rehabilitation was provided by the local neuro-rehabilitation team.
- Historically there were good links available with the Stroke Association with two family support worker roles that worked with staff to support families and take an active part in providing information. Immediately prior to the study starting these posts were vacant due to Stroke Association re-organisation but by the time data collection had started they were once again active.

In the 2006 Sentinel Audit of stroke services Salford was in the top quartile of stroke services in terms of delivery on the top 12 key process indicators for stroke practice derived from Royal College guidelines (Royal College of Physicians, 2007). They also had a track record of interest in information provision having previously tested a patient held discharge information booklet and with one of the current stroke physicians undertaking a review of information
provision within the department. It could be argued that this made them in some ways an atypical or unusual stroke service, but a typical stroke service is hard to define as they may vary to meet local demands and depending on the stage of their development. More importantly in considering the needs of my study the setting for the case study needed to be able to generate useful information and accounts of information exchange activity (Simons, 2009). As a more developed stroke service that had developed beyond the point of just delivering basic stroke care Salford afforded this opportunity. An important consideration in selecting a site or setting, which is one level of unit of analysis for the case study, is what it will offer in terms of learning and opportunities to study the phenomenon of interest (Stake, 1995). The potential to increase understanding of the phenomenon is the criteria that Stake (1995) argues should be the primary guiding factor in key choices such as the setting in which the case will be studied.

Yin (2003), the main guide for my study, does have reservations about the use of single setting case design. However, in defence of my choice in this study Salford fulfils two of his potential rationales for undertaking a case study in a single setting:

1. It can be considered a ‘typical’ case (p41) in terms of being a well developed stroke service offering the opportunity to study the everyday situation of a functioning service.
2. It can also be considered ‘revelatory’ (p42) in terms of the level of access I have as an employee and the commitment of local staff to support the project.

Thus it was on this basis that I chose Salford as it offered a fertile ground for learning about the phenomenon of information exchange post stroke for all the reasons I have described above.

I planned to use a range of clinical locations and time points in Salford to gather data about how information was shared to examine the impact of context on information exchange. These included general ward observation, ward rounds, case conferences, goal planning, outpatient appointments, therapy appointments and appointments with primary care staff after discharge. The purpose of this was to get a broad picture of information exchange to elicit the times and places it takes place, the key people involved and the contents of information exchange. I will describe this further in the next chapter.
3.7 STRENGTHS AND WEAKNESSES OF CASE STUDY RESEARCH

Strengths and weaknesses of case study research are summarised in Table 1:

Table 1: Strengths and weaknesses of case study research

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td>In depth understanding of phenomena (case)</td>
<td>Challenging analysis with multiple data sources</td>
</tr>
<tr>
<td>Exploration of relationships/interactions</td>
<td>Easily misunderstood and difficult to describe clearly due to variable terminology</td>
</tr>
<tr>
<td>Studies the real life context</td>
<td>Expensive/intensive use of resource</td>
</tr>
<tr>
<td>Based on latter two is good for service/organisational research</td>
<td>Results not generalisable to populations provides instead analytic or theoretical generalisation</td>
</tr>
<tr>
<td>Can study the unusual as well as the commonplace</td>
<td></td>
</tr>
<tr>
<td>Can build concepts/theories for further investigation</td>
<td></td>
</tr>
</tbody>
</table>

from (Stake, 1995) and (Yin, 2003)

Taking these in to account a key strength of my project was that it took place in context looking at what happens at the time of information exchange post stroke from a number of perspectives. I took this approach in order to acknowledge the different possible constructions (Burgess, 1984) of information exchange: survivor/carer, health professional and policy maker. Acknowledging all these perspectives and drawing them together to reach conclusions/action points was intended to offer a unique contribution to this area of study with previous studies taking the view of one group over another. The hope was to start developing a responsive model of information exchange grounded in the experience of stroke survivors and carers and clinical practice. Case study is strengthened by the opportunity to triangulate different methods (Stake, 1995; Denscombe, 2003). This provided the potential to strip back the assumptions and discourses of different parties on this important topic and contributes to an experiential/empirical basis for future interventions. Each data collection method that was planned: interview, observation and documentary analysis is biased in
presenting one construction of information exchange. Collecting these different types of data together and comparing and contrasting them, taking a questioning approach to all sources I believed would offer a more balanced, less biased view of the topic providing more sensitive, subtle findings to guide future practice and research (Burgess, 1984).

A key weakness of my study was that as a case study, it was a locally specific project and as such would not allow for findings to be generalised in the traditional model of evidence based medicine or ‘hard’ social science. However, this is not the aim in case study research; this was an exploratory study aiming to illuminate an issue in detail in context. What this offers is transferability or theoretical generalisation (Denscombe, 2003). This means that the detailed contextual data offered will allow judgements of its utility for other settings to be made. Flyvberg (2006) argues against the traditional criticisms of case studies as not offering generaliseable data. He places this in the context of an over reliance on the hypothetico-deductive model of social science rather than the inductive model of building theories from experience. Learning from actual experience he points out is crucial to human expertise.

"Context-dependent knowledge and experience are at the very heart of expert activity."

(Flyvbjerg, 2006 p222)

The traditional criticism of the study stands if one accepts the view that only one objective reality is to be found. The study accepts the alternative view and acknowledges multiple truths of experience over and above the single truth of causality that is so valued in evidence based health care. Greater understanding of multiple perspectives is required when dealing with complex phenomena such as information exchange rather than looking for ‘quick fixes’ with oversimplified intervention studies that do not acknowledge the multiple perspectives involved.

**3.8 CONCLUSION**

This chapter has presented and provided justification for the philosophical and methodological choices that were made in designing this study. Within a broadly constructivist framework case study was chosen for its sensitivity and flexibility to study real life complex phenomena. Strengths and weaknesses of the approach were considered and case study was felt to have the best fit to the study’s aim and research questions. The case study strategy decided upon offered flexibility
to work in a practice based setting and gather data to present different perspectives on the case of information exchange in practice and to do this providing enough contextual detail to facilitate the interpretation of results by myself as researcher and by other potential users of the findings. Common elements of stroke care, such as interdisciplinary team working, meant the Salford experience was likely to provide relevant lessons for other services. In the next chapter I will describe how the strategy was made operational in practice, describing the specific approaches taken to gain access to the setting, collect data and complete analysis and interpretation of the data collected.
CHAPTER FOUR: METHODS – APPLYING CASE STUDY STRATEGY IN THIS STUDY

4.1 INTRODUCTION

This chapter builds on the presentation in chapter three of the rationale for selecting case study as the research strategy, the definition of the case, type of case study undertaken and setting for the case study.

In this chapter I present how access to the study setting was undertaken, the specific methods of data collection utilised to inform the case and the data analysis strategies undertaken with the data. Approaches used to ensure study rigour are described. The chapter closes by presenting the ethical issues that were considered and how they were addressed.

4.2 ACCESS

The case or phenomenon under study was information exchange between stroke survivors/carers and health professionals. The study was an exploratory case study using a single embedded case study model after Yin (2003). Within the case study embedded design (Yin, 2003) I considered stroke survivors, their carers, staff involved in their care and documents relating to their care as sources of data for this study, that is as units of analysis used to illuminate the case of information exchange in the setting chosen rather than ‘cases’ in their own right. The choice of setting for the study was described in chapter three. There were several factors making it a suitable setting able to offer plenty of opportunity to learn about information exchange in action which is crucial for a successful case study (Stake, 1995; Simons, 2009). One of these was my previous knowledge of the service and key staff and my status as an employee within the Research and Development department of the health economy which was an aid to negotiating access to the service. Access to the field is a crucial part of the research process and can often be challenging (Simons, 2009). My previous knowledge of the service expedited some of the initial contacts with key personnel to negotiate access as I knew who these personnel were and could e-mail them directly to introduce the study. Whilst some prior relationship with some staff members may have expedited some replies I was not currently working on the unit or in a managerial relationship with any staff so did not feel I was in a position to unduly influence responses or support to the study. As the
study was involving so many sources of data a large number of contacts were undertaken to endeavour to ensure access to all potential areas for data collection. This required e-mails and meetings with the following:

- The stroke consultants
- Director of Learning and Research and later Clinical Professional Leadership
- Deputy Director Commissioning
- Community neuro-rehabilitation team
- Research and Development
- Informatics
- Allied Health Professional and Nursing leads
- Stroke Association
- Local Stroke Research Network

Several of these contacts were started prior to and as part of the ethics and Research and Development approval processes that had to be undertaken and several were ongoing or undertaken after this initial approval process to finalise access to key areas within the setting to collect the data required. Ethical issues and processes will be discussed at the end of this chapter.

The specific methods for data collection used in the case study included key informant interviews, participant observation and documentary analysis. I will now go on to discuss how these were collected in the field. The first step in this was the identification and recruitment of the patient sample.

4.3 SAMPLING AND RECRUITMENT

Due to the qualitative/interpretive approach of the study, non-random sampling was utilised. The aim was to identify a purposive sample (Miles and Huberman, 1994) of stroke survivors able to illustrate a diverse range of post stroke experiences over a two year post stroke period. The two year post stroke period was chosen as this had been highlighted as a period over which information needs change (Hanger et al., 1998) and it was also a pragmatic time frame for accessing enough stroke survivors through their contact with services. The aim of this was to provide opportunity to explore a range of information needs and demand post stroke, how these were addressed by health professionals and/or other services/sources and impacts of whether needs were addressed.
Identifying patients was the starting point of purposive sampling and their recruitment led to the identification of other respondents (samples) linked to the stroke survivor that is their lay or family carer (the person they identified as their key support) and health professionals involved in their care.

I planned to utilise a number of strategies to identify the sample of stroke survivors in order to maximise successful recruitment. These included:

- Screening of stroke inpatients
- Screening of stroke outpatients and
- Screening of selected GP records
- Screening of community neuro-rehabilitation team clients
- Contact with a local support group
- Advertisement at a local charity resource centre BASIC (Brain and Spinal Injury Centre)

Inpatient screening was undertaken with the support of the local Stroke Research Network nurses. They were made aware of the study via e-mail and personal visit. Their role was to undertake routine screening for active studies on the stroke unit, in this capacity the unit considers them as members of the clinical team. During recruitment I was in daily to weekly contact with them to review new admissions and update them as to my studies status for recruitment. Where patients were identified as suitable for approach with me, they would visit the patient to introduce the study and offer a brief information sheet to patients. They would then notify me of who had agreed to take the brief information sheet and I would then visit these patients at least 24 hours later to answer questions and provide a full length information sheet prior to taking consent. This procedure was followed to comply with stroke unit policy and to satisfy NHS ethics guidance that first approach to take part in a study should be from the health care provider not the researcher.

Outpatient screening was done by me in conjunction with clinic staff. I sought the permission of the outpatient senior nursing staff to review outpatient lists and searched these lists to identify patients at different time points post stroke. Once I had identified potential patients to approach for the study I would ask the clinician seeing the patient in clinic to ask the patient if they were interested in taking part in my study. If I were present in clinic I would speak with the patient
before they left providing an information sheet or the clinician would provide an information pack and obtain permission for me to contact the patient by phone after clinic. I would then contact these patients by phone at least twenty four hours after their clinic attendance to discuss the study further and answer any questions. If they were willing to take part we would then agree when to meet to complete consent and data collection. As with inpatient approaches this method was used to respect NHS ethics requirements.

I also visited the community neuro-rehabilitation team (CNRT) to explain the study and engage the help of the Consultant Physiotherapist leading the team to screen patients they were seeing for approach using the same type of method of approach as described for in and outpatients.

Recruiting patients at later time points post stroke was seen as a challenge as they may not be in contact with health services. Recruitment via searches of GP practice lists was planned as one route to recruit patients at a later point after their stroke. Provision of information to a local stroke support group was also undertaken using the group leader as the point of contact to provide information to the group. She would then feedback contact details of anyone interested in taking part. These initial strategies were also supplemented by a poster advertisement at a local resource centre (BASIC) utilised by stroke survivors in order to try to recruit patients no longer involved with clinical stroke services. Staff at the centre agreed to display the approved poster advertisement on their gym area notice board. The poster had tear off contact number strips that survivors could take if they were interested in contacting me to take part in the study.

The aim of all these strategies was to recruit a core sample of ten-fifteen stroke survivors at two to three month intervals up to two years post stroke. Time since stroke was used as the primary driver of the purposive sampling. In addition an even mix of male and female survivors was aimed for, with a mixed age range from 18 years upwards and a mix of stroke types. There were no exclusions regarding stroke sub-type (as presented in chapter one TIA and SAH patients were not sought for recruitment). The purpose was to obtain a sample of patients reflecting varying type and severity of stroke symptom impact. This approach was taken to provide a range of varying experiences of information needs and how these are met up to two-years post stroke. A sample matrix was built up to
track approaches made and actual recruitment to try and balance the spread of patients across the criteria of time since stroke, gender, age and stroke type. The result was that over time patient selection became more and more selective to fill gaps in the sample matrix. The sampling strategy was a pragmatic approach to collect data about information exchange over a two year period post stroke because as noted in the literature information needs may change over time (Hanger et al., 1998). To look at a time period like this longitudinally with individual patients was impractical for the time frame of the PhD and risky due to potential loss of survivors/carers to follow up. The approach taken also limited the demand made on any one individual respondent. In terms of deciding the number of patients to be sought for the sample size unlike in quantitative work this cannot be justified by a power calculation to give a definitive number to be reached. Instead this is decided on by considering the amount and depth of data to be generated from each respondent and the numbers likely to allow achievement of data saturation in terms of generating enough material to answer study questions. The core sample of ten-fifteen patients alongside other linked samples and the range of data types to be collected would generate a substantial amount of data to achieve this and the numbers of participants involved across the patient, carer and professional samples is typical of those seen in qualitative work (Denscombe, 2003).

Stroke survivors were eligible for inclusion if they had a specialist clinician confirmed diagnosis of stroke (any type) with appropriate imaging, they were age eighteen and over, they were able to participate in an interview and give written or witnessed informed consent. Exclusion criteria were language or cognitive disability so severe as to make involvement in an interview impossible, survivors entering the end of life care pathway and those discharged to nursing or rest home where their care needs will be primarily met by professional staff. Consent to examine all recruited stroke survivor’s medical records for any reference to information need assessment, planning, provision and communication was also sought.

The identified stroke survivors were the core sample. Where possible their main lay or family carer was approached for recruitment also. The term carer in the context of this study denotes the lay or family person the patient identified as their key point of support through their stroke no matter what form that support took. The aim of this was to provide their carer’s perspective on information
exchange. The aim of studying related patient and carer experiences of information exchange alongside one another was to allow exploration of whether the two experiences were similar or different in any way to provide detail on how service providers may or may not be able to successfully meet the information needs of these two related groups. Stroke survivors when recruited were asked to identify their lay carer and asked if they were happy for their lay or family carer to be approached. If they agreed to this the initial approach was made through them leaving a carer information pack for them to pass to their carer for consideration. I would then check back with the patient at an agreed time to see whether their carer was happy to proceed and agree the best time and means to contact their carer to discuss the study further and seek their full consent to participate. As carer recruitment was directly linked to patient recruitment the sample size for carers was also ten-fifteen carer recruits. Carers were eligible for inclusion if they were the lay/family primary carer for a recruited stroke survivor, they were aged eighteen and over, able to participate in an interview and to give written consent.

Health professionals recruited to the study were primarily identified by virtue of their involvement in the care of recruited survivors and carers, whilst also aiming to represent different staff groups involved in the care of stroke survivors and carers. Any of the disciplines involved in the interdisciplinary teams spanning stroke specialist and primary care were eligible to take part for example therapy staff, nursing, medical, psychologist, social work, family support worker and health care support workers. The aim was to recruit ten-twenty staff, at least one member of staff per patient but recognising that more staff may be interviewed than patients due to the multidisciplinary nature of stroke care and multiple members of staff being involved with each individuals care. Staff members were eligible for inclusion if they were a health professional/member of the interdisciplinary team involved in the care of survivors recruited or experienced in stroke care in Salford and willing to give written consent for interviews and observation. Written or verbal consent was obtained prior to commencing any data collection. Members of staff were recruited via presentations at team meetings and direct approach in the case of a request for interview. Written consent was obtained for all those participating in a one to one interview. Verbal consent was applied in instances of observations, particularly group observations as the logistics of obtaining a full written consent from every staff member prior
to these would have been prohibitive. Also observations were primarily being used for contextual data and quoted extracts were not anticipated from these.

The approach described was designed to produce enough data to address study questions in the case study context hence it was designed to result in thirty-five in depth interviews with a range of stroke survivors, carers and health professionals, at least one observation session per patient and a review of documentation of information provision in each stroke survivors medical records.

In the next section I will describe the specific types of data collection that were undertaken with the different respondents described.

4.4 METHODS OF DATA COLLECTION

Mixed qualitative data collection was undertaken. The three types of data collection used were key informant interviews, observation and document analysis; these are all commonly used sources of evidence in case study research (Stake, 1995; Yin, 2003; Simons, 2009). This approach was used to enhance rigour by triangulating data (Stake, 1995; Denscombe, 2003) to provide as full a picture as possible of the interactions, perceptions and processes that take place during information exchange post stroke, and to capture both public and private accounts of information exchange in action. Triangulation can occur at several levels, in the current study it occurred at the level of data and methods (Adami and Kiger, 2005; Williamson, 2005). Data triangulation will occur by the use of different time points post stroke and different respondents and methodological triangulation will occur by the use of interviewing, observation and document analysis in conjunction. The use of triangulation in qualitative methods is advocated to produce deeper understandings from the research. This is not so much a ‘convergent’ function of triangulation as seen in quantitative methods but a ‘completeness’ function (Adami and Kiger, 2005; Williamson, 2005). The use of different methods and sources of data and comparing of results can be used to encourage criticalness and scrutiny of results that can contribute to rigour (Williamson, 2005). Adami and Kiger (2005) emphasise the importance of being clear about the purpose of using triangulation. In the current study it will serve to:

- enhance ‘completeness’ and deepen analysis
- enhance trustworthiness
• contribute to overcoming deficiencies in each individual data collection method used.

(Williamson, 2005)

The sources of data undertaken in the study are summarised in Table 2:

**Table 2: Sources of data collection**

<table>
<thead>
<tr>
<th>Data type</th>
<th>Who collected with and how collected?</th>
</tr>
</thead>
</table>
| Interviews | • With stroke survivors, stroke carers and health care providers.  
• Semi-structured using topic guides.  
• Held in a private venue most convenient for the respondent.  
• Audio recorded with consent of the respondent and transcribed verbatim for analysis. |
| Observation | • Undertaken with stroke survivors, carers and health professionals.  
• General, that is not specific to recruited survivors these were familiarisation observations completed in hospital clinical areas to collect general data about the clinical context and test out observation methods. These allowed me to get used to observation and for staff to become familiar with it.  
• With specific stroke survivors further observation was undertaken of clinical interactions aiming to complete at least one observation per patient.  
• Data from observations were recorded by a combination of field notes and audio recordings, the latter were transcribed verbatim. Observation data included discussion with participants about their impressions of events observed. This was completed immediately post observation. |
| Documents | Read and review of:  
• Medical notes paper and electronic, particularly focusing on documentation of key points for information exchange for example ward rounds, case conference, goal planning, outpatient appointments and discharge letters.  
• Guideline documents for example NSF, RCP guidelines for references to information provision, its purpose and how it should be delivered. |
4.5 KEY INFORMANT INTERVIEWS

Interviews in their many forms, structured, unstructured and open-ended, are one of the most popular research tools of social researchers (Fontana and Frey, 1998). This is in part because of their familiarity for both respondent and researcher being an easily recognised medium of conversation that we use and witness in day to day life (Holstein and Gubrium, 1995). With skilled questioning and listening, they are the vehicle by which respondents voice their perspective on the phenomenon of interest. The interviewer must also be aware of their perspective on the phenomenon and how this interacts with that of the respondent through the course of the interview remaining sensitive to avoiding leading or favouring topics (Holstein and Gubrium, 1995). A bias inherent in interviewing is that respondents may be dishonest giving an account either of a view they want to present to the outside world or that they think the researcher wants to hear. This was addressed during interviews by using open questions, encouraging respondents that no right or wrong answers existed but that the experience they had was of value and probing for additional information and sometimes repeating a question in a slightly different way to check responses for consistency (Denscombe, 2003). In this study particularly interview data was also balanced by the use of observation and document analysis that offered a record of actual public behaviours which could be compared and contrasted with personal accounts (Williamson, 2005).

The interviews undertaken with stroke survivors, carers and health professionals were semi structured. Interviews were used as a primary source of data collection because of my interest in eliciting the expectations, perceptions and interpretations relating to information provision post stroke of the different groups involved. Topic guides were developed from the research questions of interest in the study and these were derived from my issues of concern or propositions in the study (see Appendix 10). The schedule started by asking for personal accounts of either the stroke event experienced or work with survivors. More probing questions about information exchange accounts were introduced as these were mentioned to focus the discussion on the details of information exchange pertinent to answering questions about how, when and why this took place. Perceptions of impact and what worked or didn’t work were also explored. If spontaneous accounts were not forthcoming specific time points would be asked about to generate discussion on the topic. Thus the topic guides were used as a starting point and guide for each interview but the form and order of
each interview was always responsive to the account of each respondent. Questions were asked about information sought/delivered, place/context, mode of delivery, motivations in sharing, desire to share, readiness to share and participants' thoughts on how best to evaluate the success of information exchange. The topic guide for interviews was used flexibly as an aide memoire during the interview process. Respondents were asked to talk openly, initially about their stroke and connections made with the topic guide questions as references to information received or sought were made. Taking this approach sought to progressively focus the interview or conversation on the topic of information as discussion progressed. The topic guide was therefore to hand but not followed rigidly and generally only referred to towards the end of discussions, to check if there were any areas for further question and discussion. Over the course of the study, particularly with stroke survivors and carers, it became apparent that information was not always a foreground topic for them nor something they naturally engaged with. This lead to the exploration of other related topics such as the role of support and challenges around engaging with information sought and provided. The topic guide was not formally adapted but topics were added as hand written notes to the guide as the study progressed. This was done when a new guide was printed for each respondent. The topic guide sheet was used as a place to make notes of pertinent points, either briefly during interviews or in more detail immediately afterwards. Such notes might entail a general feel of how the interview had gone, any areas of difficulty engaging with the topic and any new or interesting topics that arose.

All interviews were held in a private venue most convenient to the respondent. They were audio recorded with the respondents' permission and transcribed verbatim. I transcribed three initial manuscripts myself to gain insight in to the process but due to time constraints the bulk were undertaken by a professional transcribing service. Quality of transcription was checked by listening to recordings when first reading the transcript through

4.6 OBSERVATION
The purpose of undertaking observation work was to capture actual behaviour in response to information seeking and provision and consider this in the analysis alongside individuals stated views and beliefs on the phenomenon (elicited from interviews).
Participant observation was carried out at key opportunities along the patient journey when information around diagnosis, prognosis, progress and plans were normally shared. The role undertaken as observer was as participant-as-observer (Gold, 1957/1958) or in terms of membership roles as a peripheral-member (Adler and Adler, 1987). This was feasible as I have a clinical background so had knowledge of the areas where observations took place but I was not undertaking a clinical role through the study.

Substantive field notes (Burgess, 1984) were recorded during or as soon as possible after observations. These recorded the individuals present and verbal and non-verbal interactions witnessed. Other specific points of observation were the content of information shared, who led exchanges, opportunities for checking information/understanding and methods utilised for supporting recall/review of information. As with the interview guides these areas of interest came from my research questions derived from clinical experience, literature and policy. A field note prompt sheet was designed as an aide memoire particularly for completing notes immediately post observation (see Appendix 11). I also endeavoured to remain aware of any impact my presence may be having on interactions in relation to noting if I was drawn into discussion, if non verbal attention was paid to me or any other feedback or comment made about my presence. This is something that must be monitored as it acknowledges a known risk of observation that the presence of the observer may have an impact on behaviour (Denscombe, 2003). However in a naturalistic study the key is to be aware of the potential for this and record any impressions of it rather than to seek to control it. Field notes and any audio recording transcripts from observations were used in conjunction for analysis.

4.7 DOCUMENTARY ANALYSIS

Written text or documents are an enduring record of a phenomenon at a point in time (Hodder, 1998). They are man-made and offer insight into what individuals deem important to record about something and may represent the influence of both personal viewpoint and contextual influences. The data they present has to be interpreted by the researcher as they are an inanimate source of data and there is no interaction with the writer of the document. Though in this study, questions were asked of staff regarding their behaviours in relation to recording information provision activities in clinical notes and communications.
Documentary analysis undertaken in this study included:

- medical notes (paper and electronic)
- letters
- information packs
- and policy guidance on information provision.

The aim was to identify the standard guidance given for information sharing, this was discussed in the literature review, policy documents were not put through a line by line summative content analysis but critically appraised to summarise the best guidance/directives for information provision published at the time of the study and so potentially influencing practice.

Documentary data collection in the field aimed to find what evidence was provided in formal records of efforts made to provide information. Both electronic and paper records were reviewed to document clinical recording of information provision. A structured proforma had been envisaged to facilitate the review process of medical records however; a shorter aide memoire was ultimately used (see Appendix 12). The aim of reviewing medical records and communications was to seek out any evidence of professionals recording information provided in order to see if this could be an aid to team approaches about information exchange.

4.8 DATA ANALYSIS

Clarity about how different data sources will be used and analysed is important in case study research (Yin, 2003).

Qualitative data analysis strategies seek to reduce/translate large quantities of text into a manageable number of categories without too much loss of quality description and insight into the phenomenon under study (Weber 1990 in Miles and Huberman, 1994; Hsieh and Shannon, 2005).

My study was a qualitative case study from a constructivist perspective. The requirement was to try and make sense of information exchange post stroke from a number of perspectives in one setting/context. Then, through my interpretation of comparing and contrasting these perspectives offer insights in to the dissatisfaction reported with information exchange in the literature. Hence,
the overall driving aim of the analysis was to identify areas of consensus and
divergence around expectations and motivations that underpin information
seeking and provision and through this to offer guidance and clarify the role of
health care professionals in facilitating information provision.

I required an analysis strategy that could identify the key responses or parts of
textual data and offered flexibility to work with different sources of data that is
interview data, observation data and documents. I also required an approach
that could deal with a large amount of data and embrace the practice based and
theoretical ideas I came to the study with a priori as well as remain open to
identifying any new ideas in the data collected.

I therefore chose to use content analysis. Hsieh and Shannon (2005) define
content analysis as:

“...a research method for the subjective interpretation of the content of text
data through the systematic classification process of coding and identifying
themes or patterns.”

(Hsieh and Shannon, 2005 p1278)

They describe its purpose as being ‘to provide knowledge and understanding of
the phenomenon under study’, this fitted with the aim of a case study approach.
However, content analysis encompasses a broad spectrum of techniques; it can
range from counting words to looking at the characteristics of language and its
use in context. Hsieh and Shannon (2005) describe three approaches to content
analysis conventional, directed and summative. Conventional content analysis is
used when little is known about the phenomenon under study and coding and
analysis starts directly with raw data drawing codes from the data to build
analysis up from the raw data. In directed content analysis there is more known
about the phenomenon and a priori and theoretical ideas produce initial codes to
be applied to the data though generation of further codes from the data itself can
go alongside this. In summative content analysis a more quantitative approach is
used to search for specific terms in text and examine their usage.

These ideas clarified my thoughts about the principles to be achieved by content
analysis and with these ideas in mind I looked at The Framework Analysis
approach of Ritchie and Spencer (1994) as a set of guiding procedures for the
thematic content analysis I needed to undertake. Framework Analysis was
developed in the applied policy research field of social science. It therefore allows for the acknowledgement of the knowledge and preconceived issues of the researcher as well as the identification of respondent concerns. This fitted well with the case study methodology allowing the ideas reflected in study propositions and questions to be acknowledged as part of the analysis. This plus the approach’s ability to facilitate work with multiple types of data and its focus on producing results with real world applicability made it the analysis strategy of choice for the study. On a practical note I also had local access to researchers who had worked with the method to guide and help me.

Ritchie and Spencer (1994) highlight the aims of applied qualitative research:

- a requirement to meet specific information needs
- potential for actionable outcomes
- the provision of insights, explanations and theories of social behaviour.

The objectives of qualitative research they describe include the following:

- Contextual
- Diagnostic
- Evaluative
- Strategic

Contextual objectives are about identifying the form and nature of what exists. For example what is the nature of people’s experiences? What are the needs of the population? What elements operate within a system? Diagnostic objectives seek to examine reasons for or causes of what exists such as why decisions or actions are taken or not taken, why particular needs arise, why services are or are not being used. Evaluative objectives appraise the effectiveness of what exists, what affects successful delivery and what barriers may hinder systems operating. Strategic objectives look towards identifying new theories, policies, plans or actions for instance the type of services that are required to meet needs, how systems can be improved what actions are needed to make programmes more effective.

Framework is espoused as an explicit methodology to support transparency and accountability in analysis to achieve functions of defining concepts; mapping the range, nature and dynamics of phenomena; creating typologies; categorising
different types of attitudes, behaviours and motivations; finding associations between the latter; seeking explanations explicit or implicit and developing new ideas, theories or strategies. The method has proven flexibility for a range of different studies and has been used for in depth group interviewing, longitudinal studies, case studies, projects involving different groups of participants (allowing between and within case analysis) and to aid joint working where a team of researchers is working (Ritchie and Spencer, 1994).

I therefore chose to use Framework Analysis as it offered a flexible approach able to accommodate the different groups of participants involved and types of data generated. It provided a structured and transparent enough analysis approach to ensure that Yin’s (2003) requirement for clarity about how different data sources will be used and analysed was met and would support the rigour of the study by providing clear processes for analysis. A clear approach to analysis would also aid the accessibility of findings to a practice based audience. Importantly it also allowed the acknowledgement of a priori questions and ideas that I brought to the study to be built in to analysis up front so these could be verified, modified or refuted as part of the analysis process.

Ritchie and Spencer’s (1994) Framework Analysis encompasses five stages:

- Familiarization
- Identifying a thematic framework or index
- Indexing
- Charting
- Mapping and Interpretation

These are now described.

**4.8.1 Familiarisation**

This involves a period of data immersion in order to become familiar with the range and diversity of the material gathered. In this study as a single researcher this process started in the actual interview process as I completed all the interviews myself and in the recording of notes on my initial impressions post interview. Then interview recordings were listened to again and interview transcripts reviewed alongside the background observation notes and transcripts that provided the contextual data for the experiences recounted. This is an
iterative process guided by study questions and propositions. The starting point is the first impressions formed about key issues as data are collected. These are then taken back to the data to check these against accounts whilst at the same time identifying other issues that come up across the material as a whole. This can be done for all study data or if there are different groups as with the current study this can be done for each. I chose initially to do this for each key informant group separately to be sure to identify the issues of pertinence to that group before bringing the issues for different groups together to look at common themes and areas of divergence. The end result of this stage is a list of key ideas and recurrent themes that forms the basis of the next stage identifying a thematic framework.

4.8.2 Identifying a Thematic Framework
The familiarisation process that is the first stage of Framework analysis is the start of the abstraction and conceptualisation process of qualitative analysis. The lists and notes made of key issues, concepts and themes form the basis of the initial ‘thematic framework’ or coding index that can then be taken back and applied to the data to sift and sort the data in to themes that address study questions. Again this is an iterative process and additions or changes may be made to the index as it is applied. The final coding index derived is presented in Appendix 13.

4.8.3 Indexing
So from familiarisation a provisional thematic framework is derived and this is used to index or code the hard data from interviews. This can be done using paper copies or as in this study using qualitative data analysis software. I elected to use maxQDA software (MAXQDA, 1989-2012) following attendance at a general training session on different CAQDAS packages. Different packages have different strengths and weaknesses but are common in their purpose as a tool to support analysis aiding the tracking and recording of analysis decisions. I chose maxQDA as I found the computer interface more intuitive and could visualise how I would use this with my data. I undertook further specific training for max QDA. The software was used to develop and apply the index of codes. This, as with other parts of the analysis, is an iterative process involving rereading and reapplying the code index until satisfied that all key and informative data has been captured within the index. The software also made it easy to extract sections of data coded under different parts of the index once this
had been applied, and so was able to collate data in code groups and so support the move to the next section of the process charting.

4.8.4 Charting
In moving to charting the maxQDA software was invaluable as it allowed the collation and extraction of all segments coded under the same themes/headers quickly and efficiently. These were then read to summarise the material under each theme for each respondent and these summaries were then transferred on to matrices or charts produced in excel. A chart for each main theme header and sub themes was produced. Direct quotes were not transferred on to the chart but rather a synthesis or summary of what was said with reference to possible quotes. This move to summarise data on charts is classical to the Framework approach and is seen as the start of the move towards more conceptual interpretation of the material. Critically for the present study charting allows comparison of thematic content across respondents and gives a sense of the density of references to different themes.

4.8.5 Mapping
There is least said about how to conduct this stage of the process but it is here where final conceptual work is carried out to interpret data. Charts are reviewed and interrogated to identify categories amidst the data to identify connections, patterns and propositions to explain what has been observed or heard. Some guidance is offered by Ritchie and Lewis (2003) who suggest listing categories in further tables. This approach was adopted and adapted as analysis progressed. An example of a section of a table used for this is given in Appendix 15. As analysis progressed I required a way of working dynamically with categories identified by this process so I could sift and sort them to make links between them. This was done initially by transferring categories in to a Microsoft Word document for sorting but overtime I found using post it notes and large pieces of paper to move categories around and link them proved more user-friendly. So this was undertaken to gather common categories and related groupings of categories together under question derived headers that formed the basis of the results presented in later chapters. Seeing categories visually linked also helped develop concepts for more detailed discussion in relation to the literature.
4.8.6 Analysis of observation and documentary data

The approach taken to observation was unstructured taking an open and flexible approach to data collection. As described earlier this combined audio recordings and field notes to record interactions of interest and their nature and content. Such an approach can be used in single case study work looking at complex social phenomena such as information exchange (Pretzlik, 1994). Audio recordings and field notes from observations were fully transcribed or typed up; hence observation data was narrative in nature. In line with the unstructured nature of the observation data collected a qualitative content analysis was undertaken with the data (Ashworth, 1994). The data was analysed to offer insights into how and when opportunities were used for information exchange and whether respondents’ accounts of their behaviour could be matched to observable behaviour. Whilst not subject to the same level of line by line coding and analysis as interview transcripts, the narrative observation data was read through on several occasions to provide contextual information for respondent accounts. Sections of interest were highlighted to be linked to main themes identified within accounts of respondents. Therefore observation data was reviewed for relevant examples to link to the accounts of behaviour and preferences by respondents. Transcripts of interactions between survivors/carers and professionals were also examined for who took the lead in exchanges and the relative amounts of time spent interacting by the different parties involved. The aim of this was to assess any dominance in interactions and to look at the degree of two way interaction or equality within exchanges.

A more summative content analysis was undertaken with documentary data (Hsieh and Shannon, 2005). There were two elements to documentary analysis. First was the approach taken to policy guidance and second the approach taken to survivor specific written records. Guidance documents were searched for the key word ‘information’ to identify specific references to and guidance offered on the topic of providing information. This material was appraised within the literature review and provided detail of the policy context of activity undertaken. Survivor’s written records were read for the presence or absence of references to providing information and what this entailed when present. Data were recorded on hand written sheets guided by the aide memoire in Appendix 12. This was then compared with professional accounts of the use of medical records to record the exchange of information with survivors and carers. The areas of notes checked for records included: information checklists, relative
meeting sheets, clinical notes, discharge summaries and clinic letters. Any more complex analysis other than a noting of presence or absence was not required due to the paucity of references to information exchange at all within medical records.

4.9 RIGOUR

Establishing rigour in a qualitative study is about ensuring the quality of the conduct of the study and furthermore the trustworthiness of the findings (Koch, 1994). Trustworthiness is about producing believable and plausible results and documenting how these have been reached.

The idea of trustworthiness in qualitative research can be compared with the concepts of reliability and validity in quantitative work. Koch (1994) does this based on Guba and Lincoln’s (1998) criteria of credibility, transferability and dependability (see Table 3).

Table 3: Comparing Elements of Trustworthiness with Reliability and Validity

<table>
<thead>
<tr>
<th>Meaning</th>
<th>Constructivist</th>
<th>Scientific</th>
</tr>
</thead>
<tbody>
<tr>
<td>Truth values</td>
<td>Credibility</td>
<td>Internal validity</td>
</tr>
<tr>
<td>Applicability</td>
<td>Transferability</td>
<td>External validity</td>
</tr>
<tr>
<td>Consistency</td>
<td>Dependability</td>
<td>Reliability</td>
</tr>
</tbody>
</table>

(Koch, 1994)

Koch’s paper provides an overview, with examples, of how the elements of trustworthiness may be delivered. Credibility is about producing faithful descriptions with a view to readers recognising experiences. This requires self-awareness of the researcher by describing their own experience and interpreting this alongside the analysis of collected data. I endeavoured to take this approach by describing my own clinical background, using study propositions to define my early ideas and using interview and field notes to record reflections and developments along the research process. Consulting participants about the analysis undertaken called member checking (Lincoln and Guba, 1985) may also serve as a quality check on researcher interpretations. However, this was not carried out in this study because of pragmatic considerations of the duration of the study and the potential burden and difficulties of respondents in reading and reviewing their transcripts. Therefore the analysis presented represents my own
construction of the activities observed and accounts witnessed. As an alternative
to member checking and to aid rigour, my supervisors read transcripts and
reviewed developing analysis, in order to offer critical feedback on interview
technique and concepts arising and so stimulate my own critical reflections on
the analysis undertaken.

Transferability entails detailed description of context to allow research
consumers enough information to judge the meaningfulness and applicability of
the work to their own setting or experience. This was provided in the last chapter
detailing the choice of study setting, the stroke population served and services
provided. Also in the presentation of the results verbatim quotations are offered
to illustrate findings in a way that hopefully produces resonance for readers in
assessing the transferability of findings to their practice.

