

Patient information provision and involvement of patients by stroke professionals: implications for the patient-provider relationship

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I declare that the work presented in this thesis is the work of the author and others' work is fully acknowledged where included

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Abstract

Despite significant moves to inform and involve patients in their care, implementation of this vision has only been achieved with limited success. Part of the problem appears to stem from an insufficient consideration of the processes underpinning patient participation in the first instance. To help resolve this, we ask *what* factors drive the patient information provision and participation processes and *how* these factors have their impact.

A significant barrier to the improvement of patient information and empowerment is the incomplete understanding of the interaction between patients and health professionals – commonly termed the patient-provider relationship (PPR). We argue that the PPR has not been fully developed in the context of stroke care specifically and we therefore propose a revised framework for understanding the nature of the patient-provider interaction, specific to stroke care. The new framework more realistically conveys the context for stroke care services in the UK today.

The work first evaluates the research literature on the PPR in general, before focusing on the PPR in the acute phase of stroke care. We therefore place stroke care in the context of what is already theorised about the PPR. Based on the results from 50 semi-structured telephone interviews with stroke professionals, we then propose that a revision of our understanding of *stroke* PPR is needed to more fully take into account the dynamic external influences acting upon it. The general analytical approach is an inductively driven constant comparative method of qualitative analysis, conducted in line with grounded theory.

Significant findings include: (i) the provider may no longer be the most important source of information for the patient within a revised stroke PPR model; (ii) stroke physicians reported cases involving lucid patients refusing thrombolytic treatment. Studies reporting stroke patients playing active, participatory roles in acute decision making do not appear in the literature and policymakers have tended to assume that the involvement of patients should only begin *after* the hyper-acute stages of care have passed. The findings here challenge this position and suggest that participation in decision-making during the hyper-acute phase is feasible and should be considered in clinical practice and policy making.

Further, stroke care policy and practice recommendations arising from the study include: (i) greater consideration needs to be given to the allocation of resources designed to psychologically support stroke patients, (ii) audits must be designed to assess better the *quality* of stroke patient information provision, (iii) more information should be provided to patients and their families about what they can reasonably expect from the service they are using, (iv) priority should be given to the production of high-quality online material to complement the existing offline offering, (v) longer-term strategies should be developed for sustaining the sense of empowerment stroke patients have outside the hospital, when they generally ask more questions and demand more say in their care.

Table of contents

Acknowledgements..... 2

Abstract..... [3](#)

Table of contents..... 4

List of tables..... [13](#)

List of figures..... [14](#)

Abbreviations..... [15](#)

Chapter One – Introduction

1 Introduction..... [19](#)

1.1 Study rationale and research questions..... [19](#)

1.1.1 The importance of understanding the processes of patient information provision and patient involvement and their impact on the concept of a patient-provider relationship (PPR)..... 19

1.1.2 A study of the PPR in stroke care: establishing the importance of the research domain 21

1.2 Thesis overview..... [25](#)

Chapter Two – Stroke care and the patient-provider relationship: background

2 Introduction..... [29](#)

2.1 Study background: stroke care..... [29](#)

2.1.1 Stroke types..... 29

2.1.2 Stroke care service innovation – the historical context and current progress.....	30
2.1.3 National stroke policy and practice.....	31
2.1.4 National stroke guidelines.....	32
2.1.5 National public awareness campaign.....	34
2.1.6 Local stroke policy and practice.....	35
2.2 Study background: observational work.....	<u>37</u>
2.2.1 What is i-Health?.....	37
2.2.2 How did the observational period inform the subsequent fieldwork and research?.....	37
2.3 Summary.....	38
 <i>Chapter Three – Literature review</i>	
3 Introduction.....	<u>40</u>
3.1 Approach to the literature.....	<u>40</u>
3.2 Health communication and the patient-provider relationship.....	<u>45</u>
3.2.1 Sociology as the forerunner of health communication studies.....	46
3.3 The importance of patient information to the patient-provider relationship.....	<u>49</u>
3.4 The importance of patient information provision and involvement to stroke care...<u>50</u>	
3.4.1 Key studies relating to stroke patient information provision.....	50
3.4.2 Key studies relating to stroke patient involvement with care.....	54
3.4.3 Key studies relating to both stroke patient information provision and involvement.....	58

3.5 Factors that influence information provision and involvement of patients by health professionals.....	<u>63</u>
3.5.1 Government policy (as a factor affecting patient information provision).....	64
3.5.2 Government policy (as a factor affecting patient involvement).....	66
3.5.3 Social structures (as a factor affecting both patient information provision and involvement).....	69
3.5.4 Technology (as a factor affecting both patient information provision and involvement).....	71
3.6 Factors mostly affecting patient information provision by health professionals.....	<u>73</u>
3.6.1 Mode of information delivery.....	73
3.6.2 The patient’s specific illness and impairment.....	76
3.6.3 Resources and sources of information.....	76
3.6.4 Patient’s needs change with time.....	78
3.7 Factors mostly affecting patient involvement by health professionals.....	<u>78</u>
3.7.1 Professional complacency.....	78
3.7.2 Training.....	78
3.7.3 Provider’s and patient’s personality.....	79
3.7.4 Presence of family and the role of carers.....	81
3.8 Overview of the literature: the research questions.....	<u>82</u>

3.9 Chapter summary.....89

Chapter Four – Research approach and methods

4 Introduction92

4.1 Methodology and research paradigm.....92

4.1.1 Rationale for choosing a qualitative, grounded-theory inspired approach.....92

4.1.2 Theoretical perspective: epistemology and ontology.....96

4.1.3 Rationale for choosing semi-structured interviewing for data collection.....99

4.2 Research methods.....102

4.2.1 Rationale for study design: telephone interviewing.....102

4.2.2 Sampling.....103

4.2.3 Participant recruitment.....106

4.2.4 Ethical considerations.....109

4.2.5 Data collection.....110

4.2.6 Data analysis.....112

4.2.7 Data validation.....114

4.2.8 Limitations.....116

4.3 Summary.....121

Chapter Five – Findings and Analysis, Part One: Factors influencing patient information provision and involvement

5 Introduction.....	<u>124</u>
5.1 Decision making in healthcare.....	<u>126</u>
5.1.1 Cultural issues and decision making.....	127
5.1.2 Characteristics of the individual patient and provider.....	132
5.1.3 Context in which decisions are being made.....	134
5.1.4 Summary of key points relating to decision making as a core category.....	139
5.2 Patient information.....	<u>140</u>
5.2.1 Patient heterogeneity.....	141
5.2.2 Timing of information.....	146
5.2.3 Sources, and types, of information.....	148
5.2.4 Summary of key points relating to patient information as a core category.....	152
5.3 The patient-provider relationship.....	<u>153</u>
5.3.1 Cultural changes.....	154
5.3.2 Characteristics of the individual patient and provider.....	156
5.3.3 External influences on the traditional patient-provider interaction.....	159
5.3.4 Summary of the key points relating to the patient-provider relationship as a core category.....	163
5.4 Factors affecting both information and involvement	<u>165</u>
5.4.1 Patient personality and background.....	166

5.4.2 Patient capacity and acuteness of situation/decision.....	168
5.4.3 Changes to length of stay (LOS) and the service delivery model for stroke.....	169
5.4.4 Government policy.....	170
5.4.5 Social structures.....	171
5.4.6 Auditing, setting and service demands.....	172
5.4.7 Technology.....	173
5.4.8 Neuro-psychology shortages.....	175
5.4.9 Overburdened staff.....	176
5.5 Factors mainly affecting patient information provision.....	176
5.5.1 Patient-specific impairment(s).....	178
5.5.2 Patient’s needs change with time.....	179
5.5.3 Post-traumatic amnesia (PTA) and the patient’s psychological state.....	180
5.5.4 Source of information.....	181
5.5.5 Resources.....	182
5.5.6 Inter-provider integration.....	183
5.6 Factors mainly affecting patient involvement.....	184
5.6.1 Professional complacency or lack of self-awareness.....	185
5.6.2 Provider’s personality.....	186
5.6.3 Presence of family and carers.....	187

5.6.4 Training.....	188
5.7 Summary of factors influencing information provision and involvement of patients by health professionals.....	189
5.8 Conclusion.....	190
 <i>Chapter Six – Findings and Analysis, Part Two: Improvements in patient information provision and involvement</i>	
6 Introduction.....	195
6.1 Service reconfiguration.....	196
6.1.1 Addressing resource limitations.....	198
6.1.2 Improving navigability and access to information.....	202
6.1.3 Reassessing performance measures.....	204
6.1.4 Summary of key points relating to service configuration as a core category.....	208
6.2 Inter-agency workings and the PPR outside hospital.....	209
6.2.1 Increase awareness of issues surrounding patient transition from hospital to community care.....	210
6.2.2 Improved integration amongst hospital and social service providers.....	212
6.2.3 Improved continuity of care throughout the patient journey	216
6.2.4 Summary of key points relating to inter-agency workings and the PPR outside hospital as a core category.....	220
6.3 Technology.....	221

6.3.1 Computer literacy.....	222
6.3.2 Audio-visual delivery of information (hospital).....	224
6.3.3 Social media and online material (home).....	227
6.3.4 Summary of key points relating to technology as a core category.....	230
6.4 Suggested improvements in service configuration.....	231
6.5 Inter-agency workings and the PPR outside hospital.....	233
6.6 Using technology to improve patient information provision and involvement.....	234
6.7 Conclusion.....	236
 <i>Chapter Seven – Discussion</i>	
7 Introduction.....	241
7.1 Building a new model of the patient-provider relationship in stroke care.....	245
7.2 This study’s contribution.....	251
7.2.1 Understanding of the patient-provider relationship in stroke care.....	251
7.2.2 Methodology in stroke care research and that relating to the PPR in stroke care.....	252
7.2.3 Policy and practice in stroke care and that relating to the PPR in stroke care.....	254
7.3 Summary.....	255
 <i>Chapter Eight – Conclusion</i>	
8 Introduction.....	257
8.1 Limitations.....	257

8.1.1 Wider applicability of results.....	257
8.1.2 Grounded theory.....	258
8.1.3 Balance of participants.....	259
8.1.4 The views of health professionals only.....	259
8.2 Implications for practice.....	<u>260</u>
8.3 Future work.....	<u>263</u>
8.3.1 Potential case study of a London HASU.....	263
8.3.2 More quantitative approach and the inclusion of stroke patients and their carers.....	264
8.3.3 Economic case for improved patient information and involvement.....	265
8.3.4 Professional disempowerment and patient provider role convergence.....	265
8.4 Final thoughts.....	<u>266</u>
Bibliography.....	<u>267</u>
Appendices.....	<u>283</u>
<i>Appendix I: Categorising the literature.....</i>	<i>283</i>
<i>Appendix II: Identifying and categorising key themes from the literature.....</i>	<i>284</i>
<i>Appendix III: Consent form.....</i>	<i>285</i>
<i>Appendix IV: Example of recruitment email that was sent to potential participants.....</i>	<i>287</i>
<i>Appendix V: Informational sheet sent to potential participants as part of the recruitment process.....</i>	<i>288</i>
<i>Appendix VI: An example of some early stage questions used to guide initial semi-structured interviews.....</i>	<i>290</i>
<i>Appendix VII: An example illustrating the formation of analytical constructs.....</i>	<i>292</i>

List of tables

Table 3.1: Emanuel’s four models of the doctor patient relationship.....	47
Table 3.2: Models of clinical decision making.....	68
Table 3.3: A summary of the factors affecting patient information provision and involvement of patients by health professionals: key, general findings from the literature.....	83
Table 3.4: A summary of the factors affecting patient information provision and involvement of patients by health professionals: key, stroke-specific findings from the literature.....	84
Table 3.5: A summary of the factors affecting the patient-provider relationship at a system and individual level: key, general findings from the literature.....	85
Table 3.6: A summary of the factors affecting the patient-provider relationship at a system and individual level: key, stroke-specific findings from the literature.....	86
Table 4.1: A summary of possible epistemological and ontological positions.....	99
Table 4.2: A summary of the study’s participants.....	119
Table 5.1: Core categories relating to the first research question.....	125
Table 5.2: Cultural issues and decision making excerpts (I).....	129
Table 5.3: Cultural issues and decision making excerpts (II).....	131
Table 5.4: Context in which decisions are being made excerpts.....	136-7
Table 5.5: Patient heterogeneity excerpts.....	141-2
Table 5.6: Sources of information excerpts.....	150
Table 5.7: Cultural changes excerpts.....	155
Table 5.8: A summary of the factors affecting patient information provision and involvement of patients by health professionals: key, stroke-specific findings from the data.....	166
Table 5.9: A summary of the factors affecting mainly patient information provision by health professionals: key, stroke-specific findings from the data.....	177

Table 5.10: A summary of the factors affecting mainly involvement of patients by health professionals: key, stroke-specific findings from the data.....	185
Table 5.11: Factors identified in response to RQ1a.....	189
Table 6.1: Core categories relating to the second research question.....	196
Table 6.2: Addressing resource limitations excerpts.....	201
Table 6.3: Social media and online material (home) excerpts.....	228-9
Table 6.4: A summary of the response to the second research question.....	235-6
Table 7.1: The main similarities and differences in the factors affecting information provision and patient involvement between the stroke literature and the data from this study.....	242

List of figures

Figure 3.1: An historical, sociological model of the PPR	49
Figure 3.2: Information, decision making and the PPR.....	88
Figure 4.1: The interpretivist research approach.....	97
Figure 4.2: The stroke pathway.....	107-8
Figure 5.1: Decision making – overall coding structure.....	126
Figure 5.2: Patient information – overall coding structure.....	140
Figure 5.3: The patient-provider relationship – overall coding structure.....	154
Figure 6.1: Service configuration – overall coding structure.....	197
Figure 6.2: Inter-agency workings and the PPR outside hospital – overall coding structure.....	210
Figure 6.3: Technology – overall coding structure.....	222
Figure 7.1: The study’s core categories.....	245
Figure 7.2: Establishing the PPR as the key core category.....	246
Figure 7.3: The revised PPR model for stroke - factors affecting, and related to, the PPR according to the literature (both general and stroke-specific) and the data from this stroke-specific research.....	248

Abbreviations

AF – Atrial fibrillation

BCCN – Black country cardiovascular network

CC – Core category

CD – Compact disc

CIS – Clinical information system

CST – Community stroke team

CT – Computed tomography

DGH – District general hospital

DM – Decision making

DoH – Department of Health

DPR – Doctor patient relationship

Dr. – Doctor

EHR – Electronic health record

EPP – Expert patients programme

ESD – Early supported discharge

ESDT – Early supported discharge team

FAST – Face, arms, speech and time (public awareness campaign)

Fig. – Figure

GAfREC – Governance Arrangements for Research Ethics Committees

GDP – Gross domestic product

GP – General practitioner

GT – Grounded theory

HASU – Hyper acute stroke unit

HIT – Health information technology

HP – Health professional

ICT – Information and communications technology

Info. – Information

LOS – Length of stay

MDT – Multi-disciplinary team

MHRA – Medicines and Healthcare Products Regulatory Agency

NHS – National Health Service

NICE – National institute for health and care excellence

OECD – Organisation for economic co-operation and development

OT – Occupational therapist

Physio. – Physiotherapist

PPI – Patient and public involvement

PPR – Patient provider relationship

PSD – Post-stroke depression

PTA – Post-traumatic amnesia

RCP – Royal College of Physicians

REC – Research Ethics Committees

RQ – Research question

RTC – Road traffic collision

SALT – Speech and language therapist

SASC – Satisfaction with stroke care

Sch. – School

SDM – Shared decision making

SG – Standard gamble

SHA – Strategic health authority

SSNAP – Sentinel Stroke National Audit Programme

TIA – Transient ischaemic attack

tPA – tissue plasminogen activator

UK – United Kingdom

Univ. – University

USA – United States of America

w.r.t. – with respect to

Chapter One – Introduction

1. Introduction

In this opening chapter, we will present the motivation and rationale for this health services management study, in addition to the research questions that the work seeks to address. A brief guide to the thesis will also be included here via chapter-by-chapter synopses.

1.1 Study rationale and research questions

1.1.1 The importance of understanding the processes of patient information provision and patient involvement and their impact on the concept of a patient-provider¹ relationship (PPR)

As we shall see from the literature, the consensus is that the adequate provision of information to stroke patients and their carers is important to health outcomes (in particular, patient satisfaction) and is currently still an unmet need. Part of the problem appears to stem from a lack of knowledge about the precise information needs of individual stroke patients. A larger part of the difficulty comes from trying to understand better *how* information can be customised to the individual within a time and resource constrained health system and *how* patients can be encouraged and empowered to participate more in their own care. By understanding the processes of patient information provision and patient involvement in greater detail, we may be able to begin to answer these types of key questions. Then, by applying the knowledge gained from the answers to these questions, and others, we may start to facilitate improvements in both information provision and participation and accomplish the

¹ In this study, the term *provider* should be understood to mean the health professional attending to a patient's clinical needs, be they nurse, therapist or doctor. Most often, the word is used in reference to the specific interaction these professionals have with their patients, in what is known as the patient-*provider* relationship. Where the term is not being used in this sense (for instance, in reference to a *service provision*) this will be explicitly stated or made clear from the context.

ultimate goal of increasing stroke patient satisfaction. In short, this project is a piece of health services management research, focusing on ways to improve the provision of healthcare. A wide range of disciplines need to be applied to research on the organisation and delivery of health services (Fulop 2001; Fulop, Allen et al. 2003). Therefore, important theoretical and other differences between and within disciplines, and their implications for the research, are discussed in the literature review.

Before this goal of improved health delivery is realised, however, we must firstly identify the factors currently affecting patient information provision and patient involvement in decisions about their care. As we shall see from the literature review to follow, a number of factors have already been suggested. These factors will be tested in this study, and their importance will either be confirmed or refuted within the specific context of stroke care. Through this exploratory study, we aim to uncover other factors that have not received much attention in the literature. However, as explained above, it is likely that the greatest benefits will come from exploring *how* some of these factors impact patient information provision and involvement. It is anticipated that the more explanatory aspects of the study may result in new implications for the PPR in stroke, as information, decision making and the patient-provider interaction are all inextricably intertwined. This will in turn form the main contribution to understanding of the work. The main practical contribution is likely to emerge from greater knowledge of how to improve information provision and participation and thus, in turn, boost patient satisfaction. Methodological contributions arising from the research will also be considered in the discussion chapter.

1.1.2 A study of the PPR in stroke care: establishing the importance of the research domain

Stroke is amongst the top three causes of death, after heart disease and cancer, and the greatest cause of adult disability in England, costing the NHS over £3 billion each year. The World Health Organization estimates that its incidence will rise by another 30 percent within the next 10 years. In the UK, stroke is the single largest cause of adult disability, with a third of patients being physically dependent on others to be able to leave their house 6 months after their stroke (Logan, Armstrong et al. 2014). Strokes have a major economic impact with the latest estimates for the total societal cost (direct, indirect and informal care) in the UK ranging from £7 billion to £8.9 billion per year (Saka, McGuire et al. 2009). This places stroke care at the forefront of the healthcare agenda in many developed countries, including the UK and is one of the reasons it is an important area for research. Improvements in our understanding of the patient-provider relationship (PPR) in stroke and other patient processes central to stroke care, through health services research, will be crucial if the UK is to successfully diminish the adverse health and economic impacts of stroke itself.

Aside from the economic, political and demographic arguments making the PPR in stroke care a vital and interesting field of investigation, there are other aspects of the research domain which command specific attention. For example, many stroke patients face severe difficulties in communicating with health professionals. As a result, information provision and the involvement of the patient by health professionals is more poignantly brought into focus, involving (as it often must) persons other than the patient themselves i.e. family and/or carers. It follows then that the nature of the information that is provided involves greater

complexity (e.g. the modalities that are best suited to aphasic patients will differ greater from those that are not).

Additionally, as the condition involves different stages, the information and involvement of the patient shifts as they progress from hyper-acute [first 72 hours (DoH 2007)] to chronic phases of management (e.g. there are periods in the hyper-acute stages of a stroke when the patient will be incapacitated, making – for instance – the timing of information important too). This complexity is often lacking in more general studies of the PPR.

Stroke is the focus of much current research in the area of patient empowerment and involvement, as demonstrated by the importance placed on this precise issue in clinical guidance issued by NICE in 2012 (CG 138: this point is returned to in more detail in the literature review to follow) (NICE 2012). For these reasons, the PPR in stroke care is seen as an important, interesting and timely piece of research.

However, it is important to recognise that, by its very nature, findings from research into the PPR in stroke care will not be able to speak to the debates occurring in other conditions, nor the PPR more broadly. Whilst this is a concern, it is felt that the insight gained from the added complexity (in addition to the relevance of stroke to current policy debates) more than offsets any potential drawbacks in terms of the generalisability of findings. These matters will be expanded on in the thesis' final chapters, where the study's implications and limitations are considered in depth.

Despite extensive government policy promoting the empowerment of patients through improved information provision and policymakers encouraging greater patient involvement

in care choices, no clear strategy for implementation has emerged. This can only come from a deeper understanding of the processes of patient information and involvement, which in turn requires us to look at the factors driving these processes in the first instance.

Researchers have identified several factors that may influence information provision and involvement of patient by professionals; however, less is known about *how* these factors affect information provision and patient involvement. Additionally, few of these studies have been conducted in the specific context of stroke care. Therefore, whether these previously identified factors are applicable to stroke is unclear. An exploration of these uncertainties and opportunities forms the work's central research focus.

As we have already mentioned, the involvement of patients in care decisions has been linked to patient satisfaction. At the same time, stroke patients are dissatisfied with the information they are currently provided (Eames, Hoffmann et al. 2010). Therefore, finding a way to improve both patient information and patient involvement in stroke will lead to increased patient satisfaction. This will be the study's main practical contribution.

We also aim to confirm or refute factors already identified in the literature as having an influence on patient information provision and involvement in non-stroke settings, by suggesting factors that are specific to stroke care.² As patient information provision and participation are frequently influenced by the patient's health provider, we anticipate that our findings will have an impact on our understanding of the patient-provider relationship in stroke care too.

² For this reason, the literature review will also be looking at general (non-stroke) studies – a point made in further detail at the start of the review chapter.

The data for this study will be collected from 50 semi-structured interviews with stroke professionals, working across the acute stroke pathway³. Importantly, the research explores health professionals' views only. Patients and carers have not been included. This will be returned to in more detail in the *Research approach and methods* chapter and will also be discussed in the limitations section of the thesis.

However, prior to commencing the main fieldwork of speaking with health professionals, one patient representative was interviewed. The individual had been acting as a carer for her husband from the time he suffered a stroke until his passing. What she had to say provides further confirmation of the study's rationale, as the issues she raises are consistent with some of the problems already highlighted. An excerpt taken from that interview neatly summarises the difficulties stroke patients and their carers often encounter when they want improved information provision and greater involvement in care, a situation this study aims to improve:

I think in the original incident, it was okay, and I asked lots of questions, and some people responded less positively to questions, and my questioning was to do with wanting information, rather than making a judgement, on what had and hadn't been done. And some people did not like to be judged, I think, by someone they perceived to be ignorant of what they were trying to do, but I wasn't ignorant. I understood more or less everything there was to understand about [my husband's] individual case, although I wasn't a neurologist, for example. So, I think a willingness to...almost make the assumption that the person you're

³ The acute stroke pathway refers to the patient journey up to 6 months after a stroke, with the initial 72 hours being the "hyper-acute" stage. At the 6 month point, a reassessment normally takes place and it is the time when therapy is typically stopped. Rehabilitation and recovery may continue for many years after this point, but this is considered the chronic phase of the condition and will not be the focus of this study [Royal College of Physicians (2012). Care after stroke or transient ischaemic attack: information for patients and their carers]. The implications of this are discussed in the limitations section of the thesis. Furthermore, any reference to the study involving the "full" or "entire" stroke pathway should be interpreted as the full or entire acute stroke pathway only, i.e. excluding the chronic management stage of the disease, as defined here.

speaking to is of equal intelligence and will understand, because there must be the first time that they heard this, and they must have understood, so why wouldn't I? (Patient representative 1)

1.2 Thesis overview

Chapter One: Introduction

This chapter covers the work's motivation and states the research questions that it seeks to answer.

Chapter Two: Stroke study background

The study is placed in its proper context through background information relating to current and historical stroke care policy and practice.

Chapter Three: Literature review

The existing body of knowledge relevant to this study is looked at in detail in this chapter. The work's research questions emerge from areas that have yet to be fully explored by researchers in this area, with the aim of furthering our knowledge. The chapter is broadly divided into two parts; one for each of the two research questions.

Chapter Four: Research approach and methods

Here we outline the methodology and methods that were used to answer the research questions identified from the examination of the literature. A methodological discussion, largely around the work's epistemology and ontology, is also included. In this chapter we present the research design and provide details of how the research was actually carried out,

how data was generated and how it was analysed. The chapter concludes with a consideration of the methodological limitations.

Chapter Five: Findings and Analysis, Part One – Factors influencing patient information provision and involvement

The first of the two findings chapters describes the main findings pertaining to the first research question. Headings comprise core categories (CCs), sub-headings show second order themes and examples of major first order concepts are shown in schematic diagrams at the end of each section. Here, we take a closer look at each core category in turn, through the use of direct participant quotations. The inclusion of excerpts from transcripts enables us to understand better how the concepts and themes relating to each category were formed and helps to clarify links between data, researcher interpretation and conclusions. An analysis of the findings pertaining to RQ1 is also contained in this chapter. This includes a revisiting of the literature to place the data in their proper context.

As this is an exploratory and explanatory study, here we look to gain an understanding *how* the factors identified by the participants affect patient information provision and involvement in stroke, not just *what* those factors are. Both aspects (that is, ‘what’ and ‘how’) taken together, will form the answer to the first research question.

Chapter Six: Findings and Analysis, Part Two – Improvements in patient information provision and involvement

In this chapter we present the main findings relating to the second research question. Once again, the core categories are examined, having been generated in accordance with the techniques outlined in the methods chapter. Again, we take a detailed look at each category, as well as its associated themes and concepts, using supporting excerpts from the interview

data. An analysis of the findings relevant to RQ2 is also presented in this chapter, to include a revisiting of the literature. The answer to the second research question is also put forward here.

Chapter Seven: Discussion

In this chapter, a synthesis of the project's key findings and arguments is outlined. The theoretical, methodological and practical contributions that arise from the study's key data are also considered. As part of this, we reflect on the results' possible impact on the current literature and explore the potential implications for health service researchers and practitioners alike.

Chapter Eight: Conclusion

Finally, the limitations of the work are discussed, alongside the potential areas for future research.

Chapter Two – Stroke care and the patient-provider relationship: background

Stroke care and the patient-provider relationship: background

2. Introduction

In the first part of this chapter, essential background information relating to current and historical stroke care policy and practice will be outlined, in order to place the case study in its proper context. Following this, more details will be given about the background observational work that was carried out as part of the i-Health team, in preparation for the main fieldwork.

2.1 Study background: stroke care

As previously noted, stroke care is at the forefront of the healthcare agenda in many developed countries – thereby providing a topical and important research area. Whilst considerable challenges remain, some recent health service innovations have brought about considerable improvements in stroke care; some of these are discussed in more detail below.

2.1.1 Stroke types

Stroke can be categorized into two main types - with approximately 80 percent being ischaemic in origin and the remainder being haemorrhagic. The former is the result of an atherosclerotic cerebral vessel causing a reduction in the brain's blood perfusion (a similar mechanism of action results in heart attacks) whilst the latter is caused by a buildup of intracranial pressure resulting from a ruptured artery.

Within this framework exist various sub-types depending on the size and location of the brain area affected, with each producing its own unique set of symptoms. Typically however, a stroke will cause a unilateral loss of mobility in one or more limbs, unilateral visual

impairment and an inability to understand or formulate speech.

When these symptoms resolve completely within 24 hours, the patient is said to have suffered a TIA (transient ischaemic attack) - a separate, albeit related, syndrome. Thus, a stroke can be defined as a loss in brain function owing to disturbance in the brain's blood supply, which does not completely resolve within 24 hours. Advanced age, previous stroke or TIA, hypertension, hyperlipidaemia, diabetes and smoking are the major risk factors for stroke.

2.1.2 Stroke care service innovation – the historical context and current progress

Until recently, NHS stroke care services have been designed around the notion that the condition does not fall neatly into one branch of medicine. With no uniform care service in place, stroke patients would be treated by neurology, care of the elderly or general medicine teams. This has made coherent and consistent *information provision* to stroke patients difficult to achieve and has increased the cost of care without returning commensurate improvements in health outcomes. This arrangement also makes agreement on a new, uniform approach to stroke sufferers tough to accomplish. There has also historically been a lack of stroke specialist physicians as a result of the condition not being recognized as a separate branch of practice.

The Department of Health's 2005 publication *Reducing brain damage: faster access to better stroke care* concluded that stroke had suffered (until then) as a low priority within the NHS, since it was viewed as an inevitable risk of ageing and technological developments which could improve outcomes were not being widely implemented.

Stroke services have not been designed to operate with acute care at their core. This

organizational weakness became increasingly apparent with the establishment of thrombolytic therapy as an effective immediate-term treatment for many stroke sufferers. Historically, the UK fared badly in comparison to other economically developed countries (such as the USA and Australia) in terms of the percentage of all stroke patients who actually go on to receive thrombolysis.

Moreover, following a stroke, the average stay in a UK hospital for patient rehabilitation was about 27 days approximately a decade ago, whereas under Medicare in the USA rehabilitative stays averaged less than a week at that time.

Timely brain imaging was another area of hyperacute stroke care where the UK lagged behind – that despite much research showing the diagnostic and treatment cost-effectiveness of prompt scanning. In the past ten years, redesigning stroke services with an emphasis on acute processes has made innovative (and often time-sensitive) treatments easier to implement.

The organizational shortcomings described above were recognised in the National Audit Office's 2005 report into stroke services. The report's authors estimated that a service redesign addressing these deficiencies could potentially save £20 million per annum and would result in 550 fewer deaths and 1700 more patients making a complete recovery.

2.1.3 National stroke policy and practice

In response to the 2005 D.o.H. report mentioned earlier, a *National Stroke Strategy* was published (December 2007). The strategy document provided actions and progress measures

for achieving its vision over a ten-year period. Implementation of the strategy has been facilitated by strong leadership at the national level, backed up by several note-worthy examples of regional and local commitment to improving services. The ‘Accelerating Stroke Improvement’ programme was launched to expedite the Strategy’s implementation throughout 2010/11, for example.

2.1.4 National stroke guidelines

Within hospitals, acute care has been reorganised in order to deliver the key elements of care that are known to improve patient outcomes. Since 2006, there have been measurable improvements, including the adoption of new technologies.

At the time, NICE guidance recommended immediate specialist stroke unit admission to optimise outcomes. Soon after, the percentage of stroke units meeting key clinical requirements rose from 73 per cent in 2008 to 82 per cent a year later. The proportion of stroke patients who spent more than 90 per cent of their hospital stay on a stroke unit increased from 51 per cent in 2006 to 59 in 2008 – so there were significant improvements at that time. However, in 2008, only 17 per cent of stroke patients reached the stroke unit within four hours of their arrival at hospital (i.e. outside the therapeutic window for tPA therapy). In 2015, 56.8 percent of patients are directly admitted to a stroke unit within 4 hours of clock start, according to the Royal College of Physician’s (RCP) Sentinel Stroke National Audit Programme (SSNAP), which provides annual key indicator figures⁴.

⁴ Royal College of Physicians (2015). Sentinel Stroke National Audit Programme. Available from: <https://www.strokeaudit.org/results/Clinical-audit/National-Results.aspx> [Accessed 17th February 2016].

Brain imaging to diagnose stroke type is vital for stroke victims and the strategy recommended that access to scans and, where clinically appropriate, thrombolysis should be available 24 hours a day, seven days a week. Therefore, all hospitals provided access to scans by 2008, with 59% of applicable patients in England given a brain scan within 24 hours – an increase from 42 per cent in 2006. Weekend and evening access was still significantly more limited however. In 2006, fewer than 20 per cent of trusts offered access to thrombolysis for at least part of the week; 3 years later, two-thirds did so. Overall, the number of eligible stroke patients receiving thrombolysis more than doubled between 2008 and 2009. According to the Royal College of Physicians’ Sentinel Audit, 0.2% of all stroke patients received thrombolytic therapy in 2004 – this increased to 0.8% in 2008 and to 1.4% the following year (Guyler 2010). Between April 2014 and March 2015, the RCP’s latest SSNAP shows that 11.6 percent of all stroke patients (i.e. all stroke types) were given thrombolysis. Breaking this down further, we see that of those patients eligible for thrombolysis (in accordance with the RCP guideline minimum threshold) 74.3% were administered the therapy in 2013/14, increasing to 80.7% the following year (2014/15).

Improving stroke outcomes in a cost-effective way meant shortcomings in multidisciplinary rehabilitation had to be addressed. A decade ago, only 36% of stroke patients had an Early Supported Discharge Team (ESDT) of any kind available to them (Van Exel 2005). According to the 2015 SSNAP, the percentage of patients now treated by a stroke skilled ESDT is 28.2 (an increase from 24.7% in 2014).

Furthermore, the level of treatment of stroke risk factors as a means of primary prevention remained unchanged until around a decade ago. For instance, NICE guidelines at the time indicated that all stroke patients with concomitant Atrial Fibrillation (AF) should be

discharged with Warfarin – but as of 2008 only 24% of these patients received this treatment. This is in stark contrast to the percentage of applicable patients in atrial fibrillation on discharge who are now discharged on anticoagulants or with a plan to start anticoagulation. The figure for this metric stood at 92.9% for 2013/14 and 95.4% for 2014/15, according to this year's SSNAP.

Other general trends in the NHS which filtered through to stroke care included clinical guidelines recommending that healthcare professionals should involve patients in decisions about screening, treatment, and other interventions (Department of Health. The NHS Constitution for England, 2010).

For many years policy makers in the United Kingdom advocated a stronger role for patients (including stroke sufferers), for instance in the NHS constitution. Indeed, it became a central part of the health reforms at the time, with 'nothing about me without me' seen as a defining mantra (Department of Health. Equity and excellence: liberating the NHS 2010).

2.1.5 National public awareness campaign

There was an improvement in public and professional awareness of stroke symptoms, and the recognition that it represents a medical emergency, following the DoH's 'Stroke – Act F.A.S.T.' advertising campaign, started in February 2009. The campaign cost approximately £11.5 million and saw early improvements result. For instance, an Ambulance Trust audit soon after implementation showed that the number of calls categorised as being a suspected stroke from April to June 2009 increased by 54 per cent in comparison to the same period the previous year (Morse and Auditor General 2010). In addition to responding to more calls,

ambulance staff became better trained in stroke symptom recognition and, in some regions, started to travel further to deliver patients to specialist urgent hyper-acute stroke care.

2.1.6 Local stroke policy and practice

By the end of 2011, the Department of Health had invested an additional £105 million into implementing their stroke care strategy. Much of the money was allocated to strategic health authorities (SHAs) and through ring-fenced grants to local authorities. Beginning in 2008/09, the extra funding saw the establishment of 28 new stroke networks in England (these were intended to improve the coordination and provision of local care), along with massive acute care reorganization in the form of ‘stroke units’ at every hospital; this was carried out in line with NICE recommendations issued at the time. The DoH also allocated £30 million to local authorities to improve post-hospital support for stroke survivors.

In addition to reconfiguring stroke care within individual hospitals, the strategy required SHAs to consider how best to reorganize services to optimize specialist care access. While rural and urban locations needed different approaches, progress in reconfiguring services varied substantially across the country. The Greater London and Manchester areas established business cases that outlined the costs and benefits of reorganizing their services and have since been successful in implementing their plans. Some rural hospitals made use of new technologies, such as telemedicine (which enables doctors to make diagnoses and interpret scans whilst away from the hospital site) to overcome geographical constraints. The move towards remote care was largely evidence-based; for instance, a systematic review of the topic at the time found that telemedicine systems could be safe, feasible and acceptable in acute stroke management. The publication also asserted that telestroke could be associated

with an increased delivery of tPA (Johansson 2010).

Outside of the London and Manchester projects, another notable example of a regional-scale pilot scheme involved the NHS institute for innovation and improvement. This body oversaw the implementation of redesigned acute stroke pathways in 9 NHS Trusts. Known as the ‘rapid improvement programme’ and conducted over a 9 month period (between May 2007 and February 2008) – impressive results were achieved, including a reduction in average length of stay at 7 out of the 9 participating trusts (NHS Institute for Innovation and Improvement 2009). At the time, it was calculated that if the same level of performance were to be replicated across all 124 NHS hospitals in England treating acute stroke, £36.5 million pounds could be saved (NHS Institute for Innovation and Improvement 2009), highlighting the financial aspects of effective service redesign.

The national ‘F.A.S.T.’ campaign was also successfully adopted at a local-level. An early note-worthy example of translating national stroke awareness incentives into local campaigns was the BCCN’s (Black Country Cardiovascular Network) use of the ‘F.A.S.T.’ logo on local football team strips. Patient representatives from the group proposed and developed the scheme to donate football kits bearing the acronym in 2008 – 10 teams participated and the scheme continued into the 2010/11 season. Unfortunately, the scheme is no longer operating. However, as a result of its successful implementation at the time, local public awareness of stroke increased markedly. This increased awareness and knowledge amongst the public may have driven a heightened desire for future patients to be involved in decision making. Overall, the public has been provided with significant amounts of information on stroke. However, this has tended to be generic in nature, with information on more specific aspects of care often lacking (an issue that will be addressed in this study).

2.2 Study background: observational work

2.2.1 What is i-Health?

Before beginning the study's main fieldwork, a nine month period of observation of leading stroke professionals was carried out. During this time, weekly meetings were attended as part of Imperial College's i-Health team. The vision of the iHealth team was of an information-driven healthcare initiative which builds upon many years of research in medical ICT by Imperial's Health Informatics Department. Its aim was to develop and implement a new clinical information system (CIS). Pilot studies of an electronic version of the care pathway took place at several NHS hospitals, including Charing Cross from which the stroke pathway in Chapter 4 is taken.