Dependability is addressed by striving to produce an auditable decision trail that
documents the process and key decisions taken by the researcher in such a way
that another researcher could follow the same steps and produce comparable
findings. This has been addressed by the account given in this and the last
chapter of methodological choices and actions carried out. During study conduct
this was supported by recording of field notes and analysis notes. As described
earlier the Framework approach to analysis was used because of its structured
stage by stage approach that provides an auditable trail to demonstrate
accountability in how analysis has produced the findings presented.

Another contribution to the quality or rigour of the study is a particular strength of
case study research that is the use of multiple methods of data collection. This
provides the opportunity for triangulation of methods to overcome potential
biases in individual data collection methods (Williamson, 2005). The use of this
in the present study was described earlier in this chapter in section 4.4.

4.9.1 Reflexivity
Another contributory factor to rigour in qualitative research is the reflexive
account of the researcher demonstrating their awareness of the impact of
themselves and their experience on data collected and analyses developed from
the data (Mason, 1996; Gibbs, 2007). Reflexivity addresses the researcher’s
conscious awareness of potential biases, values and experiences that they bring
to a qualitative research study (Cresswell, 2007). A key issue in my study was
my previous experience as a practitioner in the stroke setting. As such I was not
coming to this topic naïve or without views and experiences of my own. Giving
an open account of the personal characteristics, professional and research
experience of the researcher and describing the nature and extent of
relationships and interactions with study participants, is key to addressing
reflexivity and rigour and aiding readers in the interpretation of findings (Chew-
Graham et al., 2002; Tong et al., 2007). In the reporting of this study I have
sought to address this by providing details of my career history and describing
initial study propositions synthesised from my experience as a practitioner and
my reading of the literature. A purpose of propositions is to offer a sense of
direction or focus to case study research in order to document the starting point
of ideas and act as a reference point for how these evolve over the course of the
research undertaken (Yin, 2003). These and study questions are then brought to
the data collected critically, avoiding forcing data by pursuing a priori ideas if not
supported by the data, and being sensitive to emerging ideas and themes from
respondents. This process was supported by the analysis approach chosen
which was Framework Analysis (Ritchie and Spencer, 1994) which offers an
iterative approach particularly to early stages of coding the data. This
encourages critical reflection of the coding framework developed, to only
maintain a priori ideas supported by the data and bring in new ideas generated
from the data. This was achieved and supported by reviewing and revisiting the
coding framework with my supervisors who brought both specialist stroke and
information provision knowledge to their critique of emerging codes and themes.
There was a definite recognition over the course of analysis of information
provision as an independent topic having less direct relevance or significance to
patients and carers. They did not talk of it in isolation from other issues such as
support. To some extent this was a difficult realisation to make as I had come to
this topic with a health professionals desire to seek a solution to issues of
dissatisfaction with information provision. However, the data suggested
solutions would likely be more complex or multidimensional than my prior
assumptions had led me to believe.

Another key issue to consider reflexively when entering an area in your own field
for data collection is to be aware of how one is viewed by respondents and any
potential perceptions about power relations. Respondents may perceive you as
either an ‘insider’ or ‘outsider’ and in turn this may impact on what is revealed to
you during the course of data collection (Hammersley and Atkinson, 1995). I was
entering a field and setting where I had worked previously however at the time the study started I had been away from the setting for two years and was not employed in a clinical capacity. I did not have any managerial or even direct working relationship with any staff involved. I had no clinical contact with any survivors or their family members and was introduced to them via staff managing or previously managing their care. I consciously chose to work in an area known to me to ease access issues and this was described earlier in this chapter. In the context of data collection my prior experience worked to my advantage too, as I was seen as an informed yet independent researcher in the field and this resulted in open and frank accounts, particularly from staff, about the challenges of providing information effectively and consistently. Therefore my prior experience afforded me insider advantages in terms of negotiating access, identifying opportunities for observation and gaining the trust of participants. However, the fact that I wasn’t currently a practitioner in the setting reduced the conflicts that can arise during observation in one’s own clinical setting. The latter may entail temptation to intervene or change practice, becoming too immersed or involved in the field under study sometimes referred to as ‘going native’ (Hammersley and Atkinson, 1995). My time away from the setting allowed me to come back in to the setting with familiarity yet with some distance from the events observed.

I have described my role as a participant observer in the setting. I defined my role thus because I was visible to study participants during observations and had sought their consent to be present, explaining in broad terms my intention to study communications around providing information. Therefore an awareness of my presence was inevitable with the inherent risk of potentially changing behaviour that was observed (Hammersley and Atkinson, 1995; Mason, 1996; Cresswell, 2007). Several measures were taken to try to reduce the impact of my presence. I would use my knowledge of clinical areas and practices to make observation as unobtrusive as possible. This was easier in group observations such as ward round and case conference, than in more one to one scenarios of out-patient consultations or home visits. Multiple observations were undertaken, some specific to survivors and some more general, to aid professionals in getting used to my presence. Participants did not have knowledge of the more specific issues I would look at as part of observation and I would not take notes till after observations were complete and I was out of sight of participants. When audio recording communications observed this was done discreetly to avoid making
staff overtly aware of the device and avoid disruption to their routine activity. During observations I would endeavour to remain alert to any behaviour that might be unusual or represent alterations in behaviour and I would note this in field notes including any references made to myself during observations or attempts to draw me in to conversations taking place. The latter only happened on a handful of occasions and always in the context of observations of one to one communications, where it was sometimes harder to blend in to the background. Debrief conversations were conducted with participants as soon as possible after observations, to ask about their feelings of being observed and their thoughts on exchanges that had taken place and how these had gone. This also offered insights into how conscious participants were of my presence. Several professionals commented that they felt quite used to being observed, as many had teaching roles in the context of their clinical duties, and felt little difference between my presence as a researcher and that of having a student or colleague present. This does not rule out the possibility that professionals in particular put on their best behaviour; however, this is still a valid observation as it offers a representation of what they think to be best behaviour and is likely to be part of the spectrum of behaviours exhibited in everyday practice.

4.10 ETHICS AND GOVERNANCE

In common with any other piece of research general principles of ethical conduct had to be considered. These principles are:

- Beneficence (balancing potential benefits with risks and burdens of taking part in the study)
- Respect for persons (the right to be fully informed and self determining in one’s decision to participate in a study)
- Justice and fair treatment (that is fairness and equity in selecting participants and protecting their right to privacy).

(Polit and Hungler, 1999)

Orb, Eisenhauer & Wynaden (2001) discuss the consideration of ethics specifically in relation to qualitative research. They note that ethical issues in qualitative research are often more subtle as risks to participants are less severe or overt. The key issues relate more to relationships and power relations. With the aim of qualitative research being to describe the phenomenon under investigation from participants’ points of view through interview and observation.
there is a need for open and clear explanation to build open relationships in the
cconduct of the study. This is required for trust to be placed in the researchers
listening to, observing of and interpretation of experiences encountered. This is
important both for participants and consumers of the research. The starting point
for this is in the design of the study trying to anticipate issues that may arise and
having strategies to deal with them. Issues to address in study design include
how participants will be identified and approached, how consent will be obtained,
how confidentiality or privacy will be protected and management strategies for
clarity with respect to the researcher participant relationship, data generation and
analysis and how findings will be reported.

These issues were addressed in the design of the study protocol and subjected
to external review by the requirement to submit an application for NHS ethics
approval. This was undertaken successfully attending the ethics committee in
order to be available to answer any queries. The ethics committee particularly
focus on the ethical concerns addressed in this section of the chapter in their
appraisal of the study. The study also had to go through formal NHS R&D
approval at the same time to ensure that the local NHS organisations were
happy for the study to go ahead. This appraisal also looks at issues of risk,
competence, and burden on participants including impact on services. This does
not take the form of a formal meeting as with ethics but satisfactory responses to
reviewers comments are required before the approval process can be completed.
Both NHS and R&D approvals were obtained without significant changes being
requested.

Taking the ethical principles in turn I will now discuss how issues were
addressed in the current study.

4.10.1 Beneficence
The case for the value of this research was made in the literature review with a
need for greater clarity about experiences of information exchange in order to
guide any future intervention design. As the research was qualitative and non
interventional, risk of harm was low. There was potential for distress to occur
during interviews as discussion of and reflection upon stroke experiences would
be part of this. However, as a clinician experienced in working with this group I
had the skills, experience and contacts to deal with this in accordance with the
wishes of participants. There were times of distress in interviews and where this
occurred the opportunity to stop the interview was always offered but this was never taken up other than for a brief rest before resuming the interview.

4.10.2 Respect for Persons

The voluntary nature of the research was made clear to all participants both in study information sheets and during all verbal explanations. Information sheets made clear to stroke survivors and family members that there was no direct benefit to them in taking part and that any findings may only help future stroke survivors. This was to address directly the issue of ‘therapeutic misconception’ (Savage, 2006) where participants may assume there is some definitive benefit to research participation. Equally it was made clear that deciding against participation would not impact any care they were receiving. Participant information sheets were devised using the current (at the time NHS ethics guidance) with respect to content and addressed issues above relating to weighing risks and benefits, how potential participants had been selected, their freedom to participate or decline and contact details should they require further information or wish to raise any concerns or complaint. These were a crucial part of the informed consent process for participants. All participants who took part in study interviews signed a consent form to document their consent to take part in the study. Again NHS ethics guidance was followed in the design and completion of this document (reference copies of information sheets and consent forms are included in appendices one to nine). All stroke survivors and their identified carers signed a consent form as all these participants completed an interview. However not all staff completed a written consent form due to practical constraints where several staff members may be present around the time of observations. However, health professionals were made aware of the study I was undertaking at its outset, information sheets were available to them in clinical areas and I would introduce myself on specific occasions in question and check before and after observations that they were comfortable with my presence. Thus on moral grounds I did not feel any deception or duplicity was taking place, no direct quotation or citation from these observations from these staff would occur so I felt this honoured key principles of informed consent whilst overcoming the practical logistical problems of obtaining a written consent from every staff member involved even in a peripheral way for observations. All staff that completed an interview or observation where they were the sole staff member present completed a consent form as on these occasions I needed to
be sure staff understood how data would be analysed and that anonymised quotes may be used to illustrate results.

In addressing issues of self determination and autonomy in taking part in research stroke survivors can be a vulnerable group. Savage (2006) discusses these issues at some length in relation to both acute and rehabilitation research. The vulnerability lies in the potential for issues with decision making capacity (due to communication deficits and executive function deficits) and particular susceptibility to therapeutic misconception due to the sudden impact of the stroke and intense relationships with clinicians.

When dealing with vulnerable groups the risks and benefits to research participation need to be carefully weighed. Such groups should only be involved when it is necessary to answer the research questions and any potential benefit outweighs the risk involved. In this study only stroke survivors could give their perspective on the topic of information provision and every effort was made to minimise and manage any distress that arose. In practice this did not seem to be a significant issue and most participants seemed to enjoy their opportunity to discuss their experiences. The major ethical issue in recruiting stroke patients is that of decision making capacity in relation to consent. The communication and cognitive deficits common in stroke may affect the elements of decision making used in the consent process these are understanding, appreciation, reasoning and making a choice (Savage, 2006). Savage (2006) advocates expert review for assessing decision making capacity. In this study this issue was tackled by working with the stroke research network team and clinical teams to approach patients. Both NHS ethics and local service requirements defined that a first approach had to be by a clinician/clinical team member and professionals screening for my study took into account language and cognitive assessments made clinically to guide the assessment of the potential participants’ ability to participate effectively in an interview. I had also negotiated the support of a speech and language therapist should specific communication support assessment be required. As I had to complete the consent process separately from the initial introduction of the study by clinicians I feel this means of introduction meant that I was perceived as separate from their clinical team and so addressed potential issues of therapeutic misconception. For patients with whom I had contact over several weeks I would revisit their consent with them checking they were still happy to continue and making clear that at all times they
were free to withdraw without negative repercussions on their care (Polit and Hungler, 1999).

As Orb, Eisenhauer & Wynaden (2001) state power relations need to be considered in qualitative studies. I used old clinical contacts to help gain access to the setting but had no direct clinical role with patients or direct managerial role with staff so I did not feel any sense of direct coercion was a risk. A more general sense of obligation to participate in research was a risk as the study was taking place on a research active unit, but I could not control the effect of this general unit ethos, other than by remaining alert to any reticence or contradictory communication when explaining the study and taking consents.

4.10.3 Justice and Fair Treatment

In drawing up inclusion and exclusion criteria for the study I tried to be as open as possible so as many patients as possible would have the opportunity to be approached to take part. The sampling strategy used was a purposive one in order to recruit stroke survivors at different time points up to two years post stroke. As described earlier recruitment used several routes and strategies in order to be as inclusive and fair as possible. A matrix was drawn up for this so that as it filled I was aware of the time points I needed to recruit patients to. Whilst actively recruiting I would be in regular contact with teams assisting me to try to ensure that I did not miss potential participants.

In terms of protecting confidentiality participation in the study could not be kept entirely confidential from professional teams due to the initial procedures of approach prior to consent required by ethics. However this did protect confidentiality with respect to my access to personal data as I did not have direct access to personal data for screening but worked with clinical teams to do this. Therefore my access to patient data was limited until participants consented to share this with me via the consent process formally, thus offering protection in line with the Data Protection Act 1998. Specific access to personal data was sought as part of the consent process. Once recruited to the study participants were allocated a unique identification code, this was used to identify their data so they were not named directly in any data transcripts. Transcription was undertaken by professional transcribing agencies with privacy/confidentiality agreements. Any references to named individuals were removed from transcripts once received and reviewed. Personal data linking respondents to their
identification code was kept in a locked filing cabinet separate to other study data and only accessible to me. Anonymised data was stored on password protected computers and in a locked filing cabinet accessible only to me. Therefore, stored data transcripts were kept securely in accordance with University of Manchester data protection policy.

4.11 CONCLUSION
This chapter has described how the case study strategy chosen was applied in practice in this study. This has included the specific actions for gaining access to the setting, sampling and recruitment strategy, data collection methods and approaches for analysis. The strategies employed for ensuring rigour and addressing ethical issues have been discussed. The next chapter will describe the samples and data obtained descriptively before presenting results from data analysis of different types/groups of data.
CHAPTER FIVE: INTRODUCTION TO THE RESULTS

5.1 INTRODUCTION
This chapter serves as an introductory chapter to the results section of the thesis. It will present a description of the participants that made up the study sample, reflections about the methodological choices made and how they worked in practice and an overview of the different types of data that were obtained. The chapter will also outline how the different types of data contribute to the thematic data presented in subsequent chapters.

5.2 SAMPLE OBTAINED
Participants (stroke survivors, carers and health professionals) were recruited to the study during the data collection period December 2007 to September 2009. The methods used to do this were described in the previous chapter. All stroke survivors were recruited via their contact with acute and rehabilitation stroke services within the health economy under study. Some stroke survivors recruited via outpatient contact sources had received their acute care in other neighbouring hospitals but then been referred back for local rehabilitation and follow up. This did not exclude them from participation as it is reflective of real world everyday practice and illustrates the issues encountered when transferring between health care providers.

The participants contributing to the study were:
- 13 stroke survivors (46% male, 54% female - Mean Age 60, range 42-89, all with ischaemic strokes);
- 10 carers/supporters (40% male, 60% female – Mean Age 57, range 25-82);
- 12 Health professionals (interviewed) (8% male, 92% female; 16% community based, 84% hospital based). A further 15 staff consented for participation in observation sessions alone (33% male, 67% female; 46% community based, 54% hospital based).

Stroke survivors were recruited at a range of time points between one and twenty-one months post stroke, on this basis participants could give an account of a range of experiences with information seeking and provision over a period of up to twenty four months post stroke therefore fulfilling this aim of the study. An
additional survivor was recruited who was five years post stroke. Whilst this latter time point was outside the original target range of the study this individual’s activity as a hospital volunteer talking to and supporting other stroke survivors was felt to offer additional and useful insights. The sample of stroke survivors obtained provided an almost even mix of male and female respondents, a good age range of respondents and whilst all respondents had suffered an ischaemic stroke there was a mix of severity of post stroke disabilities and as stated time elapsed post stroke. Ischaemic stroke reflects approximately 80% of incident stroke (Bamford et al., 1990) and makes up the bulk of specialist stroke service work with many haemorrhagic strokes being seen within specialist neuroscience services therefore this focus of the sample was not deemed detrimental to the aims of the study. Two stroke survivors interviewed had had second strokes since the index stroke used to identify them for recruitment, another survivor was recruited from his second stroke, another had previously experienced a subarachnoid haemorrhage and two had previously had a Transient Ischaemic Attack (TIA) prior to the stroke for which they were recruited to the study. Overall the purposive sampling strategy was effective in terms of obtaining a sample reflecting a diversity of post stroke experiences to inform the case under study that is information exchange between stroke survivors, their carers and health professionals post stroke within the Salford Health Economy. All stroke survivors took part in interviews and nine took part in the twenty two observation sessions conducted.

The carer sample was recruited via the stroke survivor participants and was slightly smaller in number as not all stroke survivors had a linked carer/supporter taking part in the study. The reasons for this included: two instances where the survivor did not want their relative approached as they did want to burden them. Another carer was approached but did not respond to the request to participate and where a survivor was recruited outside the original scope of the study (as part of the health care team due to her voluntary work) no approach was made. One stroke survivor had two carers/supporters closely involved and as they were working together to support this individual they were both recruited and participated in data collection. All carers recruited participated in an interview and four were involved in observations where they were present during a scheduled observation point with their stroke survivor. Similarly to the stroke survivor sample (within the limitations of the linked sampling strategy) a fairly even mix of men and women and a good range of ages were obtained. In addition, different
carer to stroke survivor relationships are reflected including children/niece/nephews and spouses. Most carers provided a generally supportive role with only two providing direct hands on physical care and two others providing intermittent support with some aspects of self-care particularly initially upon discharge from hospital for their stroke survivor.

The survivor and carer samples are summarised in Table 4.

**Table 4: Stroke Survivor and Carer Demographics**

<table>
<thead>
<tr>
<th>Stroke Participant</th>
<th>Gender</th>
<th>Age</th>
<th>Time since stroke (at recruitment)</th>
<th>Stroke Carer</th>
<th>Gender</th>
<th>Age</th>
<th>Relationship to survivor</th>
</tr>
</thead>
<tbody>
<tr>
<td>SS01</td>
<td>Male</td>
<td>76</td>
<td>1 month</td>
<td>--------------</td>
<td>---------</td>
<td>-----</td>
<td>-------------------------</td>
</tr>
<tr>
<td>S02</td>
<td>Female</td>
<td>56</td>
<td>1 month</td>
<td>SC02</td>
<td>Female</td>
<td>25</td>
<td>Daughter</td>
</tr>
<tr>
<td>S03</td>
<td>Female</td>
<td>77</td>
<td>2 months</td>
<td>SC01</td>
<td>Male</td>
<td>77</td>
<td>Husband</td>
</tr>
<tr>
<td>SS04</td>
<td>Male</td>
<td>47</td>
<td>12 months</td>
<td>--------------</td>
<td>---------</td>
<td>-----</td>
<td>-------------------------</td>
</tr>
<tr>
<td>SS05</td>
<td>Male</td>
<td>57</td>
<td>4 months</td>
<td>--------------</td>
<td>---------</td>
<td>-----</td>
<td>-------------------------</td>
</tr>
<tr>
<td>SS06</td>
<td>Male</td>
<td>69</td>
<td>10 months</td>
<td>SC03</td>
<td>Female</td>
<td>65</td>
<td>Wife</td>
</tr>
<tr>
<td>SS07</td>
<td>Female</td>
<td>76</td>
<td>13 months</td>
<td>SC04</td>
<td>Male</td>
<td>67</td>
<td>Nephew</td>
</tr>
<tr>
<td>SS08</td>
<td>Female</td>
<td>78</td>
<td>17 months</td>
<td>SC05</td>
<td>Male</td>
<td>82</td>
<td>Husband</td>
</tr>
<tr>
<td>S09</td>
<td>Male</td>
<td>67</td>
<td>1 month</td>
<td>SC08</td>
<td>Female</td>
<td>57</td>
<td>Partner</td>
</tr>
<tr>
<td>SS010</td>
<td>Female</td>
<td>45</td>
<td>21 months</td>
<td>SC06</td>
<td>Male</td>
<td>60</td>
<td>Husband</td>
</tr>
<tr>
<td>SS11</td>
<td>Male</td>
<td>42</td>
<td>9 months</td>
<td>SC07</td>
<td>Female</td>
<td>40</td>
<td>Wife</td>
</tr>
<tr>
<td>SS012</td>
<td>Female</td>
<td>89</td>
<td>1 month</td>
<td>SC09</td>
<td>Female</td>
<td>58</td>
<td>Niece Great Niece</td>
</tr>
<tr>
<td>SSHV01</td>
<td>Female</td>
<td>69</td>
<td>5 years</td>
<td>--------------</td>
<td>---------</td>
<td>-----</td>
<td>-------------------------</td>
</tr>
</tbody>
</table>

Twenty seven health professionals were recruited for participation in the study, twelve of whom took part in interviews and a further fifteen who were consented purely for observational data collection. Six of the professionals interviewed were also involved in survivor related observation sessions. There was a bias towards female participants which is unsurprising as females generally predominate in the health care professions and participants came from different professional backgrounds involved in multidisciplinary stroke care. Professional groups represented included medicine, nursing, therapy, social work and charity sector support workers. Health professionals who took part in the interviews were
biased toward the hospital setting, an artefact of these staff being easier to recruit as they are based in a specific location and their linkage with survivors being stronger at this time point. Health professionals involved in interviews came from the following groups: medicine (3), nursing (5) and therapy (4). They provided representation of a range of specialist stroke experience from a few months to many years approximately twenty years in some cases, thus providing some insight into the impact of increasing expertise on information provision activity.

5.3 REFLECTIONS ON THE METHODS USED
As demonstrated in the previous section describing the sample of participants obtained, the recruitment strategies used were successful in producing a purposive sample of participants representing diverse post stroke experiences from the three groups of interest. It was unsurprisingly much easier to recruit stroke survivors early in the time period of interest as at these time points patients were still in or recently in hospital when links with introducing health professionals were strongest. Recruitment of patients later post stroke was more challenging particularly as the strategy for this had initially intended to utilise the recruitment of GP practices as well. The latter was not achieved and this will be discussed in more detail shortly. As a result patients recruited later post stroke were achieved via community rehabilitation teams or by virtue of their unusual ongoing attendance at outpatient clinics. When it was realised that GP practices would not be recruited to aid follow up of survivors later post stroke, an additional strategy was employed which utilised an advertising poster in a local resource centre. The poster was designed and taken through ethics via an amendment. This was made visible on user notice boards at the BASIC (Brain and Spinal Injury Centre) centre so any patients interested could take my number and contact me to express an interest in taking part. Whilst BASIC is a national charity the local neuro-care centre is frequented by post stroke patients as it has an information resource centre, access to Citizens Advice Bureau (CAB) advisors and accessible gym facilities. This did not however generate any stroke survivor interest in the study. Information was also sent to a local support group but without the opportunity for a face to face introduction of the study this also did not generate interest. It was therefore fortunate that some patients were having ongoing contact with the stroke and rehabilitation services over a time frame that was not official policy for follow up as without this it would have been challenging to recruit any patients at later time points post stroke.
As the study was PCT funded at the outset there was interest in exploring the view of GP teams on the topic of information provision post stroke. It was planned to approach the GPs of recruited patients for their participation. Also to enhance the chances of recruiting GPs and to recruit patients later post stroke I planned to identify six GP practices initially that may have an interest in stroke to approach them to take part in the study. The plan was to identify these surgeries by nomination by senior clinical professional staff in the PCT and/or their performance on Quality Outcome Framework (QOF) indicators for stroke. Electronic records of practices would have then been searched for stroke survivors using read codes and parameters relating to time since stroke and presence or absence of carer. Unfortunately this part of the study did not successfully proceed as it became apparent in early negotiation with senior GPs in the PCT that involvement in the study, despite its PCT funding, would not be a priority as its profile was not high enough and with no funding to pay for practice staff time for involvement it would not be supported. Despite this, for some time I continued to pursue attempts to recruit the GP practices of patients recruited to the study, contacting them by letter. With no positive responses, I eventually decided not to pursue further attempts to recruit them as the efforts required were unproductive. In addition as patients started to complete interviews it became apparent that the utilisation of GPs and Practice Nurses as major sources of information post stroke was variable, but generally low. It was disappointing to take this decision and not have a record of the GP/Practice Nurse voice in the study but, after much effort, a pragmatic choice had to be taken to direct efforts towards sources most likely to yield useful data to illuminate the case. The challenges of recruiting general practitioners and their staff to research studies have been discussed in the literature (Dormandy et al., 2008; Goodyear-Smith et al., 2009) and are not insignificant. On reflection, this study was not best placed to engage GPs as it was a small scale study which, whilst it addressed a topic of relevance to them, did not have a high enough profile to offer additional incentives financial or developmental for participation.

Recruitment of staff from other areas such as acute care, rehabilitation (hospital and community) and charity sector went relatively smoothly as members of staff were receptive and interested in the study, a reflection of the general interest in the topic which was one of the factors in choosing this particular case setting for the study. Recruitment for observations was unproblematic as most health
professionals were used to having observers along for teaching and training purposes and most did not seem to view my presence as much different to this. What proved more time consuming were the efforts required to pursue staff to complete consents and to obtain time commitments for completion of interviews. All participants who were interviewed completed a full written consent form whilst familiar with clinical research, health professionals were not necessarily familiar with being on the receiving end of an information sheet and consent form. Unsurprisingly, interviews were easier to book with members of staff that were located in one setting and particularly with more senior staff who had more autonomy in terms of organising their own time.

5.4 INTERVIEW DATA

Interviews were carried out with all stroke survivors and carers and a selection of health professionals from different staff groups engaged with the care of the stroke survivors recruited.

All interviews with survivors and carers took place in their own home as they were discharged at this point and this was their preference. Most were done one on one except for three couples whose preference was to either sit in with one another’s interviews or be interviewed together. The plan at outset was to interview participants separately but the expressed preferences of these three couples were respected. It can be argued that joint interviews may prevent the expression of views or feelings for one or other of the participants however; equally it can provide illustration of the dynamics and roles assumed in partnerships. Whilst at the outset the preference was to interview separately I also decided at that point that as interviews were being conducted most often in participants own homes, expressed preferences would be respected as I felt to do this would produce a more conducive and productive interview environment.

Interviews started by asking survivors and carers about when the original stroke occurred and then picked up on references to information exchange to explore the topic. All respondents said something about information specifically as they would talk about their initial realisations of having suffered a stroke. Subsequent questions would become progressively more focused on issues and experiences around information provision and seeking. Interview duration was between thirty eight minutes and two hours and two minutes. Not all respondents however, found it easy to move from general discussion of their stroke experience onto
information exchange as a more focused topic. Some potential reasons for this seemed to come out of the interviews. Information provision was not always perceived or recalled as a discrete activity but as enmeshed with other aspects of the care experience. Some reported a lack of curiosity about their condition and a preference to put themselves in the hands of the experts. Some felt that information was not going to help them as it was not the practical support they needed. There were also preconceived ideas about what is known and which health professionals were able to provide information and finally a reluctance to be seen to be critical of care received. Sensitivity was shown to any expressed views or reticence to express views and respondents were encouraged to think about their experience reflectively and what may have been helpful to them. Participants were encouraged to see their experiences as offering constructive feedback for stroke services. However, as a result interview transcripts from stroke survivors and carers provided a mixture of data about the general stroke experience as well as thoughts on information provision. Early coding had to reflect this to draw out the different elements within transcripts so more detailed analytic coding could be pursued with data pertaining specifically to the core study questions of how and why information exchange occurred post stroke.

All interviews with health professionals were undertaken one to one and at a time and venue convenient to them. These were generally shorter interviews lasting between twenty three minutes to one hour and fifteen minutes. This reflected the fact that as the topic area was an area of concern to more of the professionals they engaged more quickly with the topic during interview and also as interview time was taken out of work hours, work pressures could also contribute to this.

The interview data obtained was subject to in depth thematic content analysis forming the core data set that contributed to the themes presented in subsequent chapters. Observation and documentary data discussed next provided more contextual data to illuminate the case and make sense of accounts given.

5.5 OBSERVATION DATA

General observations in the acute setting were undertaken for familiarisation with the setting and staff. Preparatory observation of community settings was not undertaken as these interactions are more variable as often conducted one to one in patients’ homes so it was accepted that adaptability and sensitivity would be the key to conducting survivor specific observations in home settings.
However, I did visit one of the community rehabilitation team’s regular team meetings to introduce myself and the project so staff had some familiarity with me prior to approaches being made to help with survivor recruitment and observations linked to participants. Seven initial general observations were undertaken in the acute stroke service attending the three ward rounds, a multidisciplinary meeting, a case conference and three outpatient clinics. Twenty-two stroke survivor linked observations took place with nine of the twelve survivors recruited. The aim was to undertake at least one observation with each survivor but as I recruited survivors up to twenty one month’s post stroke, not all of the participants had interactions planned whilst I was in contact with them. Table 5 summarises the survivor linked observations undertaken.

Table 5: Summary of stroke survivor linked observations undertaken.

<table>
<thead>
<tr>
<th>Stroke Survivor</th>
<th>Observations undertaken</th>
</tr>
</thead>
<tbody>
<tr>
<td>SS01</td>
<td>Rehab ward round</td>
</tr>
<tr>
<td></td>
<td>Case Conference</td>
</tr>
<tr>
<td></td>
<td>Out-patient follow up</td>
</tr>
<tr>
<td></td>
<td>Therapist visit at home</td>
</tr>
<tr>
<td>SS02</td>
<td>Acute ward round</td>
</tr>
<tr>
<td></td>
<td>Rehab Ward Round</td>
</tr>
<tr>
<td></td>
<td>Ward communication regarding plans for transfer of care</td>
</tr>
<tr>
<td></td>
<td>Family Support Worker visit at home</td>
</tr>
<tr>
<td></td>
<td>Therapist 1 visit at home</td>
</tr>
<tr>
<td></td>
<td>Therapist 2 visit at home</td>
</tr>
<tr>
<td>SS04</td>
<td>Therapist visit at home</td>
</tr>
<tr>
<td></td>
<td>Therapy session as out-patient</td>
</tr>
<tr>
<td>SS05</td>
<td>Research out-patient follow up</td>
</tr>
<tr>
<td>SS07</td>
<td>Out-patient follow up</td>
</tr>
<tr>
<td>SS09</td>
<td>Out-patient follow up</td>
</tr>
<tr>
<td>SS10</td>
<td>Out-patient follow up</td>
</tr>
<tr>
<td>SS11</td>
<td>Out-patient follow up</td>
</tr>
<tr>
<td>SS12</td>
<td>Rehab ward round</td>
</tr>
<tr>
<td></td>
<td>Case Conference</td>
</tr>
<tr>
<td></td>
<td>Carer training session 1</td>
</tr>
<tr>
<td></td>
<td>Carer training session 2</td>
</tr>
<tr>
<td></td>
<td>Out-patient follow up</td>
</tr>
</tbody>
</table>
Twenty-one staff were involved in these direct observations from the following professional backgrounds: medicine (6), nursing (4), therapy (7), social work (2) and voluntary sector support workers (2).

Observations, where possible, were recorded. Written field notes were made as soon as possible after observations to capture observed content of interactions, dynamics and my thoughts and impressions. Observation transcripts and notes were reviewed and reread several times highlighting interesting elements that could be referred to when reporting data to give contextual detail to the interview communications analysed and reported. However, they were not line by line coded in the way interview transcripts were. This was because their utility was in providing contextual detail for additional illustration of accounts and they were also very helpful when interviewing participants to know what information had been exchanged as questions of recall of information were a recurring theme.

5.6 DOCUMENTARY EVIDENCE DATA
Collection of documentary evidence data in the field consisted of noting or collecting samples of written materials available, either freely within health care provider environments, or those provided to survivors and carers by staff. Recruited survivors notes were also reviewed for the types of entries made within them that referred to information provided, any use of available check lists and content of documents such as the discharge summary or clinic letters that are generally copied to survivors.

In collecting data from clinical records, it was apparent that direct references to information exchange were rare and so data collection notes focused on recording the presence or absence of references to information exchange and where these were written. This was done to provide contextual detail when interviewing staff and asking about their habits when recording information provision activities. The review of the factual content and language used in the discharge summary and clinic letters allowed more meaningful discussion of these documents with patients during interviews. So as with observation data this data was not subject to a detailed line by line content analysis but provided context for interview discussions and contextual detail that could aid the illustration of participants’ accounts.
5.7 CHOICES OF DATA PRESENTED IN THE THESIS

A large amount of textual data was generated and particularly in the case of survivor and carer interviews not all of this pertained directly to study questions but, spoke in more general terms of the experience of stroke and its personal impact. There was also description of what types of information were sought and received both by survivors, carers and health professionals. These data were initially coded in order to understand the context of participants’ descriptions and accounts. However, as they did not add new material when compared with existing literature and were not directly answering the key study questions of how and why information exchange occurred more detailed analytic coding of these data excerpts did not take place. The matrices summarising sub-themes under the broad thematic headings of how, when, why, impacts and documentation of information exchange were reviewed to generate categories documented in the subsequent results chapters. Each results chapter focuses on a key study question describing how and why information exchange takes place and the perceived impacts of information exchange processes.

5.8 CONCLUSION

This chapter has presented a description of the participants that made up the study sample, reflections about the methodological choices made and how they worked in practice and an overview of the different types of data that were obtained and how these have contributed to the results presented in subsequent chapters. The following three chapters present themes describing how information exchange takes place, the reasons why information exchange takes place, the perceived impacts of information exchange and issues that arise in this process. Through these chapters the accounts from the different participant groups are reported together to compare and contrast accounts of relevance to the main chapter topic. Chapters are linked directly to study questions to illustrate how the different types of data collected have been used to understand better each key study question. Following the results the discussion chapter will focus on key issues identified by participants as significant to the information exchange process and examine these in relation to policy and literature to inform the study’s implications for practice and future research.
CHAPTER SIX: HOW INFORMATION EXCHANGE TOOK PLACE

6.1 INTRODUCTION
In the last chapter I described the study sample and the issues arising in the application of the study methods. In this first main results chapter, I will describe the experiences and observations around how information exchange took place post stroke. The ‘How’ of information exchange focuses on the processes involved in information exchange the people, tools, times and methods used. The themes presented are drawn from interview data with the three participant groups, observation data and medical record review to look at the recording of information exchange. Three broad themes are drawn out. In ‘Modes and media’ I will describe the different ways information exchange took place. ‘Judging information exchange’ describes how survivors, carers and health professionals assessed or made decisions about information exchange. Finally ‘Specific issues with information exchange’ draws out problematic areas identified by respondents.

6.2 MODES AND MEDIA
This theme describes the different ways information was exchanged in terms of whether this was verbal, written or using other aids such as the internet. Most of what was discussed and observed focused on verbal and written information exchange. The different participant groups placed different emphasis on the different means of exchanging information. I will consider verbal information exchange first, then written information exchange and finally the use of the internet and other tools.

6.2.1 Verbal Information Exchange
Verbal information exchange was the most pervasive form discussed by all participant groups. Stroke survivors and carers discussed verbal and written information in equal measure; however health professionals had a heavier emphasis on written information. This is interesting when all groups made reference to the fact that most information exchange that takes place is verbal whether one to one or between survivor/carer and team. Verbal information is shared on an ongoing basis through diagnosis, treatment, nursing care and therapy activities to engage individuals and hopefully inform and educate them. A key problem with verbal exchanges identified by all groups was the recall of
information. One of the professionals highlighted the distinction between more detailed personal verbal exchanges and more generic written materials.

...it’s a very, very kind of frightened family and if you are giving lots and lots of information, especially complicated information, they may not be able to take on board what I am saying, and probably most of it will be lost. Err, where there is provision I would provide them with a leaflet explaining what a stroke is and how it progresses. Literally the same information I’ve given them but a more generic version of what it is…

If we look at the distinction made by this professional that verbal information is personal but poorly remembered and thus backed up with generic written information, I think this helps understand the different focus/emphasis in accounts. Stroke survivors/carers in this study and the literature place a high value on personal or tailored information, information specific to them. On this basis survivors and carers placed equal emphasis on both verbal and written communication because, whilst they acknowledged difficulties with recall, generic sources were never entirely a solution to these problems. In contrast, professionals concerned with issues of recall and how information could be retained after interactions, were very concerned with the best use of written materials to back up messages. This particular concern of health professionals, perhaps influenced by public health, policy and organisational concerns shifted the emphasis in their discussions to focus more on written materials.

The pervasive quality of verbal information exchange was evident in health professional accounts. Their accounts spanned the basics of introductions and engagement with the environment and interventions to more specific information on topics pertaining to individuals’ strokes. Topics encompassed details of specific diagnosis, personal stroke impacts, limitations and safety issues, prevention, care requirements and symptom management. The primary advantage of verbal information was its immediate personal relevance to survivors and carer, its potential for dialogue and generating questions and identifying information needs. Some professionals were more comfortable giving verbal information as this drew directly from their professional knowledge base that was fitted to knowledge of and activity with survivors. Professionals had concerns that too much generic written information could cause fear and anxiety.
..verbal information not a problem and I feel I can judge what the patient sort of needs at the time and...and how sensitive I need to be and...I'm happy with that and my own sort of communication skills and stuff, but in terms of giving out handheld information, not happy with it really...Because I think it just needs to be standardised, it’s just the level...we’ve just got...like I say, we’ve got loads of leaflets, loads of information but, you know, what’s the right information at the right time to give to them?