2.2.2 How did the observational period inform the subsequent fieldwork and research?

This observational period was spent learning stroke professionals' main concerns and interests and proved vital to informing this study's overarching research questions and objectives. Indeed, the insights from this nine month background work led to the first interview with a stroke patient representative and carer. Some of her thoughts have been alluded to already. Additionally, as more knowledge was gathered from the time spent with the stroke professionals, it became apparent that the aims of this study should complement those of the iHealth team at the time.

The team comprised leading stroke care professionals with a keen sense of what was relevant to stroke care practice in the UK at the time, and also what may become so in the near future. Therefore, we were confident that the stroke care pathway and the information needs within it should be a major focus of this study. Indeed, as we shall see in the literature review chapter

to follow, the Department of Health continue to see this as a priority area that needs to be addressed. Moreover, the improved involvement of stroke patients throughout their journey along the care pathway also emerged as a key area for further research. Once again, this is in line with Department of Health recommendations. Indeed, despite Department of Health reports calling for greater patient involvement with care decisions, the flow of information within such pathways has not changed significantly from their original physician and management-centred paradigm. As a result, stroke patients have often not been fully enabled to gain the information they need for such empowerment to ultimately take place.

Moreover, few evaluations of the content and methods of information delivery to stroke patients have been conducted, despite widespread evidence of the need to improve information-giving to patients. As we shall see later, the nature of the condition itself (typically acute incapacitation followed by longer-term rehabilitation within social support networks) makes stroke care an important field for health services research.

2.3 Summary

In this chapter, the study background information has been described, with a particular focus on both local and national stroke policy and practices. Following this, we highlighted the preliminary observational work that was carried out as part of Imperial's i-Health team. The lessons learnt from this experience, and how these went on to inform the main body of the work, have also been considered. Finally, we have introduced the complex dynamic between patient-provider interactions, information and decision making. This will be explored in the context of the literature in the next chapter, which will describe more fully how the research questions emerged.

Chapter Three – Literature review

Literature review

3. Introduction

In this chapter, a review of the literature relevant to this study will be presented. This will broadly follow the two aspects we are most interested in; namely, patient information provision and patient involvement in care decisions. The importance of patient information provision and participation in relation to the patient-provider relationship will also be explored through an examination of existing studies on the topic. Accordingly, the literature we will examine academically falls into what can be broadly termed communication studies and more specifically, health communication. However, as noted in the thesis' introduction, a wide range of disciplines need to be applied to health services research, so other related schools of thought, perspectives and paradigms (such as psychology, sociology) will also have to be considered (Fulop 2001; Fulop, Allen et al. 2003); that is, the review and research sits within an interdisciplinary field (with a focus on health communication) and with implications for policy and practice. Based on the findings from this review, the study's research questions will be identified and the importance of answering these questions will be demonstrated.

3.1 Approach to the literature

Before proceeding with the review, the key terms which will be used within it will be defined. Wherever these appear, the definitions presented below should be taken as their meaning (unless explicitly stated otherwise):-

Patient information provision: also termed *patient education*, is the process by which health professionals impart information to patients and their caregivers with the intention of improving the outcome of patients and/or their caregivers (Smith, Forster et al. 2008). It is

also seen as synonymous with *knowledge translation* (Murtagh, Burges Watson et al. 2012). According to the NHS' Institute for innovation and improvement, "good" patient information is important, as it can "involve patients and carers in their treatment and condition." As will be shown later, there are many aspects of information provision, for example when it is delivered, by whom, how often and in what format. As a result, it follows that there are many different *types* of information and different *ways* in which information can be provided to patients. These issues will be explored fully, as confirmed by Appendix VI showing examples of some early stage questions, one of which specifically mentions *types of information*. However, patient information will not be formally categorised for analysis into the various possible sub-variants that might arise in a complex context such as stroke care; although this could form the basis of future work in the area. As we shall see later in the literature, researchers have proposed an "informatization" worldview (Mul 1999). Patients accessing their own information has been put forward as an extension of this theory (Nettleton 2004). However, in line with the use of patient involvement (see definition below), the emphasis here is on understanding the provision of information *by* the HP *to* the patient, rather than the patient (or carer) accessing information for themselves. Having said that, where "self-information provision" has implications for the PPR, it will also be considered in this research.

Patient involvement: the concept of involvement varies considerably and continues to evolve. In its narrowest sense, it can be seen as the degree to which a patient participates in treatment decision-making, with the focus on communication within consultations and/or the patient's use of information to consider the selection of one treatment option from a well-defined set (Entwistle and Watt 2006).

However, broader frameworks have also been proposed to reflect more of the complexity of the concept of involvement. These acknowledge that patients can be involved not only

because of what they say and do to influence a decision, but also by virtue of what they think and feel about their roles, efforts and contributions to decision-making and their relationships with their health providers (Entwistle and Watt 2006). As we are also interested in exploring the PPR in this study, this broader definition of patient involvement will inform the research here.

Patient participation, engagement and involvement are often used interchangeably within both in the academic literature and policy reports alike (Davis, Jacklin et al. 2007; Parsons, Winterbottom et al. 2010). A detailed qualitative study looking into the conceptual meaning of involvement enabled a taxonomy of patient-desired involvement to be derived and contrasted with professional-determined levels of involvement identified from the literature (Thompson 2007). In the work, participation was seen as being co-determined by patients and HPs and occurring only through the reciprocal relationships of dialogue and shared decision-making. It concludes that not all patients want to be involved and the extent to which involvement was desired depended on the contexts of type and seriousness of illness, various personal characteristics and patients' relationships with HPs (Thompson 2007). Thompson's study reinforces the complexities of the conceptual notion of involvement and is useful to convey the essence of what we are also trying to capture by the use of the term *patient involvement* in this research.

Patient involvement is also intimately connected to other concepts such as *self-management support*; the latter could in fact be seen as a form of patient involvement. Self-management support can be viewed in terms of its two main aspects. Firstly, as a portfolio of techniques and tools to help patients choose healthy behaviours; secondly, and more relevant to this study, as a fundamental transformation of the patient-provider relationship into a collaborative partnership (de Silva 2011). Indeed, this second component of self-management support is largely synonymous with the author's intended meaning of patient involvement in

this research and therefore highlights why exploring the concept may have important implications for the PPR in stroke care too.

Another related term is *patient empowerment*. Again, this is not a well-defined construct. There are many definitions, with most relating in some way to patients acting as self-determining agents with a degree of control over their own health and healthcare, rather than as passive recipients of healthcare (Lorig and Holman 2003; Aujoulat, Marcolongo et al. 2008). As a result of such definitions, patient empowerment is often used interchangeably with patient involvement, participation and engagement.

Most patient empowerment definitions focus on a patient's capacity to make decisions about their health (in terms of their behaviour) and to have, or take control of, aspects of their life that are related to their health. However, in the book *Empowerment Theory*, Marc Zimmerman argues that empowerment may be context and population specific and that a universal definition may not be possible (Zimmerman 2000).

As we shall see in due course, culture, age and socio-economic factors clearly influence empowerment and the extent to which different social groups can be, and/or wish to be, empowered will inevitably vary (McAllister, Dunn et al. 2012). Others have argued that empowerment can be considered to be either a process or an outcome. That is to say that patients can be empowered by their HPs through education, counselling, patient-centred care and use of community coaches and that patients can empower themselves through self-education, helped by the internet for instance, or by participating in patient organisations or community activism (Holmstrom and Roing 2010).

We aim to explore these issues of self-empowerment. However, since we are seeking to understand the involvement of patients *by HPs as a process*, these other self-empowerment ideas will not form the central focus. Notions of self-empowerment are not therefore what the

author intends to be understood by use of patient involvement in this study. Having said that, what a patient can do to empower themselves (alone or with a carer) may of course have interesting implications for the PPR in stroke and merits consideration in this research. Similarly, the ways in which patient information provision, patient involvement and the PPR, as theoretical and practical constructs, are linked together will be explored in more detail later in the thesis.

Having discussed what we mean by the key terms above, we can now move on to the review itself. This will be a narrative literature review and will include detailed scrutiny of several of the most closely related studies. Whilst this is a health service study into PPR in stroke care (and not a more general study of PPR with stroke as a case study) we will nevertheless consider the PPR and the factors affecting patient information provision and involvement in general terms, in order to distinguish what is known generally from what known about the PPR in stroke care specifically. This approach will ensure that research findings regarding the current debates occurring within stroke care will be informed by, and provided within, a useful and relevant contextual backdrop. It is also an acknowledgement that stroke care is not a system that operates in complete isolation, without requiring any attention to be paid to the other activities in the NHS.

To ensure that the review engages critically with the literature in a detailed and coherent manner, it was decided that studies of interest should be categorised according to various key attributes such as their main focus and their theoretical and methodological approaches. To begin the process, seminal studies on patient information, involvement and the PPR were sought. Once such literature was categorised as just described above, other papers and research of interest emerged – often from follow-up research and/or as a result of a snowballing effect. The resulting table has been placed in the appendix section. It shows some of the papers categorised according to main focus, methodological and/or theoretical

approaches and consideration for how these may fit into and be developed by the research here.⁵ Following this, a secondary table was populated according to the key themes which began to emerge from the literature search. A non-exhaustive consolidation of some of these themes can be seen in table labelled Appendix II. Many other themes, which are not shown in this table, are discussed later in the review.

The tables (Appendix I and II), together form a major element in the literature review process by facilitating the identification of knowledge gaps and areas where more work is still needed.⁶ For example, it helps to differentiate what is known generally in terms of information provision and involvement from what is known specifically in stroke care. It is a useful way to quickly establish whose perspective a study is from (i.e. were the research participants only patients, only HPs, or both) and, for instance, whether the work considers barriers (negative factor) *and* facilitators (positive factor) to information provision and patient involvement, or just one or the other. This may seem a semantic point, but the framing (positive versus negative, as above) may impact the way in which the research is conducted and therefore the findings too. All these issues are brought out neatly in the methodical process of table generation.

3.2 Health communication and the patient-provider relationship

Health communication relies on strong interpersonal communications in order to influence health decisions and behaviours. The most important of these relationships are the connection and interaction between an individual (that is, the patient) and their health care provider (e.g.,

⁵ The table shown in the appendix ("Appendix I") is not intended to be an exhaustive list of the papers considered as part of this review, rather to illustrate the process used whilst conducting the examination of the literature.

⁶ Ultimately, research questions were arrived at through more than just a simple "gap identification" process as we discuss towards the close of the chapter.

physician, therapist, social care worker) and an individual's social support system (family, friends, community).

There has been much work looking at this interaction within the discipline of health communication over the past fifty years or so. Here we will present an overview of the major contributions to the literature in this area and also elicit the key unanswered questions and areas worthy of further investigation, by evaluating the findings, theory and methods mobilised in others' research.

Whilst many different disciplines have sought to model and explain the patient provider relationship, from economics to informatics, it is the communication scientist's approach that will be focused upon here, as this fits in best with this study's methodological and theoretical aims. Although abstract and difficult to quantify phenomena, such as the relationship between a patient and a health provider, often lend themselves naturally to an interdisciplinary approach, it would be beyond the scope of a single project to examine each field, so here we will focus on what appears to be the most relevant discipline, namely health communication.

3.2.1 Sociology as the forerunner of health communication studies

Before health communication was formally established as an academic discipline in its own right, much of the theoretical work looking at the interaction between physicians and patients was carried out by sociologists. Therefore, we will present a brief overview here of the seminal sociological ideas for context and completeness only, rather than as the focus of our review.

Initially, the health providers featured in these sociological studies were more often than not medical doctors and the interaction in question was the doctor-patient relationship (DPR), as we can see in Figure 3.1 showing the current PPR model. Parsons was perhaps the first

sociologist to attempt to theorise the doctor patient relationship in 1952. His approach centred on the notion of norms, the view of illness as a deviation from a normative state, socialisation and the functional role performances of both doctors and patients (Parsons and Fox 1952). His role-based approach defined analysis of this relationship for several years, until it was superseded by the thinking of Szasz and Hollender – who sought to create a distinction in the doctor patient interaction based on whether the disease state being treated was acute or chronic (Szasz and Hollender 1956). They noted that doctors tended to be more assertive (and patients more passive) in acute settings and vice versa when treating chronic conditions.

Later commentators have chosen to focus on issues around paternalism versus personalisation (Siegler 1985) and modelling the relationship as either *paternalistic*, *informative*, *interpretive* or *deliberative* (Emanuel 1992). The precise meaning of these terms is shown in the table which follows:

Table 3.1: Emanuel’s four models of the doctor patient relationship (Emanuel 1992)

<i>Paternalistic</i>	Doctor makes decisions for the patient’s benefit, independent of the patient’s values or desires
<i>Informative</i>	Doctor provides information, patient applies values and decides.
<i>Interpretive</i>	Patient is uncertain about values, Doctor (as counsellor) assists the patient
<i>Deliberative</i>	Patient is open to development, Doctor teaches desirable values

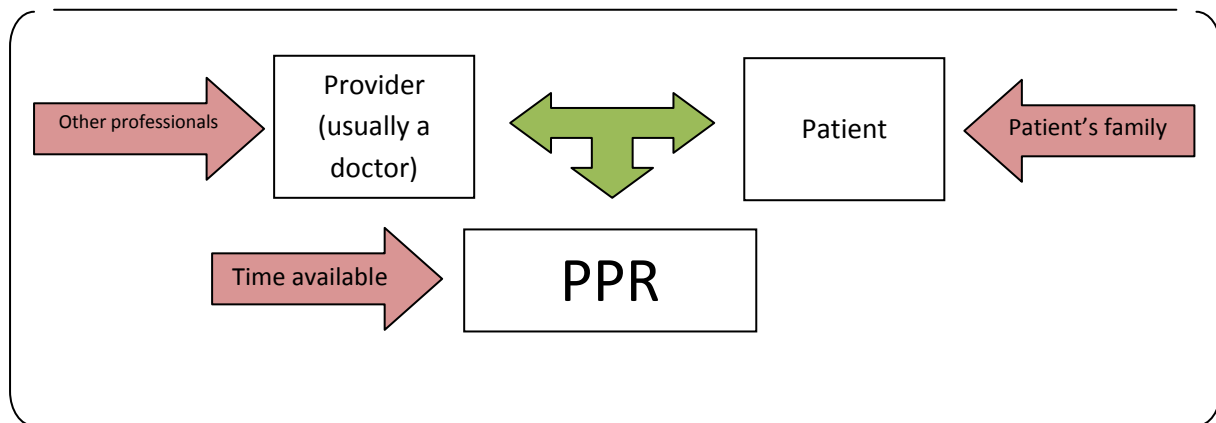
Qualitative researchers have sought to deepen our understanding of medical decision making through theory development and more abstract reasoning. Perhaps the most famous instance of this is the seminal work of Canadian sociologists Cathy Charles and Amiram Gafni (Charles, Gafni et al. 1997; Charles 1999; Montori, Gafni et al. 2006). Whilst the majority of clinical decisions involve doctors and patients (hence the focus on the doctor patient relationship above), Charles and Gafni recognise that other health professionals, and indeed the friends and family of the patient, are frequently also active participants in decision making (Charles, Gafni et al. 1997).

Indeed, themes more commonly associated with studies on the DPR, such as power, the social and cultural context and interpersonal competence, have been identified as important in the sociological literature focusing specifically on nurse–patient interactions (Shattell 2004). Other researchers have noted an increasing trend towards viewing the relationship as a *partnership* between provider and patient (Charles 1999), in which shared-decisions are more frequently made (Gabe, Olumide et al. 2004). As this study draws on the expertise of a variety of stroke professionals, we will be aiming to contribute to the health communication literature on the PPR, not just the DPR. The importance of patient information provision and participation to this interaction will be explored in greater detail in the section below.

Before that however, Figure 3.1 below illustrates how the PPR has historically been modelled by sociologists. As we have already mentioned, the earliest sociological theories in this area are based on the simplest possible model alone; that is, one that only includes a doctor and a patient. Since then, there has been considerable movement away from developing theory based on the simplest possible version of the interaction, to include the role of non-physician professionals and the patient’s family for instance (Charles, Gafni et al. 1997). However, the precise implications of this (and other extensions to the model, such as the impact of the

internet and other digital era technology on the PPR) have not been studied before in the specific case of stroke care (as we shall discover in the course of this review). This, therefore, is a key gap that we aim to address with this research.

Figure 3.1 An historical, sociological model of the PPR



An example of one of the simplest models of the patient-provider relationship. As this is a basic, historical model the inward pointing arrows (red) are showing only a few of the various external factors that are now known to impact the interaction. The other factors not shown here will be explored in greater detail in the remainder of the review, with particular attention given to differentiating between those external factors which have been demonstrated with respect to the PPR in general and those which are related to the stroke PPR in particular. The outward pointing arrows (green) join together the core elements of the model; that is, the provider(s) and the patient.

3.3 The importance of patient information to the patient-provider relationship

Despite the emphasis placed on information giving by political, professional and ethics bodies, it would appear that this is an area with which patients remain dissatisfied (Fowler 2011). Indeed, patient information for UK stroke sufferers still appears to be inadequate (Forster, Brown et al. 2012) despite attempts to improve this through calls for further research to evaluate the most acceptable and effective ways of providing information from over a decade ago (Rodgers 2001).

Indeed, a lack of information, explanation and support is a great cause of anxiety and stress in patients. Furthermore, it seems that professionals who cannot provide their patients with consistent information cannot expect those patients to be compliant or cope with their diagnosis. It is therefore essential that health professionals initially assess patients' needs and then provide appropriate information. Indeed, it is only by recognizing that the present system of information giving is unsatisfactory that health professionals can continue to improve standards of care.

The priority information needs of patients, as we shall see in the health communication literature to follow, appear to be for details about the available treatment regimes, the side-effects of treatment, the severity of their condition, the prognosis and ultimately how they can care for themselves and return to a normal lifestyle.

3.4 The importance of patient information provision and involvement to stroke care

3.4.1 Key studies relating to stroke patient information provision

In general, adequate information provision is important to patients to help reduce uncertainty, alleviate concern and maintain hope (Waitzkin 1985; Smith, Dow et al. 2010). In fact, it can help reduce an imbalance of power in a medical consultation, giving a patient the opportunity to make choices about their treatment and participate as information-givers and not merely passive recipients of 'medical facts' (Frederikson 1995; Elwyn 2000).

The provision of detailed information to patients and their carers specifically following a stroke has been identified as having a number of benefits, as outlined in *Effective patient education: a guide to increased adherence* (Falvo 2010). In her book, Falvo shows that information reduces levels of anxiety, improves outcome through greater adherence to treatment and rehabilitation programmes, improves levels of self-care, contributes to stroke

patients' sense of control, results in greater patient satisfaction and improves relationships between health professionals, patients and their supporters (Falvo 2010).

Indeed, the provision of information about treatment and progress has long been recognized as a means of developing enhanced coping skills in patients. This was emphasized by Wilson-Barnett and Fordham who identified that it is patients' own views and understanding of their illness that ultimately influences their adjustment and eventual outcome (Wilson-Barnett and Fordham 1982).

According to their joint analytical article arising from discussions about the development of a web-based patient decision support in the NHS, the provision of information has been found to play a significant role in patients' recovery process (Elwyn, Laitner et al. 2010). Patients receiving information prior to diagnostic tests and surgical procedures have been found to experience less pain and fewer side-effects, to suffer fewer postoperative complications and to have a faster recovery than those not receiving such information, according to an intervention study assessing pain in two groups of patients after total knee arthroplasty (Sjling, Nordahl et al. 2003). It is difficult to say whether these findings would apply in the case of stroke as interventions (such as thrombolysis) are time-critical and the patient context is very different from an elective, orthopaedic procedure. Through the use of qualitative interviews, a clearer understanding of this may be gained.

In a study involving 75 stroke survivors and 75 healthy, age-matched control subjects, the vast majority of patients (93%) were shown to want precise and high quality information on the risks and benefits of thrombolysis and 91% prefer to be actively involved in the decision-making process (Slot 2009). The researchers used the standard gamble (SG) method to elicit utility values for various stroke outcomes. In the SG technique, respondents are asked to

choose between remaining in a state of ill health for a period of time, or choosing a medical intervention (in this case, thrombolytic therapy) which has a chance of either restoring them to perfect health, or killing them. Patients' preferences for: (1) thrombolytic treatment; (2) the format of information on effects of treatment; and (3) involvement in the decision-making process were also assessed.

They found that preferences for thrombolytic treatment generally increase with increasing stroke severity, but individual factors or *patient characteristics*, such as previous stroke, advanced age, and living conditions can influence the patient's decision and the communication style they wanted with their provider. However, overall, most patients wanted precise information on the treatment's risks and benefits, and preferred to be actively involved in the decision-making process or shared patient-doctor decision making. Whilst the study presents some interesting conclusions, teasing out further patient characteristics which may affect the processes of information giving and patient-provider interactions would have been welcome. This is an area worthy of further theoretical exploration, therefore.

In their review of education and information provision following stroke, Rodgers et al shows that stroke patients are frequently dissatisfied with the quality and quantity of information provided by health professionals (Rodgers 2001). They conclude that there are considerable gaps in current knowledge about the most effective and acceptable ways of providing stroke patients and carers with the information that they require.

They also found that professionals and patients differ in their perceptions of what constitutes relevant information. More recent studies have focused on stroke patients' and carers' perceptions of their information needs and the barriers to obtaining the desired information

(Eames, Hoffmann et al. 2010). Identifying patients' and carers' perceptions of their information needs has been viewed as important in empowering patients to participate in making informed decisions regarding treatment options, in making good use of nurses' time and in increasing patient satisfaction.

The Australian study used semi-structured qualitative interviews with patients and carers to ascertain their perspectives prior to and 3 months following discharge from an acute stroke unit. The first stage of interviewing comprised 34 stroke patients and 18 carers; 3 months later, 27 patients and 16 carers were interviewed for a second time. The data was then transcribed and the content analysed. One of the study's key strengths is its longitudinal approach, which we will not be aiming to replicate here due to difficulties in securing access to busy health professionals for second interviews.

However, we will be able to build on the work by Eames et al by considering the patient information needs and the barriers to this from the health professional's point of view. Interestingly, this is noted as a limitation in the Eames paper and, along with looking at facilitators to patient information, is suggested as an area for future research. As we will also be using qualitative content analysis of transcribed interviews, the two studies should complement one another neatly.

Their analysis of the data revealed three broad categories of barriers to accessing information, each with numerous subcategories. The three categories were as follows: (1) limited availability and suitability of information, (2) the hospital environment, and (3) patient and carer factors. The subcategories of category 1 included (a) didn't know where to go, (b) you don't get much, and (c) information not presented in the "right way." For category 2, the sub-themes were identified as (a) continuity of care and communication and (b) no one has time/limited access to resources. Finally, category 3 was broken down into (a) a lack of time, (b)

not asking for information, (c) health “getting in the way,” and (d) poor recall as barriers to accessing and utilising information (Eames, Hoffmann et al. 2010).

It will be interesting to see how the findings from the study here, which will be derived from the views of HPs, compare and contrast with the broad themes in the Eames et al work described above, which only considers the perceptions of stroke patients and carers.

3.4.2 Key studies relating to stroke patient involvement with care

In terms of stroke patient involvement and empowerment, two key works have been identified. We will look at each of these in turn to both highlight the importance of the research domain and propose possible areas where our knowledge may be enhanced through this work.

The first is a discussion paper which considers patient involvement and empowerment at various stages of rehabilitation after stroke (Jones, Mandy et al. 2000). The researchers also looked at the relationship between patients and their physiotherapists throughout the process, which they describe as often being “close”, perhaps owing to the severity of some of the problems and the considerable length of time which may be needed for rehabilitation. They question whether the notion of patient involvement, through negotiation around “goal setting” in particular, is any more than “lip-service” and suggest that active shared-decision making (SDM) is not an automatic process or one which necessarily always occurs naturally. Amongst the barriers they mention with regards to further or genuine involvement by patients is the hospital setting itself. They see this environment as a potential obstacle, in their view, patients are “likely to have limited opportunities for control” and are thus made to feel “powerless”. Their solution to this would be to make “events seem more controllable whenever possible”. This leans on Langer’s earlier work, which suggests that an illusion of control may be beneficial to patients in such circumstances (Langer 1975).

The paper also puts forward the idea that some processes used as part of the therapy for achieving patient independence could actually themselves negate this aim and could be seen as barriers to empowerment. The example of walking is given, where often the physiotherapist will largely decide when the patient is allowed to join in and how, thereby possibly undermining the patient's belief in their own ability to move independently outside of therapy time.

The researchers here build on the ideas of Baskett and others, who showed that home-based programmes for stroke are at least as effective as hospital-based rehabilitation regimens (Baskett, Broad et al. 1999), by highlighting the benefits of framing the concept of rehabilitation in terms with which patients are more familiar, find less confusing and therefore are more likely to actively engage with. According to the paper, providing everyday tasks with individual meaning for patients can be a way to enhance motivation for involvement and self-practice and a lack of such tasks should be viewed as an obstacle to rehabilitation involvement.

Whilst the discussion highlights several important factors that may affect stroke patient involvement with treatment decisions and activities, and also considers the impact of these on the PPR, the researchers limit their contribution to the context of physiotherapists and rehabilitation patients only. Therefore, it will be useful to discover if the points and questions they raise are applicable and/or can be built on in this study which involves a range of HPs and their views on pre-rehabilitation decisions too. Of particular interest and worthy of a more detailed exploration is the idea they propose of the health setting/system itself acting as an obstacle to patient involvement. It will also be useful to consider *how* the hospital setting acts to influence patient involvement (and perhaps patient information also, which was not

dealt with in their paper) in more detail and in stroke care generally (i.e. outside of the rather narrow context they considered).

The second key study in terms of stroke patient involvement is that by Koh and colleagues, which looks at the factors influencing post-stroke rehabilitation participation after discharge from hospital in Singapore (Koh, Barr et al. 2014). As with the discussion paper by Jones et al, this study also considers patient empowerment after stroke. However, unlike the paper by Jones, Koh looks at the specific context of rehabilitation which occurs after discharge from hospital only. As with the research here, Koh chooses to conduct individual semi-structured telephone interviews with a purposive sampling of participants and then to analyse the data using a similar inductive, thematic approach (Braun and Clarke 2006) to the one we will describe in the methodology chapter. The Singaporean study recruited stroke patients for these interviews – a task made more practicable by virtue of their narrower research focus. That is, Koh et al did not look at patient involvement from admission through to discharge, as we will be doing. Another danger in drawing any direct comparisons is obviously that our study will be in the UK's NHS, not Singapore. Despite these important differences, however, the Koh paper has a number of findings that merit attention.

The chief contribution of their research is the five factors they propose as obstacles to post-discharge patient involvement in rehabilitation:

1. The means to access rehabilitative services
2. Lapse in discharge coordination
3. Family members' views and actions
4. Discrepancies in expectation
5. The perception that rehabilitation is simple

The researchers note that the obstacles to participation are “largely extrinsic factors” stemming from “gaps in the stroke care continuum”, such as a lapse in discharge coordination (Koh, Barr et al. 2014). In order to see improvements in patient involvement within stroke care, they emphasise the need to empower carers of stroke survivors, to review current goal-setting processes for rehabilitation and to establish a common understanding of rehabilitation practice between patients, their carers and the clinicians. The extent to which their findings apply in the NHS in a study that also considers pre-discharge stroke care, with views drawn from HPs (including non-clinicians) and not patients, will be discussed in later chapters.

Other major findings from their work includes participants indicating a need for timely and appropriate information, delivered according to their individualised needs. This once again confirms the importance of information provision to patient involvement, and vice versa – as well as the need to further our understanding of how best to deliver information to patients. The researchers suggest that clinicians, and other HPs, need to be more aware of their role in providing well-coordinated information about therapy to patients. This touches on aspects of the PPR, with which this study is concerned. However, since this is the view of patients only, it seems logical that we could potentially learn more by studying information provision from the HP’s perspective also, as we propose to do here.

Additionally, the Singaporean paper highlights the need to make treatment goals more patient-centred, which again engages with theories of the PPR and SDM in particular. Koh’s results also suggested that patients and their carers may be inadequately informed of the necessary follow-up in terms of the processes surrounding the transition between various rehabilitative services. Whether disjointed care and services has a similar effect on information provision in the NHS, from the perspective of HPs, will therefore need to be investigated in this work.

Finally, the role of carers is further brought to the fore by the study's suggestion that there must be greater involvement of carers in discharge planning to minimise patient dissatisfaction with care arrangement and information delivery. In short, the study brings to attention the highly relevant and interconnected nature of the research domain and provides ample scope for this work here to build on, chiefly by offering additional perspectives and contexts for the testing of their findings.

3.4.3 Key studies relating to both stroke patient information provision and involvement

Another key paper to emerge from the review tackles both patient involvement and information provision in stroke and seeks to understand the challenges to “knowledge translation” (here taken to be synonymous with information provision) and decision making, specifically during thrombolytic treatment in the hyper-acute phase of care (Murtagh, Burges Watson et al. 2012). The data were gathered using semi-structured, in-person interviews (lasting between 20 minutes to an hour) with HPs, patients⁷ and families. Whilst the interview duration is the same as what we are aiming to replicate here, we will be conducting telephone interviews with HPs only. For a fuller discussion of the rationale and limitations of this approach, see the Methods chapter which follows. This difference in approach also has implications when comparisons between findings are made, as we shall refer to later. However, like this research, the sample was selected purposively, i.e. to include those with relevant expertise or experience and data were collected until thematic/theoretical saturation, i.e. the point at which no new themes or ideas are emerging.

The main factors identified in their study as affecting patient involvement and information provision during thrombolysis are the following:

⁷In order to recruit sufficient numbers of patients, their study looking at thrombolysis had to include patients irrespective of whether the treatment was given and the patients came from three different stroke units in the north east of England. The interviews therefore had to be conducted by three research associates.

1. A lack of time for reflection in a severely time-limited setting
2. Patient and family capacity is blunted by the effects and shock of stroke
3. The situation produces reliance on the expertise of clinicians

In other words, they found that the emergency setting and the symptomatic effects of hyper-acute stroke shaped the form, content and manner of information provision, which then impacts patient involvement with decision making. Once again, their work highlights the inter-related nature of patient information and patient involvement in care decisions.

The researchers suggest four possible solutions to these problems:

1. Face to face communication
2. Shaping decisions with patients: understood as an expression of confidence by HPs that helped alleviate anxiety and offered hope and reassurance to patients and their families experiencing the shock of the stroke event. Neutral presentations of information and treatment options promoted uncertainty and contributed to anxiety. These findings are interesting theoretically as they have implications for the PPR and challenge the normative view that patients necessarily always want information delivered in a way that supports their own ability to make treatment decisions.
3. Incremental provision of information: “drip feeding” information creates moments for reflection
4. Communication tailored to the individual patient and family: this allows HPs to account for social and emotional contexts.

Whilst the factors and potential ways of improving information provision and involvement are certainly useful and relevant, their proposed set of problems and solutions may not hold true in rehabilitative and discharge settings and contexts (a limitation acknowledged by the researchers themselves and put forward as a way of building on their work). Therefore, to

better inform the strategies proposed and so that broader conclusions can be reached, their ideas will need to be tested more widely, i.e. outside the specific setting of emergency stroke care.

In the case of stroke, patients and their families have been found to have information needs at various stages after the stroke that are not adequately met by health professionals (Hafsteinsdttir, Vergunst et al. 2011). Studies in both the USA and Britain have found that relatives of patients perceive their needs for information about recovery and caring for their family member after hospital discharge are poorly met by nurses (Pringle 2008). In addition, a lack of information about the services available in the community, entitlements to benefits and who to go to for help, advice and information were identified as problem areas (Pringle 2008).

There are a number of possible factors negatively affecting information provision for stroke patients and their carers. These factors may act as partial explanations for people's dissatisfaction with the information that they receive from health professionals following a stroke. Health professionals may not provide information at all or not provide it well because they feel they lack the time (Roter 2006). Others challenge time as a viable excuse, emphasizing that it is quality of information giving that is important and not quantity (Schoen, Osborn et al. 2007). Similarly, health professionals may also lack the skills necessary to give appropriate and clear information by providing information at the wrong time, by using language that is not understood by patients and by not picking up on patient cues that information has not been understood or that more detailed information is desired (Shaw 2009).

A further explanation may be that information is not provided by health professionals on particular topics because they do not have the knowledge to provide the information required.

This may be a particular difficulty when psychological factors complicate physical illness. Indeed, the psychological aspects of stroke are shown to be important, not only for information provision but also for a patient's ability to be involved in care decisions, by a number of studies in the literature (Nelson, Cicchetti et al. 1994; Hilari, Northcott et al. 2010). However, there is also some evidence that health professionals avoid giving detailed and realistic explanations about recovery partly because they find giving bad news uncomfortable and partly because they fear it would demotivate stroke patients from participating in their own care, particularly in rehabilitation programmes (Ptacek 2009).

Despite the emphasis on communication skills and information giving, many stroke patients remain dissatisfied with the level of information they receive (Asplund 2009). Possible reasons for deficits in information giving have been proposed by various researchers. Another important reason for patients reporting poor information giving from staff is that the staff assume that they know what patients' information needs are (Schoen, Osborn et al. 2007). There is some suggestion that this form of professional complacency may also act as a factor affecting patient participation, as professionals think they are involving patients when in reality they are not, a point we will return to later.

Dissatisfaction with the amount of information provision by health professionals may also reflect patients' and carers' inability or unwillingness to take in or to accept the information being provided. Disappointment with information provision identified some time after the initial stroke may also be a reflection of the mismatch between the information patients and carers perceived they were given about recovery and the reality of their disability.

Other studies have shown that patients and carers are selective in their needs for information provided by HPs and only absorb information that they deem relevant (van Veenendaal, Grinspun et al. 1996; Wachters-Kaufmann, Schuling et al. 2005).

The van Veenendaal et al paper identified the informational needs of stroke survivors and their family members, as perceived by themselves and by health professionals. Whilst we will only be securing the views of HPs, it is nonetheless interesting to note their chief findings. Namely, the family members of stroke survivors who suffered more than one stroke seem to have received more information and to desire less. Secondly, both highly educated stroke survivors and family members were found to have received less information and to have desired more information than lower educated respondents. This once again highlights that patient and carer social characteristics (e.g. educational attainment) can have a bearing on information provision. It will be interesting to explore this from the perspective of the HPs also.

The source of information, and the desired source for future information were also explored in the Dutch study. Green's Precede-Proceed model was used as their theoretical framework (Green 1974). A fundamental assumption of this model is the active participation of its intended audience – i.e. the participants will take an active part in defining their own problems, establishing their goals, and developing their solutions. In this framework, health behaviour is seen as being influenced by both individual (PRECEDE) and environmental (PROCEED) factors, and therefore has two distinct parts. This approach has certainly proved useful as a multi-dimensional, participatory model for public health interventions, particularly those engaging in some form of cost-benefit analysis. However, since we are not conducting that type of analysis here and since stroke patients are not directly a part of the research in this instance, we will not be adopting the same theoretical model (for details of the theoretical framework we will be using, see the methodology chapter which follows).

3.5 Factors that influence information provision and involvement of patients by health professionals

Despite information provision after stroke improving patient and carer knowledge, reducing patient depression, and increasing patient satisfaction, patients and carers frequently report their dissatisfaction with the information they have been provided. Therefore, given the importance of education in post-stroke care, the identification of possible barriers to information provision is crucial for addressing these issues.

Some of the challenges already identified in the health communication literature surrounding the provision of information to this population includes factors such as individuals being overwhelmed or having poor recall, not knowing what to ask having difficulties understanding medical jargon, receiving conflicting information and feeling that they have to be demanding to get information.

As we shall see, the literature suggests that other factors to consider include the impact of a patient's cognitive impairment, passive or uncommunicative patients, busy and/or insufficient numbers of health professionals, providers having a poorly structured approach to information provision, and lack of clarity about which professional is providing the required information.

Overall, some stroke patient-related and stroke HP-related factors have already been identified as affecting the provision of information in stroke care, but this area has not been explored in sufficient detail (particularly from the health professional's perspective).

Interestingly, similar factors have been identified in other clinical areas. This has implications for the generalisability of this study's findings, as we will expand upon in later chapters.

For example, Coulter and colleagues carried out patient focus groups covering a range of health conditions (Coulter, Entwistle et al. 1998). They categorised patient-perceived reasons for inadequate information provision as being:

- (i) system problems (e.g., doctors being too busy and therefore not having the time to explain things),
- (ii) attitude problems (e.g., HPs assuming patients do not want or cannot cope with information and not taking patients' problems seriously enough),
- (iii) knowledge problems (e.g., doctors not being aware of all the treatment options available).

A qualitative study looking at rehabilitation by Magasi and colleagues, found that low health literacy limited rehabilitation patients' ability to obtain, understand and use health information to make health decisions (Magasi, Durkin et al. 2009). The study demonstrates one way in which information provision may relate to patient involvement and affect decision making within rehabilitation settings. Whilst this is an interesting finding, the paper does not focus exclusively on stroke care, so it will be interesting to see the extent to which similar conclusions can be drawn from this stroke study. We shall now consider each factor that has emerged from the literature search in turn.

3.5.1 Government policy (as a factor affecting patient information provision)

There is a growing awareness of the importance of patient information. The heightened interest in this topic may be the result of several factors. Firstly, there has historically been a strong political influence. The UK government, in recognizing the importance of information, listed information giving among their proposed reforms for the NHS in 1989. They stated that hospitals should offer patients;

‘Clear and sensitive explanations of what is happening, on practical matters such as where to go and who to see, and on clinical matters, such as the nature of an illness and its proposed treatment’ (DoH 1989) [paragraph 1.13].

These proposals were strengthened again by the Patient’s Charter (DoH 1991), which encouraged patients to become more involved in their own care and treatment. This promotion of patient participation, a topic returned to in a later section, ultimately requires health professionals to provide patients with appropriate information.

Unfortunately, the Audit Commission (Audit 1993) showed that, despite the government recommendations, patients were still reporting numerous problems with the information they received from health professionals. These included poor delivery of information in relation to timing and quality, inconsistent or even contradictory information, and a general lack of information.

The NHS once again stressed the importance of information giving, by including it as a medium term priority in their plans for 1998–99:

Health authorities and service providers should ensure that good quality information is available to patients to look after themselves better, know when and how to seek help, so that they can play an active role in decisions about their own care (NHS Executive, 1997; Objective D3, p. 13).

To support this recommendation and to link the agendas on patient partnership and evidence-based health care, the NHS Executive funded a Centre for Health Information Quality (Shepperd 1999). This centre aims to provide practical advice as outlined below:

- for those developing patient information materials
- to raise awareness of good practice in the development of patient information

- to promote the use of existing tools and guidelines which can be usefully applied to ensure the development of high quality evidence-based patient information
- to co-ordinate education and training events for those involved in developing patient information.

This initiative emphasizes the commitment and priority that the Government places on patient information. These government interventions are connected to the growth of consumerism in healthcare, whereby patients are now seen as consumers with rights to information and active participation in their own care. However, as Cortis and Lacey (1996) suggest, for consumerism to be effective it must be a two-way process: the service must give patients what they want and it must listen and respond to their needs (Cortis 1996).

3.5.2 Government policy (as a factor affecting patient involvement)

In 2012, NICE produced clinical guidance (CG 138) for improving the involvement of adult patients in their health care. It states:

Many patients wish to be active participants in their own healthcare, and to be involved in creating and managing their health strategy and use of services. Self-care and self-management are particularly important for people with long-term conditions.

(National Institute for Health and Clinical Excellence. Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. CG 138.

2012. www.nice.org.uk/cg138) (NICE 2012).

It is interesting to note that long-term conditions, of which stroke is one, are particularly singled out for attention. Their guidance goes on to outline the four key areas for improvement, which they feel will enable patients to participate better in their care: communication, information, shared decision making (SDM) and education programmes.

- (i) Communication: various aspects of communication are touched on, ranging from non-verbal cues such as the provider physically positioning themselves at the same level as the patient through to the avoidance of jargon.
- (ii) Information: this should be consistent and tailored to the individual patient and their circumstances, with different modes of information delivery being used (e.g. oral, written). Information should not be limited to medical matters, for instance expected waiting times should also be made clear.
- (iii) Shared decision making: when discussing decisions with patients, the provider must allow patients to express their personal needs and preferences. Additional time should be set aside to answer any questions the patient may have and check their understanding of the options available to them and the risks of each of these options.

Education programmes: these should be evidence-based, with specific learning objectives, and meet the needs of individual patients, whilst also promoting their ability to manage their own health care as appropriate. Similarly, patient groups such as *self management UK*, have been advocating the NHS' Expert Patients Programme (EPP) since its inception in 2002. The EPP aims to help people manage their long-term condition and its treatment in partnership with healthcare professionals, communicating effectively with providers and sharing responsibility for treatment (Kennedy, Rogers et al. 2005). Additionally,

information provision to people with stroke was highlighted as a “marker of quality stroke service” in the 2007 Department of Health’s UK stroke strategy (DoH 2007).

Furthermore, policymakers have been keen to place the patient at the centre of healthcare through the promotion of ideas such as ‘No decision about me, without me’ (DoH 2010). At the heart of this government report is what can loosely be termed shared decision making. SDM constitutes one form of clinical decision making within individual patient provider interactions. According to the literature in this area, other patient involvement and decision models include *professional choice*, *professional as agent* and *consumer choice* (Szasz and Hollender 1956; Veatch 1972; Quill 1983; Emanuel 1992; Deber 1994; Charles 1999). The various models of clinical decision making have been illustrated in the table below:

Table 3.2: Models of clinical decision making

<i>Professional choice</i>	<i>Professional as agent</i>	<i>Shared Decision Making</i>	<i>Consumer Choice</i>
Provider decides, patient consents	Provider elicits patient’s views, then makes decision	Information shared, joint decision	Provider informs, patient makes decision

Source: (Coulter, Entwistle et al. 1998)

There is considerable overlap between the clinical decision making models above and the four models of the DPR presented earlier. This commonality stems from the characterisation of the relationship in terms of decision making and identifying the decision maker in any given patient provider interaction. In this study, we are not interested in identifying the model of decision making that ultimately occurs, so much as the factors that

influence the kind of model that is followed and ideas for how the level of patient involvement can be increased.

Patient and public involvement (PPI) is central to the British government's modernisation of the National Health Service. It is argued that a patient-centred service, in which patients have a right to information to enable them to make choices about their care, is necessary to improve health outcomes, provide a better experience of care for patients and reconnect the health service with the communities it serves (Epstein 2010).

On an individual level, there are opportunities for involving patients with their own care within more effective patient-provider interactions. To achieve this, professionals should create collaborative partnerships with patients (and their families) in these interactions whereby decisions are made in light of the best available evidence and the patients' own values, goals and capabilities (Stewart 2000). Unfortunately, this ideal is seldom achieved in practice. However, by developing a deeper understanding of the factors influencing patient involvement as we aim to in this study, we will be better equipped to improve this situation in the future.

3.5.3 Social structures (as a factor affecting both patient information provision and involvement)

Another influencing factor on information giving and patient involvement has been the move from physician-led paternalism to the promotion of patient autonomy. Until the late 1960s, and even into the 1970s, it was deemed perfectly acceptable for the doctor to decide what information patients required and what should be withheld, '*for the patients' own good*'. With the promotion of patient autonomy, there developed the recognition that patients had the right to be told the truth about their condition. Indeed, treatment for many conditions (most notably, cancer) is now viewed as a partnership between professional and patient. Moreover,

in recent years, there have been numerous studies demonstrating that the majority of patients want all the information relating to their condition, both good and bad (Griffiths and Leek 1995). Nevertheless Grahn suggests that healthcare workers may still be unconsciously acting paternalistically, by filtering information to patients in a way that they consider to be appropriate (Grahn 1996).

Communicating information to patients has practical, relational and ethical goals. Informed patients are more likely to participate actively in their care, make wiser decisions, come to a common understanding with their physicians, and adhere more fully to treatment. Communicating evidence can transform a physician-dominated relationship into one that is relationship-centered (McWhinney 1993). Patients have a right to understand their illness, prognosis, and treatment options, regardless of whether they choose to participate in decisions (Sullivan 2003).

In other studies, the inter-relatedness of stroke patient involvement and information delivery have been emphasised. Smith et al undertook a systematic review of information provision for patients and their carers after stroke (Smith, Forster et al. 2008). They included non-confounded randomised trials where an information intervention was compared with standard care or where information and another therapy was compared with the other therapy alone. The reviewed studies had patients with a clinical diagnosis of stroke or TIA and their identified caregivers or both as the participants. Their meta-analysis of 17 completed trials looked at information provided with the intention of improving the outcome of patients or their caregivers or both. They excluded trials in which information giving was only one component of a more complex rehabilitation intervention.⁸ One of

⁸ In this research, whilst we look at modes of information delivery (e.g. AV, social media, written, verbal etc.) we have not formally categorised information by “type” as information is only one component (albeit a vitally important one and the focus of much of this research) within a system of complex interventions. This makes teasing out individual information types and their associated causalities and processes too nuanced a task and

their major conclusions is that the use of active involvement of patients by HPs, instead of passive information delivery to stroke patients and their caregivers during the education process is the desirable method of information dissemination. Despite significant differences in approaches, the review has important implications for our understanding of the link between patient involvement and information provision.

3.5.4 Technology (as a factor affecting both patient information provision and involvement)

With the advent of the internet and the constant improvements in information and communications technology (ICT), there has been a shift towards more knowledgeable patients, who want to be involved in a partnership with their doctor (Andreassen, Trondsen et al. 2006). The increased access to information has signalled a move away from a deliberative towards a collaborative model (Jacob 2002) with empowered patients.

In the context of healthcare, empowerment has been described as an absence or decline of powerlessness, helplessness, alienation, victimisation, oppression, subordination and paternalism (Gibson 1991). Empowered patients are said to be more in control of their health and encounters with medical professionals (Roberts 1999). The effective use of health information is said to be critical to empowerment (Nutbeam 1998).

Whilst there is evidence suggesting that empowered patients are more likely to want to be involved in shared decision making (SDM) (O'Connor, Wennberg et al. 2007) assumptions about empowerment were different across the studies in the literature. For example, Broom (2005) was interested in how empowerment was experienced from the subjective perspective of patients, whilst Henwood et al. (2003) discussed empowerment in terms of the 'informed patient' or 'reflexive consumer' who is able to make informed choices about the risks and

one which would distract from the study's overall aims. This is a limitation of the study and classification by information "type" could certainly form the basis of future work, as we will discuss later in the thesis.

benefits of different treatments. Kivits (2006) looked at empowerment from the perspective of how patients are motivated to seek information and the processes that are involved in how they manage the information both before and during patient-provider interactions.

Empowerment and increased patient involvement in care decisions appears to be a potential outcome of information use. However, this should not be assumed to be automatic. Indeed, whether patients become empowered, not empowered or even disempowered with respect to participation in their own care forms a key part of this investigation. Henwood et al. (2003) were sceptical of suggestions that the internet as an information source empowers patients to participate in care (Hardey 1999; Lee, Gray et al. 2010) remaining unconvinced that empowerment is an inevitable outcome of information use. Since then, several authors have agreed with their position. For instance, one recent study concludes that the internet only has the *potential* to empower patients to be more participatory, rather than accepting that increased internet use by patients automatically makes them so (Robinson 2013).

Not only is more information available to patients than ever before, but the source of this information has changed also and now include resources other than health professionals. For instance, studies have shown that dissatisfied patients are more likely to choose the internet over their physician as a source of information (Tustin 2010). This has repercussions on the patient-provider relationship in terms of reduced trust and has implications for compliance with the recommended treatment (Zickmund, Hess et al. 2008; Tustin 2010) . Others have noted that the rise of health information technology (HIT) has changed both verbal and non-verbal communication styles within the relationship (Guest 2010).

One study suggests that in some cases doctors are even adopting special management strategies to cope with the perceived threat informed patients are having on traditional roles and power structures within the relationship (Broom 2005). Taken together, this research

indicates that information is a key factor in the patient provider relationship and its impact is likely to continue at an accelerating pace into the “digital” future. The widening access to information for patients will likely have significant effects on patient provider interactions, particularly in terms of knowledge and power relations between patients and providers. Indeed, in an article by Nettleton, the author elaborates on De Mul’s “informatization” thesis by considering its relevance to a number of medical practices and processes, including the doctor-patient relationship (Mul 1999; Nettleton 2004). The author (Nettleton 2004) interestingly notes that “*information is provided by practitioners, but in the information age it is also increasingly accessed and produced by patients themselves.*” The idea that patients and carers are accessing information for themselves, outside of their direct interaction with HPs, may have profound implications for the PPR. Precisely what these are in the specific case of stroke has yet to be explored however. For instance, the effects of advances in information technology, particularly online social media, on patient participation and decision making have not been sufficiently explored in the specific context of stroke.

3.6 Factors mostly affecting patient information provision by health professionals

As we have seen, at the heart of the patient-provider relationship is information. In this section we will take a closer look at the factors influencing patient information provision. Due to the emphasis placed on the provision of patient information by political, ethical and professional groups alike, there has developed a vast amount of literature relating to the topic. However, our focus here is confined to a review of the factors influencing patient information provision by health professionals.

3.6.1 Mode of information delivery

The mode by which information is delivered appears to be an important factor in influencing patient information provision. In general the three most common methods are audio-visual,

verbal and written. Each type has advantages and disadvantages. Indeed, a recent review of information provision to stroke patients concluded that the best mode of delivery is still not clear (Smith 2009).

Web-based audio-visual information is a relatively new method, currently being evaluated in pilot studies (Hermann, Gautschi et al. 2009). It may involve giving patients a general information video, or alternatively a video of the interaction they had with doctors at the time of consultation. This method has the obvious advantage of allowing patients to clarify any misconceptions or refresh their memory of the information discussed. In addition, it allows family and friends to consider the available information. The major disadvantage of this method is the expense incurred in developing and producing the material.

Verbal information is often seen as the cornerstone of information giving, for in most situations information is initially imparted on a verbal one-to-one basis. The belief is that the interaction will work as a two-way process, allowing patients to ask questions and clarify any misconceptions, while gaining support from caring professionals. Unfortunately, the inherent problem here is that most of the information involves novel concepts for patients, and their ability to comprehend and retain the information is severely depleted by their unstable medical condition, their shock at diagnosis or (particularly in stroke) cognitive impairment (Maasland, Brouwer Goossensen et al. 2011). In addition, Eames et al (2010) emphasise that doctors should not rely on stroke patients to ask questions as a stimulus to the delivery of further information as this assumes that patients have an unusually high degree of knowledge and initiative.

The provision of verbal information, although important, has been shown to have limitations in that patients frequently forget much of the information they are told. The provision of written information is one way that the information needs of patients and carers following

stroke can be improved. Studies have found that stroke patients and carers value receiving written information (Hoffmann, McKenna et al. 2007). Written information in conjunction with information given orally has been identified as having several advantages. Firstly, the provision of written information provides a back-up system in cases where patients are not provided with information or cannot recall information. Secondly, written information enables people to access the information they want at the time when they want it. Thirdly, written information may be useful in clarifying verbal information and if presented clearly in accessible language may be open to less misinterpretation than verbal information alone.

The major benefit of written information is that if patients are too anxious at diagnosis or consultation to retain the information they are given, then the written data serve as a permanent record to refresh their memories and clarify any misunderstandings. It can also help to inform families and indeed community healthcare staff, so that everyone is aware of the facts and advice that patients have been given. In addition, it can act as a stimulus to generate further discussion and questions.

Indeed, written information may be particularly beneficial to patients today, since shorter hospital stays reduce the amount of time doctors and nurses have to spend discussing concerns and providing facts.

However, this should not lead to the bad practice of simply handing patients an information sheet to take home, i.e. a leaflet must only build on what is already known, rather than introducing new ideas. This ideal, of only using written material to reinforce verbal information, is strongly supported by the literature (Cortis 1996).

The greatest shortcoming of written information, according to the literature, appears to be that reading material may be pitched at the wrong educational level for many patients. An American study by Foltz & Sullivan found that the standard reading level required to

comprehend health-related information was twelfth grade education or higher, yet 55% of participants in their study (n=63) could only read to seventh grade or lower (Foltz 1999).

The provision of written information that is tailored to individual needs has been identified as important in relation to a range of conditions. Within stroke care, written information for patients and their carers is most effective when it is customised and addresses the situation and particular concerns of individual patients, rather than information that is standardized for all patients (Hoffmann 2004; Lowe, Sharma et al. 2007). The Hoffman study found that provision of individualized written information packages could be achieved by developing a computerized information database from which relevant sections could be retrieved to provide individualized information for patients and carers.

3.6.2 The patient's specific illness and impairment

The most comprehensive discussion of the general (not stroke-specific) factors influencing information provision was outlined in a review of the research by Derdarian (Derdarian 1987). Derdarian concluded that there were several possible patient-specific factors influencing information giving by professionals. These could be divided into two categories: person-related variables (such as the patient's age) and situation-related variables (for instance, the patient's specific disease or condition and the level of their impairment).

3.6.3 Resources and sources of information

The factors Derdarian identifies, whilst useful, are not exhaustive. For instance, other studies have shown that a patient's desire to use health service resources judiciously and efficiently is one key factor in influencing information provision. This is because the potential source of information (i.e. a particular health professional) influences the patient's own information seeking behaviour (Attfield 2006). Put another way, a patient may be more likely to seek

information from an approachable therapist, for example, than a provider that they may perceive to be overburdened already, such as a nurse or doctor.

Another *source of information* that impacts information provision in general is online material.⁹ Internet health information is seen by both health professionals and patients as a potential risk and source of misinformation (Henwood, Wyatt et al. 2003; Broom 2005; Kivits 2006). Some patients are able to filter out information they do not believe to be reliable or correct (Entwistle and Watt 2006). However, others respond by exclusively accepting information from a healthcare provider (Henwood, Wyatt et al. 2003; Broom 2005). Internet skills and broader computer literacy affect the risk assessment process; patients with poor search skills and limited awareness of the origin of information sources are not as able to filter out misinformation (Henwood, Wyatt et al. 2003).

The use of the internet as a source of health information is not always aimed at challenging general providers' information provision but can be used in a complementary fashion, when everyday knowledge is mixed with medical factual knowledge (Entwistle and Watt 2006). Becoming informed by multiple sources of health information in this way may necessitate self-regulation in terms of how best to assimilate both forms of information. Those with poor internet and health literacy skills are more likely to favour providers' information. Those who are competent and confident at seeking and appraising information appear comfortable in using it to inform themselves and gain understanding about their own health. It appears that patients manage information in consultations and interactions with health professionals by regulating or controlling their exchange of information. At the same time, it seems providers also regulate patients' information use and exchange through preventative behaviours (i.e. hostility, rejection, dismissal).

⁹ We have previously considered online technology in terms of its ability to encourage (or otherwise) patient participation in care decisions, rather than explicitly in terms of its impact on the way in which providers deliver, and patients receive and respond to, information.

3.6.4 Patient's needs change with time

It would appear that the information needs of stroke patients change with time and differ according to whether they are still in hospital or have been discharged. That patients' information needs are dynamic has gained credibility as a factor which affects patient information provision (Hanger, Walker et al. 1998; Wiles, Pain et al. 1998) and is worthy of further consideration in this study. Indeed, as we have already seen, recent work in Singapore also indicates that more research is needed to evaluate the timelines of information provision, in order to ensure that there are processes in place to make ongoing support readily accessible to patients who are discharged (Koh, Barr et al. 2014). We aim to build on the current research exploring the timing of information provision by looking at this important process at different points in the stroke pathway, i.e. at admission and at discharge.

3.7 Factors mostly affecting patient involvement by health professionals

3.7.1 Professional complacency

As we have alluded to previously, it may be plausible to suggest that professionals feel they encourage patient participation to a greater extent than they actually do. This could be seen as a form of complacency or perhaps simply a lack of awareness of what patient involvement is – since there is no universally accepted, standardised approach for appraising 'involvement', despite numerous attempts to devise tools to measure it (Brashers, Haas et al. 1999; Elwyn, Edwards et al. 2003). Whilst this specific factor does not appear to have received coverage in the literature, it dovetails into the next factor, training, which has been extensively studied.

3.7.2 Training

The involvement of patients by professionals in care decisions also seems to be influenced by the training the health provider has received. Indeed, a lack of professional training is one of

the main limiting factors to the widespread adoption of involving and sharing decisions with patients (Legare, Ratte et al. 2010). This study aims to explore this important issue further in the specific context of stroke care.

3.7.3 Provider's and patient's personality

The attitude and individual opinions of the provider may also play a role in influencing the extent to which patients are involved in care decisions. For example, it is likely that providers vary in their attitudes towards involving a patient's family in decisions (Azoulay, Chevret et al. 2000); perhaps some would regard a patient's family as time-intensive and unwelcome challengers to their authority, whilst others could view them as a rich resource for learning more about the patient under their care. These types of differences in a provider's approach, or 'personality', could affect a patient's likelihood of involvement in care decisions, yet they have not been fully explored in the literature. Studies that are related to this unconfirmed phenomenon have accounted for differences between physicians' propensity for participatory care by looking at gender, race, training and context (Kaplan, Greenfield et al. 1996). Whilst these are all undoubtedly important elements to consider, personality types, attitudes and outlooks have not been formally studied in relation to a provider's likeliness to involve patients in decisions.

An important study by Maclean and others emphasises the importance of the individual patient's characteristics also in considering determinants for involvement in rehabilitation. Their work, conducted using semi-structured in-depth qualitative interviews with stroke professionals in an inner-city stroke unit, found that motivation for involvement in rehabilitation depends on (among other factors, such as social ones) "personality" factors or a patient's intrinsic personality traits (Maclean, Pound et al. 2002). They also suggest that

central among the social factors are aspects of the health professionals' own behaviour, which they propose could be taken to positively and negatively affect patients' motivation for involvement in their care. In their research, some HPs reported treating those they perceived as unmotivated patients differently from motivated ones, especially if these unmotivated patients were elderly.

This has implications for our exploration of the PPR and suggests a feedback mechanism could be at play, whereby pre-existing patient personality traits that make patients less likely to seek involvement in the first instance are reinforced and exacerbated by the HPs' own attitudes and actions. Whether this is found to be a significant factor in influencing patient participation in this study and whether it could also be a factor affecting information provision will be worth exploring here. Similarly, the applicability of their findings should be tested in contexts outside of rehabilitative care only.

An earlier study by the same researchers looked at motivation for patient involvement from the perspective of the patients themselves (Maclean, Pound et al. 2000). All the patients interviewed were undergoing rehabilitation at the time.¹⁰ They concluded that information from health professionals about rehabilitation (as well as favourable comparisons with other stroke patients, and the desire to leave hospital) were positive factors in motivating patients for involvement. Conversely, they discovered that overprotection from family members and HPs, a lack of information or the receipt of "mixed messages" from professionals, and unfavourable comparisons with other patients had a negative effect on patient motivation for involvement. Once again, their research highlights the way in which information provision and involvement can be closely related and the need for clarification on precisely how inter-related concepts and factors bring about their effects. Furthermore, their work shows the

¹⁰ making participation more practicable, unlike in this more broad-based research, which includes hyper-acute stages too

impact family members (and parties outside the PPR, such as other patients) may have on patient involvement. Whether these “external influences” also impact information provision was not specifically explored in their work, so this is an issue we will be looking to consider here. Again, care will have to be exercised when making any direct comparisons between the study here and their research, as we are looking at factors from the professional’s perspective only.

3.7.4 Presence of family and the role of carers

The presence of a patient’s family has an impact on the professional’s level of patient involvement (Holroyd, Turnbull et al. 2002). A reduction in patient involvement may occur as a result of family being present when some professionals choose to avoid or minimise their interactions with the patient for fear of having to confront angry or demanding relatives. Similarly, certain professionals may be less likely to encourage patient involvement when family is present, as they often equate a family’s presence with a more protracted process. Conversely, some professionals view the patient’s family as a valuable resource for finding out more about the patient and therefore their presence may have the opposite effect. The literature has largely dealt with this area by studying the impact families have on decision making themselves directly (Anderson, Hobson et al. 1992; Azoulay, Pochard et al. 2004), rather than looking at the more indirect effects a family’s presence may have on how involved a patient may be. This is a fresh perspective that this study aims to bring to the debate.

As we have already mentioned, approximately one third of stroke sufferers have a longstanding disability, including communication difficulties. Carers therefore play an important role in the interface between stroke patients and the health system. Despite a high

level of uncertainty among caregivers in the acute and community settings, research has found that limited information is provided to assist them in their new role (O'Connell, Baker et al. 2003). The O'Connell et al study suggest that tools such as patient-held records could assist in and improve the continuity and communication of care, as would having the ongoing support of a stroke nurse who could follow stroke survivors from the acute setting to the community. The authors maintain that caregivers' informational needs must be addressed and given due attention if they are to play a full part in a stroke survivor's care. From this Australian study's findings we can infer that the carer's role in the PPR remains constrained by an educational deficit (O'Connell, Baker et al. 2003). The study focuses exclusively on carers' information needs, rather than those of the patient directly however. Therefore, to build on their work, the interviews here will explore the role of carers in the NHS (to include an assessment of their impact on the PPR) and the information needs of *both* the carer themselves and the patient they are caring for¹¹.

3.8 Overview of the literature: the research questions

The above discussion highlights that whilst many factors have already been proposed in the literature, there is still considerable scope for exploring how these factors that influence information provision and involvement of patients are connected and what their relative importance and *modi operandi* may be. For example, the importance of internet information is well recognised with respect to the patient provider relationship and communication within it (McMullan 2006; Bylund, Gueguen et al. 2007; Iverson, Howard et al. 2008). However, precisely *how* this factor influences information provision and its exact role in terms of patient involvement has not been evaluated. Additionally, it is not clear how important (in absolute terms) internet information is in the specific context of stroke care and, relatively

¹¹ A patient's family may be acting as their principal carer so these terms are often used interchangeably in the literature. That will be the case in this work also, unless explicitly stated otherwise.

speaking, in comparison to other factors. These are some of the gaps that this work seeks to address. The same questions remain unanswered for the other factors discussed here, namely government policy and social structures.

In short, although there is a consensus on the relevant factors in the literature, the findings often have yet to be applied to stroke. Therefore, many of the factors already identified in this literature review will need to be re-examined (and subsequently either refuted, confirmed or amended) in the specific context of stroke care. Additionally, whilst the literature delivers a comprehensive treatment of *what* the factors are, it is less rigorous at proposing mechanisms for *how* these factors may have their impact – a shortcoming we aim to address here. Two tables summarising the main factors identified from the literature search as impacting patient information provision and involvement (in general and in the specific case of stroke) can be seen below.

Table 3.3: A summary of the factors affecting patient information provision and involvement of patients by health professionals: key, general findings from the literature

<p><i>Factor's impact on patient involvement</i></p>	HIGH	<p>Mainly involvement:</p> <ul style="list-style-type: none"> -professional complacency -training -provider's and patient's personality -presence of family and role of carers 	<p>Both:</p> <ul style="list-style-type: none"> -government policy -social structures -technology
	LOW	<p>Mainly information:</p> <ul style="list-style-type: none"> -mode of delivery -patient's specific illness and impairment -resources and sources of information -patient's needs change with time 	
	LOW	<i>Factor's impact on information provision</i>	HIGH

Table 3.4: A summary of the factors affecting patient information provision and involvement of patients by health professionals: key, stroke-specific findings from the literature

<p>HIGH</p> <p>↑</p> <p><i>Factor's impact on patient involvement</i></p> <p>↓</p> <p>LOW</p>	<p>Mainly involvement:</p> <ul style="list-style-type: none"> -Early-supported discharge increases patient participation with rehabilitation at home; the physical and psychosocial elements of the environment influence the patients' ability to attain the targeted levels of participation during the rehabilitation process (Disler & Wade, 2003) -Hospital system itself: an environment in which patients feel powerless (Jones 2000) -The means to access rehabilitative services (Koh, 2014) -Lapse in discharge coordination (Koh, 2014) -Family members' views and actions (Koh, 2014; Maclean, 2000) -HPs own behaviours (Maclean, 2002) -Discrepancies in expectation (Koh, 2014) -The perception that rehabilitation is simple (Koh, 2014) -Hyper-acute situation (during thrombolysis decision window) produces reliance on the expertise of clinicians (Murtagh, 2012) -Patient's intrinsic personality traits (Maclean, 2012) 	<p>Both:</p> <ul style="list-style-type: none"> -Aphasia results in asymmetric interactions, hindering formation of partnership approach to care, with nurses controlling topic and flow of conversations (Gordon, 2008) -Tailoring information (such as outcome probabilities, using different modalities – particularly visual/graphical) to individual patients, may help patients/relatives make treatment decisions too (Flynn, 2013; Cunningham 2008) - Audit/target driven culture: there is a danger that pursuing greatly increased proportions of patients being given intravenous thrombolysis (in line with NAO recommendations) could come at the expense of the many other effective components of a comprehensive stroke service, such as patient participation in care decisions and information provision (Sudlow & Warlow, 2009) -Lack of time for reflection in a severely time-limited setting (Murtagh, 2012) -Patient and family capacity blunted by the effects and shock of stroke (Murtagh, 2012)
		<p>Mainly information:</p> <ul style="list-style-type: none"> -Unstable condition and cognitive impairment means verbal delivery may not be appropriate for stroke patients (Maasland, 2011) -Stroke patients and carers value receiving written information (Hoffmann, 2007); most effective when customised to the situation and concerns of individual patient (Hoffmann, 2004; Lowe, 2007) -Stroke patients have dynamic information needs which change with time and context i.e. hospital versus discharged home (Hanger, 1998; Wiles, 1998) -Patient and carer social characteristics, such as educational attainment (van Veenendaal 1996) -Government policy: information provision to people with stroke was highlighted as a “marker of quality stroke service” in the 2007 Department of Health's UK stroke strategy (DoH 2007)
	<p>←</p> <p>LOW <i>Factor's impact on information provision</i> HIGH</p> <p>→</p>	

We have demonstrated the importance of understanding the processes of patient information provision and participation, both in light of prevailing government policies and because of its potential implications for the PPR. Ultimately, improving the PPR has the potential to raise patient satisfaction and clinical outcomes (e.g. treatment compliance). It is therefore a central part of this research. What we currently know about this relationship (both in general and in the specific case of stroke) from the literature review here can be seen in the two summary tables which follow.

Table 3.5: A summary of the factors affecting the patient-provider relationship at a system and individual level: key, general findings from the literature

<p>HIGH</p> <p>↑</p> <p><i>Factor's impact on/relevance to PPR at system level</i></p> <p>↓</p> <p>LOW</p>	<p>Mainly at system level:</p> <ul style="list-style-type: none"> -Government policy encouraging shared decision making: when discussing decisions with patients, the provider must allow patients to express their personal needs and preferences. Additional time should be set aside to answer any questions the patient may have and check their understanding of the options available to them and the risks of each of these options (NICE 2012, CG138) 	<p>Both:</p> <ul style="list-style-type: none"> -power, social/cultural context, interpersonal competence (Shattell, 2004) -provider's personality and approach is impacted by their gender, race, training and context (Kaplan, 1996; Azoulay 2000)
	<p>Mainly at individual level:</p> <ul style="list-style-type: none"> -role performance (Parsons & Fox, 1952) -disease stage (Szasz & Hollender, 1956) -friends and family/carers (Charles & Gafni, 1997) -collaborative partnerships (Stewart, 2000) communicating evidence and treatment options (McWhinney, 1993; Sullivan, 2003) -self-empowerment and self-information provision: "reflexive consumer" (Henwood, 2003); "information age" (Nettleton, 2004) -responsibility for knowledge no longer just the provider's (Gerber & Eiser, 2001)-web-activated patients: shift from traditional to consumerist, patient-internet-physician triangulation model (Wald, 2007) -trust in provider: impacts patient seeking info online and/or from family and friends (Hart, 2004) 	
<p>←</p> <p>LOW <i>Factor's impact on/relevance to PPR at individual level</i> HIGH</p> <p>→</p>		

Table 3.6: A summary of the factors affecting the patient-provider relationship at a system and individual level: key, stroke-specific findings from the literature

<p><i>Impact on/relevance to stroke PPR at system level</i></p> <p>HIGH</p> <p>↑</p>	<p>Mainly at system level:</p> <ul style="list-style-type: none"> -limited information to carers in their new role: poor continuity of care; carer role constrained by system that leaves them with an “educational deficit” (O’Connell, 2003) 	<p>Both:</p> <ul style="list-style-type: none"> -psychological factors: perceived control/patient powerlessness in interactions with providers, affected by hospital setting and healthcare system e.g. in-hospital rehabilitation programmes (Jones, 2000) -patient-centred treatment goals for greater patient control (Koh, 2014)
		<p>Mainly at individual level:</p> <ul style="list-style-type: none"> -patient characteristics: previous stroke, advanced age, living conditions (Slot, 2009) -mixed messages and consistency of information from health professionals to patients (Maclean, 2000) -presence of family members and other patients (Maclean, 2000) -health professional’s own behaviour, attitudes and actions (Maclean, 2002)
<p>↓</p> <p>LOW</p>	<p>←</p> <p>LOW</p>	<p>→</p> <p>HIGH</p>

Impact on/relevance to stroke PPR at individual level

As we have mentioned, the heightened understanding of these processes can only be achieved by initially identifying the factors which affect information provision and involvement, and then analysing how these factors actually have their impact, in a specific context – here, stroke. Furthering our knowledge in this way will make us better able to effectively implement change for future stroke patients. Eliciting the thoughts of stroke professionals themselves about how to improve patient information provision and participation will also help to meet this goal and these concepts are therefore key ingredients in the study’s research

questions. Furthermore, of particular interest here is understanding how patient information provision, involvement and the PPR in stroke are inter-related. That is, we are interested in discovering how the broad connections between phenomena identified in other areas of healthcare are framed within stroke care specifically. In light of these aims, we ask the following research questions:

RQ1a: What factors influence information provision and involvement of patients by health professionals in stroke care?

RQ1b: How do the identified factors affect information provision and involvement of patients in stroke care?

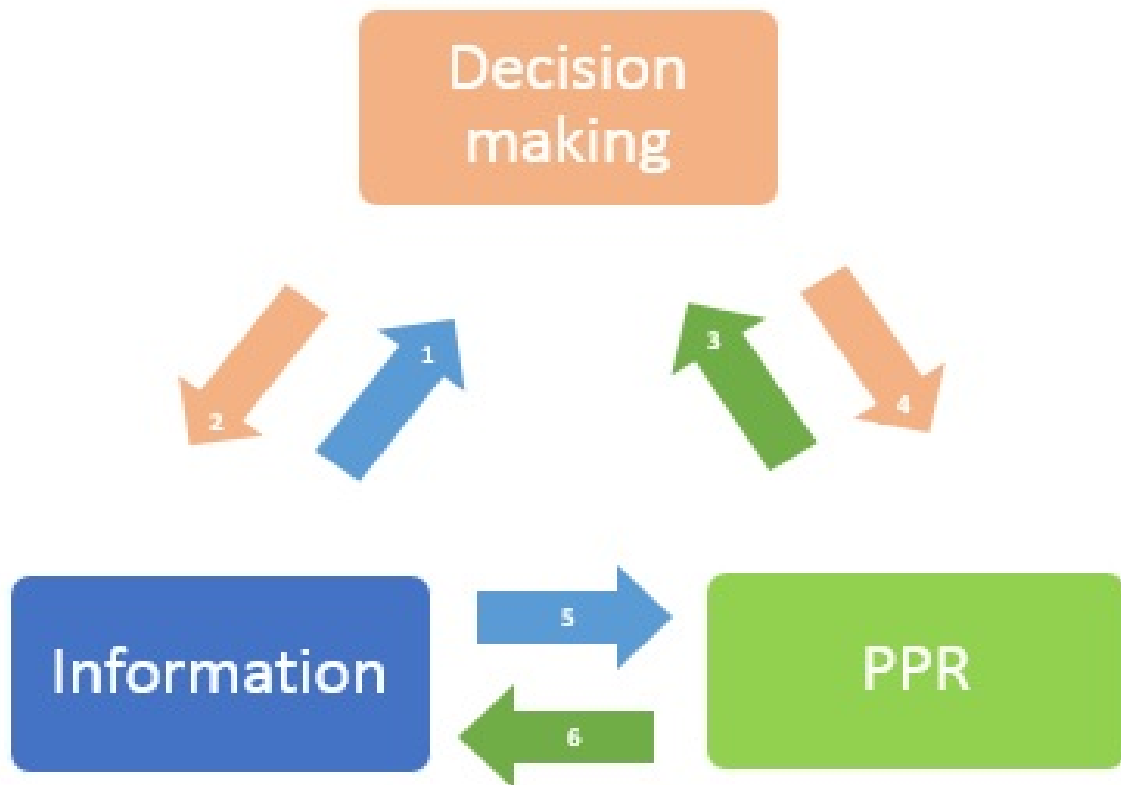
RQ2: How do health professionals think patient information provision and involvement can be improved in stroke care?

It is important to note that the research questions focus only on HPs' views of what factors influence information provision and involvement of patients by them and only HPs' views on how these identified factors affect information provision and patient involvement. That is, no patients or carers were included in capturing data to answer the research questions. By extension, we have no direct evidence of how patients and carers might experience the PPR from this work. This point is discussed in the methods chapter to follow in the section on participant recruitment and its full implications are considered in the concluding chapters of the thesis also.

An overarching theme arising from the literature that must be considered as part of this exploration is the complex dynamic between patient information, the patient-provider relationship and decision making. Figure 3.2 summarises the situation. The disparate literature suggests that many questions remain unanswered (these research gaps are

represented by arrows in the diagram) and it is the aim of this study to contribute to this ongoing debate and add to knowledge in this key area.

Figure 3.2: Information, decision making and the PPR



- 1 Information sharing leads to joint decision?
- 2 SDM leads to better information provision?
- 3 The relationship defines who will be making the decisions?
- 4 Identifying the decision maker defines the relationship?
- 5 Informed patients have more consumerist relationship?
- 6 A paternalistic health professional provides less information?

As shown in the literature review, sociologists have often characterised the PPR in terms of *who* is making the decisions within any given patient provider interaction and accordingly modelled the relationship as paternalistic, deliberative and so on. Decision making processes are thus an important component of the PPR – this is consistent with mainstream sociological thinking in this area. It is beyond the scope of this health services research project to provide answers to all the questions shown in this diagram. However, it is the intention to contribute to the discussion of the PPR in stroke specifically with this study’s findings, as we shall see later.

3.9 Chapter summary

In this chapter we have defined the research's key working terms; namely, patient information provision and patient involvement. We then sought to make a distinction between the general and stroke-specific literature relating to these two areas. In doing so, key general and stroke-specific findings have been arranged in summary grids. As part of the review, a number of important stroke studies (which are closely-related to the research here) have been identified and critiqued.

From the literature, it appears that both patient information provision and involvement are important components of the PPR. Moreover, it appears that the current PPR model for stroke may need revision and, once tested in context, could possibly be extended beyond just the interaction between stroke health professional(s) and stroke patient/carer(s) in a hospital or primary care setting.

Additionally, effective patient information provision has been associated with patient satisfaction and is also linked with patient compliance and a patient's ability to cope with their diagnosis and prognosis. However, a key difficulty is that professionals and patients often differ in their perceptions of what constitutes relevant information. Patient participation is found to be similarly important, with many stroke patients appearing to want to be actively involved in the decision-making process.

Several factors have been shown to affect both information provision and involvement such as government policy, social structures and technology. Some factors mainly affect information provision, such as the fact that patients' needs change with time. Other factors mainly affect patient involvement, such as a provider's "personality" or attitude. Whilst many factors have already been proposed and examined in the general literature relating to patient

information and participation, there is still considerable scope for exploring the factors that influence these two processes in stroke care.

Furthermore, the literature delivers a comprehensive treatment of *what* the relevant influencing factors are but is less rigorous at putting forward mechanisms for *how* these factors may have their impact. Understanding the processes of information provision and involvement is important both as a vehicle for exploring the PPR in stroke further and also as a way to ultimately improve stroke patient satisfaction and clinical outcomes (via increased treatment compliance, for instance).

Finally, an important message from the stroke-specific literature is that the patient and family's information needs after stroke are not currently adequately met. There are many proposed reasons for unsatisfactory information provision in stroke care (from time constraints to lack of communication training for professionals); however, there is little agreement on exactly why information delivery remains a cause of patient dissatisfaction.