HP13

Knowledge of and confidence in the quality of written resources was a factor in their use alongside verbal exchanges, this will be developed further under written information exchange. The main problem with verbal information exchange was the issue of recall and survivors/carers ability to take information in. Individual health professionals talked about the need for less jargon, more explanation, the use of demonstration (of skills and deficits), repetition and 'socratic' methods. The latter, involving asking questions to prompt reflection, problem solving and learning, was described as necessary to support common problems with reading and processing information for stroke survivors.

..if your ability to read is compromised... What I tend to do then is just a sort of socratic way of interacting with people, so I will simply be asking questions that I hope will challenge their way of thinking. Rather than getting them to write anything down or read anything or... It would just be that they couldn’t manage that.........And I’d say over 50% of people cannot manage the anxiety or the depression handouts and it would be difficult to get those simpler..

HP09

Verbal exchanges were discussed in a number of contexts: during therapy and care, ward rounds, case conferences and outpatient appointments. As time is always a precious commodity, professionals would blend information provision into their contact time activities. This was also proposed as making exchanges less formal and more open to dialogue and development.

I will now contrast survivor and carer accounts of verbal information exchange which will be followed by discussion of observation data of key verbal exchanges.

As with health professionals, because verbal information exchange is so pervasive survivors and carers accounts of it included many topics, people and time points. However in contrast to professionals, survivors made less reference to information provided during care and therapy. Survivors seemed not to necessarily recognise information as distinct from care and some messages
delivered during care may have been lost. Topics discussed encompassed: diagnosis, treatment, medications, lifestyle changes, varied stroke impacts, feedback on progress and recovery prospects. Survivors also highlighted the primary problem of remembering and taking in information.

Yes he gave me quite a bit. More than I could take in really. I just took... I just didn't care really. When he was telling me it was going through me a little bit. It was erm... I wasn't concentrating really properly. I knew he told me I'd had the stroke and er... But I can't really remember much about it, what he said.

SS03

Whilst things were being explained all the time, remembering and putting information together was a challenge.

Because as much as people had talked to me all the way through it and explained stage by stage; not gone in. I was... and the thing that frightened me more than anything, and that I don't think a lot of people are aware of, is how a stroke grows on to you; ... they walked me to the ambulance. I couldn't walk after that.

SS10

Survivor accounts came across as fragmented and pieced together from what could be remembered. As well as issues with recall, survivors and carers reported other issues with the quality of interaction. This included comments on professionals’ manner and delivery of information, difficulty understanding medical terms or styles of communication and moments of 'missed' communication where individuals felt wrong-footed or unclear of professionals’ intentions. To give examples of these, survivors did not like arrogant and dismissive communication and wanted straightforward communication and reassurance.

...the thing that really... I wouldn't say annoyed me, but when I thought about it afterwards the consultant... It's not... I'm not being personal. I didn't like him, I thought he was arrogant and very dismissive. And the first time we saw him which was on the third day I think, or fourth, he put the screen around me, he walked in, he said 'Do you know anything about strokes?' So I said 'No.' So he said 'Well you do now'.

SS06

Contrasted with,
He had a look at me, put the light in me eyes and that sort of thing, and he said 'You've obviously had a stroke', he said 'But don't worry you'll be alright'. You know, 'You're in the right place'. Very reassuring. And that was it.

SS06

In terms of problems with medical language, this included both more technical language and the use of certain styles of description.

It was like, they said it could be an extension to the first one or a new blood clot, I thought, how can the other one extend......Well I don't know. Obviously to extend it must be other blood clots attaching themselves to the same area.

SS11

Examples of missed communication were seen in outpatient department appointments where different expectations were evident and professionals’ attempts to engage survivors in decisions and self care were not always fully understood.

He sat back and he said, 'Well do you think there's any reason... Can you think of any reason now why you should bother coming here again?' That took me aback and I thought oh...you know, what are you supposed to say? Well the thing that puzzled me was that nobody examined me at the hospital. Nobody had a look at me throat, nobody checked me heart and my lungs or anything.

SS06

It was to try and understand some of this complexity in action that I undertook targeted observation of key verbal interactions. These were the ward round, case conference and outpatient appointments. I would like to discuss data from these observations alongside survivor, carer and health professional accounts to highlight the challenge of creating a dialogue on information exchange in practice.

Ward round

Ward round is a routine aspect of hospital care. It is an opportunity for the medical team to see the patient at the bedside, to check progress and to provide feedback on diagnosis, test results and plans for care. It has planning and communication functions within the medical team and between the team and patient. It was chosen as a discrete observable event where information may be exchanged. On the acute stroke unit ward round took place daily led by the consultant covering the unit that day or a deputising registrar. On the
rehabilitation unit ward round was a weekly event led by the rehabilitation consultant or deputising registrar. Other members of staff observed attending the ward round were variable and included ward nurses, therapists, research team staff and students. Attendance on the ward round by nurses was variable sometimes they were present; sometimes absent sometimes they came and went attending to other tasks during the round. When they were present the role taken by them was passive responding to queries and recording actions as opposed to offering any leadership or advocacy for the patient and their involvement. As nurses were also the most accessible professional group to carers, who would desire updates when visiting later in the day, it is questionable how well appraised of information nurses would be in order to respond to queries.

Accounts from survivors and professionals described a passive role for survivors on the ward round, one of being presented with information as opposed to engaging in a dialogue.

*They came down round the… The team, [Dr X] and sometimes another doctor, once a week it was. I think it was a Tuesday they used to come round. But you didn’t have much opportunity to talk then.*

SS07

*..after the initial assessment… actually, it was when the ward round was going on as well, so we all sort of stood and verbally informed X what was happening. You know, that he’d had the stroke.*

HP05

Actual observations of ward round carried out revealed variable styles of conducting the round and therefore of engaging survivors. As stated the ward round has a dual planning and communication function. Some medical staff would have a team discussion prior to starting the round allowing the bedside time to be focused primarily on talking to the patient. Time spent at the bedside ranged from six-twelve minutes so interactions were brief and benefited from focus. In two ward round observations of almost equal duration six minutes and forty seconds and six minutes and thirty four seconds, the impact of prior team discussion was seen. Where this had not taken place four minutes and fifty seconds of bedside time was taken up by team discussion allowing for only one minute and fifty seconds direct interaction with the patient. In the instance where prior team discussion had taken place the full six minutes and thirty four seconds was focused on directly communicating with the patient.
Professionals described a basic structure to what was covered in discussion with patients on the ward round:

1. How are they doing in themselves?
2. Do they know what has happened to them that they have had a stroke?
3. What treatment they are on
4. Investigations they will require
5. The plan of what is going to happen - any need for rehabilitation
6. Do they have any questions?

Points one, three, four and five were usually covered. However, there were instances where current knowledge/recall was not checked and checks for questions were not made. When all points were not covered survivors could feel short changed as along with factual information they particularly looked for feedback on progress.

_I found Dr X the least communicative of anybody I've seen in the acute stroke unit they just came in and chatted and said everything the only thing she said to me was you'll be on aspirin for two weeks and then another tablet I thought she might have discussed progress._

_SS01_

Survivor recall of information exchanged after the ward round was often poor particularly on the acute stroke unit. This was a concern to professionals and confirmed in post observation debriefs with survivors. There was fairly rapid drop off of in recall of details from the ward round. Debriefing occurred within twenty minutes and some individuals struggled to recall details of exchanges and this was recognised by them.

_.They were talking to me but I wasn't picking up much on what they were saying to me. It was hard to follow everything; I just wanted them to do it._

_SS02_

_(following observation 01)_

Another element of ward round style commented on, was the type of verbal and body language used. This was actually raised by one of the professionals interviewed who felt their style of communication was different to colleagues.

_.on the ward round sometimes you see the consultant giving the patient the diagnosis and, no names, no pack drill, but standing up talking to the patient with five people behind you. Um, so you've had a cerebral_
infarction and um, maybe an advantage for me is that I'm not - I don't talk in those words anyway. I'm not putting it on for the patient, I genuinely don't use - I'm trying to think. Someone used the word 'dichotomous' to a patient on the ward round the other day. And it's just not a word that would be in my normal vocabulary anyway…..

Within observations conducted, the degree of medical jargon used varied considerably and similarly some professionals were observed to try to tackle body language issues by stooping or squatting by patients to be on a more equal level with them. No interactions were observed where the starting point was asking about questions/concerns for the survivor first. This may reflect the multi-purpose functions of the ward round and that it is in fact, at least equally, about care planning and review as it is about information provision/exchange.

Case conference
Case conference was a formal weekly meeting on the rehabilitation ward for which patients and/or family members were given an appointment to attend and discuss their care with the rehabilitation team, theoretically the team members of relevance to them. It was usually medically led starting with introductions from team members and family, followed by presentation of a medical summary, then a therapy summary and then the opportunity to ask any questions. Within staff accounts the rehabilitation case conference came to the fore in terms of time points for communicating information. It was important to staff as it was presented as the opportunity for the patient and family to ask questions and also as a forum for raising risks and concerns with patients and families. One of the medical team felt it was important in clarifying expectations as goals could be revisited and checked. Professionals did have questions about its benefits and impact on patients and families and whether they were able to take all the information presented in. It was felt to perhaps be overwhelming in terms of the number of staff present and the language used.

..it gives the patient and their relatives an opportunity to ask everybody questions, if they have got anything specific on something. Its good and bad points in the sense that it can obviously scare people, seeing so many people in the room, it would scare me but, [laughs] I suspect that to some people it is reassuring that there are so many people looking after my relatives.

HP24
Observations of case conferences carried out showed some consistencies and some variability. The duration of the meetings observed were twenty five to thirty five minutes long. The format as described above was very much adhered to checking for questions and concerns of patient and family was always left to the end of the meeting unless survivors and carers raised an issue spontaneously. Professionals led the interaction speaking 1.3-1.5 times more often than survivors and carers and with varying use of technical jargon depending on discipline. The medical summary was the area most likely to entail language unfamiliar to survivors and carers. The number of staff present ranged from three to six depending on patient need or other staff factors preventing attendance. The role of the nurse in case conference was weak this was seen in observation by their absence and acknowledged in interviews. It was put forward that attendance of trained nursing staff was difficult because of staffing issues in covering the ward. Another reason was put forward by one respondent who felt that nursing wasn’t asked about with families focusing more on medical and therapy issues.

‘cos all they’re interested in really in that case conference is, from the medical point of view, is why have they had a stroke and where’s the clot gone? You know, is the clot still there and what are you gonna do about it? And therapy. A lot of the time they don’t ask about nursing side of it, because all they’re interested in is the therapy point of view.

Survivors and carers also clearly identified case conference as being informational in purpose however it was seen as dominated by the health professionals’ agenda.

...it was tailored to their, their wants and needs, rather than ours, definitely. You know, because I mean I came out of the meetings feeling right, well, they want her out as quick as possible, they need the bed.

Some families really appreciated the update and overview it offered others identified issues with the meetings format. Patients could sometimes be taken aback listening to staff accounts of themselves that sounded worse than they felt or overwhelmed and ill prepared to respond when given their opportunity to respond or question following staff summaries.

But they worried me when… We had a meeting with my sons and my nephew was there as well. And they more or less said that I wouldn’t be
able to do this, and I wouldn’t be able to do that. That frightened me, because I didn’t feel that bad then even, you know.  

Well I didn’t have time to read it there because she sort of presented it to me and er at that conference er but I’ve read it since two perhaps even three times 

I think you sit there and a lot of it goes over your head, basically. Erm, and they talk about you in a way as if you’re not there, but then suddenly look at you as if you’ve got to answer them, and you’re like…what? Is it my turn, what am I supposed to say, you know.  

Both patients and staff commented on the group dynamic being potentially inhibitory to raising real questions and concerns, and that some topics would not be mentioned unless in a private one to one setting.

Case conference provided an example of an exchange where the primary purpose of the event did seem to be information exchange however, aspects of the dynamic and planning of the meeting meant that the discourse tended to be dominated by the professionals’ priorities. To potentially improve upon this, survivors and carers could be consulted further to investigate if they would like a choice of meeting format and or support to prepare them for this meeting and be more involved in the discussion. The dominance of professional discourse in such meetings has been noted elsewhere in the literature (Hedberg et al., 2008).

Outpatients
Outpatient appointments offer the first time to see a doctor or nurse on a one to one, private basis unless this has been specifically requested as an inpatient. As we saw in earlier quotes however, issues can arise in terms of the roles expected in such settings. Confusion can arise when professionals may try to undertake a more engaging style of communication with patients without making clear the purpose of this to survivors.

Amongst professionals discussion of the outpatient forum was by medical and nursing staff who worked in this setting and survivors and carers who attended for follow up. It was clearly identified that it was not unusual for there to be a lot of questions remaining even if staff thought they had provided a lot of information previously.
And then when they come back to outpatients it’s quite interesting. Because actually you think you’ve given them a lot of information, but there are still a lot of questions.

HP15

There was more than one outpatient clinic running, each with slightly different purposes and different staffing. These were:

- Acute stroke unit follow up clinic (acute consultant led)
- Neurovascular clinic (neurology consultant led stroke/TIA assessment clinic)
- Stroke rehabilitation unit follow up clinic (rehabilitation consultant and stroke specialist nurse joint clinic).

As a result of different staffing and aims there were different assessment and communication strategies in place so equality of service could be questioned. For example, nurse led clinic was more proactive in terms of seeking out problems that could lead into information provision activity by use of a clinic assessment proforma. The stroke specialist nurse also offered a telephone contact number when discharging patients in case they had later issues they wished to raise. In the follow up clinic to the acute stroke unit the senior consultant liked to see all these patients as it was seen as an opportunity to revisit and readdress issues, to get a sense of what had been dealt with and what had been missed. To some extent this was an aim in all clinics but it was seen as even more pertinent in this clinic as some patients would have had a very brief stay on the acute stroke unit and may have seen a different consultant each day during that stay. The ability to draw things together and produce a narrative of the stroke during the appointment and in the clinic letter was felt to be important both for the survivor and their GP. We will see in the next section on written communication that some of this purpose linked to concerns over the quality and functionality of the ward discharge summary to provide an overview of the stroke experience.

Observations of outpatient appointments were undertaken in the acute and rehabilitation follow up clinics. Duration of appointments ranged from twenty to forty minutes in length. Interactions as with the ward round and case conference were professional led however, after an initial greeting the format of interaction
was very variable. Some professionals would simply start a series of questions to check about a range of topics including function, coping and medications with any enquiry as to survivor questions and concerns left to the end as in the ward round and case conference. This was the more common approach. In the nurse led clinic, there was more of an introduction to the aims of the clinic followed by the format already described. In one unique outpatient interaction with a repeat attendee the survivor was given the lead resulting in a very different dialogue style. Survivors would usually follow the professional lead allowing the professional to deal with their concerns and endeavouring to present themselves well. Hence when in some interactions the dialogue then suddenly changed to try to engage the survivor with a decision to discharge from clinic or to take some responsibility for activities such as blood pressure monitoring the survivor felt taken unawares. As with ward round the outpatient appointment has dual functions for the professional. For example, to check that all tests have been completed and that all is progressing well alongside the need to engage survivors with information about their stroke. However, the emphasis should perhaps shift to focus on the latter more.

Survivors and carers reported mixed feelings about the utility of the follow up appointment:

"it was alright really weren’t it, you know…. I think she just, you do get the feeling though that people just want to, oh you are doing alright yeah [laughter]…….they’ll support and all that but it’s, it’s all the hassle we’ve had getting the support in, it’s like been down to us to organise it.

SC09

You have the same conversation in every department you go to….Well it's always that safety blanket  there, you know, if you come in and you are in the system its like if anything untoward did happen you are already there….. That's the only reason for me to come and see someone in four months and have somebody at the end of the phone if I have got a problem. And what does it take out of me day, half an hour. It's nothing.

SS10

All ward follow up appointments were undertaken at approximately six weeks post discharge, this timing is fairly traditional and historical. The justification offered was that it’s long enough for services to have got in but not so long that any serious problems could have arisen. That a shift occurred between discharge and outpatient follow up was seen in the nature of the questions raised, their nature and quality became more specific. This reflected that survivors were
starting to understand more the actual impact of their stroke for them in the context of their life. This is pertinent to note and suggests to me that the outpatient review is a time point when a clearer and different emphasis needs to be put on information exchange activities.

It actually seems to be the people who have got passed their sort of physical disability problems, or are further on with that and are improving more, who are then starting to think outside of that box and thinking I need to know in the long term how is this going to affect me. You know, specific information and specific support issues, erm, and they don't seem to sort of, they've taken their grieving time to get over the stroke initially, and now they're starting to focus on this is what I need now, I've come to terms with it a bit more, and now I'm ready for some more information about how to deal with this long term...

HP19

This represents a potential shift in information given from that used to engage people with care activities, to information as a tool to take charge of your own recovery and health needs. This agenda sat beneath many exchanges I observed but was not brought to the fore. I will describe this more in the next chapters about motivation for and impact of information exchange. I think the outpatient appointment is an underutilised opportunity for bringing together key information and trying to engage survivors in how they can use this to self care for the future. Messages given at this point, when stroke has started to be understood in the home context, may be more meaningful.

At the time of the study, the official policy was to offer one outpatient review however this was not consistently adhered to. Some staff felt that the scope of follow up was just too limited.

I think there should be more support for patients when they are discharged home because I think the information they receive seems to stop a lot of the time from a medical nursing point of view from the ward um, they get discharged home but they get seen in outpatients again, you know, a month and a half later and then after that, that's it. There is no information there to help them maybe three years down the line I suppose. I think that, I think that's missing..

HP22

Availability of written materials to distribute was variable in all the clinics.

Where the outpatient appointment could function better was if a patient was able to see a staff member they already knew so previous communications could be
built upon, however this was not always the case and some patients described seeing a different doctor on each occasion of their visit. However, being generally a private one to one interaction the outpatient appointment held more potential for meaningful communication and was occurring at times when the patients and carer were more aware of their own stroke issues and starting to deal with these. An important consideration from the carers perspective was that they did not all attend appointments with their family members, either due to work commitments or, because they felt they were private appointments (not all family supporters are active carers). Where a carer or family member did attend they would often view the appointment as belonging to the patient so refrained from raising questions or intervening unless they felt their relative required this. Hence, they would not use this time to raise their own specific concerns or worries.

The outpatient appointment presented as an important opportunity for information exchange that was not being fully utilised. Professionals could re-evaluate the main purpose of some exchanges and if the purpose is to inform and address patient concerns and support a shift to more active self care then adaptations to format and style of interactions could better support this.

6.2.2 Written Information Exchange

Stroke survivors and carers commented less on written information exchange than health professionals. In common with health professionals, leaflets were the most frequently discussed written method.

The stroke service had strong links with the local Stroke Association and the family support worker role was seen as part of the multidisciplinary team. Stroke Association leaflets were not freely available across the whole service. However a standard pack of leaflets was provided to stroke patients on the acute stroke unit either via the nursing staff or when the family support worker visited the ward. This was a blanket approach with no assessment of the particular relevance of the leaflets to an individual. The leaflets were presented and left with the patient to be read and shared with family as suited them. Therefore unsurprisingly these were the most frequently mentioned leaflet source.

Views on these leaflets were variable. Not all survivors in my study received them or retained them depending on when they had their stroke, where they
were cared for acutely, whether they had multiple transfers of hospital care and depending on their own attitude toward them. There were only three accounts (two survivors and one carer) where respondents gave a concrete account of reading the leaflets and identifying beneficial information from them. These benefits were linked to dietary advice. These particular individuals had a view that the leaflets must be positive as they had been provided to them and were willing to read through them to identify relevant information. More commonly there was a general recollection of the leaflets, but little recollection of specific content or a sense that they didn't add much new information to what was already known. Five respondents made this type of comment (three survivors and two carers). Other limitations identified in using written leaflets were: lack of interest in reading, difficulty with long-winded language, perceived lack of relevance and it not being a replacement for direct instruction and support. Examples of lack of relevance were a stroke carer who perceived the leaflets as for his wife and a stroke survivor who stated they only applied to severe stroke patients who needed a lot of help.

There's none for people who have had small strokes like me, and there must be a lot of people like me who've had a minor stroke. But there's none for that. But saying that I wouldn't think you'd need any because you don't need anything, I don't need anything. I don't need help to get up the stairs, I don't need...... The only thing I've got is a bit of numbness in me leg, in me knee, and that's it. So I really don't need anything. But the literature is all for people who've had big strokes. So I can't see any point in giving it to somebody like me.

Four survivor/carer pairs clearly identified that they had received plenty of written information very soon after the stroke. However this was more than could be dealt with at the time and was sent home and reviewed later when energy and concentration allowed. One couple commented that by the time they were able to read and review written materials they had discovered much of what they needed by trial and error.

I think the way in particular that we received the communication was just a load of paper. Here you are sort yourself out......Neither of us ploughed through that till a long time afterwards. That's the sad thing really that I mean you're probably thinking, or maybe the thinking is that people should be given information as quickly as possible. And yet that's the very time when you're just not receptive to it......And you can't really take in technical details or anything that anybody's saying to you. It just sort of becomes a blur..... You're so worried that your worry takes over from your ability to
reason and think doesn’t it, you know. It knocks one, it knocks something out of gear.. You don’t, you can’t accept information readily…..No, like I say it was only weeks afterwards that I thought, I think I’d better read that leaflet that [Husband] was given. But by then we more or less knew how to cope on a day-to-day basis.

SC03

This highlights a key issue with generic written back-up materials, they require reviewing for relevance; this may require a few readings. This type of reading and concentration after stroke was problematic for four of the survivors in this study. This was a persisting problem in some cases.

I couldn’t read after I just had my stroke and I love flicking through magazines and reading. I couldn’t read because things in the paper would jump out or, you know, mess up and I just couldn’t. I just used to feel travel sick looking at a piece of paper, if that makes sense….that sickly feeling, because everything was moving on the page I couldn’t do it. And I still can’t do a long amount of reading like I used to do..

SS10

More personal forms of written information exchange described by survivors/carers included: copies of discharge summaries and clinic letters, care plans (for carers), risk assessments for discharge and handwritten notes given by doctors about actions to be taken. All of these would be personally relevant to survivors/carers; however there could still be problems in using these to help action or self-management. Format and medical language was a problem with discharge summaries and clinic letters.

The second time I walked in, well the first time I’d actually seen a doctor, I walked in the room and they said to me ‘How are you?’ So I said 'I'm improving', you know trying to be, you know what’s a name, optimistic, but I wasn’t really. I said 'I feel as if I’m improving’ I said 'But I still can't swallow.' And I said 'My arm and my leg are not in the best condition because I'm losing my balance quite a lot'. Anyway I got a copy of a letter that he'd written to my GP saying that 'He’s vastly improved. His mobility is pretty good and coming along. There’s a slight problem with his swallowing but that will hopefully be sorted out'. And I thought well this is just from me sitting in his chair and him asking me how I was, you know.

SS06

I don't know what those other things mean, it says ischaemic stroke, doesn’t it? I dunno what this other is? That’s another stroke as well?
I: This word dyslipidaemia?
C: Mhm.

SC01

(discussing discharge summary)
With even more personal communications such as care plans, risk assessments and blood pressure targets, the usefulness of these was mediated by the relationship with the professional, the sharing (or not) of expectations about the information and the manner in which it was presented.

SC09: ‘...oh yeah, we’ll sort, I’ll sort out a care plan for you.’ Week after week, ‘well, have you got this care, have you got this care...’ ‘No, no, no, we’re doing it, I’m doing it, I’m doing it.’
SC10: Then you get a bit of paper with it all written on.
SC09: Yeah.....It’s taken them four weeks to write that. Aha. I kinda would’ve expected something a little bit more...
SC10: Well presented.
SC09: ...professional, together and well presented...
SC10: Something legible.
SC09: It’s like...yeah, somebody had, yeah, somebody had just jotted it down when they had a spare five minutes like... A lot of thought had gone into that, hadn’t it?
SC10: Yeah... [SS12], accident, [SS12], commode, [SS12] accident, cleaned up.
I: So it was really just, it was like a catalogue of events?
SC10: Yeah
SC09: What they’d done during the day....nowhere near a care plan, that... I’ve seen care plans ‘cos of where, when I used to work, a project worker. And that, that was a doodle that not a bloody care plan.

A unique account of helpful written information was a carer who had been provided with a book about a stroke survivor story. Benefit was found through recognising common experiences between the survivor story and her husband’s experience.

Health professionals had more to say about written information as a mode of communication than any other. This appeared to relate to the perception that written information was the standard acceptable mode of backing up personal information given verbally. Provision of written information had been a topic of attention in clinical governance meetings and there was concern about the lack of readily available written information resources.

In common with survivors/carers the predominant written materials used and discussed were Stroke Association leaflets. These were seen as a credible and reliable source of written information. This was important as some professionals were particularly concerned about the quality and universal applicability of written materials. The potential for fear, confusion and misinformation were primary
concerns. In practice there were two main issues with the use of stroke association leaflets. First they were not readily available across the service, so whilst they were preferred for their credibility they were not always to hand. This limits the building of habits of using leaflets actively and being familiar enough with their content to refer specifically to them in discussions. Newer staff members were unclear about departmental arrangements with the provision of leaflets. The second key issue was how actively staff could engage with written materials to make them relevant. Staff gave highly variable accounts of the use of leaflets in information provided by them. Therapy staff made more mention of linking patients to the content of specific leaflets with information on specific post stroke problems such as perceptual problems, fatigue, anxiety, depression and other hidden symptoms. Medical and nursing staff made less direct links to the leaflets with only one of these staff discussing direct interaction with the leaflets by adding to the illustrations within them. The view was expressed that leaflets were probably appreciated but it was difficult to make direct reference to them due to lack of familiarity with their specific content.

*The Stroke Association give out their little folders, which are really good and I think the patients really appreciate that. But, you know, how do we… I don’t… I don’t necessarily refer to that. You know, when I come round I want to say ‘Well you’ve had this folder from the Stroke Association. This, this and this is in it’. I’m not actually quite sure what’s in it, actually. I just see it reassuringly sat there on the bedside table.*

*HP15*

Senior team members highlighted the need to make written materials personally relevant to individuals in order to increase their potential utility.

*..what I notice is, you give somebody a leaflet, it goes in the drawer. But when I give people the fatigue leaflet and we really talk through it, it’s sat there on the coffee table and they’re actually referring to it and they’re showing their friends, and they’re showing their family. So it’s a difference between a leaflet relating to them personally and a leaflet that doesn’t. The same information but different.*

*HP09*

This was presented as a particular skill requiring good knowledge of both written materials and the survivors/carers being worked with. Lack of familiarity with materials and no sense of ownership of them presented a challenge to this.
It was apparent in accounts that there was tension between the perceived need to back up verbal information with written materials. Professionals found it challenging to consistently signpost survivors/carers to written sources, and were cognisant to the fact that written materials alone did not suffice, that information exchange required dialogue to clarify what was communicated.

*the patient then takes you off down a completely different pathway sometimes. So I think you couldn't give all of your information in written format, even if written format were the right way to give it. Because you don't get that two-way process. You don't get the patient informing you of what their understanding is.*

HP15

There was largely overlap with survivors and carers in discussing the same types of more personal written materials. Concerns with some of these from the survivor/carer perspective have been presented already. Professionals shared concerns about the usefulness and appropriateness of the copied discharge summary and clinic letters with survivors and carers.

*you see a lot of doctors' letters, where I go through the notes to try and get a history about the patient before I see them, so I'm not just asking them and relying on what they're saying, but I've got a, a record of what they've said, er, of what's been said about them previously. And some of it's in so many abbreviations I struggle to understand what it is. I just think well, how's a patient supposed to know? It says on here they've got a copy, but it's just rubbish to them, isn't it? It doesn't mean anything to me.*

HP19

However, the twenty four hour care plan to document care requirements was thought to be more useful by professionals than the account described earlier. Health professionals also discussed concerns and ideas for improving written information provision. A paramount concern was the ineffectiveness of the discharge summary. It was felt important to provide a patient-friendly summary of the hospital stay more consistently to all. This was perceived however, as requiring significant input from more experienced clinicians and was therefore a resource challenge. Some small business cards with details of the FAST (Face Arm Speech Telephone) guide to recognising stroke and local contact numbers had been produced but were not in regular use. There was uncertainty about how best to distribute these consistently. There was a constant tension between trying to be both consistent and personal. Despite concerns about leaflets there was desire to have more, more readily available. This again presented a
resource issue as there was no budget for materials so there was reliance upon free of charge materials. As no professional had dedicated responsibility for information provision, tackling issues such as pursuing financial resource or developing novel materials was seen as a challenge. Overall there was a mixed knowledge of written information resources with some staff having greater knowledge and seeing it as part of their role to encourage other staff to give out more information but generally as there was no consistent lead for information within the service it was difficult to tackle uneven knowledge, practice and access to resources. Survivors discussed difficulties with reading as problematic in using written materials, three health professionals referred to issues with reading ability. Only one of these made any clear reference to a need for alternative media in this instance. There were no alternatives such as audio materials available within the stroke service during the study data collection period.

Health Professional Communication & Documentation of Information Exchange

All health professionals interviewed were asked about their practices in terms of communicating with their colleagues about information provided to patients and families about their stroke. I was interested in asking about this and in reviewing documentation as I wished to address the premise that good documentation of information exchanged would be an aid to team working and overcome a lack of continuity of staff in the care process.

Least was said about verbal exchanges with colleagues these referred to handovers (formal and informal), joint therapy sessions and telephone calls. The type of material covered would be rehabilitation progress and any concerns with this and whether patients were ‘getting things’ and what could be done to help this. Updates of what had been said on ward round or case conference were also potentially shared. Untrained staff would pass on to trained colleagues any requests for information they had received. Recall and retention of information was a primary professional concern. Therefore, if therapists had particular concerns that they did not think would reach a GP on discharge they would sometimes call the GP to share these. Similarly community therapists whose main source of information was patients themselves would sometimes ring the ward to clarify issues.
Much more was said of written documentation. All participants discussed this in response to the question with just over three quarters of the responses being focused on written methods and their issues. There were a variety of places where information provision activities may be recorded in writing. These included:

- Medical records (paper and electronic (EPR))
- Nursing evaluation notes
- Nurses diary (ward round notes)
- Case conference record sheet
- Psychologists case notes
- Home visit reports
- Risk lists (for specific patients)
- Discharge summary
- Contact/Overview assessment sheet for single assessment process
- Community rehabilitation team notes
- Clinic proforma (nurse led clinic)
- Clinic letters.

The primary area of written recording discussed was written records in patient’s records. Two issues immediately arose out of the accounts, first there is no truly universal record shared by all staff and second even within a particular recording system there was no standard for recording information exchange in terms of location of recording or content of recording. During the period of data collection paper medical records and an electronic patient record were both in use alongside one another, the latter was used by medical staff and therapy staff but nursing staff still maintained a separate nursing evaluation record so used the electronic patient record (EPR) for recording less. However as nurses professed to record little about information provision activity (confirmed in document review) the separateness of this record would not be critical on this topic. Within the EPR there did exist an information checklist, a tick box list of information topics that could be marked as dealt with but with no narrative description. This was little used as not all professionals were aware of it and those that did know of its existence did not necessarily use it as they did not feel it had great utility due to its brevity and it being separate from the main area for recording clinical notes. It was highlighted that different professionals had different levels of access to the record and there was more than one area where information provision activity could be recorded. The areas for potential recording were clinical notes,
discussion and patient and relatives meeting section. The most commonly used area was clinical notes as this was the day to day activity recording section of the record so most frequently accessed. Frustration was expressed by some staff that recording of information in other sections was sometimes overlooked.

*I had written a massive essay about it, but I just don't think anybody had read it. You know, discussions with patients and relatives comes up separately on ISoft in the clinical bits.*

HP21

Factors influencing the amount and content of material recorded included:

- Type of health professional
- Personal style of professional
- Time available (related to acute versus rehabilitation care)
- Identification of risks and concerns (cognition, understanding, family concerns).

*I know that certainly X documents in the notes what she’s spoken to the patient about. So she’ll say that she’s given information about the silent symptoms of stroke and fatigue, and whatever. But if she’s doing that on a ward round and one of the juniors is typing, they won’t mention that.*

HP15

..*we'd probably document something like erm give information on secondary prevention, advise not to smoke and refer to... So I don't think we go into loads of detail. But then I suppose you have to just record that you've done specifics. And I think if I ever had...I'm concerned you know, if I was saying something specific that I didn't think it was being taken on board, then I would be a lot more detailed. But if it's been quite sort of general and I feel that things have been understood and appreciated by a patient, then I'd probably just sort of mention it in ISoft, in clinical notes.*

HP04

It was identified that history taking had become less narrative and more abbreviated and therefore less useful in supporting information provision. This trend was attributed to standardisation of history taking via proformas and the advent of the electronic record.

..*we used to take your history and then you'd sit down and you would write down what the patient said to you. And you'd often put in inverted commas the actual words that they use, which I still try and do, because I find that really helpful to actually say what words they have used. But I don't know what's gonna happen when we move to the actual clerking-in being on EPR... the notes are very telegraphic, aren't they?*
During the study I did review both handwritten notes and electronic notes and this trend was confirmed that all groups of staff who wrote entries on the electronic record did write less. This is an interesting point and would require further study in its own right. I would hypothesize that influences on this are the availability of computers for making entries and professionals speed and comfort with making electronic entries.

Overall the idea of the written record as a reference point for team members as to what information exchange had taken place or needed to take place was brought into question.

Discharge summaries and letters to colleagues were the other key methods of written communication between health professionals. A lot of concern was expressed about the lack of content and true utility of discharge summaries as they were written within a standard computerised non-disease specific template and often completed by junior medical staff. It was felt that important information about therapy assessments and input was overlooked and that they lacked a narrative that gave a good account of the patients care experience and any information provided. This was a problem area that did not have easy solutions as it was acknowledged that leaving such documents to the least experienced staff did not necessarily make for effective communication even if it made sense in terms of manpower availability.

I do go on and on to the juniors about the discharge summary. I’ll say ‘I want to hear the story. I want to hear the story of the admission. I want not just cut and pasted CT scan result, doppler scan result. I want this fifty-four year old gentleman with a previous history of hypertension and diabetes, was admitted with an x, y, z. CT scan confirmed A, you know, carotid dopplers confirmed B, his secondary prevention is X. But he had a long period of time in rehabilitation with, you know, a lot of difficulties around discharge planning, because of cognitive issues. However, at the time of discharge…’ And you don’t get that, you get very poorly written discharge scripts, which are written in a hurry. And often by a doctor who wasn’t looking after the patient.

Letters to GPs from outpatient appointments suffered from similar issues as discharge summaries as their content was very variable depending on the experience of the professional creating them and different approaches to assessment in different clinics. However, by some professionals they were also seen as an opportunity to compensate for the lack of narrative in discharge
summaries. Some therapy staff used letters as a means of bypassing problems with discharge summaries where they wanted to document to the GP their own actions or to express concerns they felt the GP needed to know but that the patient may not share.

6.2.3 Use of Internet and other tools

Patients and carers generally reported low use of the internet as a source of information post stroke. Only three survivors and two carers made a direct reference to using it to seek information at all and a further two carers were aware that younger family members had looked up information. Of the five direct users four were under fifty years of age. Reasons given for not using the internet were a lack of familiarity with internet resources and not all had home internet access. An identified advantage of the internet was that it is available when the individual is ready to pursue specific information queries allowing them to seek information at their own pace.

Well I think maybe the internet’s the most useful isn’t it….I mean, for me……..Well I think it’s because you’ve wanted to go and find about…about it. You know, it’s not like being pushed onto you, read that…It’s something you’ve come to grips with and you want to go and look at it yourself.

SS11

Those who did use it described issues with the wide range of sources available making searching potentially time consuming and overwhelming. Similarly to written information, language and jargon meant that understanding retrieved information could be challenging.

..we’re not on the internet at home unfortunately but I have it at work. So I have been able to, but it really just goes into a little bit more detail what’s already in the leaflets and that, you know, and it just explains to you a little bit more…a bit more technical and that, which isn’t always as easy to understand. You want it in layman’s terms really. You don’t want it too complicated.

SC08

Contradictory online sources could turn the exercise into one a bit like reading the papers where you are not sure what to believe or what to take on board. Language and the indiscriminate nature of information on the internet meant that some who did start to look online for information stopped at the point that they felt things were going over their head or could be potentially overwhelming. This
emphasizes the fine balance between what and when is enough or too much information for individuals. The internet was seen to be fraught to some extent in terms of the breadth of information available and its quality but it had the advantage of allowing information seeking at a pace and time controlled by the individual. The only other examples of seeking information via other routes were use of television and an exhibition to pursue specific areas of interest.

Health professionals talked more spontaneously about use of the internet. There was a perception that there was a greater trend toward its use with younger patients in particular and more generally with increasing internet access. There were similar cautions to internet use as with written materials; this was the fear of causing undue anxiety or information overload. The latter was felt to be even more of a risk due to the breadth of internet information and concerns regarding accuracy and quality. In survivor accounts this was noted but self regulated by individuals as they could stop looking when they had reached enough information for them. In light of this the Stroke Association website was the most commonly used website. In view of concerns regarding the quality of internet information there was desire for a recognised portal to reliable web resources. National initiatives of this type such as NHS choices were also mentioned. Comparisons were made with other internet resources with information on local resources for other conditions, for example the Greater Manchester Multiple Sclerosis website, and a desire expressed for a similar resource for stroke to which patients could be directed or that staff could access for them.

Other tools mentioned as used to aid information provision included: cognitive workbooks, pictorial communication aids and the sharing visually of results such as CT scans and ambulatory blood pressure monitoring. The first two additional strategies are targeted at specific post stroke issues of cognition and communication impairment. Visual evidence of test results were described as helpful for some in making real for patients what had actually occurred in the brain or issues to be aware of regarding risk factors.