Chapter Four – Research approach and methods

Research approach and methods

4. Introduction

In the previous chapter, we assessed the relevant literature to place the research in its proper context and to identify the unanswered research questions¹². In this chapter, we will outline the methodology and methods that we will be using to answer these questions. A methodological discussion, largely around the work's epistemology and ontology, will also be included. We will then present the research design and provide details of how the research was actually carried out, how data was generated and how it was analysed. The chapter concludes with a consideration of the methodological limitations.

4.1 Methodology and research paradigm

4.1.1 Rationale for choosing a qualitative, grounded-theory inspired approach

As we have seen from the literature, a number of factors have already been identified as important in influencing patient information provision and involvement in decision making. Here, we aim to build on this work by understanding in depth the phenomena and processes that give rise to these factors in the first instance and their relationship to one another (the *how* component of the first research question, RQ1b). In other words, this study is exploratory and explanatory rather than descriptive. This approach to answering the first research question lends itself best to qualitative methods.

Through the second research question, we look to understand what improvements can be made from the perspectives of UK stroke professionals. This is an inherently complex

¹² It is important to reiterate at this point that the research questions focus only on HPs' views on what factors influence information provision and involvement of patients by them and only HPs' views on how these identified factors affect information provision and patient involvement. That is, no patients or carers were included in capturing data to answer the research questions. By extension, we have no direct evidence of how patients and carers might experience the PPR from this work. The full implications of not including patients and/or carers in this work are discussed in this chapter and in the concluding chapters of the thesis also.

question dealing, as it does, with multiple sites and stages of the stroke pathway. It is therefore easy for more positivistic, quantitative approaches to overlook these complexities and subtleties, which often only emerge from the closer researcher involvement gained from qualitative methods.

As we have seen, the acute stroke pathway is not a static system in isolation. Many agents interact with each other through relationships (e.g. inter-professional, intra-professional, patient-provider) both inside and outside of the hospital setting. Moreover, the condition itself affects people in different ways. As a result, any single patient's journey and experiences along it will differ from the next, making a standardised, comparative study (often associated with quantitative methods) inappropriate (Punch 2005). Qualitative descriptions on the other hand can play an important role in understanding these types of dynamic processes and the relationships contained therein. They can also shed light on possible causes, effects and the ways in which seemingly disparate complex phenomena may relate to one another (Burns 2000). These different forms of knowledge, and the new insight gained from them, may not be as readily attainable using a purely numerical approach to data collection.

The literature does not show a preference for qualitative or quantitative methods in other studies examining the factors that influence patient information provision and involvement in decision making. Both appear equally valid depending on the exact objective of the researcher, practical issues and philosophical stances. For instance, quantitative research is generally geared towards allowing the researcher to quickly establish relationships among variables, but is often less useful when it comes to exploring the reasons for those relationships. A qualitative study on the other hand is often a more time-consuming process but can be used to explain the factors underlying the broad relationships, which is part of the objective of this work (Delamont 2002). Additionally, quantitative studies tend to be driven from the researcher's perspective, whilst qualitative projects are typically focused on the

subject's perspective (Punch 2005). As both research questions are asked from the point of view of stroke professionals, a qualitative approach is more suitable here.

Whilst qualitative methods are most fitting in this instance, it is not to say that qualitative approaches are without their limitations. Precisely because of the subjective nature of qualitative data, it is difficult to apply conventional standards of reliability and validity (Burns 2000). To overcome this in part, data was gathered from multiple sites and a variety of contexts (e.g. participants were drawn from England, Scotland, Wales and Northern Ireland and from HASUs, stroke units, DGHs, rehabilitation centres and other community settings).

Moreover, it is difficult to entirely eliminate the effect that a researcher has on the study's subjects. This problem was mitigated for partly by conducting interviews by telephone, so the impact of being physically present was removed.

In addition, researchers conducting qualitative studies are at particular risk of introducing bias into their data by not identifying their own viewpoints prior to data collection and allowing these to unduly affect the participant's responses (Burns 2000). To minimise this, here we take a grounded theory inspired approach to data collection, which calls for as close to a clean slate as possible before commencing the investigation. Note that a grounded theory inspired approach is not one devoid of epistemological or ontological stances (Holton 2009); the theoretical lens for the study is discussed in detail later.

In its simplest form, grounded theory can be described as a qualitative, investigative research method with no preconceived hypothesis and involving continuous comparative analysis of data. It was first developed by American sociologists Glaser and Strauss in 1967. Their contention was that theory generated through its use would be truly grounded in the data (Glaser and Strauss 1967).

The central aim of the grounded theory approach is the development of theory with explanatory power. That is, a theory that may be used to explain how a particular aspect of the social world works. Stated another way, the aim is to develop a theory that is wholly contiguous with the reality from which it emerges and, at the same time, can be used to explain that very same reality. According to Creswell, grounded theory can be defined as;

“a qualitative strategy of inquiry in which the researcher derives a general, abstract theory of process, action, or interaction grounded in the views of participants in a study” (Creswell 2008).

The grounded theory process calls for multiple stages of data collection, between which refinement, categorisation and the establishment of interrelationships in the collated information takes place (Strauss and Corbin 1990; Strauss and Corbin 1998; Charmaz 2006).

In short, grounded theory is effective in allowing researchers to generate high quality, novel theories and to understand complex, social phenomena (Allan 2003). Data from a grounded theory approach is collected over time (as opposed to a single ‘snap shot’) and at multiple levels. This helps to ensure that meaningful results are obtained. Whilst these are great strengths of this approach, we should also consider a few of the potential drawbacks.

Grounded theory studies require enormous volumes of data, which need to be gathered in a precise fashion over a period of time. As we shall discuss later, analysis of this data is often not straightforward as the researcher must be adept at teasing out nuances of meaning, subtleties of expression and differentiating the relevant from the irrelevant, amongst other things. Judgement around category saturation¹³ and the point at which a theory is adequately developed are other potential pitfalls (Allan 2003).

¹³ Saturation is the point in data collection when no new or relevant information emerges with respect to the newly constructed theory (or category, in this case).

Finally, it is not possible to begin a study without some prior theoretical ideas, knowledge and assumptions. Since, in this case, there was *a priori* knowledge of the research domain, one cannot label the study as grounded theory in the strictest sense. For this reason, the approach here can be described as being inspired by grounded theory. Despite the potential weakness of GT, the exploratory nature of the study, the complexity of the phenomena under examination and the explanatory contributions we seek to make in addressing the research questions, make this approach appropriate.

4.1.2 Theoretical perspective: epistemology and ontology

Here, we will outline the epistemological and ontological views taken in the study in order to provide an understanding of the research's theoretical perspective and philosophical framework. This is important to justify the research approach and provide a context for its logic and criteria.

Epistemology is essentially concerned with what constitutes valid knowledge and how one goes about obtaining it, whilst ontology deals with what constitutes reality and how existence can be understood. Epistemology and ontology fall into three broad categories; objectivism, interpretivism and subjectivism. The largest debate often centres on positivist (or objectivism) versus interpretivist approaches to research.

The interpretivist view asserts that all knowledge is a compilation of man-made constructions rather than the neutral discovery of an objective truth (Raskin 2002). Furthermore, whilst the positivist is concerned with the object of our knowledge, the interpretivist researcher places the emphasises on how we go about constructing knowledge (Jonassen 1991). Interpretivism suggests alternative definitions for knowledge and truth that form a new paradigm, built around inter-subjectivity in lieu of traditional objectivity, and on viability in place of truth. Indeed, interpretivism denies that there is an objective truth waiting to be discovered at all.

Instead, the interpretivist proposes that truth and meaning are discerned from the engagement of our minds with the world. Moreover, interpretivism maintains that different people may understand meaning in different ways, even with respect to the same phenomenon, such as between those in different eras or cultures.

As a result, the former (objectivism) is usually associated with natural sciences and theory-testing of objective knowledge in quantitative studies underpinned by a realist or objectivist ontology (simply put, facts are facts), whilst the latter (interpretivism) is more commonly linked to social science investigations where a subjective, theory-building approach guided by a subjectivist ontology (i.e. people are people) is central. The interpretivist approach to research can be summarised as follows:

Figure 4.1: The interpretivist research approach

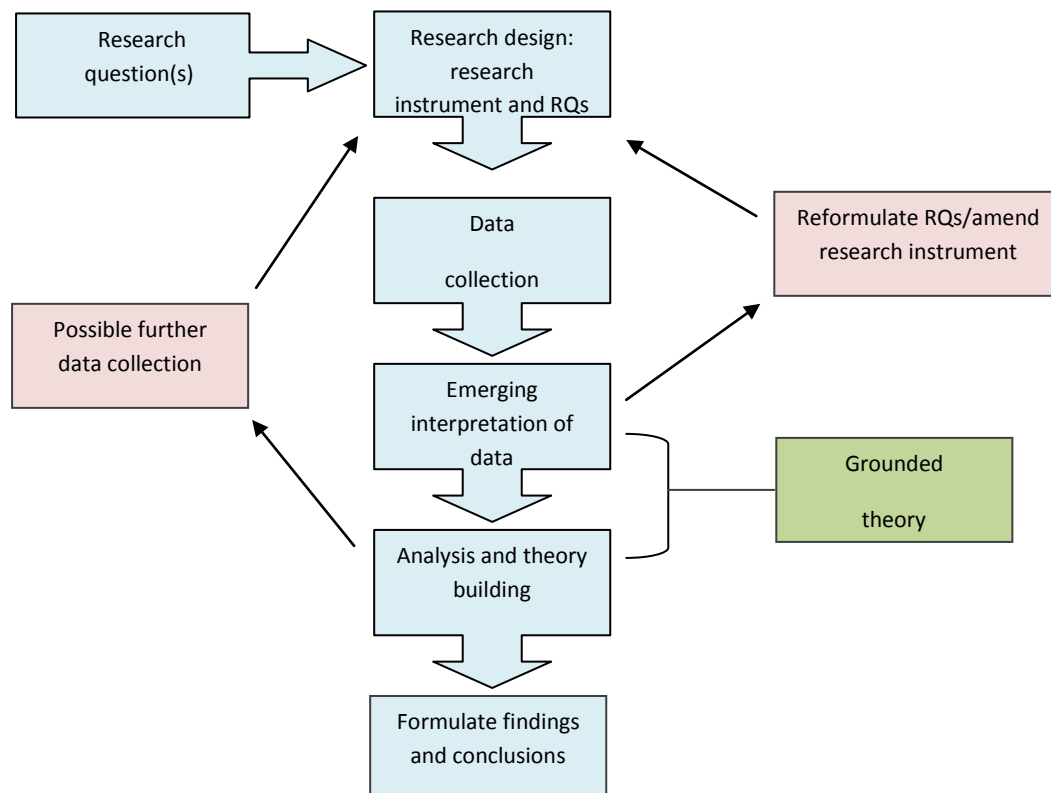


Fig. adapted from Dr. Raddon, The Centre for Labour Market Studies, Sch. of Management, Univ. of Leicester

A third epistemological possibility is subjectivism (also referred to as structuralism), which contends that all meaning originates within a person's mind, without the contribution of the object or any measure of inter-subjectivity (as we have already seen with the interpretivist epistemology) (Crotty 1998). The ontological implication of this is that what is perceived is what is real, and that there is no underlying true reality that exists independently of an individual's perception (Crotty 1998). Here, we accept the ontological stance of the subjectivist whilst rejecting the epistemological view. For, as we have outlined above, this study draws meaning from inter-subjectivity and social constructions consistent with an interpretivist epistemology.

As we have seen, the project does not seek to address specific hypotheses nor does it look to deductively generate objective, measurable knowledge in the form of facts. Rather it aims to elucidate meaning by inductively building a model for understanding complex social processes, within different contexts. In other words, here we aim to discover not just what has happened but how and why it has occurred from the perspectives of the subjects being interviewed.

With these objectives in mind, the project can be firmly placed within the interpretivist school of philosophical thought. In summary, the work assumes an interpretivist epistemology with subjectivist ontology. The various theoretical lenses are summarised in the table below.

Table 4.1: A summary of possible epistemological and ontological positions

Epistemology		
Objectivism (positivism): there exist measurable facts, independent of self	Interpretivism: world is independent of human minds, but knowledge of the world is always a human and social construction (Crotty 1998)	Subjectivism (structuralism): all knowledge comes from within a person’s mind
Ontology		
Objectivism: reality is independent of our beliefs and thoughts	Relativism: no real, objective truth exists	Subjectivism: whatever is experienced by one’s self is real

Note: the epistemological and ontological stances of this research are highlighted in blue

Overall, therefore, the study is a piece of applied, health services qualitative research in the interpretivist tradition using grounded theory.

4.1.3 Rationale for choosing semi-structured interviewing for data collection

As shown in Appendix V, the original intention was for a more quantitative approach which would have allowed patient satisfaction to be correlated to information provision and patient decision making in a quantifiable way.

The Satisfaction with Stroke Care (SASC) questionnaire lends itself well to this type of quantitative evaluation. The SASC is a UK developed validated self-report instrument for the measurement of patient satisfaction. It comprises two subscales and 20 items – satisfaction with inpatient care (8 items) and satisfaction with care after discharge (12 items) (Boter 2003). At least 3 of the items deal directly with patient information (and can be independently analysed), whilst the remainder could provide useful supplementary data relevant to the PPR,

such as whether or not the patient felt they had been treated with *respect* by their health provider. In addition, the instrument has had a high response rate in previous studies. The short completion time means it has been successfully self-administered by discharged stroke patients.

For measuring decision making, the OPTION scale could be used (Elwyn, Edwards et al. 2003; Elwyn, Hutchings et al. 2005). This is an item based instrument completed by raters who assess recordings of consultations. It was originally developed to evaluate shared decision making specifically in the context of general practice, but it is intended to be generic enough for use in all types of consultations in clinical practice. The OPTION scale is designed to assess the overall decision making process. In summary, it examines whether problems are well defined, whether options are formulated, *information provided*, patient understanding and role preference evaluated, and decisions examined from both the professional and patient perspectives.

Ultimately, however, difficulties securing the requisite ethical approval for the direct recruitment of stroke patients (essential for the use of the tools described above, and a point returned to later in this chapter) meant that gathering this quantitative data became beyond the scope of the project.¹⁴ We chose therefore to focus on a purely qualitative interview approach.

¹⁴Nevertheless, this appears to be a fruitful area for future stroke care research as we shall discuss in Chapter 8. Indeed, future work could draw on some of the items included in the OPTION scale in developing a proprietary data capturing and observation tool.

Interviews are one of the most used strategies for data collection in qualitative studies (Patton 2001). They can be conducted in various ways and range from structured survey interviews and questionnaires to entirely unstructured, ethnographically based observational work.

One commonality amongst all interview approaches is that one of their primary purposes is to know the interviewee better. However, the objective of that knowing will be different according to the research question(s) and the disciplinary and theoretical perspective of the researcher (DiCicco-Bloom and Crabtree 2006).

For instance, as we have already seen, some studies are designed to test *a priori* hypotheses. This type of research often uses a very structured interviewing format in which the questions and analyses are standardised. Other research, such as the study here, aims to explore meaning and participant perceptions to gain a better understanding of complex social phenomena and/or generate hypotheses (DiCicco-Bloom and Crabtree 2006).

In this case, a form of qualitative interviewing is needed as this format encourages the subject to share rich descriptions of phenomena, while leaving the interpretation and analysis to the researcher (Warren and Karner 2005). In short, the goal of the qualitative interview is to contribute to knowledge in a conceptual way, based on the meanings that participants' life experiences hold for them.

Qualitative interviews come in three main formats; structured, semi-structured and unstructured (Fontana and Frey 2005). The first of these (structured) usually produces quantitative data, as it is essentially an orally administered survey. We rejected the structured interview technique on the grounds of the epistemological and ontological discussion presented previously. Therefore, the choice rested between semi-structured and unstructured approaches. We will now take a closer look at these two.

Semi-structured interviews are more flexible than structured interviews, allowing the researcher considerable freedom to divert from the pre-prepared questions and to explore themes generated from the informant's responses and the specific contexts being discussed. Semi-structured interviewing is therefore consistent with the grounded theory inspired methodology described previously. Both open and closed questions are used as part of this process and these are viewed as an interview guide rather than a rigid formula that must be adhered to (as is the case with structured interviews).

The unstructured interview technique was developed by anthropologist and sociologist as a way to elicit people's social realities (Zhang and Wildemuth 2006). In contrast to structured and semi-structured interviews, unstructured approaches do not use predetermined question or answer categories (Minichiello 1990), relying instead on the social interaction and spontaneous generation of questions in the natural flow of an interaction between researcher and participant (Patton 2001).

Whilst unstructured interviewing would have been consistent with the epistemology adopted here, its premise of approaching the interview with no predetermined theoretical framework, and therefore no questions about the social phenomena being studied, are not suitable for this study (Zhang and Wildemuth 2006). We recognise that prior knowledge of some aspects of stroke care processes will be taken in to the interview and will be the focus of certain pre-formulated lines of enquiry. Therefore, we opted for a semi-structured approach that allows for this.

4.2 Research methods

4.2.1 Rationale for study design: telephone interviewing

The study's data were generated from 50 semi-structured telephone interviews with stroke professionals. One family carer and patient representative also participated in the preliminary stages of the research for background gathering, bringing the total number of informants to 51.

Telephone interviews are seen as a viable alternative to face to face interactions by qualitative researchers (Burke and Miller 2001; Opdenakker 2006), with no significant difference in data being noted between the two techniques in a 2004 study by Sturges et al (Sturges and Hanrahan 2004). Additionally, this study and another from Carr et al, highlight that through telephone interviewing researchers are able to ensure a higher response rate compared to the use of questionnaires or in-person interviews (Carr and Worth 2001; Sturges and Hanrahan 2004). In fact, conducting interviews by telephone may confer certain other advantages, such as a reduction in the interviewer's impact on the informant, resulting in a relaxed participant who is better able to disclose sensitive information (Novick 2008). Other researchers similarly note that this mode of data collection allows for an open and free discussion of thoughts that may not be easily discussed through in-person interviews (Mitchell and Chaboyer 2010). Furthermore, the researcher is free to conduct the interviews over a wider geographical area as resource-consuming travel between venues is no longer a limiting factor (Rubin and Rubin 2011). This broadens the potential pool of interview respondents and results in richer data. A more comprehensive discussion of this, and other issues, follows in the *sampling* and *limitations* subsections.

4.2.2 Sampling

The probability sampling techniques used for quantitative studies are rarely appropriate when conducting qualitative research (Marshall 1996). Instead, we use non-probability sampling and, more specifically, purposeful (judgemental) and theoretical sampling here.

The latter describes an iterative sampling technique that involves the choice of new informants based on what has emerged from participants who have already been interviewed. It emanates from the grounded theory approach and is seen as the hallmark of the grounded theory methodology (Glaser and Strauss 1967; Draucker, Martsolf et al. 2007). Unlike probabilistic sampling, which aims to generate a representative pool of subjects, theoretical sampling is concerned with acquiring a fuller understanding of selected participants in order to further the development of conceptual research frameworks.

Purposeful sampling is also a non-probabilistic technique that allows the researcher to select participants based on the richness of the data they perceive will be gained from that particular individual (Patton 2001; Merriam 2009). For instance, in this study all the doctors approached for interview were at consultant level. Purposeful sampling was used here in the early stages of data collection. Since this initial selection inherently involves preconceived notions and tacit knowledge of what may make a specific case valuable to the study, it is not compatible with grounded theory sampling in the strictest sense.

In practical terms, potential participants were first identified using a combination of online medical directories, such as the NHS' *Service Search* and hospital websites' own stroke pages, which often contain details of the unit's staff members in addition to information on areas of special clinical interest. From this, further searches were carried out on the individuals identified e.g. using search engines, professional social media platforms, journal databases to search for publications (as appropriate), in order to create a fuller profile of the potential participant.

On the basis of this, those who were seen as having an active voice in the stroke community were sent a recruitment email (See Appendix IV). Other opinion leaders were identified by the author's attendance at stroke conferences and then contacted in the same manner.

Once initial these interviews had been held, we used a theoretical sampling approach (as outlined above) in the recruitment of further interviewees. This technique, a form of snowballing, continued until data saturation occurred.

Junior health professionals were excluded from participation for the following reasons:

- Information on junior doctors (and other HPs) is less readily available. That is, directories and hospital websites often only name more senior members of the stroke team. Therefore, gaining an insight into the individual's clinical/research interests and, in turn, their suitability for the study is not often feasible. Contact details for more junior staff is usually not attainable.
- As a health services project which focuses on the PPR in light of policy trends emphasising patient involvement and also changes in the way stroke services are delivered, it was felt that the fullest picture would be gained from those that had worked long enough in the NHS to have experienced (and therefore be in a position to fully reflect) on such changes in their working environment.
- More senior HPs are generally more involved in managerial issues and therefore are often better placed to comment holistically on the changing nature of the PPR, with targets and other external pressures for example, being more prominent features of their daily practice.

The limitations of this pool of interviewees is discussed in more detail in the thesis' final chapter.

The sampling strategy used in this study allowed for data triangulation, thereby enhancing the validity of the results. Triangulation is discussed in further detail later in this chapter, within section 4.2.7 on data validation.

4.2.3 Participant recruitment

Recruitment is a vital component of research and one that is often problematic. This is particularly the case when the research domain concerns a vulnerable population, such as stroke patients (Schulz, Wasserman et al. 2006). Indeed, the advice of several stroke specialists was that including patients and/or their carers would not be appropriate in this case, so we decided to focus on interviews with HPs only.

The full implications of not including patients and/or carers in this study are considered in the limitations section at the close of this chapter and in the thesis' concluding chapter also.

We were keen to speak to as many professionals who interact with the stroke patient as possible. As previously shown, the literature on patient information and decision making largely focuses on the interaction between the doctor and patient, as though in isolation. They are not often considered as part of a complex network or system of individuals. Therefore, when selecting our sample, we also ensured that there was representation from non-clinician health professionals, such as occupational therapists.

A formerly overlooked component of stroke care (now incorporated in the Sentinel Audit¹⁵ in the form of a “mood assessment”) is the mental health status of the patient. This can have a profound impact on patient information seeking behaviour and decision making, which is why clinical neuropsychologists were also interviewed (Drake, Deegan et al. 2010).

In summary, just under half (twenty-one out of a total of fifty-one) of those questioned were stroke consultants (medical doctors) with the remainder comprising senior stroke nurses (eight), physiotherapists (five), speech and language therapists (two), occupational therapists

¹⁵ The Royal College of Physicians (RCP) conduct the National Sentinel Stroke Audit every two years to monitor the rate of progress in stroke care services and includes organisational and clinical components.

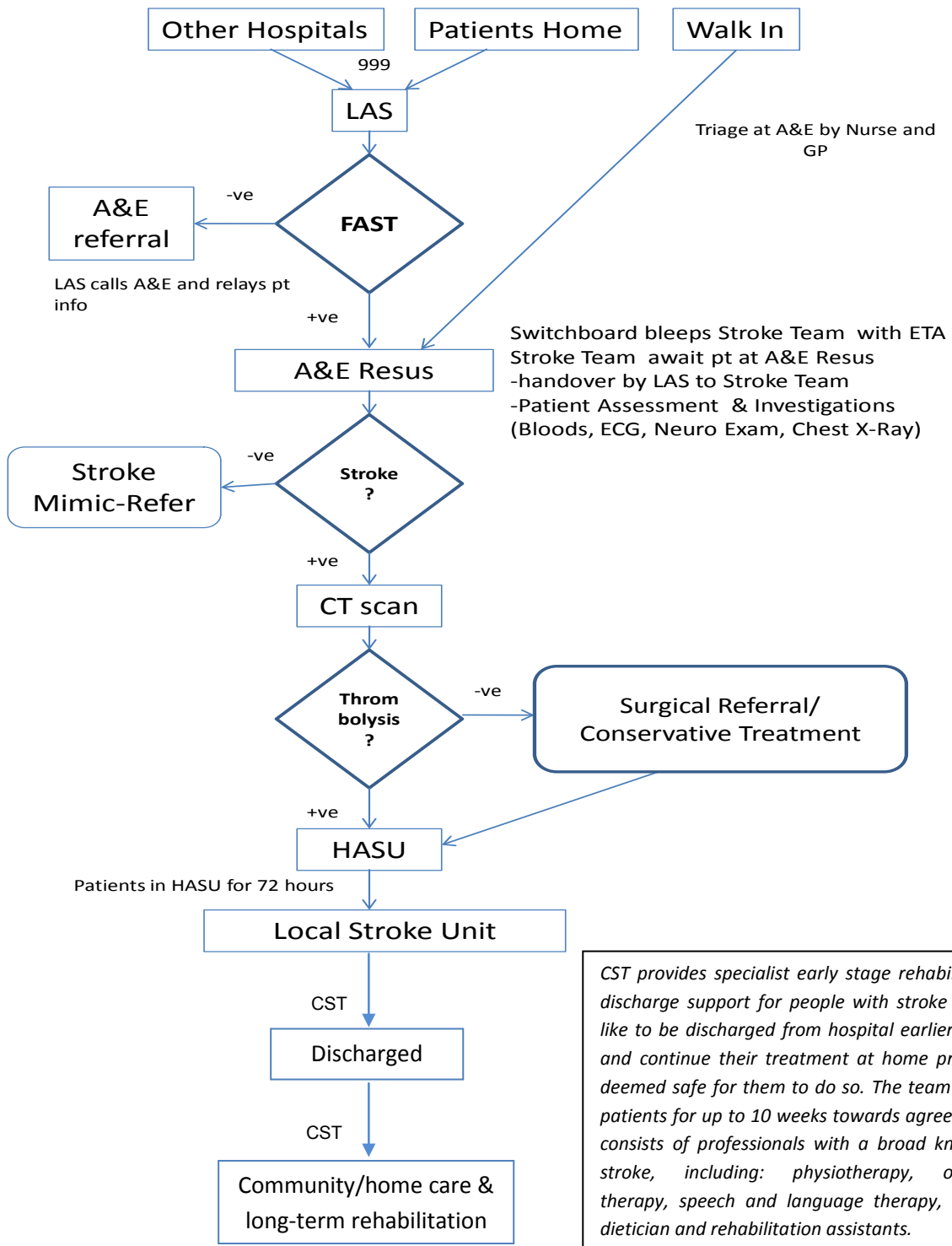
(eight), clinical psychologists (four), a stroke medicine academic (one) a performance improvement manager (one) and a patient representative (one).

The participants' expertise covered the entire acute patient journey, from pre-admission through to discharge and finally care in the community (over months, not years as noted elsewhere). An adapted example of the stroke pathway to include the community phases of care, to reflect the full spectrum of participants in this study, is shown in the figure below. The diversity in interviewees' backgrounds and practice areas lends itself to semi-structured interviewing, as flexibility in questioning (dependent on the context being discussed, for example) is required to fully abstract all relevant data.

Figure 4.2: The stroke pathway

Pathway shown on next page

Charing Cross Acute Stroke Pathway



Adapted from Imperial College Healthcare NHS Trust

4.2.4 Ethical considerations

In accordance with the harmonised edition of the Governance Arrangements for Research Ethics Committees (GAfREC), which was issued by the UK Health Departments in May 2011 and came into effect from 1 September 2011, NHS Ethics approval was not needed for this study.¹⁶

As participants in this study were interviewed from 2012 on, in their professional capacity and no identifiable patient data was discussed, NHS ethical approval was not needed and an internal review from Imperial's REC was deemed sufficient.

Nevertheless, participants were assured that any information they disclosed during the course of the interview would remain strictly confidential and that data generated would only be used in an anonymised fashion and would not lead to easy identification of the informant. This is vitally important not only for upholding standards of good practice in qualitative research, but for freeing the participant to discuss issues openly, without fear of having their position in the system jeopardised (DiCicco-Bloom and Crabtree 2006). However, a balance had to be struck between protecting the participant and allowing rich, detailed data to be fully reported (Kaiser 2009). For this reason, participants were asked to sign a consent form allowing direct quotations from them to be used here (see Appendix III). This form also acted as an agreement to be audio-taped for transcription purposes.

Secondly, there must be sufficient communication of the investigator's intent and objectives for the study (DiCicco-Bloom and Crabtree 2006). Since this was to be a grounded theory

¹⁶Under the harmonised GAfREC, certain types of research no longer require REC review. Previously, under the 2001 edition, REC review was required for research involving NHS staff recruited as research participants by virtue of their professional role. Since 1 September 2011, such research, or equivalent research involving the staff of social care providers, is excluded from the normal remit of RECs under the harmonised edition of GAfREC. For example, a research project limited to administration of questionnaires or interviews with care staff or managers (such as this project) no longer requires review by a REC within the UK Health Departments' Research Ethics Service. Alternative sources of review may be available, for example from a university REC.

inspired approach, it was not known at the outset precisely what data would emerge or was being sought. For this reason, participants could only be given general information on the nature of the study and its broader context, initially. As data was generated and analysed in an iterative way however, more concrete ideas could be provided to the participants that had yet to be interviewed.

We did not communicate our interview guide to the informants ahead of the interview as, on balance, this was viewed as more likely to introduce unwelcomed bias and compromise the authenticity of the responses than yield richer data from the interviewees having had more time to think about some of the questions they would be asked.

Potential respondents were identified using the sampling approach discussed previously and initial contact was made by email. Those that showed an interest in participating were subsequently sent further background information to the study and asked to sign a consent form ahead of arranging a suitable date and time for interview. As is most typically the case with semi-structured interviewing, respondents were only interviewed on one occasion, with the average length of interview being 30 minutes. This is in line with commonly accepted standards (DiCicco-Bloom and Crabtree 2006) and generated over 25 hours of audio data. Owing to the grounded theory inspired research design, there was no predetermined number of interviewees that needed to be questioned; rather, data continued to be gathered until thematic and theoretical saturation had been reached (Miller 1999; Bowen 2008).

4.2.5 Data collection

As outlined already, data collection inspired by grounded theory is invariably guided by theoretical sampling and typically involves interviewing. That is not to say that other means of data collection are not compatible with grounded theory. In fact, any data collection method may be used, from focus groups to informal conversation, so long as the activity

yields data (Dick 2005). The rationale for semi-structured interviewing in this instance has been discussed previously.

One of the most important aspects of effective interviewing is the development of rapport between investigator and respondent (Douglas 1985; Palmer 2007). It is only through the establishment of trust and respect for both the interviewee, and the information which they are sharing, that their personal experiences and perspectives will be properly recounted and relayed. It is precisely this open communication that allows interview research to contribute to our knowledge of the meaning of the human experience and facilitates the conceptualisation of complex social phenomena (Warren and Karner 2005).

Various stages of rapport building have been identified and usually include apprehension, exploration, co-operation and participation (Spradley 1979; Briggs 1986; Rubin and Rubin 2011). Apprehension is overcome by the use of open-ended questions in the early stages of the interview. Exploration sees the researcher actively listening and sharing information to improve bonding with the participant. This leads to the co-operative phase of rapport building, where interviewer and interviewee are comfortable enough to correct one another as necessary, with no fear of causing offence. The highest level of rapport is said to occur when the interviewee is guiding and teaching the interviewer – this is termed participation. Prior to commencing data collection, familiarisation with these concepts and techniques took place to ensure an effective interaction took place with each participant.

All interviews were audio-taped with the permission of each participant. This audio data was then transcribed verbatim by *Way with words*, a group specialising in transcription services, and subsequently checked for fidelity to the original recordings ahead of analysis.

4.2.6 Data analysis

The general analytical approach we took can be described as an inductively driven constant comparative method of qualitative analysis, conducted in line with grounded theory. Constant comparison is the data analytic process whereby each interpretation and finding is compared with existing findings as it emerges from the data analysis (Lewis-Beck, Bryman et al. 2004).

The data analysis itself firstly involved the coding of the verified transcripts. These codes then had to be arranged into first order concepts and second order themes, until final core categories emerged from the data. This analytical process allowed the schematics and constructs shown in the findings chapters to be generated. An overview of the process is contained in Appendix VII. Here, we will look at each of these analytical processes in turn, starting with coding, then concept formation and finally category generation.

Coding

There are different schools of thought on precisely what coding is and what it ought to involve. Hay outlines a two-step process starting with basic coding to identify overarching themes, followed by a more detailed, interpretive code in which more specific trends can be elucidated (Hay 2000). Meanwhile, Allan describes coding as a form of content analysis and views it as a one step process used to find and conceptualise the underlying ideas amongst the “noise” in the data (Allan 2003). He goes on to explain that during analysis of an interview transcript, it will become apparent that the participant is using words and phrases that emphasise an important issue or something of interest to the researcher, and that these should be noted and briefly described each time they arise. To him, this short descriptor phrase is a code and the process is coding (Allan 2003). Since we are using a grounded theory inspired approach here, we will now look in more detail at the coding procedures pertaining to this particular method of data analysis.

In the language of Strauss and Corbin, the first step of data coding in grounded theory analysis is known as open coding (Strauss and Corbin 1990). That is, the formation of initial categories of information about the phenomena under investigation from the collected data. This open coding process involved the “breaking down, examining, comparing, conceptualising, and categorising” of data (Strauss and Corbin 1990).

Concept formation

The next step in data analysis sees codes being grouped together around a common theme. This higher order of commonality is called a concept (Allan 2003). Grounded theorists, however, term this stage of concept formation *axial coding*.

Axial coding is the process by which the data is assembled in new ways following open coding and includes the development of a coding paradigm (or logic diagram) to inductively identify key phenomena and their associated causal conditions and contexts (Strauss and Corbin 1990).

Category generation

The final stage of the analysis involved the generation of even higher orders of commonality, termed categories, through the grouping of concepts. These concepts and categories collectively lead to the emergence of theory (Allan 2003). Grounded theorists refer to this final analytical step of category and theory generation as selective coding. In grounded theory analysis, selective coding concerns the integration of the central themes in the axial coding model, resulting in a unifying core category and theory. It is usually at this point that conditional propositions and hypotheses can be put forward.

The coding procedures outlined above can be carried out by hand or with the use of computer software, such as NVivo. Both are equally valid approaches and the choice is seen to be

largely dependent on the size of the project, the funds and time available, and the inclination and expertise of the researcher (Basit 2003). With that said, there was a fear in this study that the over-reliance on computer-aided coding would restrict, rather than facilitate, the analytical process (Blismas and Dainty 2003) so the extra time was invested in using manual coding techniques.

4.2.7 Data validation

Constant comparative method

It is important to note that grounded theory analysis allows for considerable flexibility and the three types of coding were originally delineated for guidance rather than prescriptive adherence (Strauss and Corbin 1990). Owing to the iterative nature of grounded theory data collection, it follows that the three stages of coding need not necessarily be sequential and do, in reality, often overlap.

In this study, analysis and coding took place each time additional data were collected. In this way, the new insights gained from the analytical process could be used to inform the next cycle of data collection. This process continued between each wave of new data, until a deep understanding of the social phenomenon under investigation had been established.

Reaching the point of theoretical saturation in this way is known as the *constant comparative method* (Glaser 1965). When done properly, constant comparison validates the grounded theory proposed as it continues until no new categories emerge from the data collected. At that point, we can claim that the theory or understanding of the phenomenon is sufficiently developed (Boeije 2002).

Triangulation

The purpose of triangulation in qualitative research is to increase the credibility and validity of the results, by providing a more detailed and balanced picture of the situation under investigation (Altrichter and Feldman 2008).

However, the literature fails to offer a single definition of triangulation with Cohen seeing it as an attempt to map out, or explain more fully, the richness and complexity of human behaviour and social phenomena by studying them from more than one viewpoint (Cohen 1989). Others, however, view it as a method of cross-checking data from multiple sources to search for regularities in the research data (O'Donoghue and Punch 2003).

Overall, whilst there is no agreement on precisely how the term should be defined, it is clear that triangulation is undoubtedly considered to be one way of establishing rigour in social science research; hence its importance here.

Classically, triangulation has been classified into four main categories: data triangulation, investigator triangulation, theory triangulation and methodological triangulation (Denzin 1970). In this study, we use the first three of these forms of triangulation. We will now look at each of these in turn;

- data triangulation: this can be said to have occurred when data is obtained through different sampling strategies, so that segments of data at different times, as well as on a variety of people, are gathered. In this study data triangulation can be seen in the iterative way in which data was collected over a period of time, using both theoretical and purposeful sampling techniques, and the way in which the data collection involved a variety of stroke professionals.

- investigator triangulation: whilst the author was the only researcher in the field gathering data and carried out the initial interpretation of it alone, a research collaborator was involved in independently coding 10 percent of the transcripts in search for agreement. This process is known as inter-rater or inter-coder reliability and it reduces the possibility of a biased interpretation of the data from a single perspective – as such, it is a form of investigator triangulation (Meijer, Verloop et al. 2002; Polit and Beck 2004).
- theoretical triangulation: this refers to the use of more than one theoretical position in interpreting data. Since the independent coder in this study was from another discipline, bringing another perspective to the data set, theoretical triangulation was achieved here (Guion, Diehl et al. 2011).

However, since semi-structured, in-depth interviewing by telephone was the only method used to gather the study's data, no methodological triangulation occurred. The limitations of telephone interviewing, and other issues, are addressed in greater detail in the limitations section which follows.

4.2.8 Limitations

Here we deal with limitations and potential drawbacks in the methods used. A fuller exposition of the study's limitations as a whole follows in the conclusion chapter.

A major concern with the use of in-depth interviewing as a method of data collection is the unwitting introduction of a researcher's own presuppositions and biases. This would be a deviation from grounded theory in the strictest sense and, left unchecked, would also invalidate the data collected.

The first potential problem, an incorrect application of grounded theory, was resolved by describing the approach here as *inspired* by grounded theory rather than pure grounded theory. The second difficulty, the danger of invalidating the results, was overcome by an awareness on the part of the author that their involvement as an active participant in the study would shape the nature of the process and the knowledge produced through it; a concept known as reflexivity (King and Horrocks 2010).

The author had to reflect on the nature of his involvement just as he considered the meaning of his participants' contributions. There are numerous suggestions in the literature as to how such reflection can be facilitated (Ahern 1999; Watt 2007). Here, the author used the strategy of listening to some of the taped interviews with a focus on his own performance as an interviewer, so that any biases could be noted and mitigated in subsequent interviews (King and Horrocks 2010).