..sometimes people like to look at the scans, I suppose that's one way of giving information, if they are able to um and they are able to understand quite well what you are explaining to them...they are quite interested when you talk about the scans about what's been going on inside their head, and that helps people to understand what's happened when they see the damage pointed out on a screen that's happened to the brain, you know, it
However such strategies were not observed during observation sessions so did not appear to be everyday practice. Notably considering the issues patients highlighted with reading written materials there was no ready access to other forms of information back up such as audio recorded information. Only one professional made a reference to the need for other media for those with pre existing or stroke related reading difficulties.

6.3  JUDGING INFORMATION EXCHANGE

6.3.1 Survivor and carer judgements

Stroke survivors and carers did not report active, anticipatory strategies to gauge their information needs and information seeking behaviour. To appraise the situation they found themselves in they would draw upon any previous knowledge of stroke or other illness and rely largely on observation. Observation would be of themselves (or their relative) and their progress, others who had had a stroke and the actions and responses of health professionals. This provided a sense of how they were doing in unknown territory. As time progressed, the most common strategy was to rely on experiential learning in response to problems and challenges encountered. Survivors and carers reasons and motives in seeking information are explored more in the next chapter.

6.3.2 Health professional judgements

For health professionals there was no specific and formal assessment of information needs.

I don’t think it is a formal process. I think it’s much more of a, based on the experience of the clinician and, you know. Personally I make my own decision about whether I think somebody can take onboard that information. Then some people are deceiving, that you think that they’re quite cognitively well, then you’ll read the CAM assessment on the computer, and you’ve just given them lots of complex information in leaflets, and it says poor memory or unable to attend, and you think well, I probably haven’t done that as well as I could’ve done, I should’ve read that beforehand, and made sure that they had that information given to somebody who would remember it.
There was no documented plan for information provision. No particular team member had responsibility for providing information, the whole team would provide information on an ongoing basis specific to their own working areas of concern and, where able, in response to questions and concerns. As we saw in the last section there was not consistent written documentation of information provided to survivors/carers in health records. Therefore, with several professionals usually interacting with a survivor records did not serve as an aid to continuity, consistency and more streamlined information provision.

Despite the lack of formal documented assessment for information provision, health professional accounts did highlight various influences on their approach to providing information to specific individuals. They would draw on other routine assessments principally demographics (age), functional assessments, cognitive assessments and lifestyle history. This background information and discussion within the team about progress and recall would influence information sharing and approaches to this. Where there were particular memory problems or risks identified this would make the provision of written back-up materials more likely.

Information provision would also depend on the time since stroke, therapy activities, requirements and goals. Therapists would try to discover more about survivors pre-stroke interests in order to; if possible, incorporate these into activities making these more engaging and relevant.

Personal judgements were made during interactions with survivors/carers combined to varying degrees with results of routine assessments to inform the approach taken with individuals. Professionals described a cumulative gauging process in relation to how they provided information this drew upon a number of factors. The most common means of gauging information provision were a variety of ways of ‘following the patient’s lead’ and ‘getting to know them’. Following the patient lead related to listening and observing various factors within interactions in order to match information provided to the need/demand perceived. The factors included:

- listening to the language they used
- responding to questions
- type and depth of questions
- questioning them about what they understand and remember
• observing responses to questions
• asking about personal preferences about further information
• observing body language.

You usually find that it’s questions that they’re asking. You know, the type of questions that they’re asking is at a higher level. You know, straightaway if they say to you ‘Well I’ve had an ischaemic stroke and I know it’s affected me like this, but…’: And then straightaway they’ve remembered what kind of stroke that they’ve had, and they know specifically how it’s affected them. But, yeah, it’s the type of question that they ask you, the language that they use and the words that they use.

HP10

How effective any of these measures could be would vary depending on staff skill and experience, whether interactions were one-off or part of a longer term working relationship and the frankness or transparency of survivors/carers. In the next chapter, reviewing reasons and motivations for engaging in information exchange, I will describe that survivors and carers were not always frank about their concerns, their understanding or their confusion within interactions. It was acknowledged that responding to information needs was much easier where there had been opportunity for repeated and/or more extensive discussions.

you do know your patient and you learn your patient and you know which patients are more likely to want more information and if you can be seen as a resource for other things not just about their own care but you might be able to help them or direct them to information about something else then they’re more willing to take on board, the information you give them about their own care, erm, you know, if you can give them advice about, you know, useful websites, or useful leaflets, or contact people and things like that

HP16

Through this there could be greater insight into personality, attitudes to health, primary concerns and family dynamics. As professionals used a combination of history review and first hand personal impressions it is pertinent to note earlier comments on the quality of documentation practices. On the point of making an assessment, concern was raised that the quality of initial patient history taking had changed with the advent of structured proformas and electronic records, the result being a more abbreviated, less narrative account that provided less information to the whole team to support later activities around information.
I think that, like everything, it comes back to quite careful history taking at the beginning. And, you know, having the relatives there and sort of reinforcing to everybody the importance of getting as much information, and documenting as much information as you can. About, you know, what the patient was like beforehand and then that helps you to formulate what you’re going to say to them, doesn’t it?

A general principle behind all these questioning and conversational approaches was trying to take the lead from the patient and sense concerns and fit information to them, but then this sat alongside an agenda of concerns and topics that professionals also wanted to address with people. Some nursing and therapy staff had either internal or documented lists (proformas) as a prompt to consider all (as they saw it) relevant topics to be covered. This can be seen to strive towards comprehensiveness in topic coverage, but may result in overwhelming survivors/carers and not necessarily tackling their primary concerns when needed.

In terms of assessing the impact of information provided, change in function and/or behaviour was the ideal but difficult to assess as such changes may not occur till sometime after information was provided. With relatively limited contact time with survivors and carers any impacts of information were often uncertain. Professionals did not routinely assess impact of information as information was predominantly exchanged during one to one verbal interactions. Within interactions professionals would use similar techniques as those used to gauge information provided to see if information was taken on board. The usual approaches were to observe body language, to ask for verbal feedback, to ask if survivors/carers had understood information and to ask if they had any questions. Unless information was required for a consent procedure professionals would not necessarily pursue detailed questioning about understanding as it was felt to potentially make survivors/carers nervous. Perceptions about the impacts of information exchange are discussed further in chapter eight.

6.4 SPECIFIC ISSUES WITH INFORMATION EXCHANGE ACTIVITY

6.4.1 People involved in information exchange/who’s responsible?

From the perspective of stroke survivors and carers the groups of people discussed as potential sources of information about stroke were:

1. health professionals (22 participants, 315 extracts)
2. family and friends (15 participants, 50 extracts)
3. third sector/support agencies (13 participants, 47 extracts)
4. other stroke survivors (7 participants, 28 extracts)

This demonstrates the predominance of professionals as a source of information. Amongst the professionals the following list ranks separate professional groups in order of the most referenced in survivor/carer accounts to the least referenced:

1. Hospital (specialist) doctors
2. Hospital nurses
3. General Practitioners
4. Physiotherapists
5. Occupational therapists, psychologists, practice nurses
6. Speech and language therapists, dieticians, NHS direct
7. Paramedics
8. Home carers, social workers

Some professional groups will be mentioned more in view of having more contact time with a greater number of survivors/carers. The dominance of doctors at the top of this ranking reflects the view that they have answers about what has happened (a primary area of concern as we will see in chapter seven). Other team members however, may be seen to have more specific technical or applied roles. In this light questions may be reserved for the specialist and different knowledge and division of labour in relation to information provision within the team would not necessarily be appreciated by survivors and carers.

I don’t know. It would probably be somebody, not so much like a physiotherapist because to me again, they... You know, a physiotherapist deals with someone who’s broke their arm, you know...they’re not like say yourself, you’re focused on I presume, just on strokes and things like that. Whereas a physio she could be dealing with me today, tomorrow she could be dealing with someone who’s you know, smashed their leg up in a car crash. So they’re not a master of one trade, you know, just... You know, a bit of this, that, and the other.

SS04

So I don’t really know what other verbal information [Husband] was given because you don’t get to see the doctors of course because they do their rounds, you know, outside of visiting time. And the nurses can’t really give you very much information of course because that’s not their job.

SC03

There were not always great distinctions made between staff unless they were better known to the patient and family. They would not always be sure who was
who or would see so many people that it was difficult to remember who had told them what. In some accounts generic terms like ‘they’ were used to refer to staff where patients were unclear who it was who had specifically told them things. There are assumptions from survivors, carers and professionals as to who does what and no overt effort to clarify these and neither set of assumptions clearly identifies whose responsibility it is to provide relevant information to patients and their families. Seeing so many different professionals and not necessarily being clear about different roles did not facilitate engagement in information exchange. For those that needed to get to know and trust a professional before actively asking questions it was more problematic.

Just over half the survivors/carers interviewed talked about seeing their GP in positive terms, though not all consultations were focused on stroke. Survivors/carers were more likely to see their GP if they already were in the habit of attending the surgery for checks and felt they had a good relationship with them and that they would be listened to. Having or needing to change GP, not trusting the GP team and not being used to seeing the GP were the main reasons discussed for not having seen the GP. The topics discussed with GPs in relation to stroke included: driving, blood pressure monitoring/control, clarification of diagnosis, pursuing specialist follow up and medication checks. Practice nurses were seen in a more technical light as doing blood tests and blood pressure checks. There were no accounts of more detailed discussion of stroke with them. Two respondents described interactions with the practice nurse as ‘bland’ or ‘chit-chat’ neither suggesting a significant informational role.

Communication with family and friends about information were variable depending on individual networks and dynamics. There was co-dependency between survivors and carers for information. Carers reported being often reliant on survivors for information as professionals (particularly doctors) were not usually present at visiting times. This could be problematic when recall of information was an issue for survivors. The other side of this was when carers remembered much more of the acute stroke experience when the survivor had been very poorly during this time. In this instance they would provide information and fill in the blanks for the survivor as far as they were able. There were mixed accounts and views from carers and professionals about pro-activity within visiting hours for information exchange between families and the most readily available professionals, nurses.
Third sector/support agencies discussed in rank order were:

1. Stroke Association family support worker (FSW)
2. BASIC (Brain and Spinal Injury Centre – local gym and resource centre)
3. Carers Centre (local)
4. AGE concern

In view of the reliance of some professionals on the family support worker role to support secondary prevention and lifestyle advice at the time of the study, it is worth noting that not all participants had received direct contact with workers. Seven stroke survivors had seen the FSW, one was waiting to see them and four had not. Two carers had seen the FSW directly, one had received a letter with no planned contact, two were waiting to be seen and two had not been seen as their relative was seen alone. This demonstrates the challenges in providing a consistent service to stroke survivors and their families. Views on the information and support offered were mixed depending on sometimes personal factors. There was only one survivor/carer couple with longer term FSW input in relation to financial concerns.

Survivor/carer accounts of gaining information and support off other survivors were mixed. Contact spanned discussion with fellow ward/therapy patients, keeping in touch with fellow patients by phone, contact with other survivors further on in stroke recovery (arranged by professionals) and attendance at a support group. Where appreciated the benefits of such contact included:

- Relief – it’s not just you
- Feeling less alone
- Shared experience/understanding
- Inspiration and encouragement
- Advice and tips for coping.

For some with good recovery and/or those who did not want to acknowledge their stroke overtly, some forms of contact such as a support group were of no interest or, if tried, found to be depressing and not for them. The survivor, who through volunteering saw many other stroke survivors, also expressed a tendency for renewed worry about recurrent stroke, through seeing others going through this.
Amongst health professionals’ accounts of the people involved in information exchange, there was the same recognition that no one individual or group was responsible for information exchange. It was a team effort with some broad division of labour. Doctors dealt with medical information (diagnosis/medical treatment), nurses and FSWs secondary prevention and lifestyle advice and therapists/other disciplines information specific to their rehabilitation roles. These were broad divisions in principle but not absolute guides to information exchange activity. Other factors also came in to play affecting who got involved with information exchange. The type of factors influencing this included:

- Time/work pressures
- Training and experience in stroke care
- Personal styles of working and interest in providing information
- Life experience and drawing on own experiences of illness (self or family) and consequences.

In terms of time pressures, staff did not see information exchange recognised as a core activity. In this context it could be seen as an ‘end of the queue’ job with direct patient contact time taking precedence. In the study setting there was awareness of issues around improving information provision, for instance the need to review and sort available resources to support information provision, but it was this type of activity that was not recognised as part of activity monitoring.

Professionals recognised that the knowledge and skills to provide information built over time both in terms of accumulating factual knowledge of stroke and local resources, but also in terms of relating this to individuals with greater empathy. It was also identified that certain individuals had a different work ethic, or work style and a particular interest and as such were better suited to providing information and invested more in this activity.

*it depends how you see your job I suppose as a person. Some people come to work to do the job to get paid to go home and that’s as far as it goes I think. Whereas some people are more perfectionists and want to make sure they have done the best they can and, so I think a lot of the time it depends on your work ethic or your personality as to how much information you give. To some nurses I think that they think it’s enough to come in um, their observation is okay, they’ve had enough to eat, their IV fluids are okay, their venflons alright, that’s it, they have looked after the patient as far as they are concerned. Um but to other people and to me I don’t think it’s as simple as that….I can think of doctors that just come in and do the job and go home again and, but then I can think of other doctors that will be here til eight o’clock at night every night because they*
This could also lead to delegation of responsibility. This will be discussed further in chapter seven in relation to the potential burden of this. Relating this to calls within policy for an information co-ordinator role/function (Stroke Association, 2006; Department of Health, 2007a) it is not obvious from this study who that role would fall to. It is also suggested that fit to any such role would be a combination of breadth of knowledge, interest and style of working. If the role entailed active involvement in providing information, peer support and supervision would be another important issue to address.

In view of the numbers of professionals involved in information exchange post stroke some benefit could be yielded from more overt documentation of team aims and methods of working relating to information exchange. Documentation of a plan for information exchange for individual survivors or an agreed means of recording information provided may be of benefit. However, as highlighted under the section on documentation if professionals are unable to review such records due to access or other issues these efforts would not streamline or tailor information provided any more effectively. The most consistent person to hold such a record would be the survivor. Efforts to explore this type of approach have been explored with some success (Lowe et al., 2007; Jones et al., 2009). Application in practice of this type of approach needs further exploration and consultation with stroke survivors.

6.4.2 The right information at the right time
With respect to timing of information provision post stroke, the main focus of patient and carer accounts was to understand this in the context of the evolving stroke experience. Patients and carers did not identify specific times when they would particularly seek information as this was dependent on their own particular needs and developing awareness of these. As one of the patients described it ‘stroke grows onto you’ and you neither know what you are up against immediately or are able to take in information easily. Stroke was also described as ‘like a puzzle you put together over time’. Respondents universally described the stroke onset as a shock, an unexpected event, of feeling grateful to be alive, and in the context of not knowing what was necessary, putting themselves in the
hands of the professionals. One gentleman described the initial experience as being ‘in the thick of it’, you don’t need information you are just getting on with it. Memories of early admission were blurred for many with descriptions such as ‘being in cloud cuckoo land’, ‘I just couldn’t care less’, ‘it was like a blur’, ‘she was in a dream world’, ‘in a state of limbo’ and ‘in a cocoon only able to take in so much’. The stroke was an evolving, learning experience with most starting with little knowledge and learning from a combination of provided information, sought information and, in large part, experience over a protracted period of time. This time went well beyond the inpatient admission when most professional driven information provision was undertaken. Many did not start to process information or reflect on needs till they got home, this is in part due to the time respondents identified they needed to take in and process information and also the fact that the residual impacts of their stroke could only be fully understood and accepted for many when they returned home and could experience things in their own context. This highlights a main issue raised by patients and carers that a bulk of information provision, particularly written information, was provided when they were least able to make any use of it early on during their hospital stay. I have given examples of this under verbal and written information accounts and the implications of this are presented further in the next two chapters.

Discharge was a particularly stressful time and specifically mentioned by half the respondents. This fits with the accounts of difficulty processing information provided but also raises other issues over the time frame of planning discharge and the support available through it. Stroke survivors may be in hospital for variable periods of time from a few days to several weeks however, accounts of discharge feeling rushed and disorganised were given by patients and carers with both shorter and longer stays. In the case of the shorter stay, this can be rationalised in terms of the amount of time available and the difficulties of processing information. However in the longer term rehabilitation stays there seemed to have been difficulties either in agreeing goals between the patient, family and team or between the timescale of goals within the team itself. This conflict resulted in training and preparation for discharge not integrating soon enough into therapy/care activities and thus feeling rushed at a time when processing new information is already made harder.

_İ mean we were getting, I think the day before, it was getting training on the PEG, wasn’t it… the day before she was coming out, I’m thinking oh my_
God, you know, what’s going on? Erm, that was very poor really when you think about it, it was really poor that, to be you know, showing us like, I mean it should’ve been offered before that, to us, really…it was just, it was, it was like the last week, we were like bombarded with stuff, you know.  

SC09/10

Even with the best preparation, discharge is a scary time moving from the perceived safety of the hospital environment with care immediately available to being self sufficient (supported or unsupported) again at home. It takes time to appreciate what is available and what can work for you and how to adapt, whilst respondents described doing this by applying common sense, automatically adjusting/adapting, learning from experience good and bad, they felt more immediate support straight after discharge would be beneficial. The preparatory nature of much information provision perceived by staff (described in chapter seven) does not appear effective in patient and carer accounts and presents challenges for how information provision could be carried out in a more paced fashion when required by survivors and their families.

6.4.3  Could things be improved?
Participants from all groups either volunteered or were asked about what things would improve information exchange. Areas of shared concern included:

- More/flexible support immediately post discharge
- A regroup/summary session or letter
- Key worker or advisor role
- Targeted/different input for younger survivors/carers.

6.5  CONCLUSION
This chapter has drawn together different data sources from written records, observations of key interactions and interview accounts of information exchange activity, in order to describe how information exchange activity took place during the time frame of the study. Such a descriptive account was one of the key aims of the study in order to describe how information exchange took place in practice. Describing activity in detail is a vehicle for looking at areas for potential improvement.

The first theme presented modes and media described the three main modes of information exchange encountered and described. Verbal information exchange was the dominant force for all concerned as this dealt with the personal
information relating directly to an individual's stroke. This was most relevant to survivors and carers and information that professionals could be confident of within the bounds of their roles and responsibilities. The main problem with this was the survivor/carers' ability to take in and retain this information particularly during the hospital stay. Written back up materials were the most commonly cited solution to this problem. Manpower issues however, were a key problem in generating more high quality, personalised written back up materials and staff lacked detailed familiarity with generic written sources in order to actively connect these to individualised verbal messages provided. Generic sources were not always seen as relevant and the written format was problematic for some survivors. The internet was seen as a growing force however it shared many problem areas with generic paper based written materials and as an unregulated source of information required careful scrutiny.

Although information exchange activity was taking place professionals did not have a mutually agreed and formal assessment process for this. Documentation of activity was also variable and therefore did not support team working and communication on this topic.

In view of the number of professionals involved in information exchange activity with individual survivors and carers, and a lack of clarity amongst all respondent groups about key areas of responsibility, a clearer strategy for information exchange and better documentation would likely be beneficial. Such a strategy would require input from survivors and carers as well as professionals. This would be required to produce a lay friendly approach that could be made available as a guide to services provided. Timing of information exchange was also identified as a key issue. The survivors and carers in this study openly discussed being aware of receiving a lot of information when they were least able to make use of it, during the hospital admission. Some materials were reviewed later down the line and were appreciated then but lessons may have already been learnt by experience at this point.

The need to tailor information is raised in guidance (Department of Health, 2007a). The material in this chapter starts to highlight that tailoring needs to incorporate both the various factors already informally assessed in professional information provision exchange, along with consideration of timing issues in order to plan for and pace information provided. This is a significant challenge in
view of the numbers of people involved in any one individual's stroke care, I will return to this in the discussion chapter. The next two chapters will consider first the motivations/reasons for information exchange and then the perceived impacts of information exchange to provide insight into the challenges inherent in taking a more tailored or paced approach to information exchange.
CHAPTER SEVEN: REASONS FOR AND BARRIERS TO INFORMATION EXCHANGE

7.1 INTRODUCTION

In this chapter, I will present the categories generated from codes around why patients and carers sought information and why health professionals provide information. These categories were also cross referenced and informed by some of the themes about what types of information were sought and provided and health professionals’ accounts of challenges experienced in information provision activity. The categories presented are drawn from interview data. The reasons offered for information exchange are presented in three broad categories: making sense of the stroke, dealing with life after stroke and dealing with emotions. Interviews also sought reasons for not pursuing information exchange. Reasons given by stroke survivors and carers are presented first followed by those of health professionals. These provide insight into some of the barriers to effective information exchange despite overlap and shared ideas for the reasons behind getting and giving information.

7.2 REASONS FOR/UNDERPINNING INFORMATION EXCHANGE

Study questions were used to organise thematic coded material from interview transcripts. Therefore themes relevant to why information exchange took place and motivations underpinning it were drawn together in topic specific matrices for the three respondent groups. These were then reviewed and re-read to generate categories that could describe the scope of the reasons given for information exchange. It was possible to organise these into three broad category/thematic headings that could then be reapplied to the matrices in order to check they captured all the data.

The content of categories were then examined for those with most ‘weight’ (this considered the number of participants contributing to and the number of codes and extracts linked to them). They were also examined for whether all respondent groups contributed to them. As it was possible to generate shared broad category groups across the respondent groups this was done to get a sense of whether there were different areas of emphasis within the categories for the different respondent groups.
Stroke survivors and carers spoke most of ‘dealing with life after stroke’, then ‘making sense of the stroke’ and then, ‘dealing with emotions’. Carers in particular contributed more to the category ‘dealing with life after stroke’ due to their concerns with planning for the future, learning new skills and shared concern (with survivors) regarding the risk of further strokes in the future. Health professionals also had most to say about ‘dealing with life after stroke’. However, their next most heavily discussed category was ‘dealing with emotions’ then ‘making sense of stroke’. Amongst health professional accounts there was much more cross fertilisation of ideas and linking of content across categories. The fact that the category/theme ‘dealing with emotions’ was more heavily discussed by them highlighted their belief that information could contribute to the processing or managing of emotions about the stroke. This did not resonate with survivor/carer accounts and I will return to this when discussing this category.

I will now describe the contents of the three themes highlighting areas of contrast and providing illustrative quotes where pertinent.

7.2.1 Making Sense of the Stroke
This category brings together reasons for information exchange that relate to wanting to understand the stroke, its effects on the body and its functions and the reasons why the stroke happened.

For survivors and carers, these were the three main sub-categories identified under this grouping. They wanted to understand what this stroke was, its nature and how bad it was. This was linked to questions and concerns about whether or not they would get better and would be able to go home.

*I remember asking at the time is that because the muscles are not working or is it because the nerves that are operating the muscles are not working? And erm, got the reply it’s the nerves that are operating the muscles that are slow to react and I would say that’s probably the most interesting thing that it’s not muscular its nerves.*

SS01

*I: What were your primary questions?*

SS09: *Am I gonna get better? And what has happened? And why?*

SS09

Understanding the nature of stroke was perplexing for some as it was seen as somewhat abstract and not easy to grasp as you could not see it or feel it one
could only experience it through its remote effects, the symptoms felt elsewhere in the body.

I think it's because there's no physical signs, you say... you say to yourself, "What have I done?" As if you, the I, is inside your brain, "What have I done here to myself?" You know, you can't see a broken foot, you can't see a bleeding knee or whatever, what have I done?

SS10

In relation to this, there was some interest in understanding the effects of the stroke on the body and on function and linking the stroke in the brain to the symptoms experienced and grappling with.

The final sub-category of major importance to some survivors was the desire to know why their stroke occurred. Some survivors did not dwell on this and some did not believe the reasons for stroke were always clear. For others however, where the stroke appeared to be an affront to their perception of themselves and who struggled to relate to medical explanations of their stroke, this was a real area of persisting frustration and discontent.

I've had cameras down my throat. I've had all these... They've done all that and all my neck veins and more vessels and whatever, and they can't home in on basically anything. You know, there's nothing there that they could say this is why it's happened..... You know, there was a little bit of thinning of one of the valves in me heart, and that could possibly be it. Er whether it was the blood pressure... Me blood pressure was high. Cholesterol was quite high. So... You know they just..... I don't know whether it's just prevention but you're talking like it's happened, you don't know why...they've never told me that's the reason why it happened. I've never had that because I don't think they know.

SS04

One younger carer, whose mother had had a stroke, was also concerned as to the causes of stroke and whether this had future implications for her.

'Will I have a stroke when I am older?' 'Is it hereditary?' Or is it because of whatever that has been done, or has not been done, or is it just one of those things that happened? Or was it because of all the dramatic weight loss, did it cause pressure on her body that is why she had it.

SC02

Whilst this was a single occurrence it raises a pertinent concern that some particular groups of carers may require particular information. This participant did not feel confident to raise this with her GP or other professionals so the worry
remained with her and the opportunity to suggest any relevant actions was lost. Within health professional accounts growing awareness of the unique needs of younger carers was raised.

Health professionals were also concerned that survivors know what had happened to them, how it was affecting them and what they might expect to happen. They linked understanding what was happening to getting some power or sense of control back for survivors. This distinction was not seen in survivor accounts. Health professionals were in general agreement with survivors/carers of the need to understand and make sense of symptoms. However professionals were also cognizant that for some survivors the stroke itself may be limiting their perception and ability to understand and make sense of their symptoms. For those with longer term contact with survivors, there was also recognition of the need for explicit explanation even quite late on in rehabilitation to make the stroke something tangibly understood.

I'm sure they have been told that they've had a stroke, and I suspect they may have been told where they had the stroke, but people don't always know. So when you say, well you've had it in the hypothalamus and that's the structure right deep down inside the brain and it takes pathways all around the brain, so it's a bit of a pre-junction in the brain. Sometimes just that sort of information… “Oh, is that right. So is that why I get that funny feeling? Is that why I get all emotional? I can't add up or…” And just, you know, just taking the time to explain to people where their stroke was and whether it was a little stroke or whether it was a sort of slightly bigger one. Again, that sort of information means that people… It’s like swimming in a sea and not seeing any land! But when people have got some information they can sort of start…sort of anchoring themselves to something that feels very real.

The use of scans to illustrate their stroke to survivors was not seen in practice but mentioned in interviews. This was seen as useful for some people who appreciated visual images to help them appreciate the stroke effects but was not seen as suitable for all.

Professionals also appreciated that ‘why?’ was an important question for survivors but they did not discuss this as much as survivors. As survivors did not necessarily relate their ongoing questions, confusion and concerns this may be because professionals were not always aware of ongoing confusion about causation. Also the reasons for the stroke from the professional perspective
were primarily the platform for the discussion of preventive strategies. I will return to this later.

So concerns with understanding the stroke, its effects and causation were three clear areas of overlap across respondent groups however, in health professionals' accounts three further sub-categories were identified. These were: to accept stroke as a life changing event, to make connections with prevention and to engage survivors in care. Two of these had linkages with other categories of ‘dealing with life after stroke’ and ‘dealing with emotions’. The sub-category ‘to accept stroke as a life changing event’ could be linked to both ‘dealing with emotions and ‘dealing with life after stroke’. This dealt with understanding stroke as something that was not going to go away, that may require a potentially long recovery and would require coming to terms with.

_I often say to people it’s like having a black cloud over your head. It’s like, you know, it’s there over your head. And I say ‘It’ll never go away. It’ll get smaller and sometimes you won’t notice it. And sometimes it’s just like a little black pinhead there, but it’ll never go away. You will never ever be able to forget that this thing has happened to you. So what you’ve got to do, is you’ve got to let time pass and you’ve got to think about other things. And then you’ve got to let that black cloud get smaller’. HP15_

For professionals, there was also the sub-category ‘to make connections with prevention’ linking to ‘dealing with life after stroke’. This was describing the health professionals’ view that part of understanding the stroke was the understanding of the need to try to prevent future strokes and to take responsibility for this.

I think this distinction of professionals having a more evident sense of connection between different themes or information functions is interesting. It highlights the different starting points for health professionals, survivors and carers when undertaking information exchange. The health professional has a ‘birds eye’ or ‘panoramic’ view of all that stroke is and could be for a person and very often when giving information will be seeing a potential connection for it or use for it that they do not make explicit. Survivors and carers in contrast unless unusually knowledgeable are naïve to stroke. All they have is their unique stroke experience unfolding before them frame by frame. They are often acting and reacting, trying to understand each new revelation however, doing this with
impaired recall, processing and concentration, therefore struggling to make links across information topics covered.

Finally, a third sub-category for the professionals was ‘to engage survivors in care and rehabilitation’. This highlights an understandable background agenda for professionals. A clear benefit in someone understanding what is happening (even if moment by moment) is greater co-operation and engagement with you in the tasks you need to undertake.

\[
\text{if you don't explain anything or do anything it tends to just worry people and er, it secures for me a better co-operation because they understand what I am trying to do.}
\]

HP24

Again, there was some linkage with other areas in ‘dealing with life after stroke’ with a key message being the need for survivors to take an active role in rehabilitation as a starting point for active management of their stroke longer term. Within such exchanges there would also be motivation to try to establish survivor and carer expectations for recovery and rehabilitation with a view to dialogue about what is and isn’t possible in rehabilitation. I will now describe ‘dealing with life after stroke’.

7.2.2 Dealing with Life after Stroke

This category dealt with desire for information relating to the concerns about moving on to deal with life after stroke. It encompasses preventing further strokes, preparing for and handling stroke at home, caring responsibilities and financial concerns.

Again within this theme there were shared sub-categories across the stroke survivors, carers and health professionals. These were ‘preventing another stroke’, ‘preparing for and handling stroke at home’ and ‘caring responsibilities’. Within these there were different points of emphasis for the different respondent groups. For stroke survivors and carers there was an additional sub-category ‘financial concerns’. This was drawn out as a distinct sub-category for them as it was not mentioned by health professionals under the shared sub-category ‘preparing for and handling stroke at home’.
The first thing to say about the sub-category ‘preventing another stroke’ was that this was discussed much more heavily and with much broader content by health professionals. From the perspective of survivors and carers both groups contributed to this with carers often equally aware of and fearful of ongoing risks for their loved one. But there was unsurprisingly more input to this by survivors as the risk of future stroke is theirs and they will have had more direct information on this. The desire to do what they could to stop another stroke was expressed. However, their discussion of this was at a general informational level rather than at a specific action level. There was relatively little discussion of actual lifestyle change and active risk factor management, though there were accounts of some dietary changes as a result of information supplied. This could be attributable to poor recall and/or reluctance to change and in one case the latter was true. Importantly, there was also a sense that the lifestyle modification message raised ambivalence and was often met with frustration and uncertainty as to the actual real benefits to be reaped. As a result more detailed information could be required on personal risks for the individual. For some respondents, they did not have several vascular risk factors before their stroke or others had been taking steps to manage their risk factors yet had still gone on to have a stroke. The sense of frustration or having been cheated was strong for such individuals.

I couldn't believe it ... I've always been extremely fit, building, squash, playing football always.....I'd actually been running that... The night before this happened. I've done half marathons. I've done all sorts.... Don’t smoke. Don't drink a great deal. I mean smoking was a big part of it apparently but I've never smoked a cigarette in me life. I eat tons of vegetables and fruit, so I just couldn't get me head round why is this happening to me?

SS04

This highlights the need for at least some survivors to have a more in depth discussion of the complexity of stroke causation and their own personal risk profile in order to achieve or maintain engagement with preventive self-care. The awareness of not just the risk of future stroke but its actual occurrence was very real to respondents. This was either through discussion with other stroke survivors or first-hand experience.

..when you talk to other patients who say, “Yeah I’m in here because I had two strokes”, how can you have two strokes, you know, looking like that.
So you always think then am I going to have another stroke because people’s had two or three strokes.

SS11

Within the small sample of this study, two survivors had had a previous TIA and three a second (though milder) stroke. In contrast to health professionals with only a personal not a public health agenda in the context of prevention it is understandable that for survivors, prevention whilst a desirable topic, is also a thorny issue.

In contrast health professionals talked at length on the importance of prevention and lifestyle change as part of this. With a wider agenda than just the personal this is unsurprising (Bensing, 2000; Redfern et al., 2006b). They talked of the importance of providing information to facilitate informed choice about changes; that people may not be ready to change, or want to change. In this context, there was a need to sow seeds for change, revisit the topic, to be creative in packaging the message, negotiating moderation and praising any achievements.

when he comes in to see me he’s going to be told the same things again so I try to give it to him in a slightly different way and I always try and focus on the positive, you know, even if he hasn’t, you know, done anything, I always try and say well cutting down cigarettes that’s excellent, you know, and try to focus on the minor achievements… then it’s not that you’re constantly on their case telling them what they should and shouldn’t be doing..

HP16

This last description was of a professional with ongoing contact with survivors over a period of time allowing better knowledge of the person and the building of some relationship with them. However, if contact was intermittent developing and personalising the message was not easy. Health professionals were aware of the role of health beliefs in mediating change and that that some people are more fatalistic whereas others are more active responders. In light of this more experienced staff highlighted that due to variable beliefs and knowledge there was a need to clarify connections between behaviour and stroke. As such connections were not obvious for survivors; it was also acknowledged amongst professionals that information about the need to make changes may be like receiving more bad news.

if you’re thirty cigarettes a day smoker, I can say this until I’m blue in the face, saying ‘Stop smoking!’ I can bring the smoking cessation advisor
along and that’s probably very helpful because they’re somebody who’s gonna follow them up, you know, further on and provide them with support. And that’s really helpful. But if they don’t take onboard the fact that they have had a stroke, or what the mechanisms are. Then they’re going to see it almost as two bits of bad news in one. Not only have you had a stroke, I’m gonna tell you to stop smoking. And if you don’t see the link between the fact that carbon monoxide makes your platelets sticky. And giving you Aspirin to make your platelets less sticky, so how daft…..If you don’t put it across in those sort of terms, so that you actually make a connection. You’re just giving you two pieces of bad news for the price of one, then they won’t change their lifestyle.

Evidence of such explanations and actions did not come through survivor accounts or from observations for the study. Again this could be attributed to problems with recall and lack of robust back up of more personal messages. However, there was also the worrying recognition that the skill and knowledge to provide such personal and detailed messages may not be present amongst all nurses, a group who were seen to be particularly responsible for lifestyle messages by medical colleagues. The ambivalence of the prevention message was also touched upon that is that it was about reducing risk as much as possible rather than eliminating it.

The sub-category, ‘caring responsibilities’ was shared between stroke carers and health professionals. There was very similar content with carers wanting to know what was required to deal with the stroke and its impacts, in order to feel confident in their caring role and feel prepared and supported for discharge. Health professionals talked about the need to prepare people for future caring tasks and responsibilities. This encompassed demonstrating care required and advising and questioning how they would manage at home. Implicit in this was that sometimes this would be about confronting what were felt to be unrealistic expectations. Health professionals had differing views with respect to letting people take the risk to attempt home care and unfortunately it appeared that this could sometimes lead to delays in providing hands on experience of care so critical to supporting and preparing survivors and their carers for discharge home.

‘Preparing for handling stroke at home’ for stroke survivors and carers was predominately about a desire to know what is going to happen and when in recovery.
It was about four days before we actually got to sit in a room and speak with somebody who told us exactly what was happening. And that she was going to need an operation, and why she’d had the stroke. And that she was gonna need a lot of care when she come out of the hospital. But that, I would have thought, that should have been done straightaway not taken so long to do.

SC02

How long it may take to recover and when this could be expected was a primary concern. It was apparent in accounts that the term recover was used variably amongst respondents. Stroke survivors using the term in the sense of a recovery to normal to being like I was before my stroke, this focus on a return to normal for survivors has been identified in the literature (Dowswell et al., 2000; Gallagher, 2011). Professionals on the other hand viewed recovery in terms of a return of best possible function but not necessarily back to normal. The emphasis here was a desire to know the unknowable in terms of when recovery would take place and a hope for recovery that was back to normal. This difference in emphasis was a point of tension in communications around what to expect.

Practical concerns included what to do and not do, what to do to keep getting better, what to watch out for and dealing with falls.

.. needing to know whether I’m doing the right things to get better. I don’t just want to go into it blindly and make mistakes. I don’t want to make anything hinder me. Because I do, I do want to get better quickly. But I want to do it the right way. I don’t want to be in the dark about it. And I want to know what I’m doing, if I’m doing it rightly or wrongly.

SS02

The same sub-category for health professionals had similar content in terms of things to look out for, how to avoid these and where to get help, resources and support. Topics highlighted were fatigue, mood, return to driving and symptom management. However, the difference in emphasis was similar to that under ‘caring responsibilities’, with discussion of concerns about confronting unrealistic expectations, making people aware of their limitations, and trying to manage and negotiate expectations. There was an awareness of the ‘crash’ that could occur after discharge and a desire to counsel people to prepare them for this.

I don't think we're good at counselling people about how awful it’s going to be when they go home. I try and say to people, I try and say ‘It’ll be fantastic going home, but it will also be emotionally overwhelming. You will
be absolutely exhausted and you will be shocked to find that you're not quite the same person that you were the last time you were in your house'.

For the small number of staff with longer contact this evolved into concerns around trying to get people to face that they wouldn’t get back to normal as understood by the professional. This could involve offering objective feedback about progress, or plateaus in progress at key points such as discharge from therapy in order to try and help people realise that getting back to normal wasn’t possible. Professionals may think in terms of normal physical function whereas survivors are more concerned with normal social function. This tension between the global view of the health professional seeing the stroke survivor as forever changed and the survivor striving to return to normal is documented (Gallagher, 2011), I think it is critical to understanding how we work with people in a ‘tailored’ way. I will return to this in the discussion.

The sub category ‘Financial concerns’ was pulled out separately to highlight it as an area of concern particularly for younger stroke survivors. Health professionals interviewed did not specifically mention it as a topic. That it did get addressed was evidenced in survivor and carer accounts and in some observations. Advice could not address all concerns depending on circumstances, or was not received in a timely fashion and in both cases the outcome was considerable financial strain and stress.