As mentioned previously, the interviews were all conducted by telephone mainly for practical and budgetary reasons, as the participants were recruited from across the UK.

Some researchers suggest that telephone interviews restrict the development of rapport seen in the "natural encounter" of a face to face interview (Irvine, Drew et al. 2013). Opdenakker describes telephone interviewing as an "asynchronous communication of place" and cites the reduction in social cues (such as body language) and an inability to standardise the interview situation as potentially disadvantageous (Opdenakker 2006).

However, he goes on to say that other social cues, such as voice and intonation, are still available and that, dependent on the research problem, social cues and standardisation may be less important or not important at all as information sources for the interviewer (Opdenakker 2006).

With the qualitative approach adopted here, it was not such a concern that the interview situation could not be controlled or ‘standardised’ for all participants. In fact, only one interview with a hospital consultant (who had remained visible on the ward) had to be ended abruptly as she attended to a patient. The phone interview resumed shortly thereafter. Clearly, had the interview been taking place face to face in a setting that could be controlled, such as an office, this would not have occurred. Having said that, such distractions have also been reported during in-person (or face to face) interviews (Sturges and Hanrahan 2004).

Qualitative telephone data have been considered to be vivid, detailed and of high quality by many health service researchers (Kavanaugh and Ayres 1998; Chapple 1999; Sturges and Hanrahan 2004). In addition to the advantages of telephone interviewing in contrast with in-person interviews that we have already mentioned, there is also the possibility of unobtrusive note-taking (Tausig and Freeman 1988; Carr and Worth 2001), both participants can be on “their own turf” (McCoyd and Kerson 2006), more anonymity and privacy is obtainable (Sweet 2002), there is decreased social pressure and enhanced rapport (McCoyd and Kerson 2006).

Nevertheless, reported limitations may include no telephone coverage for some participants (Carr and Worth 2001), an absence of non-verbal or visual cues (Garbett and McCormack 2001; Irvine 2011; Lechuga 2012) and the potential for participant distraction by unrelated activities in their environments (McCoyd and Kerson 2006; Opdenakker 2006) [as previously discussed]. Another reported disadvantage according to some researchers is that telephone interviews must be kept short compared to face-to-face interviews, limiting the opportunity for in-depth discussion (Chapple 1999; Garbett and McCormack 2001; Sweet 2002; Sturges and Hanrahan 2004; Creswell 2008).

However, little evidence is provided in support of this claim in these studies. Indeed, other researchers have reported that their telephone interviews typically last 1.5-2 hours, with little participant fatigue (McCoyd and Kerson 2006). In this study, the average interview was 30 minutes as originally envisaged and intended – although some participants were questioned for over an hour. Overall, it was felt that given the nature of the research context (hospitals and other healthcare settings, which have closed or limited access to people) insisting on face to face interviews would have been incompatible with the ambitions of this current study.

It is worth noting that another limitation of telephone interviews (that would only become apparent should the work be extended to include patients) is one of consistency in the data collection approach. Stroke affects people in a wide variety of ways, resulting in varying degrees of incapacity and a heterogeneous patient group. Communication difficulties are common and often severe, so maintaining methodological consistency by insisting on a telephone interview will clearly not be a viable option, should this work be extended to include patients. A summary table showing the number of participants for different stroke care roles is shown below.

Table 4.2: A summary of the study’s participants

Participant role	Number of participants
Academic	1
Neuropsychologist	4
Occupational therapist	8
(Patient representative)	(1)
Performance improvement manager	1
Physiotherapist	5
Speech and language therapist	2
Stroke consultant	21
Stroke nurse	8

Note: the participants were classified according to the main capacity in which they were being interviewed. For example, a number of the stroke consultants that were interviewed are professors of stroke medicine and/or clinical researchers too. They have been enumerated here as stroke consultants rather than academics as the focus of this study draws more heavily on their expertise as practicing physicians rather than their clinical research activities as academics. Similarly, one of the neuropsychologists initially worked as a physiotherapist. However, since their psychological expertise informed their responses more than their physiotherapy background, they are listed above amongst the neuropsychologists. As explained previously, the patient representative was approached before the main fieldwork and data collection had started, for the purpose of additional background material only. As mentioned, patients and carers were not among those interviewed in this project. The advice from leading stroke specialists was that recruiting patients and families/carers would not have been appropriate in this case and to fulfil the vision of the study.

In an era when PPI is expected, if not mandated, the exclusion of patients clearly limits the study in a number of ways. As the voices of patients are integral to any health service proposals, this study is naturally limited in what it is able to offer in terms of policy and practice recommendations. Furthermore, any findings regarding the nature of the PPR are also naturally limited in that they are derived only from the perspectives of HPs.

That said, this study will still be able to contribute significantly to these knowledge and policy/practice debates. Indeed, studies from the perspective of HPs are often lacking in the field of stroke, as the literature review has shown and as we shall explore in depth in the discussion chapter.

Moreover, whilst not providing a whole picture as a stand-alone project, the aim is that the research here will provide a comprehensive insight into one side of the coin and, in so doing, will provide the foundations, insights and tools necessary to explore the other side in future work also.

As stroke is a condition encompassing a spectrum of severity and resultant deficiencies, interviewing a small sample of patients, and then considering them to be representative of all

stroke patients, is itself fraught with danger. To avoid this, what tends to happen is that researchers will choose instead to focus on a specific subtype of stroke, e.g. those with aphasia.

However, the problem characterising the findings from these types of studies is that they are too narrow in focus and cannot fairly speak to the broader issues that concern the type of health service management research we are looking to conduct here. In a case study where a specific subgroup of stroke patients had been recruited, the HPs would have to be questioned on their interactions with only that particular subset of stroke patients, thereby severely restricting the scope of the project's findings.

Indeed, previous stroke studies have demonstrated the difficulty in gaining sufficient numbers of participants when patients/carers *were* interviewed, regardless of whether the patients were recruited according to a predetermined, stroke-type inclusion/exclusion criteria (Kerr, Hilari et al. 2010).

Any research in this arena is therefore compromised in some way and there is no right or wrong approach, as long as limitations are recognised and their implications are fully understood and acknowledged. Findings presented later in the thesis will be interpreted in light of what has been stated here.

4.3 Summary

In this chapter, we have delineated the methodology and methods that we will be using to answer the study's two research questions. As part of this, we have discussed the work's epistemological and ontological positions and carried out an assessment of its methodological limitations. Here, we have also described the research design and provided details of how the study will actually be conducted, how data will be generated and how it will be analysed. In

the two chapters to follow, we will see the results of this data analysis, as we present the detailed findings that have emerged from the methodological approach described in this chapter.

Chapter Five – Findings and Analysis,
Part One: Factors influencing patient
information provision and involvement

Findings and Analysis, Part One: Factors influencing patient information provision and involvement

5 Introduction

The research findings have been divided into two chapters; part one and part two. The first of these two chapters describes the main findings pertaining to the first research question, whilst the second part looks at findings relating to the second research question.

In the previous chapter we looked at data collection and data analysis. This chapter will look at the findings from this approach in detail. Headings will comprise core categories, sub-headings will show second order themes and examples of major first order concepts are shown in schematic diagrams at the start of each section. This coding schema has been developed in the way we described in the methods chapter; an example of how the constructs were derived is included in the Appendix VII.

The inclusion of excerpts from interview transcripts enables us to understand better how the concepts and themes relating to each category were formed and helps to clarify links between data, researcher interpretation and conclusions (Long and Godfrey 2004). Wherever possible, concepts have been illustrated using the interviewees' own words. This serves several useful purposes; namely, to enable the participant's voice, enhance readability, improve transparency of results and ultimately deepen the reader's understanding (Corden and Sainsbury 2006).

We will also revisit parts of the literature to place the research findings pertaining to RQ1 in their proper context. In addition to the purely descriptive findings that will be presented, we will also analyse the study's results in light of what is currently known. To answer both parts of the first research question in this chapter, we will assess *how* the factors identified in

response to RQ1a have their influence. Below is a reminder of both parts of the first research question:

Research question one

RQ1a: What factors influence information provision and involvement of patients by health professionals in stroke care?

RQ1b: How do the identified factors affect information provision and involvement of patients in stroke care?

The three core categories that emerge from the data analysis as most relevant in response to RQ1 are displayed in the table which follows.

Table 5.1: Core categories relating to the first research question

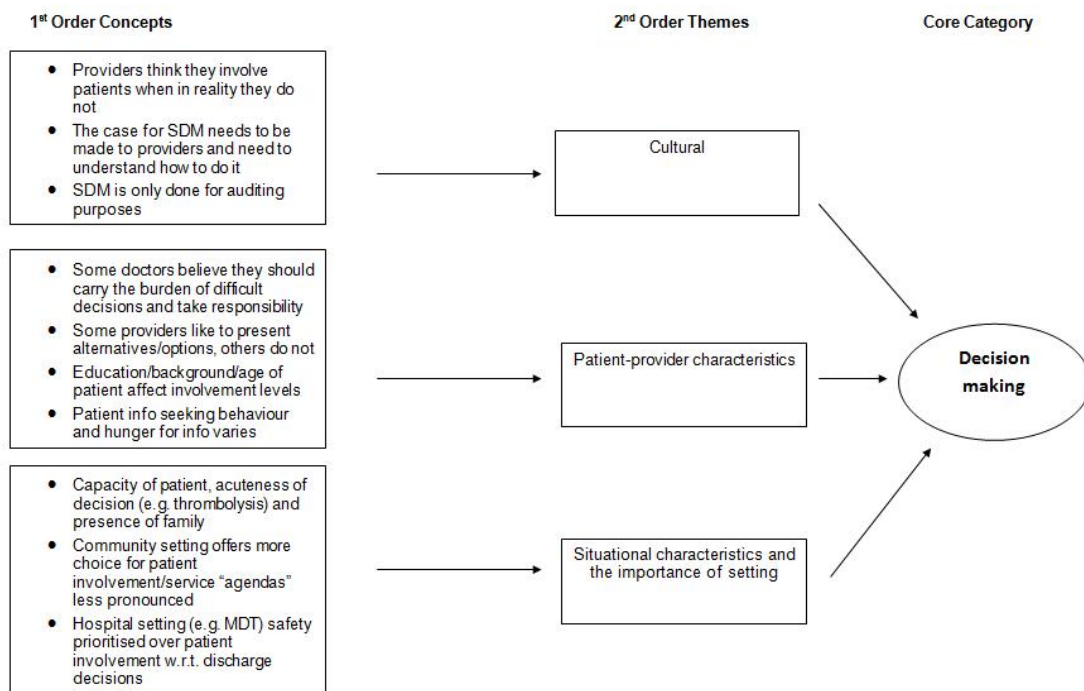
Core category	Second order theme
<i>Decision making</i>	Cultural
	Patient-provider characteristics
	Situational characteristics and the importance of setting
<i>Patient information</i>	Inhomogeneous group (patients)
	Timing of information
	Sources of information
<i>PPR</i>	Cultural changes
	Patient-provider characteristics
	External influences

What follows is an exposition of each of these core categories, with participant quotations used to illustrate individual points.

5.1 Decision making in healthcare (core category)

A core category emerging from the data was decision making and the processes and issues surrounding this within stroke care. The overall coding structure for this core category has been summarised in the schematic below.

Figure 5.1 Decision making – overall coding structure



Note that the first order concepts shown in the schematic are examples only and are by no means intended to be an exhaustive list of the concepts that emerged from the data, as we have shall see from the quotations which follow.

5.1.1 Cultural¹⁷ issues and decision making (second order theme)

Many respondents suggested that there is now an increasing awareness of the need to involve patients in decisions about their care, albeit without the associated knowledge of how to implement this in real terms. Consistency of implementation was also cited as a problem. One performance improvement manager said:

*I think [shared decision making] is on the increase. Multi-disciplinary teams are still settling down, even working with each other, let alone working with patients and carers but it is definitely something that is on the horizon for the teams I've been working with. And the involvement varies, in terms of quality and quantity and **I don't think the stroke teams necessarily realise the different mechanisms you can use to get patient involvement and patient decision making. It doesn't have to be just an audit that's given to the patient, it can be different mechanisms. I don't think they necessarily understand that** (Performance improvement manager 1)*

The same stroke manager goes further by suggesting that some professionals do not even recognise why shared decision making, and other patient involvement strategies, are important in the first place. We see from his comment that far from upholding patient involvement as a central tenet of an improved care culture, it only really occurs as a by-product of the current audit culture¹⁸:

*Well in the first instance **I don't think the stroke teams necessarily understand, first of all, why it's a good practice to do it [SDM] and secondly how they could go about doing it. I think it is one of the things they don't know what they don't know and they are only really doing it because it's recorded in the log quality audit** (Performance improvement manager 1)*

¹⁷ By culture, we are referring here to a *culture of care* that recognises and promotes patient involvement.

¹⁸ The ways in which this audit culture affects information provision too will be explored later.

The view that stroke teams do not understand why shared decision making is important was challenged, however, by several hospital consultants. They were able to describe in detail exactly why patient involvement in stroke care decisions is important. Others noted that there is a gulf between perception and reality. That is, many professionals feel that they include patients in decisions about their care when in reality they do not. These findings are shown in the table of excerpts below:

Table 5.2: Cultural issues and decision making excerpts (I)

Interview excerpt	First order concept	Second order theme	Core category	Interviewee
<p><i>Nothing else is quite like stroke with regards to how much the patient and the family is involved in every decision about them. For example, a chronic lung condition which they've had for 20 years, so a small change in pattern in their condition that they've got time to reflect on. Stroke is not like that at all. Stroke is big decisions that are going to necessitate major life changes for everyone and for that reason the patients have to be involved if they're able to be involved in that decision. So it is a life changing illness. And the thing which people don't always appreciate is it's a life changing illness in one day, and for that reason I think, yes, sharing decisions is very important. But it's not always possible</i></p>	<p>Difficulty implementing shared decision making, even when its importance is acknowledged</p>	<p>Cultural</p>	<p>Decision making</p>	<p>Stroke consultant 16</p>
<p><i>I've found ... what people report and what they do are two different things. So while they will tell professionals, they'll say, oh yes, we do that, actually in reality I don't think we do it [include patients in decisions] as well as what we think we do it, or that we do it at all</i></p>	<p>Providers think they involve patients when in reality they do not</p>	<p>Cultural</p>	<p>Decision making</p>	<p>Stroke nurse 4</p>
<p><i>I think as health professionals we want to do shared decision-making, and again I think at times we think we do it, but not in the true sense of shared decision-making...I mean, patients are involved in the sense that they have multi-disciplinary team meetings, especially in the rehab phase, and we discuss goals, or where they go in and potentially what the patient is or isn't, maybe, going to achieve in that inpatient stay. But the true sense of shared decision-making is, isn't it, that everything is discussed with the patient and you come to a, you know, a decision between yourselves, but I don't think that happens</i></p>	<p>Providers think they involve patients when in reality they do not</p>	<p>Cultural</p>	<p>Decision making</p>	<p>Stroke nurse 4</p>
<p><i>Unless those MDT environments actually genuinely include the person who's had a stroke and their main carer or nominated person in those discussions and actually actively listen and take account of what they have to say then shared decision making is still not central to stroke patients</i></p>	<p>SDM superficially implemented; providers need to understand how to do it better</p>	<p>Cultural</p>	<p>Decision making</p>	<p>Stroke nurse 5</p>

Indeed, the extent to which we have moved away from a paternalistic model of care was the subject of debate for many respondents, with little agreement. Some saw no movement away from paternalistic models of decision making, whilst others noted small, but significant, cultural shifts away from paternalism and changes in expectations on the part of patients and providers alike. There was also the perception that there have been cultural changes in the way decisions are approached now. These findings are shown in the table which follows:

Table 5.3: Cultural issues and decision making excerpts (II)

Interview excerpt	First order concept	Second order theme	Core category	Interviewee
<i>It's quite difficult to engage them in making decisions, and I think that the starting point these days is very much that doctors try to persuade patients that they should be involved in decisions (Stroke consultant 13)</i>	It is the patients themselves that need to be encouraged to be involved in decisions	Cultural	Decision making	Stroke consultant 13
<i>I would probably say it's probably more a traditional medical model, in the sense that I wouldn't discuss a lot of decisions with patients or call it patient-led (Stroke nurse 2)</i>	The case for SDM needs to be made to providers	Cultural	Decision making	Stroke nurse 2
<i>I suppose, we're all very good at goal setting, but how much again do we involve the patient in that? I'm sure that the majority of the goals we set are very therapist led and a lot of our patients don't even know what goals we've set them, so I think it's about having a bit more of a partnership in their rehab, the patient and the therapist, and it being a bit more of an equal relationship rather than a kind of me telling you or prescribing to you; I think that's quite important, especially now that the patients are getting into the era that they want to, they're going to search for stuff, they're going to ask more questions on things so I think we can't just tell anyone, we need to involve and empower patients a bit more (OT 1)</i>	Patients do want to be more involved and the culture of care has to change to reflect this more	Cultural	Decision making	OT 1
<i>I can remember when we used to use streptokinase for heart attacks, you never used to be asking people to consent to that; you'd just go ahead and do it because you knew it was the best thing. But, of course, nowadays we talk to our patients about the treatment, but it's really whether the benefits are going to outweigh any harm to that patient (Stroke nurse 6)</i>	Culture of care has changed: starting point now is that patients should be informed and involved in decisions	Cultural	Decision making	Stroke nurse 6

5.1.2 Characteristics of the individual patient and provider (second order theme)

The level of patient involvement with care decisions appears to be dependent on, amongst other things, the individual provider's stance and approach to care, as well as the patient's own background and personality.

With respect to the former, a spectrum appears to exist from the professionals who make decisions paternalistically, through to those who see themselves as taking the responsibility for a decision after a full discussion with the patient, to the professionals who are constantly seeking ways and opportunities to involve patients. Examples of some of these differing levels of involvement are illustrated below. When asked if information empowers patients to make decisions about their treatment, one stroke nurse responded:

Haven't we already decided their treatment? What we do is we give information about the treatment that we're providing. A lot of the time, we start people on warfarin. These are major drugs so it's not so much giving them information about treatment options, because there isn't really [one]. I'm not going to sit down and discuss [medications] directly with the patient. I'm going to say, we're starting you on the water tablets for your blood pressure. And then, obviously, give them an information leaflet about blood pressure, so they can know a little bit more about blood pressure or there's another leaflet on blood pressure tablets, so I might give them that. So it's not about treatment options (Stroke nurse 6)

The tone of the response, in addition to an apparent unwillingness to discuss medications with a patient directly for instance, are suggestive of paternalistic practice. A step along from this paternalistic attitude can be shown through one doctor's approach to thrombolysis decisions. They thought it was best to remove the "burden" of responsibility from the patient by making the decision for them, whilst still discussing it in detail first, in partnership with the patient and/or their carer. In this way, decisions could still be made by the doctor, without

being paternalistic in the HP's view. One consultant felt this approach was important to ensure patients would not be able to blame themselves for any wrong decision made:

*It's too simplistic to say, it's not the doctor's decision, it's the patient's decision or the family's decision, because the burden of that decision has to be on the clinician's shoulders. **Those people must not be allowed to blame themselves for making the wrong decision.** So if I were to say to someone, would you like to run a thrombolysis or not, she's got a one in 20 chance of having a fatal bleed, that's a terrible decision to lay on someone's shoulders. So what I say to them is, it's my decision, I'm going to make the decision. I'm not going to make the decision without discussing it in detail with you, but the burden of the responsibility for the decision is on my shoulders. Now I think that's really important. What I'm trying to put across is that **the decision making is always a partnership, but it will vary, according to the state of the patient and their relative representatives.** Sometimes, some of that decision making has to be made by a doctor, but it's not paternalistic (Stroke consultant 17)*

Finally, many doctors appeared to prefer a more patient-led approach. For example, one doctor explained that after agreeing on what the treatment options are and fully exploring these with the patient, in their view the physician should then support the patient with whatever decision they had arrived at. Similarly, another stroke consultant outlined their approach as informing the patient of the "pros and cons" of a particular decision (whilst presenting the patient with alternatives if available), then allowing them time to think about it, before supporting the patient in whatever course of action they decide to pursue. Many doctors were also keen to express that they even try to involve incapacitated patients, rather than instantly deferring to family members or acting paternalistically. To this end, one consultant commented that:

Incapacitated patients should still be involved if and when possible in decision making and we're quite careful about that and reassessing capacity on a frequent basis (Stroke consultant 11)

The patient's own background and preferences also impact the level of involvement they choose, or can expect to have with care decisions. For instance, the level of discussion with the health provider often appeared to vary according to the professional's perception of the patient's intelligence and education (separate from or in addition to any communication difficulties they may be experiencing as a result of their stroke) Similarly, doctors generally agreed that an individual patient's ability to understand what is being discussed is an important factor in how involved they can be in their care. To illustrate these points, this is what one stroke consultants had to say:

At one extreme, there's a group of medical, or nursing colleagues, or therapist colleagues, who have a high level of understanding to start with, get a very detailed discussion about the stroke, and then clearly is going to have the raw materials to start feeling very involved in decisions about their own care. At the other extreme, there's going to be patients who may be on the one hand, are not able to take information in at anything other than a fairly superficial level, either because of dysphasia or because of their educational background or their intelligence, and that if you find yourself pitching things at a very basic level, then it's quite likely, anecdotally that these are the patients who are going to trust their doctors to make decisions about everything... Their natural starting point in any discussion about their care is, well, I'll leave it to you, doctor. I think it's up to you (Stroke consultant 13)

Another doctor agreed that an individual patient's ability to understand what is being discussed is an important factor in how involved they can be in their care:

If it is clear that they aren't fully understanding what we've said, it's very hard for them to get involved in a complex decision (Stroke consultant 12)

5.1.3 Context in which decisions are being made (second order theme)

Several informants felt that context¹⁹ was the key issue and that the level of patient involvement in any given situation very much depended on the exact circumstances. For instance, many health professionals felt that the capacity of the patient and the acuteness of

¹⁹ At both the organisational and individual level.

the decision at hand dictated the extent to which patients could be included in care. Select excerpts illustrating their thoughts are shown in the table below:

Table 5.4: Context in which decisions are being made excerpts

Interview excerpt	First order concept	Second order theme	Core category	Interviewee
<p><i>If they're able to, they participate and they have full, sort of, control over what their goals are, and it takes a fair amount of skill, I would say, to facilitate that. People with aphasia and communication problems are actively engaged in that process and we use accessible forms of communication to help them and also, the staff will use communication support to help them decide on their own goals. Some patients... we don't tend to use goal setting in the very acute stage, because people are still obviously being medically managed. But as soon as they're identified as requiring some form of rehabilitation, that process will begin. Some patients who are markedly cognitively impaired may have their family or carers act as their advocate for goal setting</i></p>	<p>Capacity of patient and acuteness of decision are important determinants of patient involvement</p>	<p>Situational characteristics and the importance of setting</p>	<p>Decision making</p>	<p>OT 5</p>
<p><i>In a hyper acute setting, I really don't think that we're in that kind of...that's extremely difficult to take on information and to process it enough to then start to make a contribution to their ongoing care, is not happening in the time frame that works for that, so a very occasional mild stroke in a very articulate patient, that patient can then take on a lot of information and they're able to make intelligent decisions about how things are going to move forward, but that would be extremely, not extremely but relatively unusual</i></p>	<p>Capacity of patient and acuteness of decision are important determinants of patient involvement</p>	<p>Situational characteristics and the importance of setting</p>	<p>Decision making</p>	<p>Stroke consultant 13</p>
<p><i>Patient involvement depends on the context, because if it is acute, quite frankly, people are so dazed, it is such a frightening experience. Someone who was well in</i></p>	<p>Capacity of patient and acuteness of</p>	<p>Situational characteristics</p>	<p>Decision making</p>	<p>Stroke consultant 10</p>

<p><i>the supermarket and is struck down with an episode of inability to speak or maybe confusion, maybe dramatic left sided, right sided weakness, it's something which is frightening for the family, that's not a time to negotiate whether you should treat or not, you obviously should treat. So you explain to them, you explain to them, the problem is that most likely this person has suffered a stroke, we need to confirm whether it is a bleed or a clot, and we use as simple terms as possible, we're going to do a CT scan and once we've done the CT scan we will then let you know. And then obviously they want to know from you what the prognosis is, because at that particular point in time, it is recovering function, making them feel better. Yes. So the context is crucial</i></p>	<p>decision are important determinants of patient involvement</p>	<p>and the importance of setting</p>		
<p><i>I think shared decision making should have a big part to play in stroke care, I think it should have a big part to play in any kind of health care really. I think probably in sort of the acute stages of stroke, particularly when people are in hospital, and just sometimes through the nature of what's happened to them, sometimes patients aren't always in the right, not that they're not in the right frame of mind, but I think it's often very overwhelming, and it's quite hard for them to sort of really take ownership and take part in decision making. So I feel like probably professionals tend to do a lot more at that stage, but that's not necessarily right. I think that's just how it tends to happen, really</i></p>	<p>Capacity of patient and acuteness of decision are important determinants of patient involvement</p>	<p>Situational characteristics and the importance of setting</p>	<p>Decision making</p>	<p>Physio. 1</p>

Others were keen to emphasise the importance of setting on patient inclusion, noting that decisions in the community and about discharge to the community tended to be more patient-led than those in the hospital environment, where service and practitioner agendas were felt to be more evident. Others commented on the disparity between provider and patient goals and felt that this was less pronounced in the community setting; an issue explored further in the discussion chapter. Additionally, findings suggest that patients only become fully involved in decision-making around the time of discharge, as this quotation shows:

*The patient properly gets involved in decision-making when they're coming up for discharge from the acute setting. Probably up until that point it's more led by the professionals. Hopefully each of the professionals should be speaking to the patients in their treatment sessions, as to what decisions are being made and what their opinions are, but I wouldn't necessarily say that the patients are influencing the decisions up until discharge, really. **Discharge decisions ... should definitely involve the patient and the family.** I guess that's more difficult when the patient's really quite severely affected, so the patient's got significant cognitive and language problems it's more difficult to engage them. But I would hope we make every attempt over an appropriate period of time to involve the patient in that and get their opinions on it. That might involve lots of different professionals, so OTs, other therapists and social services all seeing the patient together (Occupational therapist 4)*

One consultant clinical neuropsychologist commented on the disparity between provider and patient goals and felt that this was less pronounced in the community setting:

*Further down the line, again, it depends on hospital setting. Some of our wards have goal setting, not all, but most do, formalized goal setting with key workers setting goals for people. Trying to involve them as much as possible and I'm not sure that patients are all involved as much as they could be, a lot of the time. The treatment goals that are set are quite therapist-focused and the way they work, medical-speak. I think the wards would say they try for that not to happen. People should be involved if possible. **Often goals are about mobilizing 50 yards, or being able to transfer from wheelchair to chair, and they're not necessarily people's goals. I think we get that right more in a community setting where people get more choice** (Neuropsychologist 2)*

This view was mirrored by the majority of the nurses that were interviewed. For instance, one stroke nurse specialist made the following observation:

*Further goals maybe tend to be discussed more, but whether it's where they ask the patients, what do you want to do, I'm not sure, because I think as well they're governed, often, by organisational issues and this issues of getting patients... **I think there's a lot of goal-setting around getting patients up and walking, rather than asking them, is that really what you want to do?** (Stroke nurse 4)*

Finally, a stroke care researcher highlighted the importance of setting on levels of patient involvement through the following statement:

I think that there's a will on the part of the clinicians to be very patient-centred, certainly more in the community setting than in the acute setting. In the acute setting, it's probably more of a steer from the professional in terms of how that patient is managed, because it's at the start of their recovery post-stroke, often, and people are looking for that sort of support from professionals (Academic 1)

5.1.4 Summary of key points relating to decision making as a core category

The interviews suggest there has been an increasing awareness of the need for professionals to involve patients in decisions about their care. However, a gulf between perception and reality exists. Professionals may think they involve patients when in reality they are not. It is therefore unclear whether and how far (if at all) we have moved away from a paternalistic model of decision making. Indeed, the level of patient involvement appears to be dependent on (amongst other things) the individual provider's stance and approach to care, as well as the patient's own background and personality.

Moreover, several informants felt that context was a key issue and that the level of patient involvement in any given situation very much depended on the exact circumstances (e.g. capacity of the patient, acuteness of the decision that has to be made). The importance of

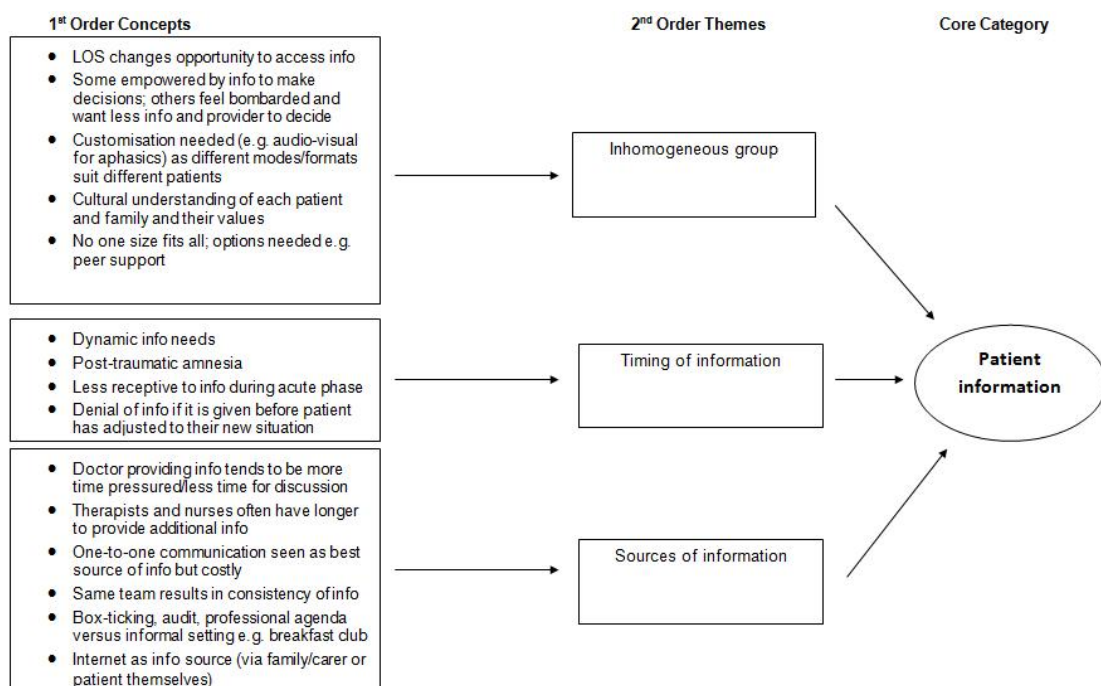
setting on patient involvement was therefore also noted. That is, decisions in the community and about discharge to the community tended to be more patient-led than those in the hospital environment, where service and practitioner agendas were felt to be more evident.

Additionally, there appears to be a disparity between provider and patient goals, which was felt to be less pronounced in the community setting. How these findings sit in the light of the literature and their importance in helping to explain the PPR in stroke (and how they may inform policy and practice in stroke) will be explored in the analysis at the end of the chapter.

5.2 Patient information (core category)

The second core category to emerge from the data was information provision to patients from professionals within stroke care. The overall coding structure for this core category has been summarised in the schematic below.

Figure 5.2: Patient information – overall coding structure



5.2.1 Patient heterogeneity (second order theme)

Respondents generally felt that it was too simplistic to treat stroke patients as one homogeneous group of people, with the same information requirements, expectations and access. On the last point, for instance, one stroke nurse specialist felt that disparities in the length of stay (LOS) between patients often results in different access to information:

*A lot of our patients are in for a day and they don't get access to good information. So for those patients, blood pressure, driving, I will try and see them very, very quickly and give them an information leaflet, but that's all they leave with. And if they're in the rehab process or the stroke unit pathway, then they can have access to lots of other information, like Stroke Association stuff. Obviously, their deficits are picked up and we would give them information about that. The relatives are given information ... contact numbers on discharge. So I think **the ones who stay in for a bit longer have better access to information** (Stroke nurse 6)*

As we have discussed in the literature review, there is an ongoing debate surrounding information provision and patient empowerment. This was addressed by several informants, with little agreement on whether information helped or hindered patient involvement. Perhaps unsurprisingly, the main consensus to emerge on the matter, however, was the view that different patients respond differently to information and have individual information requirements. This can be seen from the following table:

Table 5.5: Patient heterogeneity excerpts

Interview excerpt	Interviewee
<p><i>Giving more information makes it more of an informed choice because some patients will deny having had information, although you know absolutely you've given it to them, and it's because of that bombardment sometimes, I think, that people will just switch off. So it's about being select, making sure that people have access to information again if they want to, and being prepared to share it with them again in a variety of formats, I suppose</i></p>	<p>Occupational therapist 5</p>

<p><i>There is a sort of handing over of responsibility to the medic and saying doctor knows best, I'll just go with whatever. Other patients are much more actively engaged in their care and would want to know the benefits and risks of what are the treatments, what's happened to them, want to know what alternatives are. They're information hungry. Having that information to hand, if you had the choice of either too much information or too little information I think too much information is the easiest one because then the choice of not reading that or being aware of the information is still the patient's, it's not the healthcare providers. I would much rather provide more information than less information. By providing less information you are disempowering the patient again, you are completely cutting out them as the decision maker. It is very much a medical model of well, we know best, we'll tell you what we think you need to know. Actually that's for them to decide</i></p>	<p>Performance improvement manager 1</p>
<p><i>Yes, you've got to be careful about how much is more [information]. They can't be flooded because then they just, they switch off if they're flooded with information; if they have the right information, and it is, it is all about being tailored to their needs, if they've got the information that the clinical staff feel is appropriate for them then that should empower them to go forward</i></p>	<p>Stroke consultant 2</p>
<p><i>Sometimes giving information can be quite a dangerous thing, in that you can completely medicalise certain patients. Somebody who was previously reasonably well, just because they have one TIA, next thing you know, they stop going to their swim, they stop doing their exercises, because they think that they've got all the problems in the world, I think. Then instead of enabling them with information, you are potentially disabling them with information as well</i></p>	<p>Stroke consultant 9</p>
<p><i>I think more information is good, and that absolutely it can empower people, provided it's given to them in an appropriate way, whether it's verbal, written, whether it's aphasia-friendly, shared with the family, you know, I think it's not just a case of giving somebody a leaflet and hoping they'll go away and read it on their own. It's very much, having assessed somebody, identifying how best to impart that information to the person and the family, and then they have the choice and they should be empowered to make the decision that's right for them</i></p>	<p>Occupational therapist 2</p>
<p><i>From the patient's perspective, I'm not sure. I think some of them do, are empowered by it, but often it's the ones who are cognitively more able right from the start. And also – and this might... I don't know – it's often the ones who are in a higher social class anyway, or have a more professional job, people who are hungry for information in their everyday lives, I think often maybe go out... and also I think it depends on the personality. Some people are controllers, aren't they, and they need to have control over everything, and then the way they do that is through information. So they will information-gather</i></p>	<p>Stroke nurse 4</p>

Building on the idea that information may empower some patients to be more involved in their care, whilst having little or the opposite effect for others, is the notion that information

needs to be customised to suit different patients, particularly to take into account their different educational and social backgrounds²⁰. For instance, one doctor observed:

Every patient you see, you need to make a judgement about what level you can realistically deliver the information at. You're trying to work out whether the patient is following what you're saying, and there are some patients in whom you'd have to present things in a very simplistic framework and other patients who may be doctors, who clearly you're starting from a high level, in terms of their background knowledge, and there's going to be a correlation between the level of information that you feel you can realistically deliver, and how involved that patient is going to be in their care anyway, so if you were trying to measure this in a formal way, there would be a huge compound there...the answer is if you've given a patient practically no information, it's really not possible for them to be engaged in their care (Stroke consultant 13)

Echoing this need to tailor the information sharing and discussion to suit the individual patient, is the following comment taken from an interview with another stroke physician:

I think that you should give them enough information for their level of understanding; some patients will need an awful lot of information, and they will need it down to the nth degree, for example I have a lady who researches every little thing, and that is fine – I will deliver information at that level then. But there are others who would want it kept very simplistic, so I think that has to be an individual patient need and some patients, I will guide them to articles and say I suggest you read this, I suggest you do that; I think that would depend on the discussion I had with the individual (Stroke consultant 14)

Reflecting the heterogeneity of stroke patients as a group, several respondents felt that patients should be presented with options for information provision and that there should not be a 'one size fits all' approach to patient information. Indeed, others even hinted that "care" (in the sense of being there for the patient/family and listening to their ideas, concerns and expectations to aid involvement) might be more important than standardised information at

²⁰How information provision and involvement are related will be discussed in more detail later in the thesis; as the excerpt indicates, it appears that information is necessary but not sufficient for patient involvement and any attempt to measure the concepts is thwart with difficult owing (in no small part) to confounding error.

times, or at least that health professionals should not provide information without such care in place, as the two are closely linked. Indeed, their comments tie in with the idea of a “culture of care” mentioned previously and are expressed below:

You're never going to find one informational intervention that works for everybody, but you want as many options as possible (Physiotherapist 2)

*I think any form of communication has potential. I don't get caught up in any particular one format, because people are human and like a whole range of formats. And **I don't necessarily think one format is the solution for all** (Stroke nurse 2)*

***It's thinking about the needs of the individual**, isn't it, and not just treating them all as the same; here's a stroke, this is just one pack, one fit, if they don't fit into this, well, tough. You've got to get away from that, you know. And again, I think it's care and consideration on the part of a clinician, isn't it, as to what depth they take that to? (Stroke consultant 2)*

*So I don't think you can say, you know, everybody needs leaflets, or everybody needs this or everybody needs that. **What everybody needs is the undivided attention of senior clinicians for as long as the family need it to help them make that decision** (Stroke consultant 17)*

An additional illustration of the importance of recognising the heterogeneity present within the stroke patient population can be seen in this response from a stroke researcher who was asked if providing access to peer-to-peer information as an option to stroke patients would be too difficult to implement:

*No, I really don't. If it can be done in some areas, why not others? And also, **one size doesn't fit all**. That might not be right for some people. A lot of people like the doctor to tell them what to do ... people still think along those lines. Other people may want that sort of explanation from the doctor, but may also want to be able to share their concerns with somebody who they feel less inhibited with (Academic 1)*

Whilst patients suffering from other conditions also exhibit differences from one another, stroke in particular results in an especially disparate population, as the condition affects sufferers in very distinct ways; each according to the deficits that result. In short, no two strokes are the same, nor are the set of symptoms and disabilities that each patient experiences. As a result, the need for a variety of information delivery modalities is particularly acute in stroke care. One doctor emphasised the need to give information that is relevant and adjusted to meet the needs of a particular patient's state, as stroke should not be seen as a single condition but rather as a variety of conditions. They explained that they provide information verbally and/or in writing dependent on whether the patient predominantly has speech or physical problems or indeed a combination of the two.