7.2.3 Dealing with Emotions

This category describes reasons for using information to try to deal with emotional impacts of the stroke experience. For stroke survivors and carers there were three identified sub-categories ‘understanding emotional sequelae of stroke’, ‘to feel better and get on with life’ and ‘desire for reassurance’. In the main there was much more contribution of survivors rather than carers to this category overall, with only two carers making direct contributions. This may be because I was not working with carers who all had hands on care responsibilities. However, I don’t think this is the only factor. Carers with greater responsibility did not necessarily connect information with emotional needs. Information was not always perceived as supportive; it was on some level potentially an additional burden. I will return to this in the next chapter looking at information impacts. Also for family members of more mildly affected survivors they derived their
reassurance from observable improvements in their relative as their personal contact with health professionals was often low.

If she’d have been disabled in some way I would probably have, you know had more to tell you as to whether the... you know, she got the follow up treatment and all the rest of it, but I mean she was as right as nine pence isn't she?

For health professionals there were six sub-categories identified. Three had clear overlap with survivor/carer categories ‘Normalising the stroke experience’, ‘To feel better’ and ‘Reassurance’. The three others drew out specific concerns of professionals these were ‘Point of contact’, ‘Help with emotional decisions’ and ‘Integration of stroke’.

‘Understanding emotional sequelae of stroke’ and ‘normalising the stroke experience’ were very similar in content.

a lot of people just want to know that they’re normal, and what they’re going through is normal and they can see a light at the end of the tunnel.

For those who perceived changes in their emotions and ability to cope with day to day activities it was good to know that this was a part of the stroke as otherwise this was difficult to comprehend. There was a need to recognise just how difficult the experience of stroke is emotionally and this was recognised by survivors and health professionals. In terms of the idea of normalising the post stroke experiences of survivors, this may make more immediate sense to professionals who have dealt with many strokes and work from the position that stroke is a life changing event. For survivors it may offer reassurance but also represent a tension or challenge to the desire to return to a pre-stroke 'normal' state. However, that distinction is not meant to detract from the fact that survivors did appreciate information supporting that they were not alone or the first to feel the way they did. For some survivors, professionals could offer this for others this more meaningfully came from someone who had experienced stroke first-hand too.

I was talking to another lady .....she had two TIA's......they're only small strokes, but it really affected her in a lot of ways.....She said ‘Oh, I'm alright’... ‘But oh, I have this... I can talk to you about it though. And she
said ‘But I have this like not knowing where I am for a second’. She said ‘It’s not like thought-blocking, but it’s just….I said ‘I have it’. I said ‘I can be in the car and for a second I’m thinking… it just goes only for the second’. ‘Oh’ she said ‘Oh, thank goodness for that’, she said ‘I thought it was me’. I said ‘No’ I said ‘It does happen.

SSHV01

With respect to the sub-category ‘to feel better and get on with life’ survivors wanted information to help ease their mind, relieve worries, to make them feel better, to reduce doubts to feel they could get on with life and to relieve feelings of being stuck relating to future uncertainty. The tension inherent in this is that not all information received would necessarily alleviate such feelings.

When discussing the provision of information for survivors ‘to feel better’, health professionals discussed providing information to: tackle self-criticism, provide new techniques to handle emotions, focus on the here and now, deflect ruminating worries, to increase quality of life, reduce the pain of the experience, to relieve the fear of the unknown and to diffuse tensions.

I mean again information is power, if you know what you’re dealing with then you’re more likely to have a management plan in place for how you go about doing it. If you know that the worst thing to do when you have fatigue is to run around on a day when you feel as though you’ve got energy. If you’re minded to then it gives you a management strategy how to deal with it.

HP09

Some of these aims and hopes for information provision are admirable but perhaps unrealistic. On balance, health professionals made more of what information could do to help tackle difficult emotions than survivors did. This links to the double edged sword that information can be in that, it doesn’t necessarily at a factual level make people feel better. The impact of information may be linked to its presentation; purely providing facts to assure someone that an experience is normal may only briefly allay troubling feelings. However, if facts are supported by discussion as to how they can be used to manage situations this may have longer term benefit. This is developed more in the next chapter. What is often needed is information to support the handling and processing of information and its link to emotions, the benefits of this were seen in accounts of the use of psychology therapy post stroke. However access to stroke psychology services is not always readily available. Use of more psychological cognitive
approaches by non-specialist staff has been explored (Byers et al., 2010; Watkins et al., 2011).

The topic of ‘Reassurance’ was shared by survivors and health professionals and is linked to wanting to feel better. It is drawn out for separate discussion as it relates least to factual information and is more about a need to be encouraged and supported and for one’s belief in one self to overcome challenges to be bolstered. The core message from survivors about reassurance was that for them this was about hope and the belief that they will make it. Professionally qualified members of staff were not always seen as the best source of such reassurance. Instead this may come from other survivors further down the line or very experienced nursing assistants. Because of the uncertainties of recovery this can be a tricky area for some professionals with concerns about supporting unrealistic expectations. Survivors were aware that such information was not certain but being told something was better than nothing.

You just don't know and I don't think everybody wants to leave themselves open to sort of saying, well you told me this or you told me that, which I wouldn't do anyway because it's impossible to be definite, but you just want to be told that, you know. "I reckon it will be 2 years, you'll be alright." Do you know the only ones who ever told me anything in the hospital was the… You know the auxilliary nurses, because they says, "We're not doctors or nurses. But I've worked on this ward for 10 years and I've seen a million people like you..."

SS04

Staff framed reassurance in terms of providing feedback on progress to provide encouragement that survivors were moving forward in rehabilitation with the belief that this could boost low morale and mood.

I think it’s important to give patients feedback…especially if somebody’s been in for a long time and they can’t see themselves progressing. And I mean like now we’ve got patients on the ward that don’t feel they’re getting anywhere. But when you take them back to what they were when they came in, and talk them through ‘Well, that week you progressed to walking with a stick, or walking with one. Then the week after you were able to walk independently’. When you take them back and go through each stage, then they do realise, you know, how far they’ve actually come from the original point.

HP10

Again the difficulty in these strategies is the different recovery agenda for survivors (Gallagher, 2011), with their desire to return to ‘normal’ after their
stroke the feedback of small gains may or may not be experienced as reassuring. One of the nursing assistants interviewed described reassuring survivors of their ability to adapt when faced with a lack of progress or difficult decisions. The message was that they had rallied and got this far and so could continue to do so. The reassurance of being in contact with stroke professionals was recognised by stroke survivors and professionals. As a result leaving therapy or follow up was often difficult. A survivor described maintaining outpatient follow up more for the security of having contact than for the actual information and advice received there.

This concern is picked up in the professional specific sub-category ‘Point of Contact’. The three unique sub-categories were used for specific areas of concern for health professionals. Professionals’ awareness of survivors reported feelings of abandonment when discharged from services, motivated two professionals’ accounts of the provision of contact telephone numbers so that survivors could ring up with questions or concerns. Examples were provided of instances where this was made use of; however, one survivor also expressed doubt about using such contact numbers when provided with them feeling uncertain of the response he would get.

Professionals made specific reference to the need for ‘Help with emotional decisions’ which related specifically to the consideration of, and adaptation to nursing home care. This did not pertain to the survivors involved in this study.

The final unique sub-category was ‘Integration of Stroke’ which represented health professionals view of information as a tool for assimilating or incorporating the stroke into the self, facilitating acceptance, integrating the stroke and learning how to make the best of it.

*To accept that maybe they’re not quite the same people that they were before.*

HP15

These are well intentioned aspirations but represent a shift in the survivor’s view of the stroke that may take months or years to complete. Remembering that most health professionals interviewed in this study did not have longer term contact with people, this points to a tension. Health professionals have a longer term view of what information may be able to do, whilst individual survivors are
grappling with each piece of information or experience as it is presented to them, with a view to a return to normal life for them. In essence survivors, carers and health professionals are always starting in different places with a need to find common ground as a starting point in information exchange.

7.3 REASONS FOR NOT SEEKING OR PROVIDING INFORMATION
When exploring the reasons and motivations behind seeking and providing information with respondents, by far the most was said about why they would not seek or provide information. I will describe the main groupings of these separately for first stroke survivors/carers and then health professionals.

7.3.1 Stroke Survivor & Carer reasons for not seeking information
Reasons for not seeking information were grouped into seven categories. Both survivors and carers contributed to all groups but with more input from survivors. A primary concern of carer’s in relation to asking questions has been addressed in the previous chapter describing when information exchange took place. Carers did not feel they had access to the right professionals to ask questions of at visiting times and when present at appointments often felt this time was not for them. Therefore unless given specific time for themselves or unless very specific enquiries are made of them at appointments their concerns may remain uncovered.

Reasons for not seeking information were categorised as follows (starting with the most referenced to the least):

1. Happy to be looked after in the right place
2. Stroke care and recovery going ok
3. Tensions about the impact of information
4. The effect of multiple concerns/worries
5. Being disinclined to ask questions
6. Perceptions of staff
7. Being happy with information received

I will describe these in turn.

7.3.1.1 Happy to be looked after in the right place
Coded sections under this category particularly reference the hospital experience of care. Responses indicated that people were often happy to take a more passive role, they were happy to be looked after under the circumstances of
needing hospital care for a stroke. They were relieved that they or their relative were under treatment in the right place. They placed confidence and trust in NHS staff as they desired to feel safe. Hospital, particularly the ward was seen as a difficult, somewhat challenging environment that required adapting to. To deal with this, views were expressed that it was best not to question, it was best to go with the system and place yourself in the hands of the experts.

You’ve had a stroke, you’re not fully aware of what’s going on anyway, you know. Not that I’ve ever been fully aware of what’s been going on, but certainly not when you’ve had a stroke, the situation…you’re in their hands, you know. You don’t know what’s the matter with you, you don’t know what the care is, you don’t know what’s needed to get you…to get you right. SS09

Survivors and carers recognised that stroke was new to them and they were naïve so accepted what was offered and assumed care was right unless proven otherwise.

7.3.1.2 Stroke care and recovery going ok

This category relates to the perceived severity of stroke and rate of progress experienced in recovery as being a factor in driving the need for further information and questioning of staff. If we understand one of the major concerns of stroke survivors to be a return to normal, that is a normality comparable with their pre-stroke state (Gallagher, 2011), this makes sense. For those lucky enough to have very mild or negligible (to them) effects there is a sense of relief and less drive to question. This was true for survivors and carers.

I think had [Husband]’s stroke been a lot more severe then I would have left no stone unturned to find out whatever I could that could help him. But thankfully because, you know, he’s… Well as you see him, I suppose I’ve not had to. Maybe that’s the difference SC03

For those in the more middle ground of severity, whilst improvement could still be perceived this provided reassurance in itself over and above information. This highlights the power of first-hand experience in learning and adapting to challenging circumstances.
7.3.1.3 **Tensions about the impact of information**

This category relates to mixed feelings about the impact of information. This is developed further in the next results chapter. The key issue identified however, was ambivalence between the desire for information and changes that may then be required. There was reticence about negative impacts, only wanting information if it could be helpful and not wanting to go deeper than needed so as to avoid introspection.

*No when you’re in the thick of it you don’t need any information do you? Well it's happening to me anyway I don’t particularly want to read about it (laughs to self) I could write a book about it (laughs) that’s the trouble really I thought it would be far too introspective*

SS01

Some felt there was little more to be offered by further information; it represented intelligence after the event in terms of prevention. This was more strongly expressed by younger patients who felt they had already been living healthy lives. Some individuals simply preferred self sufficiency and self reliance in terms of just getting on with ‘it’ (it being life or recovery) in the face of stroke challenges.

7.3.1.4 **Multiple concerns/worries**

This category describes the impact of the stroke itself in terms of being a shocking event and on the ability to process and question. It also encompasses the fact that concerns about other conditions and family may either take precedence or add to the burden. There were particular references to the initial shock and overwhelm of the stroke impacting the ability to ask questions.

*But I don’t think I asked that much. I think to be truthful I was just relieved that I was alive*

SS02

There were descriptions of just being grateful to be alive and improving. In the midst of immediate stroke care it wasn’t possible to take in lots of ‘technical’ information. In the longer term some of this subsided but active questioning could still be compromised by impaired concentration. Also ongoing stresses and strains contributed to forgetfulness in relation to raising all questions and concerns for carers too. Stroke often does not occur in isolation and other co-morbidities may exist resulting in stroke not necessarily taking precedence for the individual. Some stroke survivors also reported being preoccupied with concerns for their family members and the impact of their stroke on the family.
7.3.1.5 Being disinclined to ask questions

This category brought together references by stroke survivors and carers who professed to not being inclined to ask questions, a personal preference to take a more passive role, not just in response to hospitalisation but more generally. These individuals declared themselves as not interested in asking questions.

*I'm not an inquisitive person no. No I never ask. No matter what it is. I never ask people... Well if they want me to know they'll tell me, you know and I'm not inquisitive at all, no.*

SS05

This related to their personal health beliefs, attitude to life and or personal confidence. Sometimes this was linked to attitudes to medicine such as being disinclined to take medication and it could also link to their own self perception of their intelligence in the face of dealing with experts that knew more than them. These were not necessarily the very elderly. Interestingly a couple of respondents commented on the question of age in relation to motivation and need for information. They concurred with staff views that age was a factor determining how much information some people would require, but it does not necessarily predict how questioning individuals will be.

7.3.1.6 Perceptions of staff

This category drew together perceptions about health professionals that influenced survivors’ and carers’ willingness to ask questions. For some it was a reluctance to stop staff to ask them questions as they appeared so busy. Individuals were not necessarily immediately comfortable to ask questions of professionals until some trust had been built up. This links to issues of continuity of contact.

*No I think I would wait to know them better. I don’t know if I have issues with that but I would wait, I suppose trust them, I felt as though I could trust them.*

SS02

There were also reports of not wishing to pursue a contact because of either taking exception to the approach of the professional or the perception that the advice they offered was too general and not of immediate use. This alludes to the unpredictable personal element of how any interaction can be perceived.
Both the professionals in these instances were third sector workers, what was at the time the Family Support Worker role of the Stroke Association. These roles have now been developed and renamed as Information, Advice and Support Coordinators. Support of the third sector in terms of provision of information and support had a major role in the case study setting of this study. Currently they are seen as important in delivering the six month review now advocated by the stroke strategy (Department of Health, 2007a). Their effectiveness has been piloted positively in this capacity (National Institute for Health Research CLAHRC, 2010). However, in the experience of some of the respondents in my study their ability to deal with the fine grain of the individual stroke experience may have limitations. To improve this would require close working between Stroke Association workers and local specialist services.

Other factors were identified under this category. Survivors and carers did not necessarily expect that staff would go through information with them. There was awareness that health professionals didn’t have answers to everything and perceptions that some staff members (doctors) were more significant when it came to answering some queries. Therefore if the doctor was absent from a meeting some questions would be deferred. Finally professionals were perceived as not being able to understand some worries and concerns as they had not been through the experience the individual was going through. The example given for this related to extreme financial worry in the context of being self employed.

7.3.1.7 Being happy with information received
This final category drew out specific references to being happy with information received and therefore not feeling inclined to pursue things further. This was sometimes because survivors/carers had received enough information for now based on how they were feeling at the time.

Yes he gave me quite a bit. More than I could take in really. I just took [hesitates] I just didn’t care really. When he was telling me it was going through me a little bit.  

SS03

This raises the issue of timing and pacing information. In other instances it linked to other categories around personal preferences for information and abatement of demand for information as recovery progressed well. In these latter instances
individuals felt they had received plenty of information relative to their perception of the need for it.

If I’d have wanted to know more, but I could…you know, I would have gone and asked more, but as it was, we did, you know, they gave us so much information, it wasn’t really necessary. Perhaps if X had been affected more, that is when I would have perhaps asked more questions, but because he wasn’t as affected as some people are…

SC08

The number of sub-categories reported here to describe the reasons for survivors’ and carers' not proactively seeking information reflects the nuanced and dynamic nature of these reasons. Reasons may not be static or concrete and may be influenced by the passage of time since the onset of stroke, perceptions of and expectations of recovery and various other contextual factors in the lives of survivors and carers. This highlights the need for sensitivity and pro-activity on the part of professionals in assessing on an ongoing basis desire and readiness for information amongst survivors and carers they are working with.

7.3.2 Health Professional reasons for not giving information

Reasons for not giving information by health professionals were grouped into four categories. These were:

1. Challenge of the scope of stroke information provision
2. Emotionally challenging work
3. Resource issues
4. Areas of ambivalence

I will describe these in turn.

7.3.2.1 Challenge of the scope of stroke information provision

Health professionals knew that the scope of the stroke knowledge base is huge and it is a challenge to stay up to date. In terms of information sharing this could present two quandaries. There are many potential factors and contributory causes to having a stroke. It was not necessarily felt appropriate to share all details of the diagnostic and assessment procedures unless relevant to the patient. Unless faced with a particularly inquisitive patient this judgement was unlikely to go challenged. More commonly a reason for not providing information was to stay in their zone of competence.
...we’ve got another lady at the minute who’s got physical problems and cognitive problems. And probably when I’m treating her I steer away from the cognitive things. So I talk very much about ‘You have a weakness in your leg. Your balance is not very good’. I don’t necessarily go down the ‘And remember you’ve also got problems with your memory’, and those sorts of things. I think I probably give the information that I feel I need to engage and progress what I’m doing really sometimes.

HP05

This is not unreasonable but, survivors and carers don’t necessarily appreciate how different types/forms of information are seen as more the provenance of some professional groups than others. Professionals did not see it as feasible to know everything which required a willingness to admit this and find out information as required.

7.3.2.2 Emotionally challenging work

This category brought together health professionals references to providing information being ‘emotional’ work. Providing information was seen as potentially emotionally draining or wearing. Maintaining a consistent approach when tired or stressed was seen as challenging. A lot of the information that may be discussed was seen to be perceived as negative potentially taking more things away from people. Certain topics such as driving and nursing home placement were seen as difficult topics and approached in the same way as breaking any other bad news. A health professional working with survivors for longer through their recovery described some communications as quite existential. The reflection on this was that this type of communication would not appeal to all health professionals.

This was not the only reflection on the influence of personal communication styles of individual health professionals on information provision practice. Individual approaches to openness and relationship building were factors identified as influencing this. It was also identified by professionals that some staff would take more interest in providing information. This was not related to a specific discipline or level of experience but to a personal interest or commitment to information provision activity. This is of relevance to recommendations around team approaches to information provision and the idea of someone to co-ordinate information provision activity (Stroke Association, 2006; Department of Health, 2007a). However in actual practice where team working practices and priorities may not have been discussed and agreed, a risk was that ‘information
provision’ fell unduly upon those more interested or motivated staff. This had the potential to become burdensome.

...recently I've felt like I'm almost sacrificing my home life to these... conversations with relatives, and they are, every single one of them is important, but I get home so late all the time. I just... there isn't something you can do about that really......but it's stealing out of my life and it is mostly the conversations that get me staying late. The relatives arrive at three, they all want to see a doctor, everybody else goes home at five o'clock and then I'm doing the conversations

7.3.2.3 Resource issues
This category drew together some references to time pressures and lack of easy access to back up resources. This was discussed further in the previous chapter.

With respect to time issues acute treatment requires the presentation of key facts so staff cannot because of the time window available for this cover material in depth. On a similar note in a service providing acute services such as a thrombolysis, demands are unpredictable. So there are occasions where staff may have arranged to see survivors/relatives to discuss information and answer questions but are called away.

At the time of the study there was not easy or universal access to generic written information so this was not always given out. It was also identified that there was a lack of resource to provide better personalised information back up for patients.

7.3.2.4 Areas of ambivalence
This category describes areas where there is tension about open communication so this may result in staff not exchanging information openly.

An example of this is where some particular piece of information is known or thought to be problematic or intensely distressing for a survivor. In this type of scenario a particular professional may choose not to raise this to avoid distraction from what they have to do with the patient in specific therapy sessions. This may be comfortable for staff or if a team decision they may not share the view. More commonly there was discussion of tensions and ambivalence around the team and patient having different goals/aspirations for rehabilitation. Professionals did not always want to confront such issues in the context of
concerns around low mood or morale, for fear of making individuals feel worse. This encompasses a concern for the individual but also for maintaining engagement with therapy. Sometimes unrealistic expectations were confronted but there was not always universal agreement within the team about his. There were different views about acceptable levels of risk for people striving to get home.

…the other thing I think is that we ought to let people have a go at being at home even if they fail. As long as they understand the risks. HP21.

The sense obtained from several health professional accounts was that the tension around ‘realistic’ goals resulted in a fine balancing act in terms of providing encouragement whilst being realistic. In view of survivors reported need in this study for lots of positive affirmation that they are doing ok, this is an important area to consider more in the discussion.

### 7.4 ISSUES EMERGING FROM THESE CATEGORIES

A major issue for stroke survivors was the timing of information. They wanted information when they could cope with it. The hospitalisation period was often an overwhelming time. Survivors and carers generally chose to take a back seat and place themselves in expert hands choosing not to question things unless gross concerns were raised. Receiving lots of generic written information at this time, whilst not harmful, was just not seen as especially helpful and was more than most could cope with at this time. Some did review written materials later but this was an exercise in picking out what was relevant to them, amidst piecing together what they could recall from what they were told in hospital. Some felt that this generic written information was just not relevant as they were not that severely disabled. The issue was the need for information to be made personally relevant to them. Survivors were very open about their difficulties in remembering information provided and hence desired back up information that was specific to them.

Making connections between ill remembered verbal information and generic written information with a starting point of very little knowledge about stroke was a challenge. There is no suggestion implicit here that information should not be given in hospital. However, the evidence from this study suggests a need to recognise that information provision, particularly early in the hospital stay, is
more about engaging people safely in care. In terms of shifting to information provision for learning, to engage someone in moving forward to manage stroke recovery themselves at home, this can start in hospital but will need to continue actively after return home. This, I would argue, requires making a shift in emphasis in communication as time goes on. This is challenging with a condition of variable trajectory like stroke. There is a need to prioritise with survivors and carers what to cover out of many topics and build confidence to deal with challenges they may face. To do this more effectively, problems with a lack of shared language and making connections between facts, back up materials, behaviours and actions requires consideration. These points have resource implications in terms of professionals being available to produce personalised backups, systems to support this and if using general back up, being knowledgeable enough of these materials to refer directly to them.

Health professionals did not appear universally aware of these types of issues and discussed various ideas of past or potential future service developments to improve things. There was an awareness of the need to recap information however, there was not strong evidence of this in interactions observed. However a challenge to this was the sheer number of professionals survivors would see, this resulted in few staff I interviewed having good continuity of care in order to revisit topics with people. Professionals identified the benefits of continuity of care as not having to go over the same ground, being able to build information up, allowing a more supportive role and through knowing the patient being able to be more creative in putting messages across to them.

Concerns about the later plight of survivors included:
- an awareness of difficult issues coming up later after discharge
- that individuals may lack resources to manage these themselves
- that support services were piecemeal and uncoordinated.

Most of the staff interviewed and indeed involved in stroke services had little involvement in any form of longer term support this contributed to the provision of ‘prophylactic’ information in the hope that it may be useful at some point. However, this is potentially at odds with a more tailored approach to providing information advocated in policy (Department of Health, 2007b). A truly tailored
approach would need to take into account the need to pace information provision post stroke and I will develop this idea further in the discussion.

Survivors, carers and health professionals do not start in the same place with information exchange. Survivors and carers may have little experience of stroke compared to the specialist professionals' wide view of causes and sequelae of stroke. Survivors (and possibly) carers will be looking towards a return to normal. Whereas professionals will view the survivor as changed forever and aim for the best functional recovery possible, ideally integrating the stroke into a new view of the person. Looking at this starting point a key requirement for effective information exchange would be the ability to bring together these viewpoints to ease communication. This will be returned to in the discussion.

7.5 CONCLUSION
This chapter has compared and contrasted accounts about the reasons for information exchange given by survivors, carers and professionals. There was considerable overlap in the categories describing why information was desired. However, within the categories there were different points of emphasis. These when considered alongside reasons why information exchange may not take place provide insight into why there is a ‘lost in translation’ element to information exchange post stroke. A focus is suggested on timing and pacing information; strategies to support connections between information and actions/behaviour so as to move forward and use information as a tool or resource for survivors and carers. The final results chapter presents the perceptions of survivors, carers and professionals on the impact of information exchange. This will draw out the need for support to use information effectively.
CHAPTER EIGHT: PERCEIVED IMPACTS OF INFORMATION EXCHANGE

8.1 INTRODUCTION
In this chapter, I summarise survivors, carers and health professionals reported perceptions of the impacts of information exchange. Matrices summarising coded material pertaining to this aspect of information exchange were reviewed to generate the categories reported.

A first impression was the difficulty in connecting information with concrete impacts or outcomes for all groups. For health professionals this may be attributable to a lack of continuity in the care provided or in the opportunity for longer term follow up to allow the observation of benefits. For stroke survivors and carers this could relate to their difficulty in seeing information exchange as an activity discrete from care and with a link to purposeful action. However, as we saw in the last chapter individual desire for information is variable and there can be ambivalence about the change that information received may require.

In looking at codes across the respondent groups what did stand out was the greater number of references to negative or challenging impacts. Therefore codes relating to impact were broadly categorised into positive and negative impacts of information exchange. These categories will be compared and contrasted for stroke survivors/carers and health professionals. Both survivors and health professionals discussed the issue of ‘Resistance’ to information; therefore these accounts are described and contrasted. Finally specific concerns identified by survivors and carers about the ‘limitations of information’ will be described.

8.2 PERCEIVED POSITIVE IMPACTS OF INFORMATION EXCHANGE
The first thing to highlight from professional accounts of perceived positive benefits is that these were more often hopeful rather than grounded in concrete examples. In this light they overlap with reasons given for providing information. We saw in chapter six that formal assessment of need or impact did not take place so this is one factor in this. However, it also needs to be understood in terms of the organisation of services and the number of staff involved in a stroke survivor's care. Relatively few professionals in my study had a longer term
working relationship with survivors allowing the assessment of any longer term impact of information.

Four groupings of positive perceptions were identified for professionals:

- making stroke effects and processes known
- relieving difficult emotions
- easing family relationships
- supporting access to further information and support.

First of all, the benefit of making stroke effects and recovery processes known to survivors. This was felt to be important as most survivors are dealing with stroke as an unknown quantity so this was perceived as able to offer relief and to reassure that all was going ok. This would include identifying that both emotional effects and bodily symptoms were part of the stroke.

Second, was the potential to alleviate difficult emotions by communication and information about such emotions, including fear, anger, grief and self-criticism. Thirdly, and this was often linked to emotions, information was thought to help where family relationships were under strain. As so many stroke effects are not obvious immediately on first appearances, it was felt that information about these could aid family understanding of seemingly unrelated changes in their loved one. The effect of this was put forward as taking the pressure off relationships.

..It’s hypercusis and it really is part of my stroke and I’m not a horrible old bag who’s turned into an evil grandmother who… then you know, you can then say look to your family. You know, I’ve got something very real. It gives you validity and explains things and it’s not all down to the fact that you’ve turned into some sort of mean, irritable dragon. It’s because genuinely you can’t tolerate a lot of noise without it swamping you.

Finally, some information was felt to support the ability to seek further information and support. The examples described were encouraging or giving permission to ask more questions, providing clarification of written information and sign posting/supporting access to other follow up services. The only areas with more concrete accounts linked to specific patients were in reducing self-criticism, sign posting on to other services and the explanation of written information received.
…the two people that did ring me, I felt that I probably helped them quite a lot, and things that they just hadn’t thought about at clinic… there was one gentleman who had problems with his vision and attention, and he wanted to drive... Well, he hadn’t been able to make an appointment for a driving assessment, every time he rang up it had been engaged or whatever problems he’d had. So he rang me up and said, ‘are you sure I still need to do this? I don’t know how to organise it. I don’t seem to be able to get in touch with them.’ So I organised it for him and got back to him about it. And queries for the doctor as well, you know, ‘I’ve, I’ve had this letter through and I don’t understand it, can you explain it to me?’

There were generalised perceptions of the benefit of support groups and stroke association leaflets. However, I have already highlighted in previous chapters that such benefits are not universal and vary between individuals.

The potential relief of some of the information around normalising stroke effects is brought into question by survivor accounts. This is a tension in information exchange activity. Unless the outlook is much better than survivor’s worst fears it may be that such information is a threat to their ideas about recovery. However as we will see in this chapter seeing information as either good or bad was not black and white. Information could be ‘parked’ and sometimes made sense of later in the light of experience.

On this note I will now turn to survivor/carer accounts of positive impacts of information received. Some survivors struggled to identify any information that was specifically positive or helpful or that required change. This could be influenced by factors such as recall or stroke severity and these factors were discussed in the last chapter. For others nothing stood out because prevention of the stroke in the first place would have been preferred. There was also the sense that there was not much expectation for some in relation to information. If they had been cared for well enough and were doing ok by their own standards that was all they asked for. One gentleman took the view that ultimately all information had to be helpful and demonstrated an evolving view of information provided over time.

I will now describe more specific positive impacts where these were identified. The overlap with reported reasons for wanting information is evident. Five groupings were identified for survivors and carers:

- Building confidence and moving on
• Healthy living
• Using preventive treatment
• Practical Information
• Knowing what’s happened and what to expect

The most commonly reported benefits were in relation to building confidence and learning to move forward after the stroke. The strongest accounts of this came from survivors who were further down the line after their stroke, who had had a period of one to one beneficial therapy support or who had benefited from discussion with another survivor who in their view had done well.

This supports the view of stroke recovery being a fluctuating and evolving process with individuals coming to different points of acceptance or adaptation over time (Gallagher, 2011). It also supports the benefit of tailored and specific information given by therapy staff working with an individual over time. One gentleman described the messages he had been given by both physiotherapy and psychology professionals who had worked with him. He described having been able to internalise the message and use it when pursuing goals and tasks alone.

I learnt a lot from him in a short period. And what I do now, I carry on what he was suggesting and it does help. Well that's the art of… kind of when the communication has worked because you're able to take their voice inside you and have it there when you're on your own.

SS06

..she listened and explained and went through things, and she made me face up to some things. She kept asking why, do you know what I mean? Why do you feel that way, and you know, what are you thinking? And.. It started working out... And I started thinking for meself then that things aren't as bad, and gradually it made me feel better. I still get a bit emotional.

SS06

Why did what they offered work well? It would appear to relate to the pertinence of the message and their delivery in the context of a supportive relationship.

The benefit of talking with others who had had a stroke would link to the need for hope that progress was possible. Getting this from someone who had been through it had the added advantage of believability. The benefits of this however were not universal depending on stroke effects and an individual’s outlook on life.
For those appreciating these types of benefits, the key points were accepting where you were, moving forward using what you had so as not to lose that and building confidence through returning to valued activities.

The next most mentioned impact were efforts to live healthily, most of these related to dietary matters. Specific changes mentioned were reducing portion sizes, reducing salt in the diet and eating more fruit.

*I think then the chap that you saw at [hospital name], he mentioned about the salt didn’t he, and so everything, I mean, I buy very little processed food as it is, anyway, but you know, just things like I use tinned tomatoes if I’m doing, um, a pasta sauce or something. I buy the organic now because there’s less salt in it and I look at everything like that don’t I. And it’s amazing what’s got salt in it and how much.*

SC08

The need to utilise preventive treatment was the next most frequently mentioned impact. This most commonly related to recognition of the importance of preventive medications. Two survivors reported having been remiss with preventive medication previously and following their recent stroke were more committed to taking medication correctly. One gentleman following his second stroke reported that after his first stroke he had remained unaware of the significance of his anti-platelet medication.

*I never realised why it was important…. Like this time, somebody, a nurse actually said it’s to… prevention of… preventing another stroke, which nobody actually said last time. And that’s the cure for preventing another so… they actually said it’s a cure. Nobody ever mentioned that last time. And it… Like I said I’m not inquisitive, I don’t… I probably don’t ask enough questions as it is. If I do ask questions I probably don’t ask the right ones.*

SS05

This highlights the need for checking understanding and revisiting topics. For those who had required a carotid endarterectomy surgery to clear stenosed or blocked carotid arteries, solace was gained from the protection or prevention this was perceived to offer. One survivor mentioned getting her blood pressure checked following advice from a hospital nurse and some other survivors were already aware of the need for blood pressure monitoring from prior to their stroke. However, in broad terms across the sample there was not a sense of a clear message to take responsibility for engaging with the primary care team regarding these matters.
The next most commonly discussed benefit was help with practical issues. This included caring responsibility, so was more heavily contributed to by carers.

Topics specifically discussed included training in managing a percutaneous endoscopic gastrostomy (PEG) feed at home. For the carer reporting this, training was received both on the hospital ward and at home from community staff. The latter was found to be more beneficial as it was less rushed, involved more detailed explanation and offered reassurance about skills demonstrated.

...she explained what it was, it’s like, just like a little catheter on the inside, and you know, but it can heal on the inside, so that was really informative, that. And I felt er, I did feel a lot more confident after that, ‘cos I mean I’ve been doing it once a week, turning it, but you’re a bit nervous...and the fact that she was here, face to face, and she was like, you know, telling me. I mean it’s alright having leaflets or somebody saying, but it’s not the same as actually having somebody there, and you know, they’re sort of...showing you roughly how to do it, you know. So yeah, I’d say that was really beneficial to me, that, yeah, very useful....

SC09

Whilst the carer here was commenting on the quality of the training received there was also a likely benefit in terms of repetition of information following skill practice. It also raises the issue of context and environment having a bearing on the perception of information or training received. The home environment was potentially a less stressful learning environment than a busy hospital ward.

Other specific practical advice appreciated by survivors and carers included:

- encouraging independence of their stroke survivor
- sign-posting to financial support
- direction in relation to how to return to driving
- and pacing yourself.

The final group of positive impacts for survivors relate back to reasons in the last chapter under ‘making sense of the stroke’ and ‘dealing with life after stroke’. These pertained to the reassurance obtained from knowing what had happened to them and being given some sense of what to expect and the plan for what would happen. This included the growth of the awareness of how long things would take the need for patience and the value of trying to anticipate problems in order to deal with them.
8.3 PERCEIVED NEGATIVE IMPACTS OF INFORMATION EXCHANGE

Again, as with positive impacts, professional’s discussions were more about their concerns and general impressions rather than grounded in concrete examples. Areas of concern were:

- That information had little or no effect
- That it could be detrimental causing misinformation, fear or distress.

In the impressions of where information had little or no effect the main mediators of this were seen to be significant cognitive deficits and overly generic information. In the case of the former this related not just to memory but the ability to attend to and process even immediately present information such as prompt sheets. Generic information was felt to potentially have little effect if not related to the individual’s needs. However, it was also thought to be potentially frightening and confusing if accessed without support.

"...we used to at one time have leaflets that we could give out, but it can be quite confusing and frightening to them actually... then you’ve gotta say ‘Well, look, you know, don’t look at... don’t believe everything that you read, because each person is an individual and it doesn’t affect everybody the same’. So sometimes it can be a hindrance rather than a help."

HP10

This was particularly related to more elderly patients who were felt to be particularly vulnerable. Staff expressed greater caution with respect to directing older patients to other sources of information such as the internet. The elderly were also highlighted by one professional as a group who may be asked about their preferences for hearing distressing news in order to protect them from the impacts of such news.

"...like if I have nothing pleasant to say, or I have something highly unpleasant to say, I always ask the patient, you say ‘I have got a few tests, I don’t know the results but if I get unpleasant news would you want to know about it?’ And, er, that patient gives a clear indication, a lot of the elderly do not want to know about it, and I would accept that then I will kind of just give them all the information required, because they have clearly indicated there is some information they won’t be able to handle, and there’s no point giving it because it causes anxiety and would probably be counter-productive in causing their quality of life to just plummet."

HP24

The potential for distress or upset was a main concern of professionals when providing information and, as we saw in the last chapter, this often related to a
perceived negative impact on rehabilitation progress as a result of this. Particular
topics discussed as likely to be distressing were seen to be: the initial diagnosis,
driving, the need for nursing home placement and lack of availability of certain
services. Concern was expressed with respect to survivors/carers not
questioning or clarifying uncertainty about information provided with resultant
misinterpretation, anxiety and/or confusion. Also as we saw in the last chapter
professionals would tend to stay in their comfort zone in terms of the information
they were confident in providing. For example, one professional was quite
specific that this was done out of concern not to provide wrong or inaccurate
information via written sources she was unfamiliar with. Discussions were
generally presented as a fear or concern of negative repercussions, if the right
balance was not struck between enough information to inform but not so much
as to worry. Both in accounts and observations in the study this felt like a tension
or a balancing act, but not one openly shared with survivors/carers.

As highlighted already in this chapter, such uncertainty about pitching
information at the right level and its actual impacts is impacted by a lack of
continuity in care. Even in the context of follow up the proactive engagement with
survivors and carers to check their understanding of information exchanged was
not consistently reported in interviews. In observations undertaken this was
usually seen to entail a general enquiry as to whether there were further
questions towards the end of interactions. How to ascertain understanding was
not clear and it was felt that survivors/carers may not always be frank about their
understanding out of deference or politeness to professionals.

*I quite often draw the idea of the penumbra, I draw a central dark coloured
in bit and then I draw kind of a cloudy thing round the edge with blood
vessels going into it. Um, which I hope people understand. Sometimes I
wonder whether they're just being polite when they're pretending to
understand me.*

It was recognised by more experienced professionals that without extended
contact it was not possible to get a sense of messages getting through. In
practice however, this contributes to a sense of ambivalence about the
connection between information provided and behaviour change or action and
perhaps may at times sap conviction for the task at hand.
Negative impacts of information for stroke survivors and carers fell under four broad categories. These were:

- confusion
- worry/fear for the future
- frustration/stress
- upsetting and depressing

I will say a little more about each of these in turn.

Major factors in the impact of confusion were the number of staff seen and problems understanding medical terminology. Whilst appreciative of all care received, equally survivors and carers were not always sure who everybody was or what they did. If we consider the observations and accounts presented in chapter six of different areas of informational expertise or focus for different staff groups, a lack of understanding of staff roles and limited opportunity to get to know who everybody is will be problematic for effective information exchange.

I dare say each one of them talked to me about something and they were all different departments I know. But I can’t remember much about it. I know they introduced themselves, “And I’m so-and-so.” And I’m… There was a lady there and there was a man who was a neurologist, I remember him. But I can’t remember anybody else on the whole.

Dealing with large or multiple teams also meant that survivors/carers experienced conflicting advice. This was more problematic in relation to practical caring tasks or issues that they would have to undertake as an action as opposed to medical treatment decisions. It was also observed that if rapid transfers of care occurred, communication about future rehabilitation and follow up plans could become unclear.

Problems with medical language and accounts were encountered in verbal exchanges and were not proactively clarified at the time in most cases. One gentleman did pursue his uncertainty regarding his actual diagnosis (TIA or stroke) after discharge with his own GP, this was an unusual action compared to other survivors in my study. Use of medical terminology was a limiting factor in terms of how much information would be pursued via the internet amongst those able to access this. Sometimes communications were partially understood or their link to desired future actions was not made. For example, one survivor had
taken in that she had a leaky heart valve but was unclear if this was a cause of 
or result of her stroke. As we saw earlier in this chapter another survivor 
explained how only after his second stroke, had he fully understood the 
importance of his anti-platelet medication aspirin. A third stroke survivor had not 
comprehended the reasons for being provided with a blood pressure target figure 
in his outpatient appointment.

*I remember it er..., you know what your blood pressure should be, and he's 
given...tore a bit of a corner off a paper, now that's very official that, isn't it 
you know, 150 over...140-something over 30-something. But that...those 
facts, I can get, so I felt he wanted to present me with that, for some 
reason. So is it...does it...obviously, he has an agenda, because he wants 
to know that you can...you know, off you go, you're...you're cured mate, 
you know,

SS09

Any of these individuals could have asked for clarification on these topics, but for 
any of the reasons described in the last chapter, they didn’t. The imperative lies 
with a professional if they are imparting information, with a view to action by the 
receiver to make this explicit and ideally to check out the capacity/inclination of 
the person to follow through on this action.

The next most discussed category in relation to impact of information was worry 
and fear for the future. This encompassed fears of the stroke diagnosis and its 
implications. Implications included functional issues about persistence of deficits, 
becoming or being dependent on others, whether they would be written off and 
reaching the edge of treatment certainty. The biggest fear of all was the worry of 
having another stroke, and of this being more serious or causing death. As 
highlighted in the last chapter this was an ever present concern, the impact of 
which had to be managed day to day. The following extract describes this 
following the experience of actually having a second stroke.

*I felt as if I’d had this safety blanket and that’s why I said it couldn’t be 
because I’m on warfarin. And she said no, it doesn't stop one. It’s damage 
limitation, but it doesn't stop one. No drug will stop one happening. And as 
soon as she said that, I wake up sometimes...if I get a headache, a little bit 
of me...I get like this little panic wave that’s...and then I have to reason 
with myself, “Don’t be so stupid, it’s a bloody headache; the world and their 
wife has headache.” But initially you’re going oh… I have to stop myself 
because you could become quite paranoid about it...I think psychologically 
the second one hit harder because it was whoa, they’re not lying here.

SS10
Frustration and/or stress occurred where information exchange did not match subsequent experiences. Also if information received was not timely or was incorrect. It could also occur if information or advice was too vague to be helpful in managing a problem such as fatigue. In terms of examples of this the main cause of frustration was for those taking up caring responsibilities. When they did not receive responses to questions and queries they lost confidence. Similarly, when services and training were not delivered as expected they felt further let down. Whilst professionals were providing information in terms of places to go and people to contact, this did not necessarily feel supportive.

I asked her about day centres, 'oh, well, you'll have to ask your doctor to refer.' I mean I thought, I thought this is what the social worker did, she’s supposed to put all these things in place, you know…..Oh no, it is right, well, there’s that number for the district nurse, there’s that number for the OT, that’s the number for this, that’s the number for that, and if you get no help there that’s the number for that, and that was it.

SC09

There was also an account of not receiving appropriate financial advice soon after the survivor’s stroke. This led to inappropriate decisions and significant debt and stress. In this example living on the boundary of different services and having input from different teams may have contributed to this scenario.

The final category concerned information being a trigger for upset or depression. This was a major area of concern for health professionals. However, this category was least discussed by survivors in this study, though upsetting impacts of information were identified in some instances. Information was identified by survivors as a trigger for feeling upset or down in relation to the imparting of diagnostic news, information about stroke implications or feedback about actual or potential impacts of the stroke for the individual. This included feedback of test results highlighting greater problems than first perceived and information relating to deficits or potential problems not perceived by the individual.

I remember erm in that erm acute stroke unit the doctor came and said how do you feel? And I said I feel fine until I listen to the doctors! (shared laughter) Hah then they would go and tell me what was wrong

SS01

Also other related news about life adaptations required post stroke could feel like further punishment. For some the support of other stroke survivors in a support
group was helpful. Others who tried this found it depressing if they were more able than other attendees.

*I only went there once, because it was so depressing. There was some poor souls, you know? And I just felt as though I was there and I shouldn't have been, you know.*

SS08

Another time when information that had been received may trigger low mood, were identified time-points for recovery milestones. We have seen previously the desire for such landmarks to provide a sense of where things are going in recovery. The tense flip side to this is when these time-points arrive and problems remain, this then confronts expectations for recovery.

I have framed these impacts as negative in order to categorise results. On face value they would seem to confirm the worst fears of some professionals; however survivors and carers did not suggest that information should not be given for any of these reasons. These emotions were part of the reality of having a stroke and dealing with it. Instead for them it highlighted the limitations of information as only one factor in what was required to support recovery. I will return to this later. First I will compare views about resistance to information between survivors and professionals.

8.4 RESISTANCE TO INFORMATION

Both health professionals and survivors talked about resistance to information. Health professionals discussed this more, which may be reflective of the bias in my study sample toward hospital based staff. Staff with greater experience and who had longer contact time with survivors could describe the movement from resistance to greater acceptance and adoption of new strategies to cope post stroke.

*At the start he was very sceptical and he was saying, “Let me go home, you know, within a week I’ll be back to work, you’ll see.” And as it dawned on him that actually that wasn’t going to happen, he became very tuned into psychological coping strategies and being able to identify and work on the next stage, very short term goals.*

HP09

These professionals did acknowledge however, that if resistance persisted this could be problematic but this scenario was seen as distinct from initial resistance.
For some staff working more acutely, apparent resistance to information provided was a source of concern or frustration. This would be a potential trigger for individually produced written back up materials. However, the professionals would not get feedback as to whether this was helpful. In my study I was able to observe such a scenario and in this case ultimately the information was both understood and appreciated by the survivor in question though this had not been the impression of staff involved. In this example the information related to risks of falls and injury in the home. Prior to discharge the material was perceived as looking for trouble by the survivor and a threat to getting home and personal autonomy. However, afterwards with some first-hand experience of the risks in question and the chance to have read and reflected on the written information provided it was appreciated and felt to be helpful.

Inevitably resistance and denial are encountered in inpatient rehabilitation as individuals deal with an unbidden event and various unwelcome news related to it. Health professionals are required to work with this and this came through in accounts. It was recognised that information was often being given at the wrong time and was blocked by emotions caused by the stroke and related information. It was therefore a challenge to find the right way for information to be communicated. The following example describes discussing the results of ambulatory blood pressure monitoring and being able to identify with someone what had caused increases in blood pressure observed. The specific nature of this information had more meaning for the individual in question than generic advice.

there was somebody who, as a result almost of a chance interaction in the clinic. I think made a real step change...after the stroke he was still angry about having the stroke. It was a, you know, something that invaded his life he hadn’t invited in. You know, this was not on my agenda. This is something I did not want to happen and I’m really angry. And then bloody hell I can’t park my bloody car in the hospital. And it was just good luck actually that I was able the next time to get this out and show it to him. And I think it had a really profound effect on him, which sort of shows you how people take in information in very different ways. And I could have said ‘Calm down and relax’ a million times

HP15

There were varying levels of sophistication in the response to this. With greater experience there was discussion of the benefits of knowing survivors and their
pre-existing beliefs and attitudes. This could aid taking a more creative or concrete approach to providing information.

Perceived resistance could also entail family communications, either family countering staff messages or a reluctance to share information within families. Professionals would take opportunities to reality check expectations by the provision of written care plans or more often the opportunity to experience care needs first hand. Consideration of a topic such as resistance is an example of the complexity and varied approaches needed by professionals to provide information in a ‘tailored’ fashion.

A major element in the information provided post stroke is the potential for lifestyle change to help reduce the risk of future stroke. Change is not necessarily a welcome or easy proposition for humans at the best of times and post stroke recovery is a challenging time. With a broader health agenda than just the individual, professionals viewed the need to provide lifestyle advice as about providing access to information to make informed choices. This allowed them to do their job whilst recognising that change may or may not take place.

Stroke survivors were aware that they were resistant to information provided. The diagnosis of stroke and related implications is a shock that is very difficult to take in, a need to protect the self and only deal with so much at a time was identified.

..you know why at that stage, why they don't; because if they said to you, listen, love, you're here for six to eight weeks; you'd go, I'm out of here now. And you'd go, you'd discharge yourself. Your body can't...and your brain cannot take it, it overloads, so they give you as much as you can take at a time, which is, “Just stay for a few days, just stay till the next assessment next week, just stay…”

SS10

Professionals were seen as necessarily complicit in this. The tension may be how openly that is agreed and communicated between team members or teams taking care on. Stroke can be experienced as a threat to self image. It can be difficult to accept as it defines one as having something wrong, being disabled or getting older. Some forms of information or support may be rejected or resisted as they draw attention to resisted changes.
They wanted me to have these hand rails up the stairs. They want these hand grips outside. I just says, "No chance." I said, "I'm not having anything like that in the house." He says, "Why?" I said, "Because I'm not... I'm not a cripple and I'm not having my mindset in that... I'm not having people come round thinking some old person lives here." And I wasn't gonna do it. I refused point blank. I says, "It is not happening".

We have seen earlier in this chapter that much information can feel negative or unwelcome. Depending on readiness to hear messages and/or how they are presented, survivors may prefer to learn by experience. It can be very difficult to accept information that cannot be directly experienced such as perceptual problems such as neglect or epilepsy where seizures are absences the sufferer is unaware of. These issues of resistance were a fact of stroke for survivors and contributed to the next area of discussion for survivors and carers, the limitations of information.

8.5 LIMITATIONS OF INFORMATION

Limitations of information was a category/theme identified from survivor and carer accounts and it aims to sum up that information in and of itself can only do so much for people.

The primary area of discussion here was the difficulty taking in information provided. Most information was provided in hospital when survivors and carers felt least able to take anything on board. Carers are additionally hindered as they receive a lot of information second hand via their relative. Most survivors could remember very little or patchy details of the acute (first week) phase of their stroke care. Remembering who said what and when from recalled details was problematic. One couple used a notebook on the rehabilitation ward so information could be written down for her husband. This was some help aiding communication. Professional generated personalised backups such as the discharge summary could not necessarily be related to due to medical jargon or the remote form of the writing. The following extract illustrates a carers lack of understanding of the discharge summary received.

*C I don't know what those other things mean, it says ischaemic stroke, doesn't it? I dunno what this other is? That's another stroke as well.

*I This word dyslipidaemia?

*C Mhm.
*I Are you not sure what that means?
*C No.
*I So have you gone through this document with anybody?
*C No.

Well just some of the terminology I found a bit difficult, you know, just didn’t... I didn’t really know what Ischaemic meant then. It’s some form of bleeding, isn’t it? I mean does that necessarily mean it’s a severe stroke or would they put that in, come what may, would they?

SC01

Generic written information was not always felt to be personally relevant or was perceived as helpful at the time but unmemorable. In this context there was little connection with information as a directly relevant tool. As we have seen, some information simply emphasised problems/issues without appearing to contribute solutions. In this context some survivors and carers reported a ‘take it or leave it’ approach to information and questioned how much it could help them.

One of the most desired pieces of information was to be told that another stroke would never happen again; however, survivors recognised that no one could give them this certainty. This type of realisation grew over time along with recognition of persisting deficits that sometimes presented significant challenges and were beyond the point of guaranteed help. As a result survivors and carers described an attitude of getting on with it and relying on common sense and experience to cope and deal with things on a day to day basis.

The greater benefit of practical support and the greater benefit of information in the context of support was something that was highlighted.

I don’t want to denigrate what you’re doing. It’s not so much information as practical help that’s the real bonus or the real benefit, you know, to people.

SC03

Any support and reassurance was valued, even if not felt to be necessary or not fully comprehended. Survivors were often at pains to say how well they had been cared for and didn’t like to comment on the lack of anything.
Where support was provided this could still feel like something to be managed and carers could feel on their own learning the hard way how things worked. As much as there are many services to support people in their own homes there is a need to understand that these can be invasive and inflexible due to logistical issues. Getting to know what is available and how to access them can be a job in itself at a time of stress and overwhelm.

The GP practice is seen as the long term supporter, gateway to services for individuals. As discussed in chapter five this was not fully explored from the GP perspective as I was unable to recruit GPs. However, interaction with GPs amongst survivors and carers in my sample was variable and the accounts given in the main did not support the view that self-management of stroke was actively facilitated. One survivor having little confidence in his GP and knowing his own laissez-faire attitude to his health chose to be involved in research that guaranteed someone was keeping an eye on him after his stroke.

The strongest account of valued support was simply having someone to talk to whether this was family, other survivors or professionals. This provided the opportunity to: express concerns, recognise how tough the stroke experience is, view things differently, boost confidence, gain tips on things to help in everyday activities and gain an overall a sense that one is not on your own.

_He enjoyed that (meeting another survivor). Because he met a few people who had had a stroke. You know and they’re sorta like sharing their experiences aren’t they?_

_..Well she’s a release like I say you know. If you feel like you’ve got the world on your shoulders and she’s sort of like…I don’t know, it’s her job innit I suppose, but she does…she does help. It helps just to have her there to talk to……because you’ve got nobody really to help you along have you?_  

SC07

8.6 CONCLUSION

This chapter has presented an overview of accounts about the perceived impacts of information exchange. For many health professionals there is a lack of concrete knowledge of impacts through limited contact time with survivors and carers. This means that much information is provided out of a sense of wider duty or hope for change and support.
Survivors and carers presented impacts some of which were the generation of difficult or challenging emotions about the stroke experience and some of which were helpful and supportive to change and adaptation.

Information alone particularly if generically factual was seen to be limited. Connection with how it helped individuals get on and move forward was not always clear. Challenges to making information more useable are: recall, shared language, personal back up materials and opportunities to revisit and check out material with a trusted person. The major limitation is that information without support can be a burden as much as a stimulus for change and self-management.
CHAPTER NINE: DISCUSSION

9.1 INTRODUCTION
In this chapter, I will draw together the material presented in this exploratory case study of information exchange post stroke in order to draw this thesis to a close. Initially, I will review the content of the chapters presented to offer a summary of how far the research has answered the study questions. From this point I will go back to review the study aims and propositions to show how the latter have evolved from the analysis of the data collected. This will contribute to a discussion of how we can develop and improve information exchange between stroke survivors, their families and health professionals post stroke.

Two key areas are drawn out for further discussion. The first is the need for clarity in the focus or language around information exchange post stroke from initial management of an acute condition to the self-management of a recovery process. The second is consideration of what is really required to provide tailored information and the challenges of applying this in practice. These two areas will be discussed in relation to study data and relevant literature.

Finally a critique of the study presenting its limitations, strengths and contribution to knowledge will be presented. The chapter will close with recommendations for future research, policy, practice and education.

9.2 REVIEW OF THE THESIS
My interest in information provision in healthcare developed early in my career as a staff nurse in spinal injury and neuroscience settings and was crystallised further when as a research practitioner in stroke I was involved in a number of practice based projects developing information resources in a hospital based stroke service. The challenges and tensions experienced in working on these practice based projects and the emerging drive to address information needs more effectively in stroke literature, policy and campaigns (Department of Health, 2001; Forster et al., 2001; Royal College of Physicians, 2004; Department of Health, 2005; Stroke Association, 2006) were the motivating forces for the study presented in this thesis.

In chapter one of the thesis I provided an introduction to stroke as a condition/syndrome highlighting its highly variable nature and significant impact
on survivors, families and health services. A brief review of policy relating to the provision of stroke services was also provided to describe the context of stroke as a ‘Cinderella’ condition or service, only fairly recently undergoing a period of rapid change and development. The aim was to provide background and orientation to the current state of interest in information provision as a topic within the stroke field.

The literature review in chapter two presented a review of relevant literature pertaining to information provision/exchange post stroke. This highlighted the perceived deficiencies in this aspect of care, the persisting uncertainty regarding how to provide information effectively and limitations identified in research undertaken to address issues of effectiveness. The review supported the case for the need to study actual activity and motivations around seeking and providing information, in detail, in practice. The purpose of this was to better understand current practice before suggesting solutions and alternatives. Further relevant literature identified during the course of the study was presented to highlight the focus of ongoing stroke information provision work. This aimed to examine any shifts in approaches and study design that could be examined alongside study data to inform suggestions for future work.

Chapter three presented my justification for my choice of methodological approach of a qualitative case study to explore the chosen topic of information exchange post stroke in its practice context. The case study approach chosen was presented, along with the operational definition of the case, the case study design and choice of setting. The study used a single embedded case study design to explore the phenomenon of information exchange in practice in Salford. The embedded units of analysis within the case offering different perspectives on the phenomenon under study were stroke survivors, family members/carers and health professionals.

Building from this, chapter four presented the procedures and specific methods undertaken in the application of the case study strategy in this study. This entailed a description of: how access was obtained, procedures for obtaining ethical and research governance approval, sampling and recruitment strategies, data collection methods (observations, interviews and documentary analysis) and the approach to data analysis.
Four results chapters have been presented. Chapter five presented details of the study respondents and reflections on the recruitment strategies and data collection approaches used in the field. Not all study objectives were achieved as it was unfortunately not possible to recruit primary care staff to the study. The reasons for this were reflected on in order to inform future studies. The aim of this chapter was to provide contextual description of the data used to inform the three main results chapters.

Chapter six presented a description of information exchange in practice and the issues this revealed, drawing upon a combination of observational, documentary and interview data. This chapter highlighted that a lot of information provision activity was taking place. However, significant challenges to this being effectively received were identified, offering evidence of limited two-way exchange processes. Verbal exchange of information was the predominant force and preferred mode for all respondent groups. Verbal information was valued by all respondents as it represented information specifically relevant to an individual’s stroke experience. Survivors/carers appreciated not just factual information but feedback and encouragement about progress achieved. Professionals were more comfortable within verbal exchanges as these were conducted within the bounds of their general stroke knowledge and their specific knowledge of the patient. The common problems with verbal exchanges were: lack of agreed aims (information and its potential uses/purpose tended not to be introduced), lack of shared language (due to medical/professional jargon) and difficulties with recall. Professionals were particularly concerned about problems with recall, resulting in them valuing, more than survivors/carers, the use of written materials to back up verbal messages. Manpower issues existed in relation to producing personalised written back up materials and this resulted in a reliance on, and much discussion of, generic written sources. Familiarity with generic written materials was variable, making it difficult for professionals to link personal messages given verbally to this type of written material. Survivors/carers often encountered these generic materials when they felt least able to make use of them. Later review of written materials by survivors/carers was variable and had mixed impacts upon them.

Problems in relation to reading level/comprehension were encountered with written information sources and internet sources. The ability to concentrate and read written materials was a problem for more than one of the survivors. Other types of back up media, e.g. audio recording, were not in use.
Professionals knew that written materials could not be relied upon and that dialogue with survivors/carers was required to fit information to needs and understanding. However, a number of issues made achieving meaningful dialogue a challenge in practice. These included:

- Brief/intermittent patient contact time.
- No formally agreed lines of responsibility for information provision.
- No formal assessment process or planning for information provision.
- Inconsistent documentation of information provided.
- Priority given to professional concerns/topics over survivors/carers concerns/questions.

Survivors and carers saw professionals as their primary source of information. Preference was given to hospital specialists, particularly doctors, as a source of information. However, these were the least accessible member of the team, particularly for carers. Use of the GP as a source of information was very variable and dependent on the previous experience and relationship with the GP. Practice nurses were not referenced at all as a source of information.

Family support workers were seen as separate to professionals as a source of information provision. Experience with these staff was variable in my sample. This was sometimes due to logistics such as the time point after stroke and geographical location of survivors and carers affecting their opportunity to access the service. However, for some survivors these professionals appeared to offer very generic advice and not information relevant to their personal needs.

Survivors and carers acknowledged they were seeing a large number of different staff and were sometimes unclear who was who. Therefore with lack of understanding of team roles there was no sense that they could discriminate how to use different team members for different information. This could go some way to explaining the preference for the doctor as a provider of information. This preference has been noted by other authors (Scott and Thompson, 2003). Several professionals in my study reported taking their lead from the patient’s questions, as a means of gauging information provided. This is unreliable if the professional in question is not seen as a primary source of information. Accounts
describing clear recall and internalisation of messages were in the context of a prolonged one to one interaction with a particular health professional.

Survivors and carers were clear they had received a lot of information early in their hospital care that they were not in a position to take in and process. Professionals reported being surprised at some of the recurring questions raised when they felt that information had already been given. This indicates a need to plan for and build up information provided. Much information given during care and therapy seemed to be lost amidst general impressions of care and not translated into something to use for later personal action.

In summary the key messages from this data were:

- A need for agreed and documented team responsibilities for information provision.
- Assessment of information needs and preferences require consistent and accessible documentation.
- A need for a plan for information exchange over time with survivors.
- A need to identify key times for bringing information exchange to the foreground of communications.

In short there was a need to plan and pace information exchange, relying to a greater extent on survivor/carer priorities and identified needs. This is a starting point for unpacking what is actually required to ‘tailor’ information and will be revisited later in this chapter.

Chapter seven compared and contrasted the reasons and motivations given for seeking and providing information by the different groups, including reasons why information may not be exchanged. This chapter drew on accounts from respondent interviews.

Three main categories describing reasons for seeking and providing information were identified for all three respondent groups. What differed between groups were the points of emphasis within categories. Making sense of the stroke (in terms of knowing the diagnosis and the cause of the stroke) was a persisting issue for some survivors several months after their stroke. In contrast health professionals would perceive that this information had been imparted fairly early
in the stroke illness trajectory and would be concerned with the provision of other types of information quite quickly. Some survivors did not dwell on any medical reasons for their stroke as they did not think concrete reasons existed and they would make their own sense of the event. For those who did dwell on this the issue seemed to be more than one of recall. It appeared to relate to difficulty connecting lay understanding of disease with professional explanations. It also linked to viewing the stroke as an affront to their view of themselves.

Information relating to dealing with emotions after stroke again had subtle differences for survivors/carers and professionals. All groups agreed information had a role in ‘normalising’ the unknown experiences (emotional and physical) after stroke. Professionals hoped this brought relief. However, the impact for survivors was more mixed, as whilst it could be good to know something they experienced was linked to their stroke, this could also be upsetting; a reminder of their changed self following the stroke. Literature describes stroke survivors’ desire to recover and return to normal after their stroke (Dowswell et al., 2000; Gallagher, 2011). This desire was seen in the current study sample and so it can be understood that information confirming changes experienced as resulting from the stroke can be as much a source of tension as relief. As a result, survivors/carers would sometimes only want to know so much to manage this tension. It also can account in part for perceptions recounted later in chapter eight of information itself not being helpful, without support to deal with its consequences. Health professionals had an awareness of such issues, sometimes managing information provision to try to contain any overwhelming emotional impact that could negatively impact on rehabilitation. With all parties ‘self-managing’ the potential emotional impacts of information without open discussion, the challenge to two-way dialogue is evident.

Professionals viewed information as potentially contributing to adaptation or even integration of the stroke. Looking at models of stroke recovery, for example Gallagher (2011) that emphasise the return to normal as an emotional desire in stroke recovery, integration of the stroke is probably for quite some time incongruent for many stroke survivors. Adaptation is probably more congruent with survivor accounts. However, the role of information in this is but one factor and may only be felt over the longer term of recovery. It is challenging to view adaptation as a goal for information exchange to contribute to, because so many factors influence this. The literature documents that adaptation to chronic
illness/disability can fluctuate even when an apparently adaptive position is reached (Yoshida, 1993; Paterson, 2003).

In terms of information to support ‘dealing with life after stroke’ the tension here was the breadth of knowledge of potential problems and issues that professionals had, versus the naivety of the new survivor/carer. Professionals, aware of the paucity of support and relatively short term specialist follow-up, would seek to prepare survivors/carers for future potential issues. Survivors/carers, with a desire for information that would be directly helpful to them, could not always see how information presented as future warnings could help. Instead it was potentially experienced as frightening or depressing. The key issue was that this was not the right information at the right time for these individuals. The issue of timing kept arising in the data and appears significant to defining in better terms how information could be more tailored or personal. The major challenge within large systems such as health services is how to provide the flexibility to be thus responsive to the individual. This is particularly challenging in such a diverse target population as stroke survivors when the right time will be different amongst individuals. This challenges the efficiency of services that would rely on predictability of timing of information provision.

Some greater flexibility or more targeted use of certain time-points in service provision could be feasibly and potentially beneficially explored. This, with a shift in focus in how information is provided, could start to tackle the difficulty in providing the right information at the right time to individuals.

Most information provision within the stroke service at the time of the study fell into a traditional health promotion/education model. This primarily entails the provision of factual information to be used by the receiver to improve their health or manage their condition. Shifting toward a more skill building, facilitative model aligned with self-management approaches (Lorig and Holman, 2003) would place a different emphasis in communications. This would be information to identify and draw out the individual’s skills and abilities to problem-solve issues as they arise. This would require a more discursive dialogue between health professional and survivor; rather than listing potential problems and pitfalls there could be discussion of an actual or exemplar problem and potential ways of tackling this. Such discussion would need to actively engage survivors/carers so they could recognise their capacity to tackle issues relating to their stroke. Active
approaches to information exchange were a factor identified by Smith et al (2008a) as improving the impact of information provision strategies post-stroke. This type of change would require education, training and support for professionals to change their underpinning approaches to and style of communication in interactions about information.

Multiple and varied reasons for not seeking and providing information were encountered. Some of these have already been touched upon in the discussion on information and ‘Dealing with Emotions’ and in relation to timing of information. However, for both stroke survivors/carers and health professionals other reasons relating to personal factors were described. Some survivors/carers, particularly initially, were more than happy to put themselves in the hands of the experts. Over time, a number of factors influenced movement towards a more active and engaged role: their experience of recovery and persisting disability, their life view and their attitudes to and beliefs about health and illness. A reason health professional’s not giving information was to stay in their comfort zone of confident knowledge. It was also noted amongst health professionals that some had greater enthusiasm, aptitude or motivation for engaging in information provision. So, for both survivors/carers and professionals elements of personal attitude and style had an influence on engagement with information exchange.

In terms of the subtle differences in emphasis between groups in reasons for information exchange and the varied reasons for not engaging in it, this again pointed to a need for more effective assessment and planning of information exchange requirements. There is a need to know individual survivor preferences and views on information better. This would aid planning of how and when information can best be introduced as survivors/carers move out of immediate acute care. There is a need to recognise the difference between information given to engage people with necessary care and information given to engage people with acknowledging and accepting responsibility for their own self-care. The latter type of information would entail discussion of the reasons for providing key information and for how this may be used. This would need to be repeated and revisited depending on an individual’s life views, pace of and view of recovery. This type of approach would aim to facilitate the use of information as part of problem-solving to deal with the challenges stroke brings. The latter is important because as started to emerge in this chapter and was more fully described in chapter eight, survivors/carers often found it difficult to connect with
the potentially useful facts presented. They could experience these as contributing to further overwhelm amidst already overwhelming new demands and experiences.

There is much focus in the stroke literature on the testing of different information interventions or approaches. This would appear to represent a search for the best, most universal and effective way of providing information (Smith et al., 2008a). Observing and discussing information exchange in practice would suggest this is an elusive search. The best way is likely to vary from individual to individual. The focus needs to shift to pursuing the best ways of assessing, planning, pacing and facilitating the need for and use of information.

As highlighted already this presents challenges in terms of workforce training and planning. Who should lead information exchange? How can a better team approach be taken? With the recent rapid development of stroke services there has been a focus on the need to develop a skilled workforce to deliver services effectively (Smith et al., 2008b; Burton et al., 2009). Looking further at communication skills, training particularly dealing with emotional concerns for all disciplines would potentially be useful. Examples of models for this would be ‘SAGE and THYME’ training in cancer care (Connolly et al., 2010). It would also be useful to broaden the scope of knowledge underpinning health promoting aspects of information exchange. Professionals working in stroke or with stroke survivors need to be able to adapt and discuss topics in different ways depending on the stroke severity and recovery prospects of different individuals.

Chapter eight drew out accounts from respondent interviews of the perceived impacts of information exchange, offering another dimension to motivations around information exchange and therefore sustainability in practice. Accounts were dominated by negative or uncertain impacts of information. Clear articulation of positive impacts did occur but was much more infrequent.

Few health professionals had a concrete knowledge of positive or negative impacts of information simply because of limited contact time with survivors and carers. This limited the opportunity to revisit and assess the effects of information exchanged. Therefore professionals provided information out of a sense of hope of better informing and preparing survivors/carers to make decisions and manage their recovery. However without feedback in terms of impacts and
results it was difficult to know what had been effective and therefore to hone their skills. Professionals expressed a mixture of philosophical resignation and frustration in relation to this. Where there was a longer term working relationship between a professional and a survivor/carer provided the most concrete examples of positive impact. This situation allowed for information to be personally relevant, provided at the right time and given with the necessary support and active encouragement for its utilisation.

The need for support, either over or above information or in order to use information, was a key message from survivors/carers in this chapter. Many of the impacts described by survivors/carers that were classified as negative related to the generation of unwelcome emotional impacts and confusion. This did not result in a desire not to have information, but rather a view of the limitations of what information could do for them personally. The need for support was seen as more important than information and information was not necessarily perceived as supportive in its own right. This highlights a missing connection with information exchange activity, particularly when framed in a self-management context. The missing connection for survivors and carers was the supposed purpose of information, why it is important as an aid to self-management. The missing link for health professionals was that information alone cannot support self-management; people require support, encouragement and recognition to use the information they are provided with. This is true of any skill building effort; there is a need for information, training, opportunity to practice, support in practice, praise and feedback on progress. This is about building self-confidence and self-efficacy, both aspects of complete self-management approaches (Lorig and Holman, 2003). Stroke often affects self-confidence, so it is pertinent to ensure this aspect of self-management education is addressed with this population (Robinson-Smith et al., 2000; Lorig and Holman, 2003). I will return to this later in this chapter in more detail.

By presenting this overview of the thesis content I have demonstrated that the case study approach adopted has been successful in answering the how and why questions posed in relation to information exchange. It has also provided data on personal perceptions of the impact of information. It has demonstrated that whilst there is much common ground in topics discussed, there are subtle differences in the emphasis placed on topics. This, alongside a lack of shared discourse about the aims and purpose of information, results in a mismatch of
expectations in relation to information exchange. Within the busy everyday practice context and under the influence of traditional roles this mismatch is often never addressed. The result may be several ‘missed’ communications in relation to information that do not support its use in influencing decisions/actions to be taken.

Following the review of the thesis findings, I would like to revisit the study propositions to discuss how these have evolved in response to the results presented.

9.3 REVISITING STUDY PROPOSITIONS

The original study propositions introduced in chapter three were:

1. The aims of information provision/exchange are unclear in everyday practice.
2. Where aims in information provision/exchange are unclear mismatches in communication are therefore likely making it difficult to provide effective tailored information to individuals.
3. Communication around information may not always be a two way process making it challenging to clarify/agree aims.
4. It is unclear at present how information can be tailored effectively in practice.

These were derived from my own clinical experience and from literature reviewed in the preparation of the study.

Propositions alongside study questions focus the attention of the researcher on what they will need to study and what data they will need to collect to answer study questions (Yin, 2003; Simons, 2009). They also make evident to readers of the research findings the frame of reference and orientation of the researcher at the start of the work. In this sense they are also a tool in analysis, as they are compared and contrasted with results as part of the analysis process and so refined and developed over the course of the study. Yin (2003) describes this approach to analysis as explanation building, the goal being to build up an explanation about the case under study. The development and refinement of study propositions is part of this explanation building process. In larger explanatory case studies there could be a striving towards developing causal links relating to the phenomenon under study. However, in exploratory case
studies such as that reported in this thesis, the goal would not necessarily be the generation of a definitive causal explanation but rather the further development of the ideas originally expressed in the study propositions at the outset. An outcome of this development of propositions could be the generation of hypotheses or questions for further study (Yin, 2003). It is through this type of process that Yin argues case study offers ‘analytic generalisation’ from the results produced. The development of propositions through the study helps the reader relate findings back to theory and practice. The aim is to facilitate the assessment of transferability of findings; it is like holding a mirror up to practice and saying, ‘…is this experience recognisable to you?’ If there is resonance with practice this can contribute to reflection upon this and the potential for challenge and change.

Revisited study propositions:

1. **The aims of information exchange are implicit and broad in everyday practice and policy guidance, and not discussed openly and negotiated with stroke survivors and carers.**
   - This lack of explicit discussion leads to a lot of undirected effort that can be purported to link to generic aims of information provision, but does not link clearly to survivor and carer aims and so can be perceived as inaccessible or irrelevant by them.
   - There is a need within teams and between the team and individual survivors to discuss information exchange more openly, to prioritise its potential outcomes and therefore activity to try to deliver these.
   - If a desired aim is to impart knowledge to facilitate self-management of stroke we need to do more than provide facts even personally relevant facts. We need to (re)activate, support, acknowledge and reward the individual survivor’s autonomy, agency, capacity and confidence to appraise situations and problem solve for themselves; or at the very least recognise and distinguish who would like to progress in this direction. This requires a different style of communication and questioning to exchange information. This would use more open questions to encourage reflection, problem solving and provide feedback and
acknowledgement of all progress. So this represents a shift in
tone of conversations from, 'you need to do this' (relating to the
topic being discussed), to 'what could you do about that topic?'

2. Communication around information provision was predominantly
led by health professionals and fraught with problems with
unshared language and a lack of clarification of understanding.

- Health professionals talked about having a checklist of things in
  their head they needed to go through with people.
- There was a lack of operational insight into the different purposes
  of information at different time points; that is in early acute
treatment to engage people safely with care, contrasting with
more active engagement later with a view to successful self-
management.
- Questions and concerns were not explicitly elicited from survivors
  and carers until health professionals had gone through issues of
  concern to them. Later checks for questions in exchanges often
did not check out or clarify understanding of information provided.
- Where information was provided with a view to the survivor taking
  some action, this was not necessarily made clear and so would
potentially have little impact on behaviour/action by the survivor.
- Verbal information exchange was the predominant and preferred
  means of information exchange. However, difficulties with recall
were acknowledged on all sides as a challenge to this. The main
back up materials used were generic written materials, often not
actively linked to verbal exchanges. Policy supports copying
formal communications such as discharge summaries and clinic
letters to survivors and this was undertaken. Whilst the latter
obviously contained personally relevant information,
communications were neither directly addressed to the individual
nor produced in a lay-friendly format.
- With a strong preference for tailored information delivered face to
  face through discussion there is a need to focus developments on
improving verbal delivery styles. Also, alternative means to back
up information, other than just written forms, could be more widely
available. Where written forms are used personal relevance of these needs to be maximised

3. **There is a lack of consensus on what tailored information requires.**
   - Stroke survivors and carers want information personal to them and policy and literature advocates tailored information provision.
   - However it is unclear at present how information can be tailored effectively in practice (Smith et al., 2008a). The experiences of survivors and carers in this study would back up this difficulty in practice.
   - Looking at what is written about tailored information in policy and papers there is a focus on information in relation to risk management and secondary prevention of stroke, leading tailoring to a focus on assessment of risk factors in order to give an individualised package of information around these (Allison et al., 2008; Redfern et al., 2008; Wolfe et al., 2010).
   - However tailoring in the context of supporting self-management needs to take in broader issues of readiness/timeliness for information exchange, preferred methods of receiving, flexibility of methods available to respond to needs and personal health beliefs.
   - For effective tailoring we need to know the patient and they need to know us, there needs to be trust and a dialogue.
   - None of these are easy asks in a health service focused on efficiency, systems and the interchangeableness of a flexible workforce.

I would now like to re-examine the aims of information exchange in relation to stroke examining issues around:
   1. Communicating information with a self-management focus post stroke.
   2. The challenges of tailoring information post stroke.

**9.4 RE-EXAMINING THE AIMS OF INFORMATION PROVISION**

Reviewing the policy and literature presented in chapters one and two on information provision, both in wider and stroke specific settings, it is possible to
identify a range of benefits and reasons why information provision is seen as an important activity to undertake and to do well.

These reasons for undertaking information provision include the following:

- To improve individual understanding of health needs.
- To be prepared (informed) to be involved in, and make (effective) choices about your treatment/health care.
- To understand required treatment and care.
- To prepare and help you manage the effects of your condition.
- To self-manage a long term condition.
- To help adapt to a long term condition.
- To prevent missing out on essential services.
- To improve speed of/aid recovery.
- To improve outcomes (may include emotional, psychological, satisfaction. quality of life).
- To aid emotional well being.
- To improve understanding of prevention and reduce the risk of further strokes.
- To empower an individual to take control of care.
- To improve appropriate medication use.
- To reduce admissions to hospital and episodes of unscheduled care.