Finally, each patient comes with their own set of values and attitudes. These are unique to the patient and may be markedly different from those of the health provider. Indeed, unless information is given in a manner that is sensitive to the individual patient's context (beliefs, values etc.) it may not amount to information provision at all. Here are the observations of one stroke physician on the issue (actual question asked; "in your view do you think that more information empowers patients to make decisions regarding their treatment?"):

*I think there is a cultural issue; not in the sense of different national cultures, but more difference in culture between professional groups and lay people in terms of how they deal with information. A lot of what we do may be less productive than it could be because **we're pouring information into patients without thinking about how it sits with their own context and health beliefs**. Getting a dialogue, if we fill people up with facts it doesn't necessarily amount to information unless the patient understands those facts and takes them on board within context (Stroke consultant 8)*

5.2.2 Timing of information (second order theme)

The second theme that emerges from the data relating to the core category of patient information provision is the importance of timing and the dynamic nature of patients' information needs. On this latter point, several informants felt that a patient's information needs change with time. For instance, what a patient may need to know and what would have relevance in the hyper-acute stage may not match their informational needs once they had been discharged. In the words of a clinical lead and neuro-rehabilitation manager and a stroke nurse:

*It's an evolutionary part of the story, isn't it; over the time post stroke,, **early on you need information about, is it going to happen again, and later you need information about how do I get around this problem that I now have as a result of my dot, dot, dot – you fill in the gap; paralysis, cognitive impairment, visual impairment, emotional impairment** (Neuropsychologist 3)*

*I don't think patients always know what they want as well, because it's like a new condition to them so they don't always know, and I think **it's not until they actually go home that this is when they start to want more information** (Stroke nurse 1)*

Associated with the concept of shifting information needs with progress along the patient's stroke journey, is the idea that information must to be appropriately timed to maximise the chance of it being empowering for the stroke sufferer. This again comes back to how information provision and patient involvement are related – here, the suggestion is that timing, particularly in relation to the patient's physical and psychological states, may have a part to play in understanding how the two concepts interact. This was put forward by several of the informants when asked “do you think the quantity of information empowers patients to

make decisions about their treatment, or do you think it works the other around, it can actually disempower people?”

*Just how empowered a patient will feel as a result of information will depend on the individual. It depends on where they are in some kind of cycle of change. So **timing of information is really important. Timing in relation to the individual's readiness for change, or ambivalence towards the material that might be given.** You know, somebody who is not ready to be told they have a permanent lesion will reject that information, arguably. You know, one contends...it's a hypothesis (Neuropsychologist 3)*

*Well, information does empower patients but it's got to be given at the right time and in the right quantity, and in the right form. Certainly **in the early days patients are exceptionally vulnerable**, and they're bombarded with... I mean, they'll go home with piles of paper that actually mean nothing to them until the actual situation arises. But yet they need the information, but they need it in a timely manner...**the wrong amount of information at the wrong time can have an adverse effect** (Occupational therapist 3)*

The dangers of providing too much information during the hyper-acute phase of stroke, when patients are likely to be least receptive to it and least able to retain it, also emerged as a common observation amongst those questioned. One neuropsychologist summarised the problem well, saying:

*It is the case that the patients come out and say things like, I was never told I had a stroke. I actually don't believe them, but I know that **they were possibly in what might be equivalent to post-traumatic amnesia.** You know, they've had a shocking experience; they're not able to take on this information at this moment. So, it is true that they, **to all intents and purposes, haven't been told** (Neuropsychologist 3)*

A similar view was voiced by one speech and language therapist who found it personally frustrating (and contended that other professionals will have had the same experience) that patients and/or carers often complain after the hyper-acute phase that information had not

been provided, when it in fact had been. The conclusion being that poor or inappropriate timing can result in information not being absorbed at the juncture it is delivered. Other participants noted that information needs to be given over a period of time and not all at once. According to an occupational therapist and an academic with a special interest in stroke research who said:

*I've seen instances where [medical staff or a therapist] may give an information session to a patient, give them education on their stroke, what happened, and think, okay, **I'll tick that box so I don't need to go back to that again**; when actually, I think with stroke patients they do have **difficulty processing a lot of information in one go and recalling it**, so I think often a drip feed approach, can be preferable (Occupational therapist 6)*

*I think some of it is the timing of when that information's given. It goes back to when giving a **simple message like plumbing early, but then not overloading people with information at that point**. That's when I hear practitioners saying that often they're doing more of a drip-feed in terms of background information for people (Academic 1)*

5.2.3 Sources, and types, of information (second order theme)

A factor which appears from the data to influence information provision is the source and format of the information itself. Several interviewees noted that the quality and usefulness of information provided will often depend on whom or, in the case of the internet, what channel is delivering it, the subject matter and the context in which that information is being given, i.e. the type of information being provided. On this last point about different settings as sources of information, one senior stroke nurse had this to say:

*Breakfast club is about socialising, assessing people on their skills, re-skilling and generally following up. It is also a really good avenue for **bringing in education in a very informal way** because people will talk about their problems together; a more normal way of being informed. As a doctor you could give a patient an information leaflet and go through it with them, but you could guarantee that if their next door neighbour's mum has also had a stroke, a lot of the information they will pick up and listen to is going to be experiential. If people who have had strokes are in a position to speak to other people who have recently had a stroke, I think **there's actually more potential value in peer to peer information and knowledge** (Stroke nurse 5)*

Here we see an example of other stroke patients, ‘peers’, acting as the information source, sharing information about their experience of the stroke itself and living after stroke. One neuropsychologist also saw value in this approach, adding:

*Meeting people with stroke is especially useful for people who have been through the patient centre very quickly. That’s quite a lonely patient stay and then they’ve been home and haven’t met many folk with stroke, and **they often say that when they catch a stroke support group or the day centre, their eyes are opened and they’re able to compare experiences with other people.** It’s not something we do very much [peer-to-peer information and using expert patients] but as a model it could be potentially very useful (Neuropsychologist 2)*

There was general agreement amongst interviewees that one of the best sources of information for the patient is communication occurring in a ‘one-to-one’ session. However, despite its obvious advantages, this type of information provision was seen as too time consuming and costly to implement universally. Comparing one-to-one tailored conversations directly with other types of information (e.g. information on drug treatment after stroke via an expert discussion CD), this is what one stroke consultant had to say on the matter:

*Probably the best way of imparting information is one-to-one tailored conversation between the patient and/or their relative and the informed health professional. Leaflets are a useful aid memoir and they're a supplement to that, but **it’s really the one-on-one discussion that counts most.** Now, I’m sure there is a role for things like CDs of experts discussing certain things like therapy practice or drug treatment after stroke, or driving after stroke, but I don’t think that would be as good as the individually tailored conversation. **The problem is that the individual conversation is heavily dependent on the professional’s time because that’s where the premium comes in** (Stroke consultant 19)*

Building on the idea of time as a resource that is often scarce, many doctors felt that when they acted as an information source for the patient there was less time for discussion and the

interaction was more pressurised than is often the case for their non-medical colleagues. The table below contains what a number of stroke physicians had to say on the issue.

Table 5.6: Sources of information excerpts

Interview excerpt	Interviewee
<i>Again, a lot of the reinforcement is really done by therapists, because they have much longer with the patients than a consultant would have, or any of the other medical team</i>	Stroke consultant 13
<i>I think then an experienced nurse or therapist, somebody who's got time – or in the case of drugs, of course, a pharmacist – to spend one-on-one time with the patient and/or their relative is, sort of, invaluable really</i>	Stroke consultant 19
<i>The underlying principle is you would obviously like to inform people fully before making any big decision. But equally you have to treat them quickly and certainly in London we have targets for thrombolysis that are trying to encourage everyone to give the drug as rapidly as possible. And that is obviously inconsistent with having prolonged discussions about decisions that you think are in the best interests</i>	Stroke consultant 12
<i>The delivery of the information is important. I mean, it's not enough just coming on a ward round very quickly and saying a few things, you know, do you understand all right? Many people will say yes to everything, whether they understand it or not</i>	Stroke consultant 10

Furthermore, a number of participants felt that having the health provider as the source of information in some ways exposed the interaction with the patient to biases arising from professional agendas. For instance, one doctor remarked:

The agenda will be driven by a doctor so what happens is, you morph the information giving into something different for the sake of box ticking (Stroke consultant 9)

Others emphasised the importance of having the same team acting as the information source for the patient in the same physical environment, to ensure consistent messages could be

given and to make sure the patient has the best possible chance of retaining the information provided. For instance, one doctor made this comment:

*I think the most ideal environment is the stroke unit and so patients should be managed first of all in a stroke unit. If they are managed in a stroke unit, you then have a consistent environment in which to operate. That's the first important thing, the physical structure. Number two, **the information should be given repeatedly and preferably by the same person, if we could** (Stroke consultant 10)*

Finally, many interviewees mentioned the role of the internet as an emerging information source for patients. Often the use of the internet as an information source came with the caveat that the patient had to be careful when assessing the reliability of such information.

One occupational therapist explained:

*Patients are only often told the tip of the iceberg, because so many people do now go off and say I've Googled this and I've heard that, or my friend's next door neighbour had a stroke and this is what happened to him. [We need to] make sure that any information that's provided is tailored and appropriate. **People have so many resources that they can turn to themselves**, and the reliability of those sources aren't necessarily robust ... so the correct information or the opportunity to ask questions is really important to ensure understanding (Occupational therapist 1)*

Others saw an opportunity to merge the use of websites and online social networks with peer learning to form another useful source and type of information for patient and families alike.

One speech and language therapist describes their experiences here:

*Having contact with other people who've been through a similar event can help people understand and accept. That's a good thing, because then **there can be networks between people who are further down the line** and who are doing that through computer use now as well. We quite often use the Connect website. They've got a really nice little film, just about Connect, plus it shows a really good range of people with aphasia. That's always very powerful to see other people who've gone through something similar. We sometimes, not very often, will **invite an ex-patient or an ex-carer to come in and meet with a family and if we feel we are really not getting the message across that can sometimes work** (SALT 1)*

5.2.4 Summary of key points relating to patient information as a core category

It is too simplistic to treat stroke patients as one homogeneous group of people, with the same information requirements, expectations and access (e.g. there will be disparities in the LOS between patients often resulting in different access to information). In terms of quantity of information, very little agreement emerged on whether more information helps or hinders patient involvement. However, the consensus was that information must be tailored to the individual patient, rather than assuming a “one size fits all” approach to information provision.

Moreover, whilst patients suffering from other conditions also exhibit differences from one another, (as discussed in the methods chapter) stroke in particular results in an especially disparate population, as the condition affects sufferers in very distinct ways; each according to the deficits that result. That is, no two strokes are the same, nor are the set of symptoms and disabilities that each patient experiences. As a result, the need for a variety of information delivery modalities is particularly apparent in stroke care.

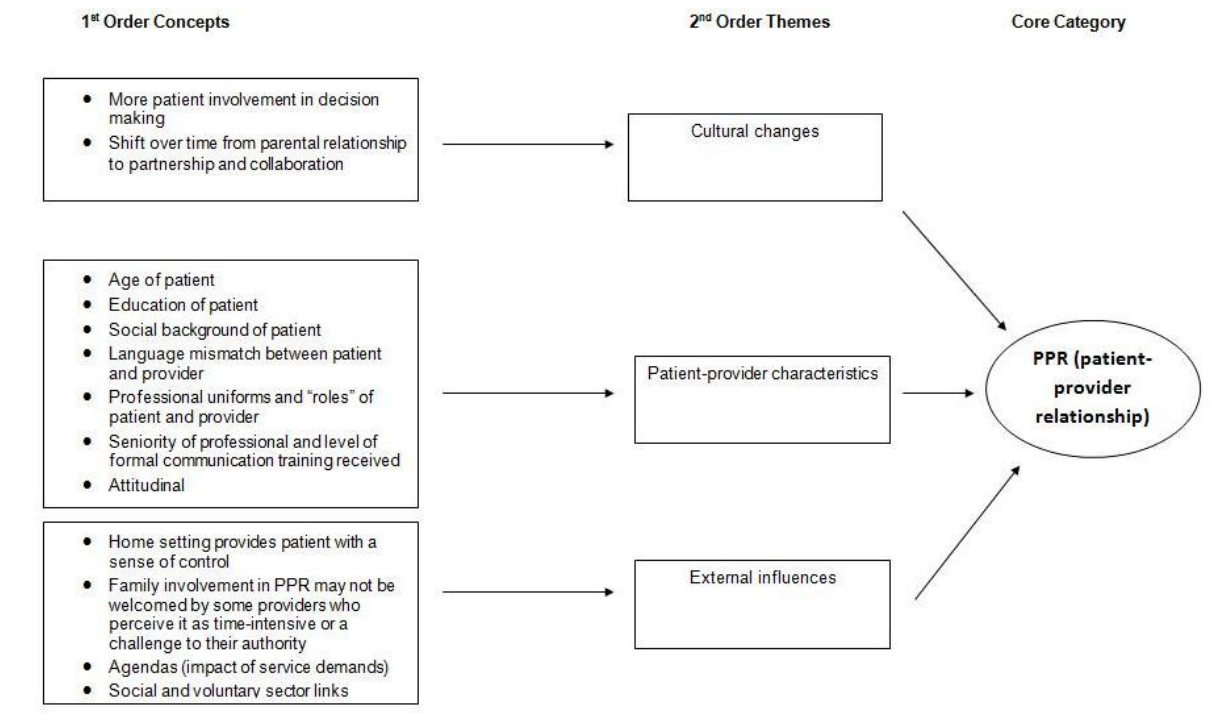
Furthermore, the timing and the dynamic nature of patients’ information needs is an important point to note. For instance, what a patient may need to know and what would have relevance in the hyper-acute stage may not match their informational needs once they had been discharged. Indeed, information must be appropriately timed to maximise the chance of it being empowering for the stroke patient. In other words, professionals must avoid providing too much information during the hyper-acute phase of stroke, when patients are least receptive to it and least able to retain and act on it.

Additionally, the questioned stroke doctors feel that when they act as an information source for the patient, there is often less time for discussion and the interaction is more pressurised than is typically the case for their non-medical colleagues. A key finding here is that having the health provider as the information source was perceived by the professionals as introducing biases to the interaction with patients, in their view this often arising as a consequence of professional agendas. Several respondents also cited the internet as an important information source for patients and their families/carers also. Again, the way these findings sit in the light of the literature and their importance in helping to explain the PPR in stroke (and how they may inform policy and practice in stroke) will be explored in the analysis at the end of the chapter.

5.3 The patient-provider relationship (core category)

The third and final core category that emerges from the data in relation to the first research question is the patient-provider relationship. The qualitative findings in this study suggest that the nature of this relationship is a key influencing factor in information provision and patient involvement in stroke care. Once again, we will use excerpts from the interview transcripts to illuminate the chief concepts and themes related to this core category. The overall schematic for PPR as a core category is shown below.

Figure 5.3 The patient-provider relationship – overall coding structure



5.3.1 Cultural changes (second order theme)

As discussed in the literature review, there has been a gradual shift over time in the relationship between health providers and patients, in part fuelled by government policy which both places the patient at the heart of healthcare and which advocates greater patient involvement in decision making. This change in the patient-provider relationship is also partly a reflection of decreased societal acceptance of the now largely outdated notion of ‘doctor knows best’ or paternalism, particularly amongst younger patients (Glass 1970; Chin 2002). These issues were discussed with the study’s participants. Other related thoughts on how the changing nature of the patient provider relationship (PPR) may influence information provision and involvement of patients by health providers were expressed by several participants. Some of their comments are summarised in the table below:

Table 5.7 Cultural changes excerpts

Interview excerpt	Interviewee
<p><i>[As a metaphor] it's like when I go to my financial advisor, and he says, this is the best investment for you ... I take it that because he's my advisor, he'll know more about it. If I take his professional advice, I will still be the one who will be making decisions, or taking the benefits of the risk. I think that being a medical doctor is not dissimilar at this point in time</i></p>	Stroke consultant 9
<p><i>Another thing that makes a big difference to the relationship is just trying to redress that balance of us being the people that have all of the power and knowledge, and the patient not having any. I've been trying to make it feel like a side-by-side relationship even though perhaps we are in control of things in a hospital setting, trying to make it feel like we're alongside with the patients rather than us dictating things</i></p>	OT 4
<p><i>I think the relationship has changed. It is seen much more now as a partnership rather than go to teacher for advice type of relationship. It's not the parental type of relationship it was certainly when I graduated. It was much more that the doctor sat and gave information and that people would be worried that they were going to see the consultant may be a bit nervous about meeting them. I don't notice that anymore. Nobody's nervous and they often come with loads of questions and things that they've printed out before they get there</i></p>	Stroke consultant 18
<p><i>I've been in medicine for 30 years and I've never gone in for paternalism. I'd be upset if somebody thought I was paternalistic. I think the relationship with the patient is a very special one ... what I teach my juniors and the nurses is that this is an unbelievably important time in this person's life, and therefore that relationship that you have, those hours or minutes that you have that relationship, is a very, very intense and important relationship</i></p>	Stroke consultant 17
<p><i>The biggest cultural change that's occurred, over the last 15 years at least, in the style of the way that doctors, probably also therapists ... what their stance is on involving patients, and I think that in the past the natural expectation on yourself and on others that are training under your supervision is that, the starting point is that patients are engaged in decisions about their care, and that whenever possible, you should try to make a decision with them, so I think that cultural change is underway, certainly in the medical profession now</i></p>	Stroke consultant 13
<p><i>A good example from my earlier days was a young man who was a joiner and had a stroke that involved his left arm; he had very intensive vocational rehabilitation, and as a result of that he actually was able to go back to work ... I remember seeing him a year after, very unhappy ... So I said, why are you miserable; he said, well, because I love to play football and I can't play football. Now, that's the sort of thing that I might be more sensitive about now</i></p>	Stroke consultant 7
<p><i>I probably communicate a lot more at an individual level with my patients now than I would have done 20 years ago. That's partly a reflection of changing times and partly a reflection of how long you've been doing this sort of work, because patients trust doctors, but to some extent doctors are bit wary of patients and relatives. And communicating with them in an open way is a skill that needs to be learned. Also, the more experienced you get, I think the more comfortable you are in doing it.</i></p>	Stroke consultant 7

5.3.2 Characteristics of the individual patient and provider (second order theme)

In addition to the general shift over time away from paternalistic models of care to more participatory ones, the data shows that the nature of the patient-provider relationship often depends as much on the practical characteristics of its component parts (that is, the attributes of the individual patient and the health professional) as it does on more abstract and theoretical concepts describing the potential interaction. These distinct attributes at the level of individuals (e.g. age and social background of patient), in addition to shifts in the relationship at a broader societal level, influence patient involvement and information provision too. This theme will be elucidated from a selection of excerpts now. Interviewees pointed out the differences between *younger* and *older* patient groups with respect to the PPR. One stroke doctor who prefers to view their relationship with patients as a partnership acknowledged the difficulty that older patients in particular can pose in this regard, i.e. they felt that elderly stroke patients often naturally defer to a position of allowing the doctor to tell them what to do, as this is what they have been historically used to doing. Striking a similar note, one physiotherapist added this:

I've never had a 90 year old patient say to me, this is what I want to work on ...very few patients present like that. Very few are clear in their minds as to what they need or want or would like to do. They seek our support trying to guide them through that discussion. But I think probably, a younger population would be even more informed about what is available or just better engaged with that discussion maybe (Physiotherapist 4)

One physician noted the effect a patient's *social* background may have on the PPR and thus information provision and involvement, saying:

*Patients and doctors obviously have very different social situations, so try to speak to the patient at the level that they will understand, and to **relate to them as a human being rather than as a professional**. If they think it's the consultant with his Rolls Royce sitting outside, they're actually more likely to ask the cleaner a question, but if they see you as a human being that is being friendly towards them, they're more likely to ask the question that's relevant and to take the information in as well (Stroke consultant 7)*

This difference in social backgrounds leads onto a secondary point about the presence of a *language mismatch* between patients and providers, which in turn may influence the PPR. Many interviewees had experience with not being fully understood by patients, with one nurse noting that often the professional and patient can be having entirely “different conversations” full of “misunderstandings” because comprehension, language and “agendas” do not match.

Others explored how the mental capacity of the patient affects the provider’s relationship with them. One stroke physician noted that the PPR looks “very different” depending on whether the patient is incapacitated or not. They were keen to stress that the whole team are encouraged to explore a multitude of communication methods (particularly non-verbal cues, such as head nodding and hand signals) and to try their “utmost” to impart information to patients who are incapacitated.

Several interviewees spoke about the various *roles* played by provider and patient and how these influence the PPR. The respondents felt that the PPR could be influenced by the extent to which the provider played the ‘professional role’ and the patient the ‘sick role’. Individual attributes, such as choice of clothing for both professional and patient, were deemed to be important here. A community physiotherapist and stroke consultant commented:

*If you arrive and try and take a non-medical view, and let them tell you what their problems are, then it becomes a partnership. **If you arrive in a uniform and you stand over them and tell them what’s going to happen, people are disempowered, and they don’t tell you what the problems are ... they don’t engage in a partnership, and don’t feel as motivated to go through what it is they want. They don’t tell you what it is they’re after ... the more personal stuff about incontinence and mood, and feelings of unworthiness and all the things people have. You only get that from someone after you’ve built a strong therapeutic relationship with them (Physiotherapist 2)***

Dress patients, empower them; don't leave people sat in bed with pyjamas on, try and normalise the hospital experience – that way you will get that patient to engage in the way they would normally engage and **not to fall into a sick role** (Stroke consultant 14)

In addition to how the patient and provider are dressed, several informants felt that the *seniority* and *role* of the provider had an impact on the PPR. For example, a specialist stroke nurse made the following remark:

*I think **patients use their therapists an awful lot**, because they build up a very, very strong relationship with them. They spend quite a lot of time with them, whereas **nurses were often seen as the busy ones who don't have time**, or we don't want to bother you. In my role I would only see patients, sometimes, only two or three times throughout their journey, as well, with being a specialist nurse. You don't have that same relationship with them* (Stroke nurse 4)

The same nurse felt that the relationship was shaped by the type of *training* the provider had received in the past and how they perceived their role. They were particularly keen to stress the difference in the training received by doctors and nurses in this regard:

***The relationship and information giving is a training issue, and I think it's how they view their role as a doctor, and how they're trained. I think it has changed over the years but I still think it's just not... whereas as a nurse, it's something that's instilled in us**, it's part of our role and it's in our training about information, and supporting, and being the patient advocate and all those kinds of things. I'm not saying nurses are any better. I think it's often because... they can add... they often go and add more information for the patients, because that's what they need, really, to be able to move on* (Nurse 4)

Building on the perception of roles, some participants emphasised that the individual attitude of the professional had a great impact on the PPR. One neuropsychologist, for instance, explained how something as simple as using the word 'client' (in lieu of patient) conveyed a collaborative attitude towards the relationship:

We explicitly use the word client in our work, because patient is etymologically about passivity, and it's true that if you embed a thinking which is these people are people we're working in partnership with to achieve adjustment in overcoming their problems of stroke, then I would argue that you're on a good starting point. But as I say, we've been at the centre for 16 years now, trying to carve a very particular neuro-psychologically driven model of stroke rehabilitation (Neuropsychologist 3)

Tying together the importance of the individual's attitude and their training on the PPR and ultimately information provision and patient involvement, one stroke consultant commented:

*There are different ways of interacting with patients and providing information. As **most stroke physicians are geriatricians by training, they will have developed a much more empathic attitude and understanding of communication difficulties** and have more time than the surgeon who comes along, says something and marches off. The tone of your voice and just a smile on the face makes a patient and their relatives respond to you much more. **If you build up that good rapport with them the moment they [arrive], the whole process of their hospital care is so much smoother ... you can have much franker and easier conversations because that trust is there.** Confidence is being built and if they've confidence in you they'll take on board what you say. Sometimes there are difficult conversations that need to be had, for example, someone who's desperate to have more physio that you know isn't going to make any difference. If you've built up that trust then they can accept that and deal with it better (Stroke consultant 2)*

5.3.3 External influences on the traditional patient-provider interaction (second order theme)

As we have seen from the literature, the general assumption has traditionally been that the relationship between a provider and patient exists in isolation and, perhaps partly as a result of this, it is still most typically studied in the hospital or primary care setting (not in a patient's home, for instance). The data from the interviews in this study suggest that looking at the stroke PPR from the restricted lens of the traditional patient-provider interaction in a

hospital/primary care environment only, does not result in a complete picture. For a fuller understanding of the relationship and its impact on patient involvement and information provision, we must also consider certain external influences. This includes looking at the effects of the home setting, the impact of a patient's family, the influence of the health system's demands and the bearing that community services may potentially have on the PPR.

Commenting on the influence the *home environment* has on the PPR, one community occupational therapist had this to say:

*Generally speaking, [the relationship is] collaborative by necessity, **because we are only treating patients within their own home, they are very much in control, and so it is very, very much a collaborative response.** I would still say that you're seen as the expert – the therapist – and the vast majority of patients, if they're advised to do something, they do it. There is still... there's a balance (Occupational therapist 3)*

When asked if the relationship with patients had changed over time, their view was that it is location that has had the greater impact on the PPR:

*It's not so much over time but as location. **As soon as the person goes into their own home, they are in charge.** It rather depends on the age as well. Older people are still very much in awe of the uniform, whereas younger people, I think, are a little more aware of their rights. But **in the hospital setting, people are very, very much more submissive and less empowered (OT 3)***

The potential impact of a *patient's family and the role of carers* on the PPR was discussed with the informants also. According to a neuropsychologist:

*I'm a trained family therapist as well as a psychologist, I try to involve families as much as possible. And I think that's **one of the areas that the wards get least right, actually. I think they involve family too little** in physician meetings, and goal setting. And for some reason, they're not an integral part of that process. They may be involved but not in any planned way (Neuropsychologist 2)*

Obstacles to achieving greater family involvement were felt to be:

*One is time and the other is probably attitudinal. It's something I'm trying to change bit by bit, but it's a bit of an uphill struggle, I've got to say that **family is still seen, at best, as an encumbrance**. And not the resource I think they could be seen as. So some of it is attitudinal, some of it's not seeing the benefits of involved family (Neuropsychologist 2)*

*I suppose **everyone tries to escape because they don't like all the questions the families are asking**. It takes us out of our jobs; we've got a job to do and there's a relative who wants to talk to you for half an hour or complain about something. So I think we like to avoid the patient and the families (Stroke consultant 1)*

However, several respondents felt that considering a patient's family, amongst other things, helped them to understand the patient as a person and is therefore beneficial to the PPR. This is what one occupational therapist had to say about the topic for instance:

We need to understand about their family life before, their home set-up before, their work life, what their competence status was, all those kind of things before, and I think really understanding the patient as a person rather than a patient is really, really important to building rapport, and I think sometimes that's missed when a patient is looked at as a collection of symptoms from their stroke, and if you really understand the person and make it personal to them, I think that makes a big difference to the relationship (Occupational therapist 4)

Others also noted the effect shortened LOS has on the ability of carers to be involved with professionals and patients in rehabilitation decisions and general patient care in hospitals. Some also observe that the situation is different in the community setting. For instance, when describing the role of carers in the relationship between professionals and patients, this is what one respondent said (actual question asked, "how can decision-making in rehabilitation be improved to better involve patients and their carers?"):

*The better the goal-setting, the better the rehab is really and that's what the therapists regularly say. It's where there's more attention to detail and **really it's about involving the patients and carer more**. I mean, patients is always easy. But sometimes **when the patient is in for such a short time nowadays, it's difficult to get the carer in**. You know, if people are at working age and that, they can't always come in etc. The community stroke unit is the place where the real goals get set, because there's much more emphasis on the rehabilitation, long-term goals there and **more opportunity for carer involvement** (Stroke nurse 1)*

Another agreed with the assessment regarding LOS but also suggested that carers may be part of the PPR to a greater or lesser extent depending on the particular hospital a patient was admitted to, with some offering services specifically targeted at family and carers, whilst others do not (the initial question eliciting the excerpt shown here was “do you view yourself in the relationship as a patient advocate or do you see it as working in partnership with the patient and carer, how do you view it?”):

*If there are relatives there when the consultant is doing a ward round on the hyper acute stroke unit during the first 24 hours, then it is very likely there will be a discussion on that first day, with the relatives that are there. If there are no relatives there, at the moment, **we don't have a carer's or relative's clinic, although we've certainly thought about it**. So, if a family is never there, whilst the patient is in, they're only in for 48 hours on average, often the family have never really had an opportunity to sit down and have a discussion with the medical team. **Other hospitals provide a carer and relative's clinic**, where they can book in and so often when there are lots of outstanding medical questions, and we haven't had time to cover them on the ward, or the relative is not there on the ward, they ring up and ask for information, which is one of the resources that is offered to them, so that they can book into a clinic, and sit down with the consultant and go through everything (Stroke consultant 13)*

Building on the O'Connell study from Australia (O'Connell, Baker et al. 2003), which looks only at the educational needs of carers, several respondents here mentioned a difference in carer needs versus those of the patient when asked the same question, which in the

professionals' views were particularly apparent around discharge planning. This is what one consultant had to say:

There are differences between what patients want and what carers want, which change over time as well; patients are much more focused on disability and functional independence and carers focus on support, what's available in terms of dealing with existing disability. That's around the time of discharge. As time goes on and the disability becomes more stable both patient and carers are more concerned with social services support than they are health or the medical model. So patients have much more of a medical model around discharge than carers, which then changes into a more social model as it goes on (Stroke consultant 8)

Professional agendas, often based on service demands such as audits and targets, have already been discussed previously as having an impact on how and what information is delivered and, indirectly, the PPR. The final external factor that emerged from the data as influencing, or having the potential to influence, the PPR was the *provider's links* with voluntary sector groups and *services in the community*. As one speech and language therapist put it when asked to consider the patient-provider relationship in this broader context:

*It is about making a relationship with that person; that you really do have a relationship where you are listening to that person and making them feel comfortable to say things to you, which may be about the service, as well as you treating them. **We have good contact with an aphasia support group in Teesside and that's a way of maintaining long-term contacts**, patients as well, who might give you some feedback and comment still quite a way down the line. So I think **having the NHS staff having links with voluntary sector groups maybe makes it a slightly different relationship than the [hospital] patient-therapist one**, which could open up hearing different sorts of information (SALT 1)*

5.3.4 Summary of key points relating to the patient-provider relationship (PPR) as a core category

The nature of the PPR is a chief influencing factor in information provision and patient involvement in stroke care. According to the responses gathered, it often appears to depend as much on the practical attributes of its component parts (for instance, the patient's age or

the type of training the provider has received and their role perception/attitude) as it does on the more nebulous and theoretical concepts of what the interaction ought to look like.

Moreover, looking at the stroke PPR from the narrow perspective of the traditional patient-physician dyad in a hospital or primary care environment only does not provide a complete picture of what is occurring in stroke care today. It seems a more complete understanding of the relationship in stroke and its impact on patient involvement and information provision can only be gained by considering certain external influences also (such as the effects of the home setting, the impact of a patient's family, the influence of the health system's demands and the impact of community stroke services).

Next, we will revisit parts of the literature to place the research findings pertaining to RQ1 in their proper context. Unlike the purely descriptive findings already presented, here we aim to analyse the study's results in light of what is currently known. Furthermore, to answer both parts of the first research question, we will assess *how* the factors identified in response to RQ1a have their influence – i.e. we will be answering RQ1b here. To do this, we will first consider those variables that affect *both* information provision and patient involvement. Subsequently, the identified factors that have their main impact specifically on information *or* patient involvement will be considered. Below is a reminder of parts 'a' and 'b' of the RQ1:

RQ1a: What factors influence information provision and involvement of patients by health professionals in stroke care?

RQ1b: How do the identified factors affect information provision and involvement of patients in stroke care?

5.4 Factors affecting both information and involvement

The following factors were determined to have an impact on both patient information provision and patient involvement in their care:

Factors at an individual level:

- Patient personality and background
- Patient capacity and acuteness of situation

Factors at an organisational/social and political level:

- Changes to service delivery model for stroke
- Government policy
- Social structures
- Auditing
- Setting
- Technology
- Neuro-psychology shortage
- Overburdened staff

An illustration summarising these findings is shown below:

Table 5.8: A summary of the factors affecting patient information provision and involvement of patients by health professionals: key, stroke-specific findings from the data

<p>HIGH</p> <p>↑</p> <p><i>Factor's impact on patient involvement</i></p> <p>↓</p> <p>LOW</p>	<p>Mainly involvement:</p> <ul style="list-style-type: none"> -professional complacency or lack of self-awareness -provider's personality -presence of family and carers -training 	<p>Both:</p> <ul style="list-style-type: none"> -<i>patient personality and background</i> -<i>patient capacity and acuteness of situation</i> -<i>changes to service delivery model for stroke</i> -<i>government policy</i> -<i>social structures</i> -<i>auditing</i> -<i>setting</i> -<i>technology</i> -<i>neuro-psychology shortage</i> -<i>overburdened staff</i>
	<p>Mainly information:</p> <ul style="list-style-type: none"> -patient-specific impairment(s) -patient's needs change with time -post-traumatic amnesia and the patient's psychological state -source of information -resources -inter-provider integration 	<p>←</p> <p><i>Factor's impact on information provision</i></p> <p>→</p> <p>HIGH</p>

We will look at each of the italicised factors in turn to explain how they may be affecting patient information and involvement, whilst placing them in the context of what is currently known from the literature in this area.

5.4.1 Patient personality and background

As we have seen with respect to information needs, patients are a heterogeneous group. Some patients feel empowered by information and often want more, whilst others feel bombarded

by it and often want less. Often a patient's educational background and ability to understand the information being provided may have an impact on how much information they wish to receive. For instance, where there is a language and/or social mismatch with the information provider, a patient may often feel overwhelmed by what they perceive as too much information. As a result, the interviewees reported adjusting the amount and way in which information is presented, to take the patient's personality, background and personal preferences into account. Similar findings have been reported in the literature pertaining to cancer patients suggesting that the findings here may have a wider resonance (Zeguers, de Haes et al. 2012). In terms of stroke, the literature is in agreement with the finding described here i.e. that survivors' social characteristics/background (such as educational attainment) do indeed have a bearing on information provision (van Veenendaal, Grinspun et al. 1996). However, the van Veenendaal study did not consider the impact of this factor on patient involvement.

This study does look into this issue and finds that stroke patients do indeed differ in the extent to which they wish to be involved in decisions about their care depending on their educational background, personality type and age. Regarding the latter, one well-known study from 1980 reported that younger patients were more likely to want to play the role of a well-informed active participant than the older research participants (Cassileth, Zupkis et al. 1980). As in this study, the literature shows that better educated patients are more likely to exhibit a preference for active involvement in decisions about their care (Levinson, Kao et al. 2005). However, neither of these studies are specific to stroke patients.

5.4.2 Patient capacity and acuteness of situation/decision

The capacity of the patient under treatment and the acuteness of the setting in which they are receiving care frequently emerge as factors that influence both patient information provision and patient involvement. The results from this study suggest that the pressure to minimise ‘door-to-needle time’ in hyper-acute stroke cases results in a considerably shortened discussion with the patient, and/or their carer(s). Information is often provided in a cursory way to reflect both the urgency of the situation and the fact that patients are commonly unable to absorb information at this stage in their journey. Thus, important acute decisions, most notably whether or not to thrombolysise the patient, with few exceptions follow a traditional medical model as a result. That is, there is minimal patient involvement and treatment often proceeds with the doctor acting in the patient’s ‘best interests’ – in line with national clinical guidelines (Party 2012).

Whilst the stroke doctors interviewed here were keen to stress that every effort is made to obtain consent from a patient directly (and, if incapacitated but with relatives present, from next of kin/carer[s]) the perceived additional time it would take to fully involve and inform the patient about a time-sensitive intervention was largely seen as an impediment to achieving the best clinical outcome. A minority of physicians reported “extremely rare” cases involving lucid patients who had refused thrombolytic treatment. *Although not commonplace, this is still an interesting finding as studies reporting stroke patients playing active, participatory roles in acute decision making do not appear in the literature, which instead emphasises the extent to which patient and family capacity can be blunted by the effects and shock of stroke (Murtagh, Watson et al. 2012).*

5.4.3 Changes to length of stay (LOS) and the service delivery model for stroke

The literature appears to have little to say on the impact of declining lengths of stay on patient information provision; indeed, the key paper in this area suggests that early supported discharge mainly affects involvement by increasing patient participation with rehabilitation at home (Disler and Wade 2003) but it does not consider ESD's impact on information provision (See Table 3.4). However, the results from this study suggest that shorter hospital stays for stroke patients equate to fewer opportunities to access the information they may want and need. As noted in previous chapters, the change in focus over how stroke services are delivered in the NHS (with earlier discharges and more emphasis on the hyper-acute stages than before) means that patients are generally in hospital for shorter periods. As a result, information provision by professionals is more pressurised and providers often have less time to deliver information to patients. As we have seen from the findings chapters, this effect is often compounded by the fact that patients are usually least receptive to the information that they do receive during their shortened stay, initially due to the acuteness of their condition and subsequently as a result of the communication deficits that commonly follow.

In addition to the effects on patient information, the change towards a hyper-acute model of care for stroke in the UK appears to have a bearing on the extent to which patients are involved in care decisions by professionals too. Many participants explained that the added time pressure brought about by changes in the service delivery model meant that they felt they had less time to involve patients in their own care. The literature has little to say on this matter, especially in relation to stroke care. However, this is a potentially significant observation, as it may have implications for how patient involvement policies can be better

implemented in the future. Indeed, it highlights the often contradictory aims of meeting targets for reduced lengths of stay whilst simultaneously involving patients more in their care – something some stroke professionals currently perceive to be too time consuming to be practically possible.