9.4.1 Discussing these aims in relation to Stroke

These aims of information provision are broad and far reaching. Data from respondents in this study suggests that when it came to the aims, reasons and motivations for information exchange, there were missing links to the wider aspirations of information provision in relation to self-management. Stroke survivors and carers did not appear to connect to the purpose of information as a tool for managing something; that is their stroke. This could relate to personal health beliefs in relation to general health and/or stroke, or it could relate to the content, timing and modes of delivery of information received. Health professionals did have a sense of there being a self-management post stroke agenda but did not make explicit links between the information they provided and their desire for survivors to use or process this information in some specific way. There is a need for negotiation and discussion of aims so survivors, carers and professionals can come alongside each other more effectively when communicating information and increase the chances of more positive outcomes.
from activity undertaken (Burton, 2000; Bendz, 2003; Jones et al., 2008; Laver et al., 2010). There is a need for greater dialogue and negotiation, ideally in the context of an on-going relationship about the aims and utility of information provided (Ellis-Hill et al., 2008); in order to activate, support and engage with the processing of information with a view to moving towards its active use in everyday life for survivors.

Stroke represents a complex and highly variable illness trajectory. I will therefore discuss some of the challenges of applying self-management thinking to information exchange post stroke.

9.4.1.1 Self management in stroke care: managing a condition versus a recovery process.

I have discussed that an implicit aim of information exchange post stroke is to prepare stroke survivors/carers to be active in and moving toward self-management of stroke as a chronic condition. However, this intent is rarely overtly acknowledged in practice and intervention design (Jones, 2006; Kendall et al., 2007).

I would like to consider why stroke presents particular challenges to a self-management approach. First, stroke presents unexpectedly as an acute and traumatic event, so understanding of it as a chronic condition to be managed has to evolve over time. There is poor perception of a distinct cause, of distinct fixes for causation and on-going uncertainty with respect to prevention of future events and the recovery process. Stroke hits at the heart of who you are, as it strikes your brain, the centre of your cognition, and therefore potentially impacts your perception of your ability to cope and adapt to it. Stroke knocks a person’s self-confidence (Robinson-Smith et al., 2000). By this, I mean that with many other chronic conditions people may feel disappointed or let down by their body and its “failure” or “disease”, but they will not feel that their usual capacities to deal with this have been affected too.

A stroke survivor who embraces self-management is not just managing a condition with a series of set parameters to guide responses in terms of treatment management. Instead they are managing a recovery process. The decisions/issues they manage may encompass: treatment decisions; the decision to recover actively; life style changes for prevention; where to live, what
care arrangements to have; if, how and when to return to work; what are
workable goals; how to cope and adapt; how to re-frame and re-evaluate their
life, if progress is not what they may want; and how not to lose hope in view of
this (Rochette et al., 2006; Cott et al., 2007; Carlsson et al., 2009; Wood et al.,
2010; Gallagher, 2011; Taylor et al., 2011).

Considered in this light, the complexity of stroke self-management and how
information may fit into this is self-evident. It is therefore no surprise that in the
most recent Cochrane review of information provision there was a call for a more
‘profound’ approach to information based interventions (Smith et al., 2008a).
What might this entail? In the first instance it could entail an opening up of
discussion on how information is supposed to contribute to self-management
approaches and the theoretical frameworks available to make sense of stroke
recovery. This would allow a greater appreciation of the potential contributory
role of information in these complex processes and the many other factors
modulating any potential positive outcomes.

Self-management approaches involve core tasks and core skills (Lorig and
Holman, 2003). These are summarised in Table 6 overleaf:
Table 6: Self-management tasks and skills

<table>
<thead>
<tr>
<th>Self Management</th>
<th>Core Skills</th>
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<tr>
<td><strong>Core Tasks</strong></td>
<td><strong>Core Skills</strong></td>
</tr>
<tr>
<td>1. Medical management (medications, diet)</td>
<td>1. Problem solving</td>
</tr>
<tr>
<td>2. Maintaining, changing and creating new and meaningful behaviours/life roles</td>
<td>2. Decision making</td>
</tr>
<tr>
<td></td>
<td>4. Forming partnerships with healthcare providers</td>
</tr>
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<td></td>
<td>5. Taking action</td>
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A key underpinning concept to self-management approaches is self-efficacy from Bandura’s social cognitive theory (Korpershoek et al., 2011). Self-efficacy is an individual’s confidence in their ability to perform a task or specific behaviour. Improvement of, or connecting with an individual’s sense of self-efficacy is seen as key to achieving the desired outcomes of the core tasks and core skills of self-management (Lorig and Holman, 2003). There are four main sources of influence on self-efficacy:

1. Mastery experience (successful performance task)
2. Vicarious experience (modelling/watching others do task)
3. Verbal (social) persuasion or encouragement
4. Interpretation of physiological signs (anxiety/stress/arousal)

(Lorig and Holman, 2003)

Looking at these theoretical underpinnings of self-management shows that information exchange can be crucial at a number of points. However, in order to support self-efficacy information would need to be part of an exchange, part of a dialogue to be linked to different tasks and skills and linked to positive feedback about achievements. This type of dialogue was not seen in practice in my study and is not built into many of the information provision interventions developed and tested to date (for example Wolfe et al (2010)). Overlooking this core concept of self-management theory could be a contributory factor in the difficulty seen in producing consistent outcomes, other than improved knowledge, from information interventions (Smith et al., 2008a). Provision of factual information...
alone is not enough; connections need to be made between information, skills, tasks and actions. Achievements, no matter how small, need recognition and linking back to information received and new approaches tried. Within stroke this needs to be achieved as part of an evolving recovery and adaptation process. This would involve cycles of appraisal/evaluation, coping/modification of coping, and resetting of expectations in the context of a desire to get back to normal (Rochette et al., 2006; Gallagher, 2011; Taylor et al., 2011). Part of the resetting and adaptation process may involve negotiating a new vision of normal and there is no set timescale for this (Taylor et al., 2011). It is also likely to be conducted amidst shifting levels of autonomy through rehabilitation (Proot et al., 2007). Proot found that shifting levels of autonomy through rehabilitation were often not openly discussed and negotiated; this again would not be supportive to recognising information received and its importance to developing self-management.

Application of self-management and self-efficacy principles to information exchange post stroke has been limited (Jones, 2006; Kendall et al., 2007; Korpershoek et al., 2011). Kendall et al. (2007), in a trial of a chronic disease self-management course for stroke survivors/carers, demonstrated improved family roles, activities of daily living, self-care and productivity within the intervention group during twelve months of follow up. However, the difference between groups had evened off after twelve months, suggesting a protective effect in relation to managing day to day functional requirements, as opposed to an ultimately different outcome. This is an important message in terms of the design and trial of interventions based on this model. Not only do outcomes need to be carefully chosen in relation to the intervention, for instance a predominantly self-management approach is more likely to have an impact on functional outcomes relating to quality of life, rather than psychological outcomes. The latter would need a more psycho-educational approach (Steed et al., 2003; Kendall et al., 2007). Kendall’s experience also cautions whether outcomes present the full picture; process and cost effectiveness measures need to be built in as well. This would seek to determine if the effect of improved self-management is to smooth processes or actually produce different outcomes. The implication of this for costs of interventions is important, as much of the promise of self-management is built on cost savings via better service utilisation of the self-managing patient.
However, an element of intervention design may have accounted for Kendall's (2007) lack of impact on final outcome as they used two of the main sources of influence on self-efficacy within their intervention. Korpershoek et al. (2011), highlights that incorporating all four sources of influence on self-efficacy is the best way of enhancing it. In the small number of studies this author identifies as seeking to harness self-efficacy in stroke recovery, none utilise all the means of influence.

The aim of the discussion so far is to highlight that whether trying to build small changes into practice or designing information interventions to be tested, it can be seen that there are a multiplicity of factors to consider.

Considering the wider theoretical frameworks underpinning self-management reveals that information alone is a small factor in creating positive change, and that the design of effective information-based interventions presents a huge challenge. In stroke there has been a holy grail-like quest for the best way to provide information, assuming its benefits are self-evident. However, the role of information and its utility will vary from individual to individual over time. Therefore the emphasis needs to shift toward better assessment and negotiation of information priorities over time. This will require an examination of stroke health professionals’ skills and knowledge base in relation to self-management support. It could also require a re-evaluation of professional roles, considering whether a multi-professional team approach is feasible or whether a dedicated educator/coordinator role would be beneficial.

9.4.1.2 What do we mean by tailoring information?

The last section aimed to discuss information as but one factor in the self-management of a potentially complex variable stroke recovery process. Wider discussion is required within the stroke professional community to agree theoretical underpinnings to approaches as a secure foundation for responding to varied needs.

Policy calls for a tailored approach to individual stroke survivor information needs (Department of Health, 2007a). However little guidance is offered on what this should entail or how it may be achieved. This lack of clarity and poor definition of terms and key concepts in strategy guidance is noted as problematic by Reed et al. (2012). In their meta-synthesis of qualitative literature and community
services they argue for a broader scope of stroke rehabilitation to focus more equally on the social, psychological and physical aspects of stroke. Reed et al. (2012) highlight the importance of trying to understand the unique social world and perspective of survivors as this will impact on outcome. Stroke survivors and carers will develop their own strategies to deal with stroke, and to offer the best advice and support in this process we need to endeavour to understand their frame of reference.

In theoretical terms this appeals to more narrative approaches that seek to understand illness and disease as a biographical disruption to a person’s life story (Bury, 1982; Bury, 2001). The idea of such approaches is that by understanding an individual’s story we can better understand their response to illness and their potential resources to deal with it (Blickem and Priyadharshini, 2007).

Understanding the patients story is also an aspect of more empowering, interactive health promotion strategies such as that reported by McWilliam et al. (1997), drawing on Mezirow’s perspective transformation theory. This study was not focused on stroke survivors but on older chronically ill adults. In McWilliam et al.’s process the participants built a relationship with the facilitator that allowed them to share their life and health experiences and reflect upon these, so identifying coping resources to deal with current challenges.

Within the context of the setting and experiences described in the present study it would be difficult to see how such a time consuming process could be built in to current services. However, I would still argue that there needs to be more effort to assess and understand more about an individual’s views of illness and their perceptions of their role in managing this.

Within the stroke literature reviewed since the study started, efforts at tailored approaches have focused on risk factor management (Joubert et al., 2009; Wolfe et al., 2010). This is unsurprising as whilst the scope for information provision was broad within the stroke strategy and no specific guidance was offered on how to tailor information, the suggested metrics for activity did relate to risk factor and lifestyle management (Department of Health, 2007a).
Risk and lifestyle factors are also potentially easily assessed with minimal survivor contact time and lend themselves to more systematised approaches (Wolfe et al., 2010). However, without suitable support and interaction, desired impacts may be difficult to obtain, as was seen by Wolfe et al (2010). Joubert et al. (2009) piloted a shared care approach which, whilst also identifying personal risk factors as the target of the intervention, offered frequent telephone and fax based support to survivors and their GPs. These authors showed positive impacts on systolic blood pressure, body mass index (BMI), walks taken, disability and recall of advice. Their results need to be treated with caution as this was a pilot study so did have some design limitations, and other tele-care based approaches have not shown similarly positive results (Adie and James, 2010). However, Joubert et al’s approach addressed many of the limitations to information exchange that survivors and carers in my study highlighted. It provided personally relevant risk factor information, it offered continuity of relationship with a named contact person for information and it offered practical support, review and feedback of progress. The latter was achieved by supporting the booking of GP appointments, reminders of appointments and review of outcomes of appointments. As stroke evolves into a chronic condition requiring self-management and in light of information processing issues for stroke survivors, perhaps a shared care approach is a useful bridging, facilitative approach to developing effective self-management in the longer term.

Survivors and carers in my study highlighted several issues that are a challenge in tailoring information. These include: the timing of information, comprehension of information, understanding medical language, personal health/illness beliefs, the impacts of their stroke and uncertainty/reticence in approaching or questioning professionals. Similar findings have been reported in accounts of stroke patient and carer perceptions of information by Allison et al. (2008) and Eames et al. (2010). The resonance of these findings with those of the present study adds to the argument for avoiding assumptions about survivor/carer preferences for information through rehabilitation; and focusing on more effective communication to ground interventions in survivor/carer experience (Alaszewski et al., 2004).

Formal assessment of information needs was not a feature of practice reported and documented in my study. I have not been able to find approaches to assessing individual’s information need in practice amongst the stroke
information provision literature I have reviewed. Instead there has been a focus on cataloguing information topics expressed as important or useful by survivors (Hafsteinsdottir et al., 2011). However this does not assist in responding to needs as they arise in practice. Looking to other disease areas, a variety of approaches can be discerned. Hale et al. (2007) discusses the use of Leventhal’s Common Sense Model of illness representation within arthritis care. This encompasses an assessment of how individuals appraise their illness in terms of its identity/label, cause, time course, consequences and curability and controllability. In relation to information provision assessing how individuals represent their illness offers a starting point for information exchange. Receiving new information may aim to modify aspects of illness representations in order to support actions to cope with the illness. Assessment of illness representations may also indicate the type and intensity of information intervention required or appropriate for an individual.

Scott and Thompson (2003) reviewed the assessment of information needs for post myocardial infarction patients and noted the predominance of professionally generated needs assessment questionnaires. They caution that without the input of patients into their development, such tools can prime or lead the identification of needs by patients. They advocate one to one verbal discussion as the most valid means of identifying needs. However, they recognise the challenges to this in terms of time management of consultations. Such concerns with time pressures within practice were identified by professionals in my study. Therefore it may be beneficial to consider assessment tools such as that proposed by Skiff et al. (1981) for use in the outpatient setting. This short assessment tool was designed to be completed in five to ten minutes prior to the consultation in order to offer a platform for prioritising discussion of information needs within the consultation. Content of the tool included knowledge of diagnosis, treatment plans, perception of own knowledge base, priorities for information and views on illness duration, some consistency with Leventhal’s common sense model was evident.

In these two sections of the discussion I have attempted to link challenges in information exchange post stroke to various theoretical frameworks that could inform them. As the stroke population is diverse, so will be their information needs, hence more than one theoretical framework can offer valuable insights. In terms of driving forward improved assessment of information needs in practice to
better tailor information exchange, there is a need for debate amongst the stroke community about the best fit of different approaches. This type of review carried out to produce a consensus view or statement on the state of the knowledge in relation to self-management education for a specific disease group has been undertaken for asthma self-management (Partridge and Hill, 2000). These authors highlighted the importance of good communication from knowledgeable professionals, drawing on the words of one of the fathers of modern medicine, W. Osler.

“It is more important to know what sort of person this disease has than to know what sort of disease this person has”

W. Osler cited by Partridge and Hill (2000 p333)

Greater consensus in the stroke community about the preferred theories for driving interventions and therefore the likely deliverable outcomes could improve the consistency and quality of future trials and evaluations of interventions, hence aiding meta-synthesis of results.

I will now offer a critique of the present study before closing the discussion with recommendations for research, policy, practice and education.

9.5 CRITIQUE OF THE STUDY
This section of the discussion will offer a critique of the study undertaken considering the limitations and strengths of the chosen approach.

9.5.1 Study Limitations
The main limitation of this study is its size and scale. As a single case study, a relatively small number of participants were recruited in one setting in order to study information exchange in practice. The different respondent groups recruited allowed for comparison of their different experiences and perceptions of information exchange. However, working in the one setting meant that influences of different local contexts could not be examined. This would have required a larger multi-site case study. This was not felt to be feasible within the constraints of a single-handed study undertaken for completion of an academic qualification. I felt that time and energy was best focused on recruiting as many participants within each chosen group in order to maximise understanding of dynamics between respondents in the one setting. Justification of this was offered in
chapter three. Description of the chosen setting has been offered to aid the reader in interpreting the wider transferability of findings.

Despite some challenges to recruitment, the numbers of each respondent group recruited were within the target range set for the study. More importantly the respondents recruited generated a large amount of rich data able to answer study questions and develop study propositions.

Challenges were encountered recruiting all respondent groups. With stroke survivor recruitment the main challenge was the reliance upon health professional screening and initial approaches. This was a necessary requirement of local ethics and research network practices. All efforts were made to ensure good communication and working relationships with recruiting staff. As the hospital setting for the study was a research active unit there were also sometimes competing demands for recruitment to more than one study. As a result of this there were agreed working practices for the number of approaches and studies individuals could be involved with. I made myself familiar with these and worked within the bounds set. Alongside my purposive sampling strategy this meant there were fallow periods of recruitment. Also as I was recruiting via staff and was unsuccessful recruiting GP practices to support the study this presented challenges to recruiting survivors later post-stroke. Fortunately there were patients still in contact with some parts of the service that made this possible. These wider recruitment issues and survivors’ interest or not in taking part in the study means no claims can be made to an unbiased or representative sample but this is not the aim with a purposive approach. The aim is instead to generate a sample offering a range of relevant experiences. Over time a group of survivor respondents reflecting an equal mix of men and women, a good age range and a diverse range of experiences of stroke severity were recruited. However without the opportunity to recruit via GP practices, the sample is biased in favour of those still in contact with some form of stroke or neurological rehabilitation service. It was not possible to recruit a carer with all stroke survivors, as not all survivors had someone they identified in this light. Some survivors were not comfortable for their relatives to be approached as they did not want to burden them. As the survivor was the starting point for recruitment these limits had to be worked within. The result was a smaller sample of carers than survivors but still with a good age range and even mix of genders.
There were two primary challenges to recruiting health professionals, wariness about involvement with the research and time constraints in relation to availability to participate in interviews. The latter was more of an issue with junior staff. For most staff, discussion and assurance of confidentiality overcame initial concerns about getting involved. As I was not involved managerially in the stroke service I was treated as an independent agent. To deal with time constraints I made every effort to conduct interviews at a time and in a venue least disruptive for staff involved. The only professionals it proved impossible to recruit were GPs as described in chapter five. As independent contractors none of the GPs approached were willing to take part in a small scale study unable to offer financial reimbursement for their time. This meant that the professional sample recruited was biased toward hospital or specialist community services. Also in the absence of GP recruitment only acute hospital records were reviewed, as these were accessible on the stroke unit and via documents in possession of survivors and carers. This limitation can only be honestly reported to allow readers to factor this into their interpretation of findings. Alaszewski et al. (2008) in their study of communication post stroke reported that GPs primarily saw their role in terms of providing secondary prevention information rather than information on broader issues such as psychological/emotional aspects of recovery. Amongst the survivors taking part in my study, use of the GP for information was variable and inconsistent. Some did not see the GP team as a source of information at all. This would therefore seem to have some resonance with the report from Alaszewski et al. (2008).

A conscious decision was taken to conduct study observations at discrete time points judged to be significant in their potential for information exchange. This meant I did not undertake extended periods of observation of general nursing care and therapy activities. This decision was justified in chapter four. However, it was disadvantageous as professionals discussed information exchange in the context of care and therapy activities. The result was that I did not have first hand observations of this to provide context for such activity and to aid its exploration within interviews. With the benefit of this hindsight additional general observation periods would have been beneficial, particularly in light of survivors making less reference to such exchanges in their accounts. Observations could have added detail to how such professional activity can be missed by patients.
Most studies represent a snapshot in time and place when studying a phenomenon. This is inevitable and particularly true of case study, where an understanding of context is part of the strategy undertaken. The focus upon information within stroke policy and campaigns at the time of the study certainly was a vehicle in raising awareness and helping engagement with the study. To address this inevitable limitation a clear record of the times of data collection, the context of the practice setting and the policy environment has been provided to aid the reader in the appraisal of findings.

The analysis presented is my personal interpretation of the data collected. In any qualitative research endeavour it has to be owned that this is the case and that other interpretations could be offered. To justify and defend the analysis presented the following strategies were used:

- The study was grounded in a constructivist approach to make clear the aim of comparing and contrasting perspectives in order to generate a new construction (or perspective) on information exchange.
- Applied research analysis tools were used in the form of Framework analysis (Ritchie and Spencer, 1994), in order to account for a priori ideas and provide an auditable account of the analysis approach, thus supporting transparency and accountability of results.
- The analysis approach was subject to ongoing scrutiny and challenge by my supervisors to ensure thoroughness in attending to all data.
- The use of study propositions made clear my initial thoughts when approaching data collection and analysis and their development through completion of analysis.

Therefore, I believe the analysis presented is an honest interpretive account of the experiences and perceptions of information exchange in the case study setting under study. The approaches used can provide readers of the research with confidence that the interpretations offered bear scrutiny and are useful for policy makers and practitioners seeking to develop information exchange activities.

9.5.2 Study Strengths

The primary strength of the study was that whilst a single case setting was used, data were collected from different embedded units of analysis and compared and
contrasted across these. The units of analysis were the three respondent groups, stroke survivors, carers and health professionals and documentary evidence. When the study commenced this was a new and unique approach in studying these different perspectives together in one study/setting. Studies reported in the literature usually addressed the topic of information provision from one perspective. Studying multiple perspectives in the one setting revealed that whilst there is much common ground in terms of topics discussed, the differences between groups are more subtle. Differences were in terms of the emphasis placed on topics and views on when and how information can be helpful. Collecting data from different respondents at the same time, in the same setting, who had been or were working together allowed analysis to tease out these subtle differences. Combining respondent accounts with observation data and documentary data allowed better understanding of the verbal accounts presented of the challenges and difficulties encountered in practice. It particularly highlighted issues with continuity of care, the lack of shared aims and language to discuss information and difficulties in providing information effectively in team settings. The approach taken in the study revealed:

- Subtle different perspectives of survivors, carers and health professionals on information exchange.
- The multiplicity of ways information is taken in (or not) and interpreted.
- A lack of formal assessment, planning and documentation of information exchange activity to underpin a team approach to information.
- The limitations of generic information that is not actively linked to an individual's circumstances.
- The crucial aspect of timing of information in terms of readiness to use information.
- A need to re-evaluate professional approaches to the presentation of information, to connect this to self-management strategies and to help survivors and carers identify sources of support to use information more effectively.

The case study strategy adopted was successful in gathering data to answer the study questions and develop study propositions, so highlighting issues for practice development and future research. The case study approach also enabled the provision of contextual description of the setting to allow for assessment of the transferability of findings despite the small scale of the study.
In literature reviewed since the study started a similar approach has since been taken in another study in Kent, ‘Communicating information to stroke survivors’ (Alaszewski et al., 2008). This work was not framed as a case study and did not incorporate observation and documentary evidence. However, it did explore at a local level via qualitative interviews, perspectives of stroke survivors, their carers and professionals on information provided by health professionals. There was overlap and agreement in several key findings:

- The potential for overload of information during the hospital stay.
- The importance of timing of information to meet evolving information needs.
- The varied roles and insights of the multiple professionals involved in stroke survivor care.
- A lack of overall co-ordination of information provision efforts.

This does not detract from the findings of the present study. Rather it adds validity to the findings and strength to the arguments presented to support the usefulness of the research strategy taken in producing findings with resonance for other stroke settings and practitioners.

9.5.3 Recommendations for Future Research

This section presents a brief summary of recommendations for future research from the current study:

- There is a need to shift from a concern with identifying the best way of giving information to identifying the best way of assessing information needs, preferences for receiving information and ways of responding flexibly to individual needs.
  - Simple questions/assessments to identify primary concerns.
  - How to assess readiness for information.
  - How to establish information preferences (ways of receiving information).
  - How to introduce important topics not identified during assessment to negotiate incorporation into preferences.

- Consensus research methods to agree preferred theories and outcome measures for testing interventions. The aim of this would be to unify
approaches in studies of information provision and allow meta-synthesis of results.

- Redesign and evaluation of personally relevant communications.
  - Review of discharge summaries and clinic letters. If we are serious about information exchange as a tool in preparing survivors and their families for self-management of their stroke condition and recovery; I would suggest considering writing discharge summaries and clinic letters to patients direct and copying these to their GPs, rather than vice versa. By writing to the patient this would make prime their responsibility in managing their stroke; and it would require a much clearer focus on the use of lay-friendly terminology. This is an idea that could be developed and trialled as a piece of implementation/action research involving stroke survivors and carers in the design of appropriate format and key content. Exploring acceptability and impact on outcomes such as knowledge, satisfaction, GP attendance, blood pressure measurement and medication concordance would refine the approach further. Survivors could be asked to bring the discharge summary to future appointments as a focus for discussion.

- Survey/scoping exercise to evaluate potential utility of information advisor role.
  - Survivor/carer views.
  - Health professional views.

- Survey/scoping exercise to evaluate potential usefulness of an ‘information regroup’ exercise to revisit information provided during hospital stay.
  - How many would want it?
  - When would you deliver it?
  - Who would deliver it?

- Study of GP/Primary Care team role.
  - As discussed in chapter five the study aspiration to engage with the primary care team to observe and discuss their information
input with stroke survivors proved beyond the scope of the study. However, the finding that information was difficult to engage with as an inpatient and that much information needed to be revisited and gone over after discharge, highlights the importance of further research investigating the role of the GP/primary care team in this important activity. The role of the GP and primary care team needs to be studied alone because of access issues.

9.5.4 Recommendations for Policy, Practice and Education

This section presents a summary of recommendations for policy, practice and education drawn from the current study:

- Support for the development of a good practice guide in information exchange post stroke.
  - Definition of terms.
  - Preferred theoretical underpinnings.
  - Preferred outcome measures.
  - Good practice examples.

- Recognition of the gap between the rhetoric of information provision guidance/aims and the actual practice of information exchange. There is little or no guidance on how to make guidance operational and the meaning of terms such as ‘tailored’ information.

- Recognition in policy of the need for funds to provide a range of tools to support information exchange, this would aid where internal cases need to be built to secure funding.

- In the absence of specific guidance I would suggest the importance of articulating team views, beliefs and strategies with respect to providing information post stroke at a local level. This could include a statement of goals, priorities and roles in relation to information exchange. This could be a written policy that could be made available to service users to clarify expectations.
• Local strategy could include a statement of key time-points where information exchange will be in the foreground rather than the background of communications. From experience of survivors/carers in this study this would focus more attention on discharge, immediate discharge follow-up (not routinely undertaken) and outpatient review. By identifying key time-points all parties could be better prepared to use these exchanges primarily for information needs.

• Have a plan for communications at time points where information provision for self-management is a primary concern:
  o Open such exchanges with an introduction of intent, ask what the survivor would like to know, check what their primary concerns are. This allows these to at least be acknowledged even if they cannot be dealt with directly and need to be saved for a later juncture. This would offer the chance to prioritise what you feel you need to say as a health professional. If there are questions or assessments that you need to carry out before providing feedback and information, make this clear. Provide information with an eye to main concerns, prioritise rather than tell survivors everything they may need to know ever or more than they can deal with right now. Consider agreeing priorities with them if you are not sure. Sum up what has been covered, making clear what are your actions and what are theirs. In the background keep the need for positive regard, recognition, acknowledgement of efforts and progress. Survivors really need to hear this and it is supportive of self-efficacy, which may support self-management. When dealing with survivor/carer questions and concerns reflect on why the topic is important to them. Is it to obtain acknowledgement and support for struggles and successes or do they need you to do anything or tell them anything specific - do they need information or support?

• Make clear where information is a prompt for action and any agency or responsibility in this. What do you want them to do? Why is it important? This may open dialogue about their perception of their ability to do so or open the possibility of exploring this by asking other questions such as:
How do you feel about that? Would you feel able to do that? What would you need to do that? This is trying to engage with and activate survivor/carers' problem solving capacity.

- Recognise the limitations of information; it is not for everyone, depending on their health beliefs and stroke impact (disability).

- Front loading information during hospital admission does not work; there is a need to pace the information provided, stripping back early information and introducing more topics later at follow up when the patient has a sense of context. This requires further re-evaluation of long term stroke support.

- Avoid a reliance on generic written information without supportive discussion. If generic information is used by survivors this appears to be on a more reflective basis after discharge it is not a high priority for stroke survivors during acute phases of care.

- Health professional training –
  - Provide ongoing training in assessment and communication skills to respond to emotional concerns, for example ‘SAGE and THYME’ training (Connolly et al., 2010). This approach, developed in cancer care, highlights that expressed concerns do not always require a solution from the health professional, rather acknowledgement and support to identify solutions.
  - Review of the training curriculum for different rehabilitation professionals to inform ongoing interdisciplinary training: topics to be considered could include the knowledge of how information is processed post stroke (Taylor et al., 2011), and alternative approaches to patient narratives/models of recovery (Blickem and Priyadharshini, 2007).

9.6 CONCLUSIONS
9.6.1 Chapter Summary

In this final discussion chapter, I have presented a review of the thesis content to summarise the rationale for the study undertaken, the key results and the revised
study propositions gleaned from the data collected. This led to a discussion of the need for improved understanding of the role of information in self-management during the variable and complex recovery process that follows a stroke. Secondly, the term ‘tailored’ information was examined to develop what this term needs to encompass in practice to provide more responsive and personally relevant information to stroke survivors and carers. Professionals need to broaden the scope of ‘tailored’ information to include not just tailoring based on diagnosis and risk factors, but also a consideration of the timing of information exchange and the influence of personal beliefs about illness.

There has been a focus within the stroke literature on a search for the best or most effective way to provide information. I would argue, following the present study that this emphasis needs to shift. There will be no best way to provide information; the focus needs to move to finding the best way to establish the most effective means for identifying and meeting an individual stroke survivor/carer’s information needs at a particular moment in time in their recovery. This requires a dialogue about information exchange.

Professionals need to agree upon key underpinning principles that inform practice in information exchange. They need to consult with survivors/carers based on these to develop user friendly means to better achieve the following key activities in information exchange post stroke:

- Assessment of needs.
- Planning/negotiation of priorities.
- Pacing/revisiting topics.
- Facilitating/supporting use of information.

In view of the uncertainty about the impacts of information on study end-point outcomes, other forms of evaluation looking at impacts on process and cost need to be built into evaluations of practice changes.

Information does not equal action. It is a starting point for action; it can only raise awareness of potential problems and concerns for action. Action emerges out of reflection and dialogue about information which contributes to an individual’s appraisal of their situation and their decisions with respect to any action taken. Stroke is often talked of as ‘the stroke event’ by professionals but it is the start of
a highly variable recovery process. Therefore we cannot afford to see information exchange as an event. If stroke recovery is an evolving process for survivors, with evolving understanding of what has happened and what is required to deal with it, then levels of information content and engagement also need to evolve with this on a continuum of passive to more active engagement. In a complex population such as stroke survivors, ‘shared’ care (Joubert et al., 2009) may be an appropriate model, offering an interim position on the road to self-management of stroke.

9.6.2 Contribution of the research to knowledge

The purpose of my study was to explore views and behaviours around information exchange activity post stroke. This was undertaken in response to the following issues highlighted in the literature:

- Dissatisfaction with information.
- Uncertainty about the most effective way of providing information and its likely outcomes.
- Wide claims to the potential benefits of information.
- The observation that stroke care lagged behind other chronic conditions in its approach to information, utilising more factually educational approaches rather than adaptive self-management approaches.

A qualitative case study was undertaken to observe communications where information exchange may be a focus, explore how information was provided and recorded and explore participant experiences of information exchange. The inclusion of three respondent groups; stroke survivors, stroke carers and health professionals was unique at the study’s inception. Previous research tended to study the topic from the survivor, carer or health professional perspective. This study was a first attempt to compare and contrast the views of these three groups in relation to information exchange in a particular setting. During the course of the study a similar approach was taken by Alaszewski et al. (2008), comparing survivor, carer and professional views on communicating information post stroke. Findings from their study and this study are mutually supportive. This is important in small, locally grounded studies as complementary and supportive findings support the central value and applicability of results identified. Similarly, Redfern, McKevitt and Wolfe (2006b) described an observational study of risk management practice in stroke outpatients. Findings from this study
similarly back up findings from the present study relating to missed communication opportunities due to constraints of systems, language and perceived medical roles.

To date I have not discovered another study that sought to combine multiple perspectives, observation and documentary analysis as I have in this study. The use of these different units of analysis within a single case study setting was successful in answering questions about how and why information is exchanged and perceptions about its impacts. This has provided data describing actual activity, expectations, motivations, needs and barriers in relation to information exchange. Contrasting views of different respondents demonstrate that whilst many areas of concern are shared there are subtle differences in emphasis and priority. More two way dialogue is needed between survivors/carers and health professionals in order to prioritise, to plan and to revisit information exchange over the course of stroke recovery.

Findings from this study have been discussed in relation to other studies and relevant theory to highlight potential recommendations for research, policy, practice and education. It is therefore hoped that this thesis can contribute to developing research and practice in information exchange post stroke.
REFERENCES


APPENDICES

1. Letter of invitation health professional
2. Information sheet health professional
3. Consent form health professional
4. Letter of invitation stroke survivor
5. Information sheet stroke survivor
6. Consent form stroke survivor
7. Letter of invitation stroke carer
8. Information sheet stroke carer
9. Consent form stroke carer
10. Topic guides for interviews
11. Observation notes guide
12. Medical notes checklist
13. Thematic framework used for coding data
14. Extract from coded interview
15. Extract from chart category identification
1. LETTER OF INVITATION HEALTH PROFESSIONAL

Dear (Insert name)

RE: Information exchange after stroke

I would like to invite you to participate in a project to explore how stroke survivors and carers receive the information they want about stroke.

Receiving the right information at the right time is important to help people manage their stroke. People who have had a stroke and their lay/family carers have reported that this is not always achieved. Health professionals have designed various interventions to help this problem including information booklets and education programmes. However, the best way for health professionals to respond to the information needs of people who have had a stroke and their carers, is still open to improvement. This study aims to observe and discuss information exchange activity in order to explore the possibilities for health professionals to provide more responsive, individualised information for stroke survivors and carers.

An information sheet is enclosed with this letter to help you decide if you would like to participate. I would be most grateful if you would please read it through and consider if you want to take part. I will contact you in a few days to answer any questions and get your response.

Many thanks

Yours sincerely

Paula Beech
Health Services Researcher
Tel: 0161 206 2013
2. INFORMATION SHEET HEALTH PROFESSIONAL

Participant Information Sheet (Health Professional)

Information Exchange after Stroke (Protocol Reference Final Version 2)

Part 1
You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.
- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
Receiving the right information at the right time is important in managing a stroke. People who have had a stroke and their lay/family carers have reported that this is not always achieved. Health professionals have designed various interventions to help this problem including information booklets and education programmes. The results of these have been mixed sometimes improving knowledge of stroke but not satisfaction with information received. The best way for health professionals to respond to the information needs of people who have had a stroke and their carers, is still open to improvement. This study aims to observe and discuss information exchange activity in order to explore the possibilities for health professionals to provide more responsive, individualised information for people who have had a stroke and their carers. This will be the basis of a PhD study undertaken at the University of Manchester.

Why have I been chosen?
You are being asked to consider participating because you are involved in the care of stroke patients and carers. You were identified from your involvement with a stroke patient or stroke services. If you decide to participate you will be one of several groups of health professionals from different disciplines taking part. You may be observed in day to day care/service delivery. Up to 20 health professionals may take part in one to one interviews to discuss their experiences.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and asked to sign a consent form. You are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your employment in any way.
What will happen to me if I take part?
If you decide to take part:
• I may observe your day to day care giving/service delivery
• I may interview you to discuss your experiences of information provision
• I may observe any current appointments/meetings you have with recruited stroke patients and carers (with their consent also)

Interviews will discuss topics including what information you provide, why this information is important, the purpose of providing information, the way you provide information, your thoughts on how you can best deliver appropriate information and challenges to this. Your main interview will last approximately one hour. Your interview will be private. You can choose the best time and location for the interview. With your permission interviews will be audio recorded to produce an accurate record of what was said. Recordings will be typed up word for word (transcripts) for analysis. You will not be named in transcripts and information that could identify you will be removed in order to protect your identity. Recordings and transcripts will be kept in a locked filing cabinet and password protected computer accessible only to study personnel. These will be destroyed five years after study completion Sept 2014. Transcripts will be analysed to identify themes that can describe important issues about information provision. You may be asked to comment on the accuracy of your transcript or the themes generated. Direct quotations from your interview may be used to illustrate study reports and publications but this will not name or identify you. Observation periods/discussion will total approximately 3 hours maximum and will be recorded with notes and tape recording subject to your consent. Data from these will be handled to the same standard outlined above.

Expenses and payments
Unfortunately there is no provision for travel expenses but every effort will be made to interview you in a setting of your choice and most convenient to you.

What do I have to do?
Be prepared to have routine care/service delivery observed. You may also be asked to participate in one main interview described above and to allow me access during your discussions with specific stroke survivors and carers also recruited to the study and discuss how these exchanges have gone following their completion.

What are the possible disadvantages and risks of taking part?
No major risk is anticipated in taking part. There is a time commitment over and above your normal activities of one to two hours to answer study questions.

What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get may help improve information provision by health professionals for stroke survivors and carers.

What happens when the research study stops?
Feedback of the study findings will be offered by written summary or team presentation if you would like this.

What if there is a problem?
Any complaint about the way you have been dealt with during the study will be addressed. The detailed information on this is given in Part 2.
Will my taking part in the study be kept confidential?
Participation will not be confidential but information shared will be. The details of this are included in Part 2.

Contact details:
Paula Beech, Health Services Researcher, R&D Department, CSB, Hope Hospital, Stott Lane, Salford, M6 8HD. Tel: 0161 206 2013. Email: paula.beech@manchester.ac.uk

This completes Part 1 of the Information Sheet.
If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don’t want to carry on with the study?
You are free to withdraw at any time without affecting your employment.

What if there is a problem?
Complaints:
If you have a concern about any aspect of the study please raise this directly with me (Paula Beech 0161 206 2013). If you remain unhappy about how you have been involved in the study you can complain to my supervisors in the first instance (0161 275 5307/8220).

Will my taking part in this study be kept confidential?
If you decide to take part in the study your participation will be known to your manager/employer, however the information and experiences you share with the researcher will be treated as confidential. Any information you give me will have your name removed afterwards so you cannot be identified. The data collected will only be used for this study. The only people accessing study data will be the researchers and NHS R&D regulatory authorities. Data will be kept for five years after the close of the study i.e. till Sept 2014 and then will be securely destroyed. Handling of your personal information and data will comply with the Data Protection Act 1998.
As a health professional the researcher has a duty to act within their professional code of conduct so if any issues arise that may require disclosure she will discuss this with you. No information will be revealed to another party without telling you first and discussing the reasons for this. If you raise any concerns that you wish to take further she will direct you towards appropriate sources of support to do this.

What will happen to the results of the research study?
Results will form the basis of a PhD report that will be presented to the Salford Trusts and the University of Manchester. Key results will also form the basis of peer reviewed publications. A written summary of results will be sent to participants if they wish. Your identity will not be revealed in any publications/reports made on the study.

Who is organising and funding the research?
The study is funded by the R&D department of Salford PCT and Salford Royal NHS Foundation Trust. The study is being organised and led by Paula Beech,
Health Services Researcher. She is an experienced nurse who has worked in the NHS for 15 years and in research for six years. Academic supervision is provided by the University of Manchester.

Who has reviewed the study?
This study was given a favourable ethical opinion for conduct in the NHS by the Stockport now Northwest 8 REC – GM East. It has also been registered by the University of Manchester ethics committee.

If you decide to take part you will be provided with a copy of this information sheet to keep and a copy of your signed consent form.

Thank you for reading this information sheet and considering participation in this study.
CONSENT FORM

Title of Project: Information exchange after stroke (Health Professional participant)

Name of Researcher: Paula Beech

Please initial box

1. I confirm that I have read and understand the information sheet dated 18.10.2007 (version 2) for the above named study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my employment or legal rights being affected.

3. I understand that study records may be looked at by responsible individuals from the NHS trust for R&D audit/regulatory purposes. I give permission for these individuals to have access to my study records.

4. I agree to take part in the above study which includes:
   - I agree for the researcher to interview me (initial if required)
   - I agree for the researcher to observe interactions with stroke survivors and carers
   - I give permission for my interview/observations to be audio recorded and used by the researcher in the study
   - I give permission for quotations from my transcripts to be used to illustrate study results provided these do not reveal my identity

Name of Health Professional          Date                     Signature
---------------------------------                 --------------            ------------------------------------
Researcher                                      Date                     Signature
When completed, 1 for health professional, 1 for researcher site file.
4. LETTER OF INVITATION STROKE SURVIVOR

Appropriate address of introducing professional/may entail change in letter header

Date

Address of potential respondent

Dear (Insert name)

RE: Information exchange after stroke

I would like to invite you to participate in a project to explore how you get the information you want about your stroke.

Receiving the right information at the right time is important in managing your stroke. People who have had a stroke and their lay/family carers have reported that this is not always achieved. Health professionals have designed various interventions to help this problem including information booklets and education programmes. However, the best way for health professionals to respond to the information needs of people who have had a stroke and their carers, is still open to improvement. This study aims to observe and discuss information exchange activity in order to explore the possibilities for health professionals to provide more responsive, individualised information for stroke survivors and carers.

An information sheet is enclosed with this letter. I would be most grateful if you would please read it through and consider if you want to take part. A researcher will contact you in a few days to answer any questions and get your response.

Many thanks

Yours sincerely

Name of introducing professional
We would like to invite you to take part in a research study. The aim is to learn more about how we may improve the way health professionals provide information after stroke.

If you decide to take part we will ask your permission to:
1. Look at your health records to see how staff record the information they provide
2. Talk to you on your own to find out more about your experiences or views of how you have received information
3. Observe communication you have with the healthcare team
4. Approach any family member or friend who is your main source of support to discuss their experiences and views on the information they have received.

Your care will not be changed by taking part in the study but sharing your experiences may help improve how information is provided in the future.

Whether you take part is up to you. **You do not have to take part.** If you decide to take part but wish to stop later that is OK you do not have to give a reason and your care will not be affected. You will sign a consent form to say that you have agreed to take part.

Any information you provide will be treated in confidence so that your identity will not be revealed by the results of the study.

If you are interested in taking part let the person who provided you with this sheet know and you will be contacted by the researcher named below.

**Contact details:**
Paula Beech, Health Services Researcher, R&D Department, CSB, Hope Hospital, Stott Lane, Salford, M6 8HD. Tel: 0161 206 2013. Email: paula.beech@manchester.ac.uk

If you decide to take part you will be provided with a copy of this information sheet to keep and a copy of your signed consent form.

Thank you for reading this information sheet and considering participation in this study.
Participant Information Sheet (Participant who has had a stroke)

Information Exchange after Stroke (Protocol Reference Final Version 2)

Part 1
You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

• Part 1 tells you the purpose of this study and what will happen to you if you take part.
• Part 2 gives you more detailed information about the conduct of the study. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
Receiving the right information at the right time is important in managing your stroke. People who have had a stroke and their lay/family carers have reported that this is not always achieved. Health professionals have designed various interventions to help this problem including information booklets and education programmes. The results of these have been mixed sometimes improving knowledge of stroke but not satisfaction with information received. The best way for health professionals to respond to the information needs of people who have had a stroke and their carers, is still open to improvement. This study aims to observe and discuss information exchange activity in order to explore the possibilities for health professionals to provide more responsive, individualised information for stroke survivors and carers.
This will be the basis of a PhD study undertaken at the University of Manchester.

Why have I been chosen?
You are being asked to consider participating because you have had a stroke. You were identified from hospital and primary care health records. If you decide to participate you will be one of approximately 15 people who have had a stroke taking part who will all be at different time points after their stroke covering a period of two years after stroke.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and asked to sign a consent form. You are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?
Depending how long it is since you had your stroke you may be involved with the research project for approximately one month.
During this time I would:
• ask your permission to access your medical records to look at any documentation of information provision
• I will interview you to discuss your experiences of information provision and I will observe any current appointments/meetings with health professionals (with their consent also)
• If you have a main carer I would also like to approach them to take part to see how they have had their information needs met.

Interviews will discuss topics including what information you want, why this information is important, how you use this information, the sources you have used to obtain information and your thoughts on how best health professionals can contribute to providing you with the information you need. Your main interview will last approximately one hour. Your interview will be private and confidential. You can choose whether the interview takes place at your home or in a local clinic or hospital. With your permission interviews will be audio recorded to produce an accurate record of what was said. Recordings will be typed up word for word (transcripts) for analysis. You will not be named in transcripts and information that could identify you will be removed in order to protect your identity. Recordings and transcripts will be kept in a locked filing cabinet and password protected computer accessible only to study personnel. These will be destroyed five years after study completion Sept 2014. Transcripts will be analysed to identify themes that can describe important issues about information provision. You may be asked to comment on the accuracy of your transcript or the themes generated. Direct quotations from your interview may be used to illustrate study reports and publications but this will not name or identify you.

Observation periods/discussion will total approximately 3 hours and will be recorded with notes and tape recording subject to your consent. Data from these will be handled to the same standard outlined above.

**Expenses and payments**
Unfortunately there is no provision for travel expenses but every effort will be made to interview participants either in their own home or in a private room at a health care facility they are already attending.

**What do I have to do?**
This study does not require any change to your clinical care. The main requirement is to participate in one main interview described above. Secondly to allow me access during your discussions with health professionals and answer a few questions about how these discussions have gone following their completion. Finally to allow access to your medical records to identify how any information provision is recorded.

**What are the possible disadvantages and risks of taking part?**
No major risk is anticipated in taking part. There is a time commitment over and above your normal activities of one to two hours to answer study questions. Depending on how you are feeling in relation to your stroke discussing some topics may be upsetting. The researcher is an experienced health professional and will support you if this is the case, interviews will be stopped if you do not wish to proceed with them. You will be directed to sources of advice and support if this is appropriate after the interview.
What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get may help improve information provision for other stroke survivors and carers.

What happens when the research study stops?
Your care will continue as before. Written feedback of the study findings will be provided to you if you would like this.

What if there is a problem?
Any complaint about the way you have been dealt with during the study will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?
Participation will not be confidential but information shared will be. The details of this are included in Part 2.

Contact details:
Paula Beech, Health Services Researcher, R&D Department, CSB, Hope Hospital, Stott Lane, Salford, M6 8HD. Tel: 0161 206 2013. Email: paula.beech@manchester.ac.uk

This completes Part 1 of the Information Sheet.
If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.
Part 2

What will happen if I don’t want to carry on with the study?
You are free to withdraw at any time without affecting your clinical care.

What if there is a problem?
Complaints:
If you have a concern about any aspect of the study please raise this directly with me (Paula Beech 0161 206 2013). If you remain unhappy about how you have been involved in the study you can complain to my supervisors in the first instance (0161 275 5307/8220). If you are unhappy with your clinical care you should contact the Hospital or Primary Care Trust (insert details).

Harm:
The focus of this study is talking about your experiences of information provision so no harm is anticipated. In the event that something does go wrong and you are harmed during the study there are no special compensation arrangements and indemnity is provided via standard NHS indemnity schemes. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in this study be kept confidential?
If you decide to take part in the study your participation will be known to your health care team, however the information and experiences you share with the researcher will be treated as confidential. Any information you give me will have your name removed afterwards so you cannot be identified. The data collected will only be used for this study. The only people accessing study data will be the researchers and NHS R&D regulatory authorities. Data will be kept for five years after the close of the study i.e. till Sept 2014 and then will be securely destroyed. Handling of your personal information and data will comply with the Data Protection Act 1998.
If questions or discussions during the study raise concerns for you it is possible to ask the researcher to pass these on to the relevant person for you. Alternatively they will advise you how to do this yourself. The researcher is a health professional and as such has a duty of care towards you. If problems or issues come up in interviews that she feels should be drawn to the attention of your health care team she will advise you of this and with your permission bring these to the attention of a relevant member of your health care team. She will not do this without telling you first and would only speak to professionals directly involved in your care at the time.

**Involvement of the General Practitioner/Family doctor (GP)**
Your GP will be informed of your participation in the study with your consent. Your GP and their team will also be invited to participate in the study as observations of consultations with them may form part of the study data.

**What will happen to the results of the research study?**
Results will form the basis of a PhD report that will be presented to the Salford Trusts and the University of Manchester. Key results will also contribute to publications. A written summary of results will be sent to participants if they wish. Your identity will not be revealed in any publications/reports made on the study.

**Who is organising and funding the research?**
The study is funded by the R&D department of Salford PCT and Salford Royal NHS Foundation Trust. The study is being organised and led by Paula Beech, Health Services Researcher. She is an experienced nurse who has worked in the NHS for 15 years and in research for six years. Academic supervision is provided by the University of Manchester.

**Who has reviewed the study?**
This study was given a favourable ethical opinion for conduct in the NHS by the Stockport now Northwest 8 REC – GM East. It has also been recorded by the University of Manchester ethics committee.

If you decide to take part you will be provided with a copy of this information sheet to keep and a copy of your signed consent form.

Thank you for reading this information sheet and considering participation in this study.
6. CONSENT FORM STROKE SURVIVOR

Centre Number: 
Study Reference Number: 
Participant Identification Number: 

CONSENT FORM

Title of Project: Information exchange after stroke (Participant who has had a stroke)

Name of Researcher: Paula Beech

Please initial box

1. I confirm that I have read/have had read to me and understand the information sheet dated 18.10.2007 (version 2) for the above named study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my healthcare or legal rights being affected.

3. I understand that study records and relevant sections of my medical notes may be looked at by responsible individuals from the NHS trust for R&D audit/regulatory purposes. I give permission for these individuals to have access to my records.

4. I agree to my GP being informed of my participation in the study.

5. I agree to take part in the above study which includes:
   • I agree for the researcher to interview me
   • I agree for the researcher to observe interactions with health professionals
   • I give permission for my interview/observations to be audio recorded and used by the researcher in the study
   • I give permission for the researcher to discuss aspects of my care relating to information provision with members of my healthcare team
   • I give permission for the researcher to access my medical notes to record documentation of information exchange activities
- I give permission for quotations from my transcripts to be used to illustrate study results provided these do not reveal my identity.

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When completed, 1 for patient, 1 for researcher site file, 1 (original) to be kept in the medical notes.
Dear (Insert name)

RE: Information exchange after stroke

We are contacting you as the person most involved in the day to day support (carer) of Insert name. Insert name gave us your name as they are participating in a research study exploring how information about stroke is received and provided. We would like to invite you to participate in this project as well to explore how you get the information you want about Insert name’s stroke.

Receiving the right information at the right time is important in managing after a stroke. People who have had a stroke and their lay/family carers have reported that this is not always achieved. Health professionals have designed various interventions to help this problem including information booklets and education programmes. However, the best way for health professionals to respond to the information needs of people who have had a stroke and their carers, is still open to improvement. This study aims to observe and discuss information exchange activity in order to explore the possibilities for health professionals to provide more responsive, individualised information for stroke survivors and carers.

An information sheet is enclosed with this letter to help you decide if you would like to take part. I would be most grateful if you would please read it through and consider if you want to take part. I will contact you in a few days to answer any questions and get your response.

Many thanks

Yours sincerely

Paula Beech
Health Services Researcher
Tel: 0161 206 2013
8. INFORMATION SHEET STROKE CARER

Participant Information Sheet (Carer)

Information Exchange after Stroke (Protocol Reference Final Version 2)

Part 1
You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
Receiving the right information at the right time is important in managing a stroke. People who have had a stroke and their lay/family carers have reported that this is not always achieved. Health professionals have designed various interventions to help this problem including information booklets and education programmes. The results of these have been mixed sometimes improving knowledge of stroke but not satisfaction with information received. The best way for health professionals to respond to the information needs of people who have had a stroke and their carers, is still open to improvement. This study aims to observe and discuss information exchange activity in order to explore the possibilities for health professionals to provide more responsive, individualised information for stroke survivors and carers. This will be the basis of a PhD study undertaken at the University of Manchester.

Why have I been chosen?
You are being asked to consider participating because you offer day to day support (care) for someone who has had a stroke. You were identified via the person you care for. If you decide to participate you will be one of approximately 15 lay/family carers taking part.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and asked to sign a consent form. You are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care received by yourself or the person you care for.

What will happen to me if I take part?
If you decide to take part I would:
• ask your permission to access your GP records/contacts to look at the number of health professional contacts you have had where you may have accessed information provision
• I will interview you to discuss your experiences of information provision and I will observe any current appointments/meetings with health professionals (with their consent also)

Interviews will discuss topics including what information you want, why this information is important, how you use this information, the sources you have used to obtain information and your thoughts on how best health professionals can contribute to providing you with the information you need. Your main interview will last approximately one hour. Your interview will be private and confidential. You can choose whether the interview takes place at your home or in a local clinic or hospital. With your permission interviews will be audio recorded to produce an accurate record of what was said. Recordings will be typed up word for word (transcripts) for analysis. You will not be named in transcripts and information that could identify you will be removed in order to protect your identity. Recordings and transcripts will be kept in a locked filing cabinet and password protected computer accessible only to study personnel. These will be destroyed five years after study completion Sept 2014. Transcripts will be analysed to identify themes that can describe important issues about information provision. You may be asked to comment on the accuracy of your transcript or the themes generated. Direct quotations from your interview may be used to illustrate study reports and publications but this will not name or identify you.

Observation periods/discussion will total approximately 3 hours and will be recorded with notes and tape recording subject to your consent. Data from these will be handled to the same standard outlined above.

Expenses and payments
Unfortunately there is no provision for travel expenses but every effort will be made to interview participants either in their own home or in a private room at a health care facility they are already attending.

What do I have to do?
This study does not affect your healthcare or that of the person you care for. The main requirement is to participate in one main interview described above. Secondly to allow me access during your discussions with health professionals and answer a few questions about how these discussions have gone following their completion. Finally to allow access to your GP medical records to identify potential points of contact for information provision.

What are the possible disadvantages and risks of taking part?
No major risk is anticipated in taking part. There is a time commitment over and above your normal activities of one to two hours to answer study questions. Depending on how you are feeling in relation to the stroke affecting the person you care for discussing some topics may be upsetting. The researcher is an experienced health professional and will support you if this is the case, interviews will be stopped if you do not wish to proceed with them. You will be directed to sources of advice and support if this is appropriate after the interview.

What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get may help improve information provision for other stroke survivors and carers.
What happens when the research study stops?
Your healthcare and that of the person you care for will continue as before. Written feedback of the study findings will be provided to you if you would like this.

What if there is a problem?
Any complaint about the way you have been dealt with during the study will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?
Participation will not be confidential but information shared will be. The details of this are included in Part 2.

Contact details:
Paula Beech, Health Services Researcher, R&D Department, CSB, Hope Hospital, Stott Lane, Salford, M6 8HD. Tel: 0161 206 2013. Email: paula.beech@manchester.ac.uk

This completes Part 1 of the Information Sheet.
If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?
You are free to withdraw at any time without affecting your healthcare or that of the person you are caring for.

What if there is a problem?
Complaints:
If you have a concern about any aspect of the study please raise this directly with me (Paula Beech 0161 206 2013). If you remain unhappy about how you have been involved in the study you can complain to my supervisors in the first instance (0161 275 5307/8220). If you are unhappy with any clinical care you should contact the Hospital or Primary Care Trust (insert details).

Harm:
The focus of this study is talking about your experiences of information provision so no harm is anticipated. In the event that something does go wrong and you are harmed during the study there are no special compensation arrangements and indemnity is provided via standard NHS indemnity schemes. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in this study be kept confidential?
If you decide to take part in the study your participation will be known to the health care team, however the information and experiences you share with the researcher will be treated as confidential. Any information you give me will have your name removed afterwards so you cannot be identified. The data collected will only be used for this study. The only people accessing study data will be the researchers and NHS R&D regulatory authorities. Data will be kept for five years after the close of the study i.e. till Sept 2014 and then will be securely destroyed. Handling of your personal information and data will comply with the Data Protection Act 1998.
If questions or discussions during the study raise concerns for you it is possible to ask the researcher to pass these on to the relevant person for you. Alternatively they will advise you how to do this yourself. The researcher is a health professional and as such has a duty of care towards yourself and the person you care for. If problems or issues come up in interviews that she feels should be drawn to the attention of your health care team she will advise you of this and with your permission bring these to the attention of a relevant member of your health care team. She will not do this without telling you first and would only speak to professionals directly involved in your care at the time.

Involvement of the General Practitioner/Family doctor (GP)
Your GP and their team will also be invited to participate in the study as observations of consultations with them may form part of the study data.

What will happen to the results of the research study?
Results will form the basis of a PhD report that will be presented to the Salford Trusts and the University of Manchester. Key results may form the basis of publications. A written summary of results will be sent to participants if they wish. Your identity will not be revealed in any publications/reports made on the study.

Who is organising and funding the research?
The study is funded by the R&D department of Salford PCT and Salford Royal NHS Foundation Trust. The study is being organised and led by Paula Beech, Health Services Researcher. She is an experienced nurse who has worked in the NHS for 15 years and in research for six years. Academic supervision is provided by the University of Manchester.

Who has reviewed the study?
This study was given a favourable ethical opinion for conduct in the NHS by the Stockport now Northwest 8 REC – GM East. It has also been registered by the University of Manchester ethics committee.

If you decide to take part you will be provided with a copy of this information sheet to keep and a copy of your signed consent form.

Thank you for reading this information sheet and considering participation in this study.
9. CONSENT FORM STROKE CARER

Centre Number:  
Study Reference Number:  
Participant Identification Number:  

CONSENT FORM

Title of Project:  Information exchange after stroke (Carer participant)

Name of Researcher:  Paula Beech

Please initial box

1. I confirm that I have read and understand the information sheet dated 18.10.2007 (version 2) for the above named study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without the healthcare of myself or the person I care for or my legal rights being affected.

3. I understand that study records may be looked at by responsible individuals from the NHS trust for R&D audit/regulatory purposes. I give permission for these individuals to have access to my study records.

4. I agree to take part in the above study which includes:
   - I agree for the researcher to interview me
   - I agree for the researcher to observe interactions with health professionals
   - I give permission for my interview/observations to be audio recorded and used by the researcher in the study
   - I give permission for the researcher to access general practice medical records to identify points of contact with health care providers where information exchange may take place
   - I give permission for quotations from my transcripts to be used to illustrate study results provided these do not reveal my identity
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<th>Researcher</th>
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When completed, 1 for carer, 1 for researcher site file
10. TOPIC GUIDES FOR INTERVIEWS

**Interview topic guide health professional**

Tell me about your role in the care of ……

Describe the information you have provided for……

Prompts?
  - Content?
  - When?
  - Where?
  - How?
  - What aides?
  - Any redirection to other sources?

What is the purpose of providing information?

How do you feel about providing information?

How do you decide what (content) information to provide?

How do you decide how (method) to provide information?

How do you know if the information has been understood or useful?

How do you record information provided?

Tell me about resources that can support you in providing information?

**Interview topic guide stroke survivor**

Tell me about the time you had your stroke

Did you know what was happening?

Who spoke to you about what was happening?
  - Prompt for detail re individual, place, time, context

What did they tell you?

How did you feel about this information - did this answer the questions you had?

Was the information useful/helpful/did you use it to take any actions?

Tell me about other information that has been useful?
• Who, when, where?

Have you used other sources of information – prompt for details prompt for details source, place, time, context, how discovered?

Describe most useful information received/found? Prompt for details source, place, time, context, how discovered?

Describe least useful/most unhelpful information received? Prompt for details source, place, time, context, how discovered?

What information do you need now? Who/where do you go for this?

Why do you want information?

How have you used information you have received?

**Interview topic guide carer**

Tell me what happened to the person you care for when they had their stroke

Did you know what was happening?

Who spoke to you about what was happening?

• Prompt for detail re individual, place, time, context

What did they tell you?

How did you feel about this information - did this answer the questions you had?

Was the information useful/helpful/did you use it to take any actions?

Tell me about other information that has been useful?

• Who, when, where?

Have you used other sources of information – prompt for details source, place, time, context, how discovered?

Describe most useful information received/found? Prompt for details source, place, time, context, how discovered?

Describe least useful/most unhelpful information received? Prompt for details source, place, time, context, how discovered?

What information do you need now? Who/where do you go for this?

Why do you want information?

How have you used information you have received?
11. OBSERVATION NOTES GUIDE

Observation schedule

Date:
Time:
Location:
People present (professional, lay, study code, not name):

Free text observation notes:

Points for observation:
- purpose of interaction
- who leads/instigates
- style (formal/informal)
- duration
- turn taking
- opportunity for questions
- questions answered
- completeness/accuracy of answers
- understanding checks
- body language
- mood/emotions expressed
- tools, aids, written materials, audio materials used for back up

Questions post observation:
- How do you feel about the interaction/information exchanged?
- Did you give/receive the information you intended to?
- Are there any outstanding issues/questions/concerns?
12. DOCUMENT EXAMINATION SCHEDULE

Document examination schedule

Policy documents
Word search for ‘(patient) information’ and ‘(patient) education’
- Number of uses of the terms
- Context of use of the term (general guidance vs specific instructions)
- Summary of guidance offered
- Any level of evidence given to support statements

Medical notes and letters
Read through hard copy medical notes and letters accessed.
- Look for any references to questions asked information provided
- Look specifically to records of ward rounds, case conferences, goal planning for same evidence
- Check for sign off of information provision in integrated pathway and any detail of what this entailed
- Check discharge summaries /letters to GP for record of type/amount of information provided and any request to follow up on this

Electronic Patient Record
- Look for records of information provision in clinical notes and discharge summary
- Is there completion of information provision checklist
### 13. THEMATIC FRAMEWORK USED FOR CODING DATA

<table>
<thead>
<tr>
<th>Index Heading</th>
<th>Sub-headings</th>
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| What types of information are sought by patients and carers | Treatment progress  
Therapy goals  
Secondary prevention  
Feedback on progress  
Thrombolysis treatment  
Managing after stroke  
Test results  
Reason/cause of stroke  
Symptoms of stroke  
Am I at risk  
Practical support  
Practical skills to help  
Will it happen again  
When will they get better  
Stroke severity  
Diagnosis |
| How information is obtained by patients/carers | Other stroke survivors/stroke meetings  
Learning from direct experience more potent than given info  
Lack of time to go through information  
Quality of interaction  
Could things be better  
Unclear roles/info  
Having to see a lot of people to get info  
Information provided but not explained/made relevant  
Support agencies  
Unsure where to go for info  
Verbal Information  
Serendipity/by chance  
Questioning/onus on them  
Other family members  
Personal observation |
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<th>When information is obtained by patients/carers</th>
<th>During therapy</th>
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<tr>
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<td>Needing time to process information</td>
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<td>Getting accustomed to the stroke</td>
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<td>wrong time</td>
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<td>It's patient's time</td>
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<td>At formal meetings/appointments</td>
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<td>When you asked</td>
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<th>Why patients and carers want information</th>
<th>Reassurance/back up of support</th>
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<tr>
<td></td>
<td>lack of expectation re information provision</td>
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<td>Unanswered questions</td>
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<td>its part of the system</td>
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<td>Not asking questions</td>
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<td>rationalising things</td>
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<td>Other worries/concerns</td>
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<td>Practical information how to manage after stroke</td>
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<td>So they are confident in caring role</td>
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<td>Influence of personal characteristics</td>
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<td>Making sense of what happened</td>
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| Impacts or uses of information for patients and carers | Upset  
Anger  
Unwelcome news/info  
Support over info  
the limits of info  
Doubts resistance about stroke diagnosis  
Depressing  
Increased ability to anticipate issues post stroke  
Confirming expectations  
Problems remembering  
Uncertainty  
Changes/actions taken  
Misinformation/doubts  
Unhelpful  
Helpful  
Frightening/anxious  
Confusing  
Feelings about stroke diagnosis  
Overwhelming |
| --- | --- |
| What info is provided by staff | Progress feedback  
Managing after stroke  
Secondary Prevention  
Test Results  
Therapy/care related  
Prognosis  
Diagnosis |
| How info is provided by staff | Assessing impact of info provision  
Other aids  
Referring on  
Internet  
Written information  
Verbal  
Gauging info provision |
| When is information provided by staff | Other meetings  
On telephone  
Out-patient appointments  
During care/therapy  
Case conference  
Ward round  
On admission |
|-------------------------------------|---------------------------------------------------------------|
| Why do staff provide information    | To help people feel better?  
To provide information to aid choices/decisions  
To encourage lifestyle change  
To prepare for discharge  
To manage risk  
To manage 'Hope'/Expectations  
To help them get some sense of control back  
So they understand what has happened  
To engage people in the processes of care  
Providing support  
Why they may not give information |
| How staff document/communicate re info provided | Reasons for recording  
Information or education?  
Improvement initiatives  
Linking people to specific aspects of written info  
Reports  
Prompt sheets  
Joint sessions  
Telephone calls  
Letters and discharge summaries  
Hand written notes  
Verbal handovers  
Use of I-Soft |
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<th>Validation</th>
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<td>Upsetting</td>
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<td>Unsure</td>
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<td>Unhelpful</td>
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<td>Helpful</td>
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<td>Resistance</td>
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<th>Challenge</th>
<th>Consistency</th>
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<td>Lack of continuity</td>
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<td>Uncertainty</td>
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<td>Time constraints</td>
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<td>It's difficult</td>
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<td>Emotional work</td>
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<td>Whose job is it?</td>
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<td>competence/skill develops with experience</td>
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<td></td>
<td>Personal experiences</td>
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<td>personal work ethic</td>
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14. EXTRACT FROM CODED INTERVIEW

Interviewer: So in a way you've been clear quite from the start that you've had a stroke but the unanswered questions are around why? 00.05.15.5

SS01: Yes (yeah) yeah got that right yeah ok... yeah and I do seem to have been left quite a lot in the sense that there were two choops in the bay where I was and they had a much bigger disease than I had (yeah) they were far worse than (yeah) so in any way I'm grateful for that. 00.05.36.4

Interviewer: So did you explore this question of why you had the stroke with several members of the team that you worked with or did you just sort of keep it to yourself? 00.06.54.3

SS01: No, I only mentioned it to the doctor I told you I just accepted it after that (right) he was so sure er that I accepted it accepted it ok... it seemed 00.06.61.5 it's the face of all this advice that we got about getting your blood pressure down and erm I had no affect at all accept the benefit of mine in my wisdom said that may be why you got on with it (right) so you don't know the answer to those questions do you? 00.06.63.4

Interviewer: Have you seen your GP at all? 00.06.67.3

SS01: No I'm at seven o'clock if you excuse me for a minute I'm going to try to get an appointment for Tuesday I've got to ring up two days before I'd like to get an appointment you see or so then and I'm hoping that I can yes you can drive as well and I've got other things to do... but actually in the week (week) in the rehab my eyesight was tested twice and I'm once by the physio (physio) and in the rehab I don't know the physio I don't know what that was the girl X... and she apparently had done it the day after I had the stroke and in the rehab ward she said the improvement was actually quite phenomenon (phenomenon) and also saw the little Chinese doctor X (mmmm) and er she was very forthcoming and er said oh yes you must have been that seen to because there's no apparent problem there now do you or was she was very communicable. 00.06.79.9

Interviewer: Yes you mentioned her when we were talking on the ward... (Oh yes) you found her quite helpful in terms of telling you, giving you information... (She was very) What made her stand out then what was different? 00.08.10.7

SS01: Hmm... well in that she did converse the sort of commented on the improvement and er and in particular the eyesight... 00.08.46.4

Interviewer: When you say converse what do you mean?... it was more... can you describe that in more detail? 00.08.55.9

SS01: I only really remember her talking about the eyesight I don't remember much there wasn't much else to talk about really the er the there was a sort... lack of sensation on the left hand side and of the physics mentioned but she didn't go into that... again I don't know why the physics were doing that I would of thought they'd be giving me exercises to get the legs going and so on... but obviously I'm misinformed about the function of physics (laughs). 00.08.46.2

Interviewer: Well, I think they have to do a few different things in order to give you things to do. 00.08.44.4

SS01: Yes, and actually they did make it plain that I had suffered a loss of sensation because if they did that (gestured) I could feel it but if I closed my eyes and I couldn't feel the hand then (I didn't know then) and then I could... 00.10.13.1

Interviewer: Did they explain the significance of that to you, did they work with those kind of findings with you? 00.10.10.7

SS01: Well erm well did they say that it would be a loss of sensation and that would mean the em for example in the kitchen it would be dangerous and em in fact of the first things that discovered when I went in the kitchen and put my hand in the radiator and found it was very hot (laughs to himself) and my hand was burned and I regretted that (yeah) but I (yeah) (yeah) the hand men was a bit slow at regaining that (yeah) and (yeah)... was that when you got home you mean? (Yes yes so it was good that they did do that but in retrospect) I only discovered it in retrospect you see I didn't sort of think of my sensations on my left hand not so good I mustn't touch that radiator (laughs to self) 00.11.05.1
Interviewer: Maybe you learn things more by experience than by being told facts in a different context (yes) do you know what I mean? 00:11:13-9

SS01: Yes particularly if its something you don't want to hear (right) yes 00:11:21-1

Interviewer: Did you feel you were being told quite a few things that you didn't want to hear? 00:11:28-2

SS01: Yes I did say I remember an arm that had acute stroke until the doctor came and said how do you feel? And I said I feel fine until I listen to the doctors (laughed) after that I would go and tell me what was wrong it just shows that I was not aware of things not being right e.g. particularly this left hand and so on and actually X noticed that I twice walked into door posts on this side (smile) but that was not unusual as I'm very clumsy in the house. 00:12:24-2

Interviewer: So you've made sense of some thing more once you got back home? (yes) and been in your own environment? 00:12:34-6

SS01: Yes and erm yeah 00:12:38-8

Interviewer: Is it still a struggle to accept these things or? 0 00:12:43-0

SS01: Oh no it does it become easier when you're here and you're... no I can accept there's no problem there I think the immediate reaction was to be more careful erm but erm I'm hoping I've not had any sort of shocks in the last week or more because I've been home for two weeks now and I'm hoping that the effect is wearing off and at this insensitivity or lack of sensitivity is not as bad as it was 00:13:11-4

Interviewer: Do you think its getting better? 00:13:15-2

SS01: Erm I'm assuming so erm yeah I'm assuming so... I'll need more time are you managing it better one or the other? yeah you don't really know where it all stands which is 00:13:33-1

Interviewer: Just going back to your little comment there you were saying like on the acute ward and you said the doctor said how do you feel and you said Oh I feel fine if you talk to me cos you're telling me what's wrong all the time (That's right) erm can you talk a bit more about that erm... is that how it felt that you were just being told things that it was all bad news rather that good news? 00:14:05-2

SS01: Erm yes possibly probably that sort of emotional yes erm (correct me if I'm wrong) No is what you were or they were quite right and the doctor upstairs was most communicative I can't remember his name he ended it I think he ended it quite well but I was on a triple band ward you know man was bandaged and he was very communicative and I learnt a lot he was the one that would do the comment and the fact was that the stroke sort of took over me and I meant when I was lying on the bed and the doctor was diagnosing me I didn't realise I had a stroke I didn't realise things were the only sort of sign that I'd had was that whenever I stood up I sort of fell over and I sort of went on hands and knees along the bed and trying to lift up to the barrier rail and when I got level with the barrier rail I fell over again and it was only after listening to him telling me what was going wrong that I realised I was probably sort of crossing on the left hand side it was the left hand side that seemed to be the problem... I was one of the times I had a heart attack before I got dressed and you don't realise the coordination that's required and I thought at the time that the co-ordination had gone (laughed) but I was when I went into hospital and was waiting on the trolley then I was lying down so it was no need to try to stand up or I was comfortable... it sort of struck upon me I was just not aware of what was going on 00:15:23-9

Interviewer: Do you think em you've identified that like the stroke sort of creeps up on you like you unaware to some extent and it brings with it quite a lot of problems and in an unfamiliar situation... the thing about being told things that aren't going to be quite right for a bit (yes) do you think it's a question of professionals or staff could communicate these things better to you or is it just that you need time to come to terms with it? 00:16:55-6
### 15. EXTRACT FROM CHART CATEGORY IDENTIFICATION TABLE

#### Making sense of what happened

<table>
<thead>
<tr>
<th>Original Extract</th>
<th>Elements/Dimensions</th>
<th>Categories/Classes</th>
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<tr>
<td>SS01 3 extracts. Info from initial Dr helped him understand it was the nerves that were affected not the muscles so helped him know why he couldn't do what was asked of him as quickly as he wanted. Reinforced by nurses asking which side was affected. Equals a kind of technical info making sense of why observed symptoms are happening. (para 89).</td>
<td>-to understand nerves affected not muscles&lt;br&gt;-to understand why he couldn't do what was asked of him quickly&lt;br&gt;-knowing which side was affected&lt;br&gt;-a kind of technical info&lt;br&gt;-made sense of symptoms observed/experienced</td>
<td>Understanding how stroke affects body&lt;br&gt;Understanding impact of stroke on function (symptoms)</td>
</tr>
<tr>
<td>SS02 1 extract. Info to help understand 'how I am and how I feel about it'.</td>
<td>-To understand how I am&lt;br&gt;-To understand how I feel</td>
<td>Understanding impact of stroke on function (symptoms)&lt;br&gt;Understanding emotions</td>
</tr>
<tr>
<td>SS04 5 extracts. Couldn't believe it had happened loads going through mind as to why. Was young and fit healthy lifestyle, still doesn't know why (para 31). Loads of investigations done not shown a clear reason only possible reasons thinning heart valve? BP? High chol? Feels he just has to stop something going wrong but they have never said why? But neither has anyone said they don't know result is frustration (para 39, 41). Would have preferred a straight answer for them to just say I don't know (para 41).</td>
<td>-Couldn't believe stroke had happened&lt;br&gt;-loads going through mind as to why&lt;br&gt;-Still doesn't know why&lt;br&gt;-investigations not shown clear reason for stroke only possible reasons&lt;br&gt;-Feels he has to stop something going wrong&lt;br&gt;-No one has said why no one has said they don't know&lt;br&gt;-Would prefer straight answer&lt;br&gt;-Frustrated</td>
<td>Desire to know why stroke happened&lt;br&gt;Issues re clarity of communication re why stroke happened&lt;br&gt;Desire to stop another stroke</td>
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<tr>
<td>SS10 2 extracts. Because of lack of physical signs i.e. outer of stroke was tending to ask ‘what have I done?’ blaming self (para 638). Want to know what’s happened and why but they don't know a reason think it’s something to do with her blood (para 643).</td>
<td>-wondering what have I done because can’t see what has caused stroke -self blame -wants to know what’s happened -wants to know why it’s happened -they don’t know a reason for it</td>
<td>Understanding what has happened to you Understanding what stroke happened Issues re clarity of communication re why stroke happened</td>
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<td>SS11 4 extracts. Describes piecing things together from memories and what people (family told him). Coming up with own rationales as to how stroke happened (para 220). Increasing understanding of what happens with a stroke (through internet in his case much gained) stroke affects different parts of brain resulting in different effects, the part it affects those cells have died (para 481,485).</td>
<td>-piecing things together from memories of what people told him -own rationales of how stroke happened -increased understanding of what happens with a stroke off internet -Stroke affects different parts of brain results in different effects -In the part of the brain the stroke affects those cells have died</td>
<td>Reconstructing the story of your stroke Pursuing additional information for self Understanding how stroke affects body</td>
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<tr>
<td>SC02 2 extracts. Information about what had happened and what was required now was ultimately helpful when it came about 4 days in but felt unclear before and didn't like to ask if you did staff rushed got lots to do. Not sure where would go now for info lots of questions about implications for own health but would feel was wasting GPs time to go and ask the Qs (para 126)</td>
<td>-understanding what had happened -understanding what was required now -helpful when received -felt unclear before received info and didn’t like to ask -not sure where to go now for info -questions re implications for own health -feels would be wasting GPs time</td>
<td>Understanding what has happened Understanding what is required to deal with stroke Reluctance to ask –staff busy Questions raised for own health</td>
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