5.4.4 Government policy

As we have seen from the literature and the background on stroke policy in the UK, there has been a considerable push in recent times, and by successive governments, to empower patients. A cornerstone of this initiative has been the enhanced delivery of information to patients by health providers. Many of the defining tenets of the policy can be seen in DoH publications such as *The power of information* (2012). Alongside the information delivery aspect of this initiative has been the drive for more patient involvement in care decisions, through reports such as *Liberating the NHS: No decision about me, without me* (2010).

The overall government policy towards greater patient-centred care appears to have gained some traction amongst providers, as the results from this study show that stroke health professionals are both aware of the general policy and are generally keen to implement it wherever, and whenever, practicably possible. Whilst information provision to people with stroke was highlighted as a “marker of quality stroke service” in the 2007 Department of Health’s UK stroke strategy, no equivalent exists for the involvement of stroke patients with care decisions (DoH 2007). That is, government patient participation policies do not single out stroke in particular. Interestingly, however, the data here suggest that there may not be a need to do so as the stroke professionals interviewed are aware of, and generally try to act in accordance with, the spirit of greater patient involvement.

5.4.5 Social structures

The results here show that the traditional roles adopted by patients, particularly *older* patients who form the preponderance of stroke sufferers, and their providers still persist to this day and continue to have an impact on information provision and involvement in care. For instance, this study shows that many patients still place the doctor on a pedestal and are less likely to feel able to ask for the information they want or to feel able to be active participants in care decisions (Ek Dahl, Andersson et al. 2010). This historical impediment to patient-provider interactions is generally maintained across all health providers, although the findings here suggest that it is somewhat less apparent with non-physicians. Indeed, the results indicate that patients are more likely to ask for information from nurses than doctors, and even more frequently patients will turn to therapists for information as they often perceive nurses to be too busy to ask. *This confirms Attfield's findings alluded to in the literature review (Attfield 2006).*

Similarly, patients appear to be more likely to engage in shared decision making with therapists than doctors. Whilst this may in part be attributable to the stage in the patient's journey at which the interaction with these various providers occurs (i.e. doctors in the more acute phases, therapists in the rehabilitation phase), there is a broadly held belief amongst those interviewed here that a historical hospital hierarchy continues to act as a barrier to patient-centred decision making. *This is made worse by what some interviewees describe as a "language mismatch" between providers and patients and confirms what was found in the literature on this issue (Shaw 2009).*

In agreement, Pilnick et al report on the “remarkable persistence” of the asymmetry between doctors and patients and it is clear from the results in this study that this continues to have an influence on information exchanges between the two groups and the levels of care involvement (Pilnick and Dingwall 2011).

5.4.6 Auditing, setting and service demands

The roles auditing, service demands and setting each play in influencing patient information and involvement are well-documented in the findings chapters. As explained previously, in this context *setting* should be taken to mean where the patient-provider interaction occurs, i.e. in the hospital or outside of it within a community stroke unit or at the patient’s home.

The results from this study indicate that information provided to patients within a hospital environment tends to be formal and delivered with a ‘tick-box’ approach and limited scope for patient input. This stands in stark contrast to patient-provider interactions outside the hospital, which were reported to be more unfettered and less formal. The professionals surveyed believed that patients are in control to a greater extent at home and consequently feel empowered to actively participate in care decisions and ask for more information as needed, in keeping with the literature (Jones, Mandy et al. 2000; Disler and Wade 2003).

Furthermore, the interviewees explained that a hospital setting may impact patient information delivery and involvement via the professional’s need to follow their own agendas, which ultimately derive from those of the service management team. This was felt to have an impact not only around the time-limited thrombolysis treatment window, in

keeping with evidence from the literature (Sudlow and Warlow 2009; Murtagh, Watson et al. 2012), but at other points along the patient journey too – for instance, at discharge.

Respondents felt that by virtue of the system in which they work (with, for instance, targets for increasing the proportion of patients being given thrombolysis [in line with NAO recommendations]), interactions with hospital patients are often biased towards their own needs and not necessarily those of the patient.

Indeed, lifting the constraints service demands place on the PPR by engaging with patients after discharge was seen by professionals as a major way for patients to regain a sense of control and assert their informational and participatory needs on the interaction. This observation is explored in greater detail below, in response to RQ2. There is a large literature evaluating the clinical benefits of early-supported discharge (ESD) and rehabilitation at home. However, there is still no consensus on the percentage of patients who would be eligible for ESD and even less agreement on the percentage of stroke patients who would benefit from such schemes (Fisher, Stariradeva et al. 2011). *Those studies that do advocate more widespread implementation of ESD cite increased patient empowerment and participation with rehabilitation at home as a key mechanism for improved outcomes and patient satisfaction – a finding echoed here (von Koch, Holmqvist et al. 2000; Disler and Wade 2003; Thorsen, Holmqvist et al. 2005).*

5.4.7 Technology

Several interviewees commented on the impact technology currently has on patient information provision and involvement and also on its increasing potential to improve future

patient empowerment. Therefore, it is clear that technology is an important factor to discuss in answering both RQ1 and 2. Firstly, we will focus on precisely how technology affects information and involvement of patients. Later, technology will be explored as a possible way of improving the current situation, in response to RQ2 below.

Technology is here being used as an umbrella term to denote both online and offline tools and materials. The rise in self-management of chronic conditions, including stroke, as a way of improving rehabilitation outcomes is well established in the literature (Jones 2006) (Jones and Riazi 2011). So too is the role of “smart” assistive technology, such as telecare (Zheng, Nugent et al. 2010), in achieving this increasing self-reliance. Similarly, in this study several respondents mentioned patients accessing more information remotely via online communication channels, such as Skype. The increasing use of online learning tools and websites was also mentioned by several interviewees as examples of how technology is shaping both information provision and patient participation with care.

Within the hospital, multimedia tools (such as iPads and other touch-screen devices) were seen as facilitators to patient involvement with care decisions and an innovative way of communicating with stroke patients, particularly those with speech and language difficulties. Interestingly, several respondents were eager to emphasise that advancing age is not the barrier to technology use that it is often presumed to be. This point will be looked at in greater depth in response to RQ2.

5.4.8 Neuro-psychology shortages

The analysis of the interview transcripts reveals an acute need for greater neuro-psychological support within UK stroke care. The perceived shortage in psychological expertise has an impact, albeit indirect, on both patient information provision and the extent of patient involvement, as patients who are not psychologically stable can neither receive information optimally nor be involved in their care to the fullest extent.

Indeed, psychological distress has been raised in the literature as a particular concern for stroke patients (Nelson, Cicchetti et al. 1994; Hilari, Northcott et al. 2010). Post-stroke depression (PSD) is the most frequent psychiatric complication of stroke and its prevalence has been estimated to be around 30–35%, ranging from 20 to 60% (Lenzi, Altieri et al. 2008). PSD is thought to impede the rehabilitation and recovery process, jeopardise quality of life and increase mortality (Gaete and Bogousslavsky 2008). However, diagnosis of PSD is challenging in the acute and chronic aftermath and, as a result, it often remains unrecognized and/or undertreated (Gaete and Bogousslavsky 2008). The lack of recognition of the extent of the problem (outside of stroke professional circles) perhaps explains why a shortage in neuro-psychological expertise persists. *It may also explain why the level of neuro-psychological staffing has not been highlighted as a potential problem in the literature, despite several interviewees expressing their concern.* Indeed, whilst there is a well-developed literature on PSD, the subsequent impact on the patient's ability to take on information and be involved with care decisions has not yet been explicitly evaluated within stroke care.

5.4.9 Overburdened staff

The professionals interviewed here all reported instances when they felt that a lack of staff negatively impacted on the provision of information to patients and their ability to involve patients in care decisions. Several complained that without additional stroke professionals to lighten the burden of care on current staff, depersonalisation of patients and loss of patient-centred care would inevitably follow. For instance, professionals almost unanimously felt that one-to-one interactions were best for both patient information delivery and to help build the trust and confidence required to empower patients to actively participate in care decisions. However, at the same time, the interviewees acknowledged that such an approach would require a commitment of time on their part that would not be feasible with current staffing levels. The difficulties associated with staffing levels in UK stroke services are comprehensively reported on in the literature (Gibbon, Watkins et al. 2002; Morris, Payne et al. 2007). *However, in contrast to the findings in this study, the connection to patient information provision and involvement does not appear to be made explicit in the literature.*

5.5 Factors mainly affecting patient information provision

In addition to those factors which have been identified as having an impact on *both* information and involvement, there are a series of others that have their greatest influence on patient information provision alone, as follows:

Factors at an individual level:

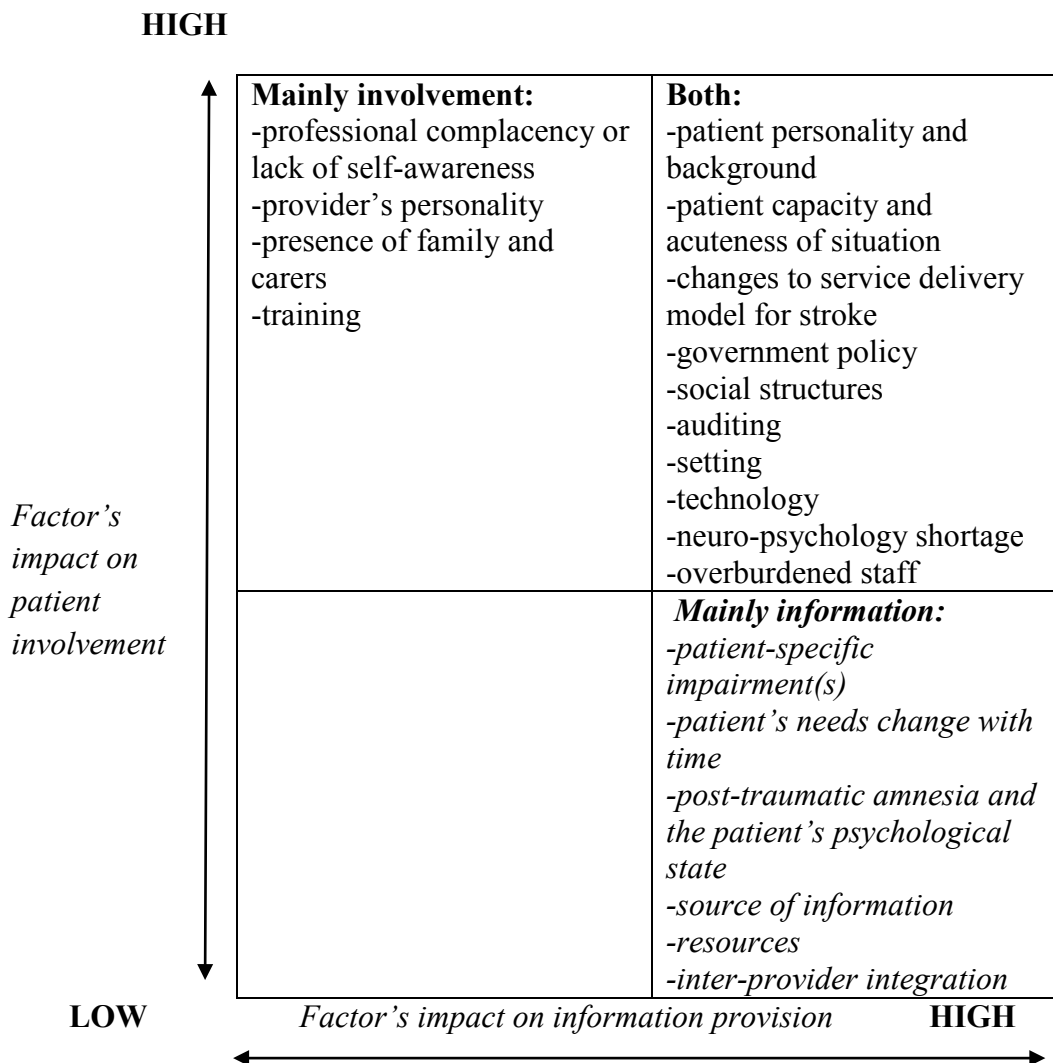
- Patient-specific impairment(s)
- Patient's needs change with time
- Post-traumatic amnesia and the patient's psychological state

Factors at an organisational/social and political level:

- Source of information
- Resources
- Inter-provider integration

An illustration summarising these findings is shown below:

Table 5.9: A summary of the factors affecting mainly patient information provision by health professionals: key, stroke-specific findings from the data



We will now discuss each of the italicised factors in turn to explain how they may be affecting patient information provision, whilst placing them in the context of what is currently known from the literature in this area.

5.5.1 Patient-specific impairment(s)

As we have seen from earlier chapters, strokes cause a wide range of impairments for sufferers. The diversity in the resultant difficulties, perhaps unmatched by any other medical condition, means patients are often left experiencing very individual combinations of symptoms and deficits. As a result, health providers have to adapt their informational offerings to match the needs of the specific patient they are treating. In other words, the findings here suggest that precise type of impairment any one patient has may impact the information they are provided with and the way in which it is delivered. For instance, we found that the use of audio-visual tools may be the most suitable means of providing information to a stroke patient with aphasia, whilst non-aphasics may benefit more from written information, such as that found in traditional Stroke Association packages. *This confirms the need to tailor information to meet the requirements of individual stroke patients based on the type and severity of their impairments; a matter which has received significant attention in the literature already (Hoffmann and McKenna 2006; Smith, Forster et al. 2008).*

However, other parts of the literature suggests that involvement is equally impacted by patient-specific impairments (such as aphasia) in contrast to the data here, which imply the effect is mainly on information provision. For instance, one key study showed that aphasia results in asymmetric interactions which hinder the formation of a partnership approach to care, with stroke nurses controlling the topic and flow of conversations (Gordon, Ellis-Hill et

al. 2009). The reason for this difference in emphasis may be that this research considers settings outside of hospital too (through interviews with community professionals, for instance, where we find a patient is more likely to be engaged with decision making), involves a broader range and number of professional perspectives (not solely nurses) and does not include patients' views directly.

5.5.2 Patient's needs change with time

As shown in the literature review previously, and confirmed by the data here, another factor influencing information provision is the dynamic nature of patients' informational needs (Hanger, Walker et al. 1998; Wiles, Pain et al. 1998). The data here shows that patients do indeed require different information, in different formats, at different times along their journey. The study's results suggest that as patient information requirements constantly evolve and change, professionals must reflect on what is most relevant for the patient to know at that time and what mode of delivery is most appropriate. Once this is established, the provider can adjust the content and delivery of information accordingly. For example, we found that a patient may need information about stroke rehabilitation in the form of a leaflet whilst in hospital, but may be more interested in learning how to access online material on self-care once they have been discharged.

The need for relevant information at all times throughout the patient's journey is mentioned in the literature as an area requiring attention (Suhonen, Nenonen et al. 2005). One study examines the changing informational needs that occur between acute and community stroke settings from a caregiver's perspective, without directly commenting on patients' information

needs (O'Connell, Baker et al. 2003). The findings here could act as a natural extension of this work.

5.5.3 Post-traumatic amnesia (PTA) and the patient's psychological state

Several respondents reported experiencing times when patients denied receiving information that they had been given. In addition to cognitive impairments affecting a patient's ability to retain information, some explained patient denial of information from a psychological perspective. That is, they interpreted it to be a form of post-traumatic amnesia or more simply an indication that the patient was not in the correct state of mind to receive the information at the time it was delivered.

Indeed, some professionals accounted for this psychological phenomenon by timing information provision to coincide with non-acute phases of care, by which point the patient was deemed by them to be more receptive to new knowledge, having had more time to come to terms with their condition. In this way, the perception of the existence of PTA and the patient's psychological state combine to influence certain professionals' patient information provision.

PTA is well-covered in the literature with respect to closed head injury and head trauma (Stuss, Binns et al. 1999; Ahmed, Bierley et al. 2000), but there is no specific study concerning its occurrence with stroke, nor the implications for how information provision may be altered by some professionals in light of its existence, as is the case here.

5.5.4 Source of information

Another important factor influencing information provision is the source of the information itself. By the term *source of information* we mean specifically who (for instance, a doctor or a nurse) and what (for example, a website or other online material) is delivering the information.

As discussed previously, data collected here shows that when information is being provided to a patient by a doctor it is often more likely to be formally presented, brief and more standardised in comparison to the delivery of information by a therapist, for instance. Reasons for this difference have already been commented upon elsewhere. The point here, however, is that the identity of the information provider impacts patient information provision. Similarly, due to disparate approaches to patient care and other reasons explained previously, information provided by medical professionals differs from that given by social workers.

Another example of how the source of the information may affect patient information provision can be seen by considering hospital providers as a collective group or team, not just individuals. Applying this to the study here, the data suggest that if information is not given by the same team of health professionals, patients are left confused by inconsistencies and “mixed messages”.

Information provision is also impacted by a patient’s ability to access the internet themselves, or have carers and family members who may do so on their behalf. Acknowledgement by professionals that there is now another source of information away from the traditional

patient-provider interaction appears to have changed the way in which some professionals now deliver information. That is to say, some providers have embraced this alternative source of information and often direct patients to websites and other online materials that they feel would be useful.

Moreover, some professionals now feel that they have to be even more careful about the information they do provide patients in light of this major, alternative source of information. Indeed, many professionals are now more prepared to defend the information that they do convey to patients, in the knowledge that it often has to stand up to more scrutiny than it did in the past. On a separate but related note, *this also has implications for the PPR, as the internet brings with it the increased possibility of informed patients (and carers/family) challenging the ‘authority’ of the provider who, in previous eras, would often have been regarded as the sole purveyor of clinical knowledge.*

5.5.5 Resources

There are two sides to consider when we speak of resources. Firstly, there are the problems stemming from an overall lack of funding which can only be tackled by increasing the pot of money available to the NHS. Secondly, there are the difficulties that could be overcome through better allocation of existing resources.

There is recognition amongst care professionals in this study that often the optimal way of providing information to stroke patients is on a one-to-one basis, confirming what is shown in the literature (Edwards, Hood et al. 2000). However, as intimated in the section above on

overburdened staff, there are not the resources in place to make this intensity of information coverage a reality. This is an example of the overall funding gap alluded to above.

In this study, an example of delivering sub-optimal patient information resulting from the poor use of existing resources would be the low levels of patient bedside television uptake. This study shows that interviewees regarded the televisions as potentially rich resources for the dissemination of patient information, but that these were under-exploited owing to organisational barriers and reimbursement strategies not being in place. *This specific issue has not been explored in the literature* but forms part of the answer to RQ2, as we shall see later.

5.5.6 Inter-provider integration

Whilst there is evidence in the literature that discharge co-ordination chiefly affects patient involvement (Koh, Barr et al. 2014), here we find that the degree of integration between health providers mainly influences patient information provision. The reason for this discrepancy may be due to a different participant mix (Koh et al asked for stroke patients' views only, here we have interviewed a range of health professionals), the fact that Koh's paper is based on research carried out in a Singaporean hospital, the paper's focus on patient participation in particular or a combination of these.

The data here show where there are low levels of integration, we see less sharing of data amongst providers acting at different sites. Indeed, it is common for each hospital to hold their own information database, with limited ability to communicate and share this with other

sites. As a result, information provision to patients treated at more than one site during their stroke journey may be haphazard and inconsistent.

This factor is related, but distinct, to the one termed *source of information*, where the emphasis was on having the same team within the single treatment location delivering information to patients for consistency. Here, the factor labelled *inter-provider integration* deals with the issue of consistency of information across multiple sites. The attempted implementation of a centralised patient database or electronic health record (EHR) in the NHS, linking different sites and providers to the same patient information, to address this issue is covered extensively in the literature and is explored in greater depth in response to RQ2 (Currie and Finnegan 2011).

5.6 Factors mainly affecting patient involvement

In addition to those factors which have been identified as having an impact on *both* information and involvement, there are a series of others that have their greatest influence on patient involvement alone, as follows:

Factors at an individual level:

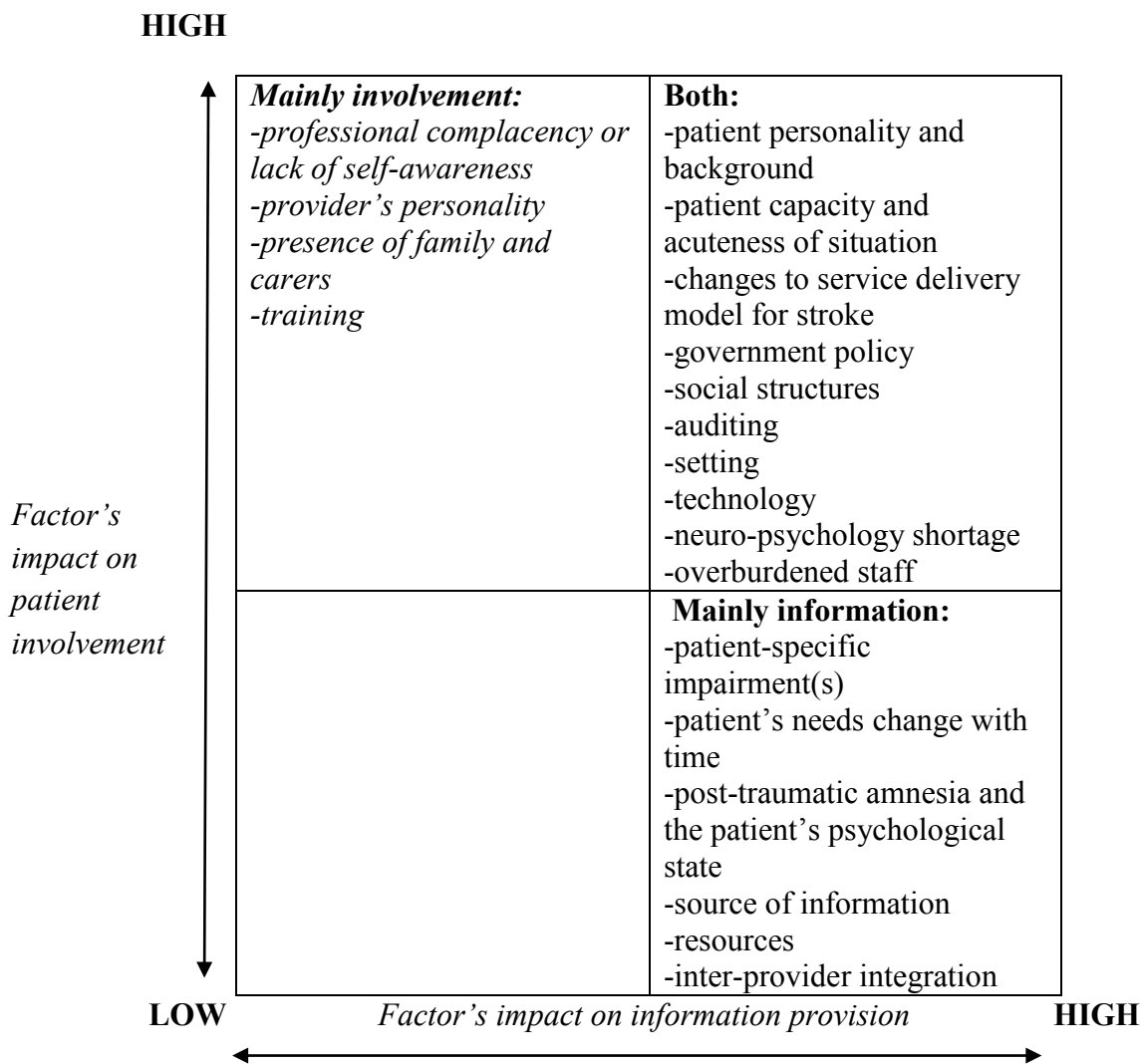
- Professional complacency or lack of self-awareness
- Provider's personality
- Presence of family and carers

Factors at an organisational/social and political level:

- Training

An illustration summarising these findings is shown below:

Table 5.10: A summary of the factors affecting mainly involvement of patients by health professionals: key, stroke-specific findings from the data



We will look at each of the italicised factors in turn to explain how they may be affecting patient involvement with their own care, whilst placing them in the context of what is currently known from the literature in this area.

5.6.1 Professional complacency or lack of self-awareness

One finding emerging from the data is that some professionals may at times be complacent about patient involvement, not placing the emphasis that this aspect of care deserves. This

appears to be particularly true of those working in the more acute phases of the patient journey. Similarly, we find that often professionals may think that they do encourage patient participation when in reality they do not. The low self-awareness or inaccurate self-assessment in this regard may stem from a lack of a standardised approach or objective way to appraise ‘involvement’. It appears that this factor has received little coverage in the literature however.

5.6.2 Provider’s personality

The attitude and individual opinions of the doctor also play a role in influencing the extent to which patients are involved in care decisions. For instance, we see from the interview transcripts that some physicians believe that they alone should carry the burden of responsibility for any decisions that need to be made, rather than the patient and/or their family.

Additionally, some interviewees pointed out that doctors vary in their attitudes towards involving a patient’s family in decisions, with some seeing family as time-intensive and unwelcome challengers to their authority, whilst others view them as a rich resource for learning more about the patient under care. These types of differences in a doctor’s approach, or what has here been termed ‘personality’, affect a patient’s likelihood of involvement in care decisions, yet they have not been fully explored in the literature. Studies that are related to this phenomenon have accounted for differences between physicians’ propensity for participatory care by looking at gender, race, training and context (Kaplan, Greenfield et al. 1996). Whilst these are all undoubtedly important elements to consider, personality types,

attitudes and outlooks have not been formally studied in relation to a doctor's likeliness to involve patients in decisions.

Moreover, this factor is not confined to physicians only. The results here illustrate that other professionals may also have personal preferences that impact the level of patient participation. For instance, some therapists like to present the patient with all the potential alternatives and treatment options that may be available for them to choose from, whilst others do not take this approach preferring instead to work in a less collaborative fashion.

5.6.3 Presence of family and carers

In the view of the HPs interviewed, and as previously hinted at above, the presence of a patient's family has an impact on the professional's level of patient involvement. According to the HPs, a reduction in patient involvement may occur as a result of family being present when some professionals may choose to avoid or minimise their interactions with the patient for fear of having to confront angry or demanding relatives. Similarly, certain professionals may be less likely to encourage patient involvement when family is present, as they often equate a family's presence with a more drawn out process.

Conversely, some professionals view the patient's family as a valuable resource for finding out more about the patient and therefore their presence may have the opposite effect. Indeed, certain interviewees mentioned that discovering more about the patient's values and background through interactions with their family, helped them to empower patients to greater levels of participation. The literature has largely dealt with this area by studying the impact families have on decision making themselves directly (Azoulay, Pochard et al. 2004)

(Anderson, Hobson et al. 1992), rather than looking at the more indirect effects a family's presence may have on how involved a patient may be as in this case.

5.6.4 Training

The involvement of patients by professionals in care decisions also seems to be influenced by the training the health provider has received. The study here indicates that inadequately equipping professionals with the knowledge and skills they need to understand both why and how to involve patients in care may result in lower levels of overall patient participation. The research highlights that junior non-physician staff (e.g. junior physiotherapists) are especially likely to be poorly prepared in this regard, often having received less formal communication training than their more senior colleagues. As a consequence, it is suggested that they are less likely to know how to involve patients in their own care. More also needs to be done to educate professionals on why patient involvement is important in the first instance. Indeed, a stronger argument must be made before a more patient participatory culture and practice is fully embedded within stroke care. *The findings here are in agreement with a Cochrane review article which demonstrates that a lack of professional training is one of the main limiting factors to the widespread adoption of involving and sharing decisions with patients (Legare, Ratte et al. 2010).*

The discussion of each factor has been presented above (i.e. sections 5.4.1 – 5.6.4) in response to RQ1b.

5.7 Summary of factors influencing information provision and involvement of patients by health professionals

Below is a table summarising all the factors identified in this study in response to RQ1a.

Table 5.11: Factors identified in response to RQ1a

Factors mainly affecting patient information provision	Factors mainly affecting patient involvement	Factors affecting both information and involvement
Patient-specific impairment(s)	Professional complacency or lack of self-awareness	Changes to service delivery model for stroke
Patient's needs change with time	Training	Government policy
Post-traumatic amnesia	Provider's personality	Social structures
Source of information	Presence of family and carers	Patient personality and background
Resources		Patient capacity and acuteness of situation
Inter-provider integration		Auditing
		Setting
		Technology
		Overburdened staff
		Neuro-psychology shortage

As we can see, there is considerable overlap between concepts and themes, with certain factors affecting both patient information provision and patient involvement (shown in the third column, above). As we shall see, the distinction made in this findings chapter is slightly artificial in as much as the core categories identified as being relevant to answering the first research question may, at times, prove useful to answering the second question also – and

vice versa. This will become clearer in the discussion chapter to follow, where the overall contributions of this study are considered in greater depth.

5.8 Conclusion

Chapter 5 has explored the three core categories relating to the first research question, namely decision making, patient information and the patient-provider relationship. These categories, along with the related themes and concepts, were formulated in accordance with the techniques outlined in the methodology chapter (chapter 4).

We have also revisited parts of the literature to place the research findings pertaining to RQ1 in the context of what is currently known. As well as presenting the findings from the empirical research, we have analysed them in light of what is currently known. To answer both parts of the first research question in this chapter, we have assessed how the factors identified in response to RQ1a have their influence.

A number of important factors identified in the stroke care literature, that impact on the provision of information to patients and their involvement in decision making processes have been confirmed by the findings. Some of these factors are shown to affect mainly information provision, others mainly involvement and yet others have an impact on both. The factors have also been categorised according to whether their effect is seen at an organisational or an individual level.

The findings in this study replicate those of the wider stroke care literature in a number of areas: auditing, patient capacity, tailoring and/or sources of information and the dynamic information needs of patients. We have explored how and why these similarities can be compared and where there are differences these have been highlighted. For example, with

respect to dynamic information needs, we note that the need for relevant information at all times throughout the patient's journey is mentioned in the literature as an area requiring attention (Suhonen, Nenonen et al. 2005). However, another study examines the changing informational needs that occur between acute and community stroke settings from a caregiver's perspective, without directly commenting on patients' information needs (O'Connell, Baker et al. 2003). Therefore, the findings from this study (which does consider the patient's needs, albeit from the professional's perspective) acts as an extension to their work.

Importantly, however, there are some differences in how certain factors are seen to be having an impact. For example, in the stroke literature early-supported discharge is shown mainly to affect involvement, whereas here we find evidence that it also affects information provision, as the results shown in this chapter suggest that shorter hospital stays for stroke patients equate to fewer opportunities to access the information they may want and need. In the discussion chapter to follow (chapter 7), we will build on these findings to explore the implications for the PPR in stroke.

It is interesting to note that several other factors that appear in the general literature (but not the stroke literature) have been identified in this chapter. In particular, technology, training, and resources/sources of information can be highlighted. The importance of these has been considered in sections 5.4.7, 5.6.4, 5.5.5 and 5.5.4 respectively and will not be repeated here; however, it is interesting to note that each of these factors are at the organisational/social and political level, rather than the individual level, suggesting that more attention should perhaps be given to overarching stroke care policy rather than day-to-day practice.

We can also identify another factor that does not appear in either the general or stroke-related literature, but for which evidence emerged from this study: neuro-psychological shortages. In

this chapter (section 5.4.8) we have discussed the importance of this finding by considering diagnosis of post-stroke depression, the most frequent psychiatric complication of stroke. Its diagnosis is challenging in the acute and chronic aftermath and, as a result, it often remains unrecognized and/or undertreated (Gaete and Bogousslavsky 2008). The lack of recognition of the extent of the problem (outside stroke professional circles) perhaps explains why a shortage in neuro-psychological expertise persists. It may also explain why the level of neuro-psychological staffing has not been highlighted as a potential problem in the literature, despite several interviewees expressing their concern.

Indeed, whilst there is a well-developed literature on PSD, the subsequent impact on the patient's ability to take on information and be involved with care decisions have not yet been explicitly evaluated within stroke care. Whilst the condition itself clearly is not only a UK or NHS issue, it does seem likely that more resources in this currently underfunded area would result in significant improvements in UK stroke patients' mental health. Recognising these four additional factors can be seen as a contributing step towards increasing knowledge in this field, with implications for policy and practice, which will be developed in 7.2.3.

In terms of decision making, a noteworthy observation within the second order theme "situational characteristics and the importance of setting" is that a minority of physicians reported rare cases involving lucid patients who had refused thrombolytic treatment. Although not commonplace, this is still an interesting finding as studies reporting stroke patients playing active, participatory roles in acute decision making do not appear in the literature, which instead emphasises the extent to which patient and family capacity can be blunted by the effects and shock of stroke (Murtagh, Watson et al. 2012).

Finally, a key finding in this chapter is that stroke patients are generally more likely to seek information and be more involved with their care once they have been discharged home. This

is perhaps unsurprising as the patient is further removed (both physically and in terms of time) from the stroke episode. A less obvious mechanism accounting for this appears to be due to the home being a familiar environment in which patients feel comfortable, in control and empowered. This has practical implications, such as the development of strategies not only for sustaining this sense of empowerment outside hospital in the longer-term but also for how to replicate feeling of empowerment prior to discharge. Proposals for what these might be and how they fit in the context of a revised PPR model for stroke are discussed in the closing chapter.

Chapter Six – Findings and Analysis,
Part Two: Improvements in patient
information provision and involvement

Findings and Analysis, Part Two: Improvements in patient information provision and involvement

6 Introduction

In this chapter we will be presenting the main findings relating to the second research question, restated below. Once again, three core categories will be examined. The core categories were generated in accordance with the techniques previously outlined in the methods chapter. Once again, we will take a detailed look at each category, as well as its associated themes and concepts, using supporting excerpts from the interview data. Finally, we will revisit parts of the literature to place the research findings pertaining to RQ2 in their proper context. In addition to the purely descriptive findings, we will also analyse the study's results in light of what is currently known.

Research question two

How do health professionals think patient information provision and involvement can be improved in stroke care?

The three core categories that emerge from the data analysis as most relevant in response to RQ2 are displayed in the table which follows.

Table 6.1: Core categories relating to the second research question

Core category	Second order theme
<i>Service configuration</i>	Resource limitations
	Navigability
	Performance measures (“targets”)
<i>Inter-agency workings and the PPR outside hospital</i>	Transition
	Integration
	Continuity
<i>Technology</i>	Computer literacy
	Audio-visual delivery of information (hospital)
	Social media and online material (home)

6.1 Service reconfiguration (core category)

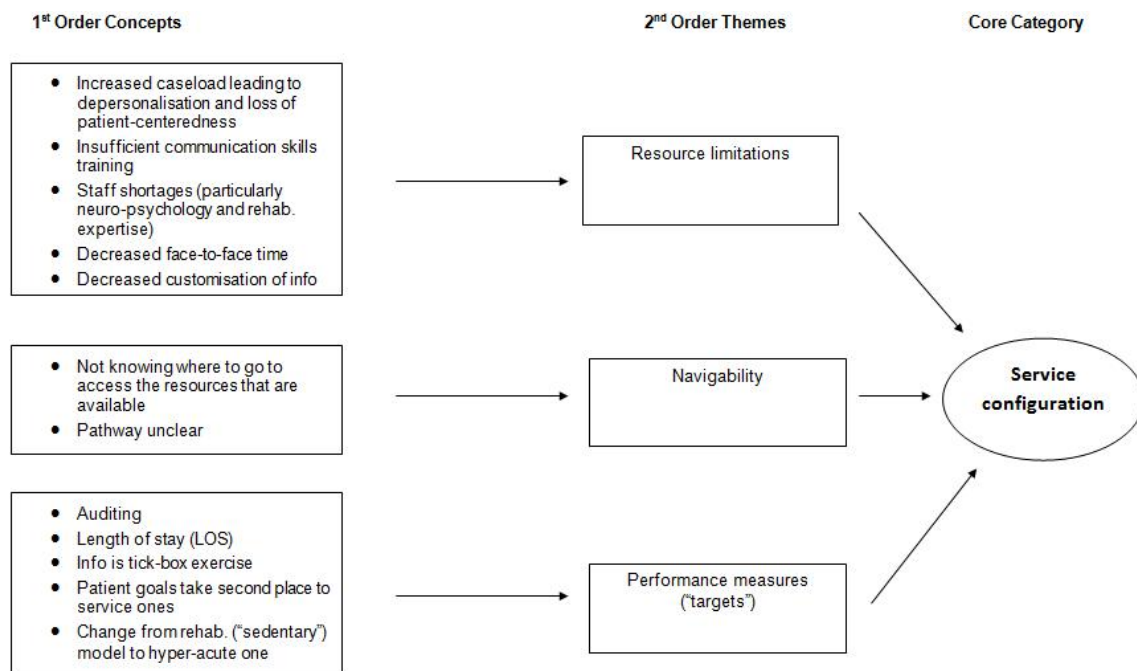
A number of respondents felt that the way in which the health system in which they worked operated had various shortcomings and thus opportunities for improvement. Some of the perceived problems were around resource limitations, chiefly in terms of shortages in adequately trained staff and time constraints on existing providers.

The way in which budgetary concerns impact on patient information provision and involvement with care is covered in more detail below; so too are the potential strategies for tackling the ensuing difficulties.

Other informants judged the overall ease of navigation through the stroke pathway, and the ability of the patient to access information and resources at key points along it, to be a key area for improvement. This theme is addressed more fully in section 6.1.2.

The third theme to be identified in relation to service configuration was the need to reassess current performance measures. It was felt that the injudicious use of targets, and the associated auditing and care model changes, negatively influences how services are aligned and the emphasis placed on various aspects of the stroke care system. Indeed, several interviewees viewed present service targets as a hindrance to patient participation and delivery of information. Therefore, a reassessment of such targets was frequently cited by informants as an opportunity for considerable improvement, as we shall see in section 6.1.3. The overall coding structure for this core category has been summarised in the schematic below.

Figure 6.1 Service configuration – overall coding structure



6.1.1 Addressing resource limitations (second order theme)

In this section we will firstly establish that resource limitations impacts both patient information and involvement. Next, we will examine some of the suggestions for remedying the situation as suggested by the interviewees.

When asked what the main obstacles to achieving greater patient involvement are, one nurse felt that it was mainly the high patient to professional ratio leading to depersonalisation of the patient, ineffective communication and a reduced understanding of their care needs:

*I think it is professionals having the confidence to actually communicate openly and feel comfortable with a patient-centred approach...and I think the challenges are where therapists or nurses have large kind of clinical areas with a large number of patients or a large caseload. **People quickly become depersonalised** and it's...well, rather than a nurse being on a ward with 30 patients, how can you ensure that she or he can communicate effectively with different patients and has an understanding, a rapport with them, that actually helps them and contributes to meaning in their recovery? (Stroke nurse 2)*

A second nurse agreed, explaining that staff cuts resulted in less time being spent on what they perceived to be quality care issues, like face-to-face information provision:

*I just did a focus group with some patients and carers yesterday so it's fresh in my mind, and what they actually said is, what they'd like is they want the written information to read but they'd like somebody face-to-face to go through it and answer questions. I think there needs to be a lot more of that. Unfortunately with the NHS **now there're more and more cuts in staff and we're having less and less time to actually spend on those quality issues really** (Stroke nurse 1)*

Other respondent felt that in addition to staff shortages, a lack of proper training could be to blame:

*Definitely training, and a resource issue; there aren't enough nursing staff on the wards to facilitate what I would like to have done, so it's actually **a lack of staff as well as a lack of initiative**, if you like (Stroke consultant 14)*

Building on this theme of insufficient staffing levels' impact on information provision, one of the stroke nurse specialists added the following observation regarding training, in line with the thoughts of the stroke consultant quoted above:

*I think people know and they're aware [of the importance of involving and informing patients] but when you're holding a patient that's really poorly and there aren't many staff and it's about somebody wanting to go through this stroke information pack or ask questions, then you're going to go to the poorly patients, aren't you? I think it's a resource issue, definitely. I think it dovetails into training as well. **Training is always the first to go when resources are scarce** (Stroke nurse 1)*

Several respondents felt that the staff shortages extended beyond just a lack of nursing personnel, pointing out that the psychological aspect of stroke care is often overlooked, with too few neuropsychologists and neuro-rehabilitation specialists being appointed as part of the stroke team. One senior occupational therapist said that the current shortfall meant that patients often lacked access to neuropsychological services entirely. Agreeing with this assessment that there is a lack of psychological expertise in the stroke rehabilitation process as it currently stands, one consultant said:

*I think there's a huge shortage of rehabilitation expertise in stroke within the NHS and that's why **people get into this issue of neglecting the non-physical aspects to recovery from stroke**. It's a therapy need, it isn't just the colour of the wallpaper; it's an unmet therapy need generally (Stroke consultant 8)*

The implication of these observations may be that if resources were reallocated to taking better care of stroke patients' psychological welfare, they would be more likely to be

involved in other aspects of their care too. In addition to the difficulties encountered from a lack of specialist staff, other participants highlighted that a lack of resources results in poorer quality information; that is, information that is less customised to the needs of the individual patient. One senior stroke nurse explains:

I think you can't ignore the resource aspects in information giving as well. Resources in terms of time, staff and resourcing time of actually developing good individual patient focused information as well, so you can't ignore that because it just frustrates people like myself, clinicians and that where they go, we're not giving this, we're not giving that, and a lot of the time it's because we haven't got the funding to provide that anymore. That's a key thing now that I imagine shouldn't be ignored, really (Stroke nurse 1)

When asked if we do enough to customise information currently, the same nurse said (actual question; “you’ve mentioned obviously giving people options and not all patients are the same, do you think that we do enough to customise information?”):

*No, I don't. Again, it's resources. I've struggled for about ten years, we developed a really good interactive stroke information pack which patients could put in their handbag, and it was really well evaluated. But we just can't pay for it anymore. So they've come up with a lesser, poorer version of it, which patients aren't using. So, again it's resources, really, that we don't [have], and the other thing is **due to resources they can't produce it in different languages** either. We live in a cash-strapped NHS and **I don't think we've got the resources to make things very customer made** (Stroke nurse 1)*

In broad agreement when asked the same question, one consultant added that the current time and resource constraints meant that information customisation, though desirable in their view, could not feasibly be achieved:

*In theory one should tailor everything, so patients should be the centre of this care and things should be tailored around [them]. It's time and resources, they're the problem, aren't they? It's the amount of extra time that takes, but then one shouldn't say that, because the patient deserves to have that extra time given, but there are constraints. But **in an ideal world, yes, everything should be tailored around that patient and what they need** but again I guess there would normally be a number of variables and then one would have to, for each individual patient, select what was most appropriate from a bank of information (Stroke consultant 2)*

Without significant additional resources, it seems reconfiguration of the service to deliver greater customisation of patient information may not be achievable. However, other ways of improving patient information provision and involvement in the face of resource constraints were proffered by several doctors. These suggestions included greater communication training for stroke doctors, improved time management and alternative communication strategies, as we see from the following table.

Table 6.2: Addressing resource limitations excerpts

Interview excerpt	Interviewee
<i>One thing is that I think all doctors employed should have communication skills training, I think that's vitally important</i>	Stroke consultant 14
<i>I'm just very sceptical when you hear the NHS say they don't have time or resources; I think we waste a lot of time because we don't communicate properly and if you think about a lot of effort goes into quite complex discharges where there may be even conflict with patients or family, a lot of it is avoided by good information, good communication. I think investment would pay off in increased efficiency...What people mean is, I think, that they haven't managed their time properly in the day so it's true that you can't have a ward round with 20 patients and expect good communication to have happened in all of those if the ward round is only an hour and a half long. So what you need to do is, as I said, approach it as a team, perhaps do a ward round and focus the ward round on a particular outcome and then look at communication in other contexts, like a formal family meeting and one to ones with key workers perhaps</i>	Stroke consultant 8
<i>The thing I would love to do to change things, would be to stop the ward round because I think the ward round is a traditional way of communicating but it's not conducive to partnership, sharing, it's very much reinforcing traditional values and traditional relationships. Having said that, I don't quite know what to do instead within the time available, because communication does take time and often having, communication is often on a, it's often easier when you're one to one than when you've got a shed-load of people listening in to your conversation</i>	Stroke consultant 21

6.1.2 Improving navigability and access to information (second order theme)

The importance of improving access to information for patients and general navigability throughout the stroke pathway is another major theme emerging from the interview data. Several interviewees felt these were key ways to improve information delivery and patient involvement with care decisions. For instance, one clinical lead and neuro-rehabilitation manager commented:

I think there's an element of knowing and navigating and helping people know the system. People don't know that there are resources out there that can help them, and sometimes there are things that they can only get access to if they apply; you know, if I refer them it'll cost hundreds of thousands, but if they apply they can get it for free – that kind of, knowing what's available where (Neuropsychologist 3)

A stroke performance manager stressed how vital it is to *coordinate* information provision in a way that ensures patients access the same information throughout their stroke journey and are not receiving mixed messages. He felt this consistency could mainly be achieved through access to the same information software and Stroke Association leaflets. An occupational therapist agreed, suggesting that a more centralised approach to information provision is required, with consistency not only in the materials themselves, but also in the various professionals' delivery of the information:

[We need] centralised resources so that lots of different people aren't giving the same information, perhaps, in different ways,, covering a uniform, information across services would be useful, so the patient is used to seeing the same information again and again rather than thinking it is different information each time. And perhaps different professionals putting things across in a similar way would be useful (Occupational therapist 4)

One stroke physician felt that a more *clearly laid out stroke pathway* would help to reduce anxiety and make patients more aware of the options they have available to them. Whilst this was not felt to have a clinical impact in terms of length of stay or outcomes, it seems that making the patient's options clearer in such a way may lead them to being more involved in their own care too, as we can see from this quotation:

*I don't know if [a clearer pathway] would dramatically shorten their length of stay or dramatically improve their outcome. It would certainly reduce the stress of the situation with perhaps a better explanation of the options available to them. So when they come in, a clearer explanation of where they could go next ... so **the different options are all laid out. Sometimes that's quite helpful and would reduce anxiety.** Equally that can cause difficulties in that people will say, why am I not allowed to go to more rehab when they're not rehabilitating at all. So I'm a bit cautious but having it all laid out for them as clearly as possible from fairly early on would certainly reduce anxiety. **I'm not sure if you'd reduce length of stay by doing that but it can't be a bad thing to make the pathway a little bit clearer** (Stroke consultant 16)*

Others voiced stronger opinions on the need to *clarify the pathway* for patients, making it easier to navigate and access information. This is what one stroke nurse thought on the matter:

*I still hear expressions, you know, **you need a satnav just to get round stroke services.** People finding things out by chance, finding their way round services and what's available can be still extremely difficult* (Stroke nurse 2)

Indeed, one doctor thought we should turn to patients who had been through the pathway for ideas on how to improve it from a patient's perspective. They felt involving the patients themselves (who has already been admitted, treated and discharged) by asking them to identify where the gaps are, would be a key way to effectively redesign stroke services.

One stroke care academic felt that we ought to be more innovative in how we go about delivering information to patients to ensure that they are accessing the information that is available to them and that it is meeting the patient's rather than the service's requirements:

*In south London, for example, they have a stroke folder which contains all the information you think you could ever want to know about a stroke. But often **that's sitting at the end of people's beds and it's not being looked at**. So although it satisfies the service that they've provided the information, I'm not sure it's really being accessed by people. I think we could be **much more innovative** in terms of how to deliver that information (Academic 1)*

6.1.3 Reassessing performance measures (second order theme)

To a large extent, the way in which performance is measured is a reflection of the way in which stroke services are designed. Whilst targets may be beneficial in many ways, several respondents felt that they could also be an impediment to providing quality information for patients and involving patients in their own care. The inference being, therefore, that a reassessment of current performance measures resulting in a change towards a set of targets more closely aligned with patients' interest, rather than those of the service providers, could improve information provision and patient participation. One stroke consultant explained how concerns over auditing interfere with adequate information provision:

*We are now required to do it all within the first 24 hours. **I've been audited whether I've told my patient the diagnosis within 24 hours, so I tell everyone their diagnosis, whether they understand it or not**...There's too much formal communication on-going and too little proper patient derived communication where you **actually have a conversation rather than ticking a box referring to what you're going to be audited for** (Stroke consultant 1)*

One stroke care academic felt that outcome measures impacted the ability of patients to be active participants in their own care, stating:

*I think more and more, the more I work with people with stroke and practitioners, I'm really realising that they're being very much influenced by the way that the stroke pathway is set up, so... you know, **the timing, how many sessions they have available to see somebody, and the sort of outcomes by which their team is being measured will also influence the content of the therapy sessions.** So, for example, if the team is being measured on, you know, functional independence and getting people less dependent on social care, you know, then that's really what guides the content of therapy sessions. **And it may not be what the most important thing at that point for the person with the stroke** (Academic 1)*

Several interviewees believed that length of stay (LOS) *targets* and changes in the stroke care model have impacted on the levels of patient involvement in decision making. One senior stroke nurse explains:

*We really try hard with making sure that the patient and carer are at the centre of goal-setting. Things have changed significantly since I've been working in stroke because patients spend less and less time in the hospital setting and more and more time in the community setting, community stroke units, early supported discharge team. **So I think what the team struggle with more and more is that there is perhaps less emphasis on the goal-setting, rehabilitation goal-setting than there used to be, because we don't have the luxury of having patients in an awful lot... the length of stay is getting shorter and shorter.** Here we're looking at two weeks. Whereas years ago when I first started out in stroke it was nothing for patients to be in for three months, so there was a lot more time (Stroke nurse 1)*

Noting the same trend towards shortened hospital stays and the implication of such targets for patient-centred care, one senior physiotherapist mentioned that attempting to run an “efficient unit” by making room for the next person, thereby meeting targets for “getting people out of hospital”, results in a lot of care not being “completely patient-led”. These sentiments were echoed by one stroke physician when they were asked to comment on what they felt was impeding greater patient involvement. Rather than citing material resource issues, they spoke

about time constraints and being “pressurised” to “move people more quickly”. Furthermore, as mentioned briefly above, several respondents felt that there has been a *change in the service model* being followed in stroke care and that this has resulted in poorer information provision and lower levels of patient participation in decisions. As one nurse put it:

There's a timeliness around thrombolysis, so the rushing is getting in, getting to CT, and a lot of the quality issues, like information giving gets a little bit lost in that because we've gone from a sedentary service where it was born from just rehabilitation to very acute, hyper acute aspect in service, and with that I don't think we've quite caught up with all the information and we need to learn from other areas (Stroke nurse 1)

The same nurse then goes on to explain that one such area is cardiac care and also makes observations on the impact stroke service model changes and targets have on the PPR and, ultimately, patient participation and information provision:

*It's a lot more [of a partnership] for nurses and therapists and less so for medical staff, particularly with the way that stroke services are following more of a model like cardiac where it's, I think now the hospital is much more of a medical model. I think because of the **reduction in time** and the length of time you actually stay, I work closely with neurologists and geriatricians, which is a similar model nationally. **The geriatricians see themselves more as partners with the patients rather than the neurologists see themselves more as the typical medical model investigation, telling the patient, and diagnosing.** I think it depends on what part of the pathway (Stroke nurse 1)*

An occupational therapist thought that a mismatch exists between the interests of the service and those of the patient. When quizzed about their views on decision making and the PPR, they had the following to say:

*I think as a therapist you're a bit stuck in the middle there, and **you want to advocate for the patient, but you're also aware of the service needs and service demands, and what the rest of the MDT are thinking, I suppose.** So it can be [a tough balancing act]; it can be, between **what's best for the patient and what's best for the service, yes** (Occupational therapist 6)*

The selection of comments above demonstrate that there is a general feeling amongst stroke professionals that the way services are currently set up, and the performance measures that are in place to assess the effectiveness of care delivery within that service, often do not meet the information (and other) needs of the patient, nor do they facilitate greater patient participation. Therefore, reassessing targets and the way in which the system is configured would clearly be one way to improve the situation. These are the thoughts of one stroke academic on the matter, who gave this example to illustrate the extent to which professionals may feel boxed-in by the excesses of the current target-driven, audit culture:

I heard an example that always sort of struck me was that one of the practitioners asked the patient what they really wanted to do, and they said they would like to be able to walk out to their bird table and feed the birds. And she wasn't allowed to put that down as the purpose of the therapy, because it wasn't going to be able to demonstrate that they were trying to reduce health and social care costs. So she had to put the aim of the therapy was for this person to be able to transfer independently on and off the toilet or something like that. But actually anyone with half a brain would know that if that person was getting up out of their chair and walking to the bird table, the chances are they would then feel more motivated, their mood would improve and they may be less likely to need support at home (Academic 1)

They concluded with this remark, reiterating their view stroke care had become too focused on the outcome of a service to the detriment of the patient and their needs:

*So I think if we really, truly want to embrace more of a person-centred approach, we should be thinking about that. There's a lovely quote from somebody high up in the Health Service Journal or something like that – which said we should be commissioning walking the dog, as opposed to varicose vein surgery. And I thought, that's really what I think the message needs to be. **We've become too driven by the outcome of the service**, without actually backtracking and thinking, well, you know, what's actually going to get that person out of bed in the morning? You know, it's not the fact that they can transfer independently, it's actually what they want to do when they're up (Academic 1)*

Similarly, one stroke consultant voiced this opinion on how performance measures could be used to work with, rather than against, the needs of patients to bring about the desired improvement in patient information:

*Well I think there are so many requirements on modern... **there are so many targets that have financial implications for the trust in service that they naturally get priority.** And sometimes you need that to be mandated centrally with funding to influence patient...to influence sort of further provision of patient information. There was a recent plan to have joint health and social care plans implemented as part of the improvement program and there was no definition of what that was for the entire first year of the project. I think those sort of things need to be clearly defined in terms of what is expected so services can take that on board and try and provide better quality information (Stroke consultant 12)*

6.1.4 Summary of key points relating to service configuration as a core category

An area for improvement was felt to be the allocation of resources so that current shortages in adequately trained staff (especially neuro-rehabilitation experts) and time constraints on existing providers are felt less acutely. In addition, the overall ease of navigation through the stroke pathway, and the ability of the patient to access information and resources at key points along it, is an important area for improvement.

In the view of the professionals that were interviewed, current performance measures need to be reassessed; that is, the use of injudicious targets negatively influences how services are aligned and the emphasis placed on the various aspects of the stroke care system. The reassessment of performance measures must result in a change towards a set of targets more

closely matching patients' interests, rather than those of the service providers²¹, in order to improve information provision and patient participation.

Furthermore, greater communication training for stroke doctors, improved time management and alternative communication strategies were all put forward as potential ways of improving patient information provision and involvement in light of the resource limitations the NHS faces.

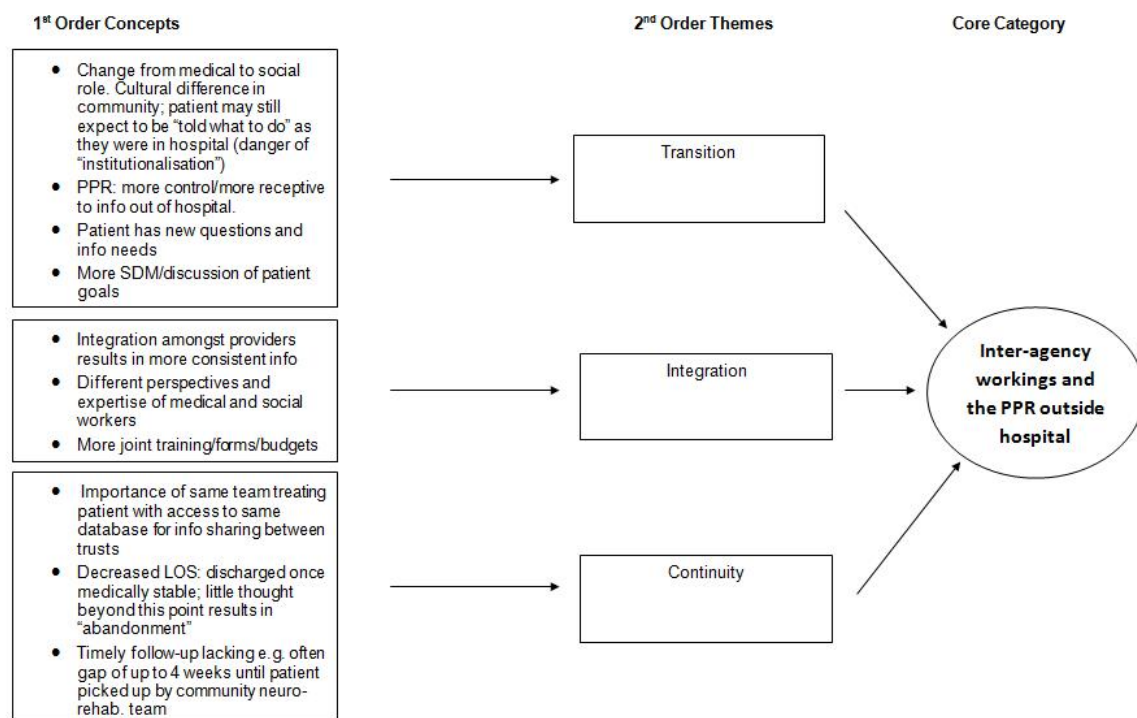
6.2 Inter-agency workings and the PPR outside hospital (core category)

A large proportion of interviewees viewed the patient's transition from the hospital to home environment as an opportunity to improve patient information provision and involvement, since acute interventions and time restricted interactions are not commonly a feature of community care. However, participants were also eager to stress that to take full advantage of these features of the community setting, there needs to be better integration amongst medical and social providers, in addition to improved post-discharge planning and continuity of care outside the hospital.

The three themes identified as part of this core category are transition, integration and continuity. As we shall see from the findings presented here, there is some overlap between these second order themes. This is an issue that will be addressed in greater detail in the discussion chapter. Where the findings sit in relation to the literature will also be considered in that chapter. The overall coding structure for this second core category is shown in the diagram below.

²¹ The term *providers* is being used in this instance to encompass not only the stroke professionals themselves (the most common usage in this work) but also Trusts, service managers and policymakers.

Figure 6.2 Inter-agency workings and the PPR outside hospital – overall coding structure



6.2.1 Increase awareness of issues surrounding patient transition from hospital to community care (second order theme)

A number of participants felt that upon discharge from hospital, the patient’s role changes from a medical “sick role” to a more empowered social role, with the potential for patients to exercise more control over their interactions with providers within the PPR context and the goals that they would like to set for themselves. For instance, this is what one community occupational therapist had to say:

*I often have long discussions with my colleagues who work in stroke units **in a hospital setting, where I think the emphasis is very much on discharge and self-care**, in making sure that you can get home and get washed, get dressed whereas by the time we see people, post-discharge, especially once they’ve been out of hospital for a while and are settling down, it’s what am I going to do for the rest of my life? How am I going to get outside the front door? How confident to I feel accessing buses, getting to the shops, they think about getting back to their local gym, but obviously **a very different set of goals and interests that people have** (Occupational therapist 2)*

A stroke specialist nurse agreed that patients become more empowered and better able to participate in decision making once they have left hospital, stating:

*I think the discussion around goals I've found in our settings with the patients tend to be more when we had the early supported discharge, once the patients had gone home and they were in their own home, it was then more discussed around leisure activities and different activities, **what is it you want to achieve? And at that point there was probably more discussion with the patients** (Stroke nurse 4)*

These excerpts highlight that the transition from hospital to home marks a shift in the PPR and taking advantage of this by encouraging early discharge (as long as it is coupled with integration amongst providers and good continuity of care) is one way to improve overall information provision and patient participation. Indeed, one occupational therapist emphasised the dangers of not discharging soon enough, saying that the longer the patient stays in hospital, the more “institutionalised” they become and the more difficult it is for them to actually “take control”. A consultant clinical neuropsychologist struck the same note, but from a mental health perspective, when he described the change from more “intensive” treatments in a hospital setting to less intensive ones post-discharge as a “difficult gap to bridge” and one that patients had “difficulty coping with”.

A senior occupational therapist within a Scottish community stroke service also observed the ‘institutionalising’ effect stays in hospital may have on some patients:

*I do notice when people come to us, because we're based in the community and there's less of an institutional setting that people come and kind of **expect, sometimes, to be told what to do because maybe that's how it was in the hospital** (Occupational therapist 2)*

Of course, decreased LOS without adequate planning and strategies for ongoing care in the community will not result in improved information provision or patient participation, a topic

that we shall look at in section 6.2.3. Encouraging the deinstitutionalisation of hospitals appears to be one potential way of more smoothly preparing patients for their transition from hospital to home and thereby also increasing the likelihood of their participation throughout the care journey.

As we have established in the previous findings chapter, information needs are dynamic and constantly evolving. That is, the information a patient may seek in hospital will invariably differ from that they may want 6 months later once they are back at home. This is reinforced by a change in the PPR which sees the patient commonly becoming more ‘information hungry’ and demanding once they are home. For instance, one lead stroke specialist nurse observed:

Often we do find that when patients have got home and they're feeling a bit better in their home surroundings, [it] is then that they have a lot of questions they want answering (Stroke nurse 7)

Therefore, one suggestion put forward by a number of interviewees for improving information provision and participation, is to delay certain information until such a time that the patient actually wants it and is judged to be more able to absorb and actively discuss it. This invariably occurs once the transition from hospital to home has taken place. Here is what one consultant stroke occupational therapist had to say:

*I think people are **more receptive to that sort of information once they're at home**, once they're more settled and therefore the personalisation of that [information] is much more appropriate and effective (Occupational therapist 5)*

6.2.2 Improved integration amongst hospital and social service providers (second order theme)

As we have mentioned, there is little point in advocating decreased LOS for stroke patients as a way of promoting information provision and patient involvement, if there is a lack of

integration amongst the medical and social teams that oversee the transition from hospital to home. In fact, the way in which these various ‘agencies’ work with one another appears to be the key to unlocking that patient’s potential to be involved in care decisions and to access the consistent information they need.

In the first findings chapter, we argued that decreased *LOS* was an example of a performance measure which negatively impacted providers’ ability to deliver information to patients and involve them in care decisions. Whilst here, we appear to be saying the opposite. These two seemingly contradictory positions can be reconciled by recognising that it is not necessarily the length of time in a hospital setting (or community setting) which determines the overall, aggregate levels of patient involvement and information provision, but rather the depth of integration between the hospital and community settings. We will now evaluate this idea further by referring to the thoughts of the interviewees on the issue. One stroke physiotherapist and academic was keen to place the debate around integration in its proper context, stating:

*The hot topic in Scotland is this integration agenda between health services and council services, where if you take the social model, **the two have traditionally been at extremes of a spectrum**, where the bisector social model brings the two together. It’s recognising at which point somebody makes the transition from being a patient, a medically, very much impairment-focused approach, to being a person, active and participating in society. I think communication needs to be a theme around that a bit as well (Physiotherapist 5)*

When asked about the existing challenges to integrating hospital and community care, one stroke academic pointed to the frequent lack of a pooled budget, social and health teams not sharing the same forms, buildings or training as the key problem areas:

*Integration has worked in areas where there's been a pooled budget, and it's a truly integrated team. It comes down to the really obvious things, like if you've got a social care team and then you've got a healthcare team, and you're supposed to be working together, you're not in the same building and you're not using the same forms and you don't have your training together, then **it's really hard to achieve that level of integration**. The teams where I think it just works really well is where you've got your Stroke Association-funded support worker working within your team, and you've got social worker working within your team. It's a shame, because now it's going to be even harder to get that sort of true integration (Academic 1)*

The same respondent felt that the differing perspectives and knowledge bases of health and social workers was an issue that needs to be addressed, so that patients can become more involved with their care and do not feel “abandoned”:

*True integration is really difficult between health and social care, because **people from health will have one perspective and people from social care will have a completely different perspective**. When somebody has finished their rehabilitation or any of their health interventions, then they're left with not very much. It might not be that they need anything from a medical model, but in terms of access to other interventions ... because it can often feel to people as if they come to an end and then **they're abandoned at that point**. And I'm not sure that people in social care have enough knowledge about stroke. It's the people in the acute and the health side that have an understanding about stroke, but maybe not the impact of stroke in the longer term in people's lives, because they're not at that end, and people from social care and the voluntary sector have a great understanding of that end but not necessarily an understanding of the complexities of stroke (Academic 1)*

In broad agreement, when asked about integration one stroke consultant added that they had great difficulty when attempting to get social services to “engage” with healthcare providers in stroke.

It is the patient's own needs and ability to participate in their own care that is diminished by being caught in the middle of the various providers' differing perspectives and approaches. Indeed, one stroke care doctor went one step further by suggesting a problem exists with

integration not only between health and social care providers but also amongst healthcare professionals themselves, working at different sites. This interviewee, based at a London hospital, felt better communication between stroke units was one way to improve the provision of information to patients. They felt that the more we are able to integrate the healthcare professionals who work on hyper-acute and acute units in the capital, the more uniform the information delivered to stroke patients will be.

Moreover, aside from healthcare and social care professionals not sharing the same outlook to stroke on an individual level, there appears to be a lack of integration at the service or system level also – boundaries still exist and the pathway is not as seamless as it could be. A patient attempting to navigate what to them appears to be a disjointed service, will invariably find it more challenging to be involved with care decisions and to access the information they need. Several respondents raised this concern whilst attempting to see the service from the patient's perspective, with two stroke consultants in agreement saying:

*We're not good at shaping services for patients. Perhaps we should be. That's probably the problem, in the NHS anyway. **We should design our services locally around the patients.** The thing about **stroke care, to us, we understand that it all feels quite joined up but it can be quite fragmented for the patients**, particularly they often feel that everything is very fragmented. They go from hyper-acute care to acute care to rehab to community and to us that feels a very compressed service, different phases, different faces, different approaches to rehab, and it's all ... not really fragmented but you can see how it could be **very difficult to navigate** if it's not seen from the inside (Stroke consultant 16)*

The second consultant struck the same note but stressed that it is perhaps more the family (rather than the patients themselves) who are most frustrated by a lack of an integrated care approach. He cited a lack of money in the system as the main obstacle to achieving this:

*From the perspective of a patient and a family, but perhaps even more the family than the patient; there's often a perception that **if only the team that treated them, either in the hospital or the community, continued to treat them indefinitely**, then they would continue to improve and they would feel much better. But then of course, that isn't something that the service can afford to do, so at some stage some other form of ongoing support comes into place, and at that point the patient still feels divorced. How we make all of this a sort of, **seamless communication process, that the patient is not quite so aware of these boundaries**, I don't know how to do that, but I'd like to find a way (Stroke consultant 7)*

6.2.3 Improved continuity of care throughout the patient journey (second order theme)

The third theme relating to this core category is continuity. Some of the main first order concepts include discharge planning, strategies for continued care and patient follow-up in the community amongst other things. There is an element of overlap with the previous theme of integration, as we shall see from some of the excerpts presented here. A hospital occupational therapist and a stroke consultant felt that considering information needs and other patient issues beyond hospital discharge is cost and time prohibitive, with anything beyond ensuring a patient is medically stable enough to go home a "luxury". They agreed that this is an area of care that is not currently well delivered, with patients being abandoned into a "black hole" at discharge:

*Absolutely, [information needs relating to activities of daily living once the person is back home are overlooked]. But I think from speaking to my colleagues, they would say that they would like to look at those things, but in reality, **bed length of stay is reducing**, because of the pressures on resources within an NHS setting, and **once somebody is medically stable** and they're going to be safe to manage at home in their house, **they will be discharged**. And they don't have the time, **they don't have the luxury**, I suppose, of **exploring beyond that** (Occupational therapist 2)*

The consultant thought contact points could be reviewed as a solution to the current difficulty:

*You get discharged and you just **drop into this big black hole and just feel totally and utterly abandoned**, you don't know where to go, who to turn to or anything, which must be awful, and that is something that does need to be addressed in terms of points of contact and again, information (Stroke consultant 2)*

Again, recognising the need for information throughout the patient's stroke journey, including after discharge (and the family's role in the ongoing communication process), one stroke consultant eloquently summarised the situation, commenting:

*I think you have to put a lot of effort and a lot of time into that ongoing communication. Providing leaflets is fine, and there are some people who really like leaflets, and there are some people who don't. There's an issue about producing stuff in aphasia, friendly, easy access format, and the Stroke Association are quite good at that, but it could probably be better. But **it's a living thing, communication, it's not a one off**. It's not something that you do and then you **tick the box** and say, I've done the communication. So **patients and family need the communication all the way along the line**, and they're going to need communication after discharge (Stroke consultant 17)*

This same participant was eager to emphasise the importance of continuity of care and presented a more optimistic outlook of the current situation than some other respondents stating:

*The Stroke Association Information Advice Support will pick up patients before they're discharged, certainly local patients, and they will then follow them up and discharge them, and they do the six month post stroke assessment, **so they're involved with the patients for at least six months after the stroke**. That I think is very important, because that is almost an honest broker, who is somebody who will follow you out into the community (Stroke consultant 17)*

It is interesting to note that despite acknowledging the importance of continuity of care, this arrangement only lasts 6 months and appears only to be available to local patients. Perhaps this is what led several informants to be rather less sanguine about the current situation post-discharge. For instance, one stroke consultant had this to say on the matter:

*Yes, because even from my point of view, sometimes I feel like I'm **discharging patients to this big, black hole, over which I have no control over**. Because obviously when they're an inpatient, I'm responsible for them, I look after them, liaise with the team, make sure they have the right information, etc, etc, and then you're discharging them into the community, and **I'm never quite sure what's going to happen to them after they go home**. You know, are social services going to come in, as promised? Is the community neuro-rehab team going to come in, as promised? **There's a big gap, for me, and for the patient, really** (Stroke consultant 6)*

Using the same analogy of a “black hole”, another consultant emphasised how widespread the problem of the sense of abandonment amongst patients is, saying it was an issue “practically every patient talks about”:

However, one stroke doctor felt that early supported discharge (ESD) has helped remedy this sense of abandonment to some extent, but does not go far enough in ensuring that patients' information and other needs are listened to in the longer term:

*I'm very aware that even where we thought we'd done very well, but the patients' perceptions may be very different. So, I think there is a big important issue. Now, in the days when we didn't have early supported discharge teams and so on, **the patient felt divorced** when they were discharged from hospital. Now, some of them feel divorced when they're discharged by the early supported discharge team. And **the issue of long term support and communication in the longer term is one that I don't think anybody has fully resolved yet** (Stroke consultant 7)*

When asked how we could improve patient information provision, several stroke doctors chose to focus on continuity of information and care. One consultant physician suggested that the patient-held record or journal might serve as an effective bridge between the hospital and community settings, in addition to the timely follow-up of therapists. Another doctor mentioned a delay in patients being seen by neuro-rehabilitation teams in the community as a particular area for improvement, citing instances of waits of up to “three or even four weeks or even longer”. They felt that patient information about what to expect after discharge was an area requiring attention also.

Several excerpts touch on both integration and continuity at the same time. For instance, two clinical stroke lead nurses pointed out that there are difficulties sharing information between different trusts, resulting in inconsistencies in patient information delivery and care:

*We then have the problem with information sharing between two different trusts. Our data systems, **our stroke database doesn't talk to the other database so we have to make sure that we let them know what we've captured.** From a patient point of view, I think it does get a little bit ... I suppose, really, the things that I know would happen here and we might be describing are not necessarily going to be the same pathways in another hospital. So, I think we need to do some work around that (Stroke nurse 3)*

The second stroke nurse thought that issues around integration and continuity were also related to differing targets driving care for hospital and community practitioners in different directions; therefore, she suggested uniting the two under a single organisation as a potential solution:

There probably is a lack of continuity of information post-discharge. A lot of services unfortunately are quite disjointed. I'd like to see stroke pathways just being owned by one organisation, be that community hospital or whatever, and I think obviously when somebody goes from a hospital setting to perhaps a community setting which is perhaps a different organisation, then I think that's when there is a gap and that's when it is a hand on and hand off with therapy staff, nursing staff, a different group of staff looking after the patients with different sorts of targets and paperwork. That's when things do get a little bit lost. What we're trying to get more of in Sheffield Stroke Services is a rotation of staff; when people are rotating they can appreciate the different services, so that they understand, and there is that continuity...that's the issue with a condition like stroke, that you do need more than anything that continuity (Stroke nurse 1)

6.2.4 Summary of key points relating to inter-agency workings and the patient-provider relationship (PPR) outside hospital as a core category

In the view of the professionals interviewed, the time during a patient's transition from the hospital to their home environment presents an opportunity for improving information provision and participation, as acute interventions and time-restricted interactions are not as frequently a feature of community care. To take full advantage of this, however, there needs to be better integration between medical and social care providers, as well as improved post-discharge planning and continuity of care outside the hospital. Similarly, the patient's role changes upon discharge from a medical "sick role" to a more empowered social role, with the potential for patients to exert more control over their interactions with providers within the context of the PPR, for example by setting more therapy goals themselves.

However, decreased LOS without sufficient planning and strategies for ongoing care in the community will not result in improved information provision or patient participation. Indeed,

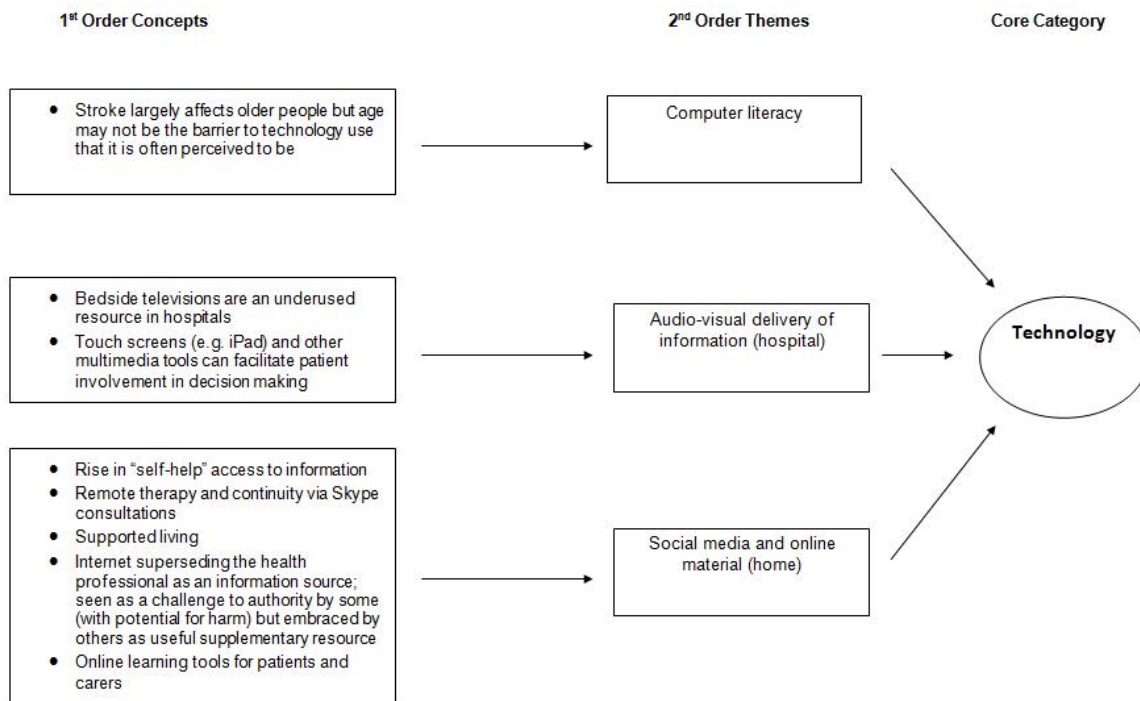
it is not necessarily the length of time in a hospital setting (or community setting) which determines the overall, aggregate levels of patient involvement and information, but rather the depth of integration between the hospital and community settings, where boundaries still exist preventing the pathway from being as seamless as it could be from the patient's perspective.

Furthermore, the consensus view held by the professionals interviewed was that promoting the deinstitutionalisation of hospitals appears to be a potential way of more smoothly preparing patients for their transition from hospital to home – thereby also increasing the possibility of patient participation throughout the care pathway. Another important area for improvement in their opinion would be to remedy the continuing difficulties encountered when sharing information between different trusts. Currently, this results in inconsistencies in patient information delivery and care.

6.3 Technology (core category)

When stroke professionals were asked how we could encourage greater patient participation in care and improve the delivery of information to patients, almost without exception technology featured in their thoughts. We have identified three main themes relating to the core category of technology and will present some of the key direct participant quotations here. The overall coding structure for technology as a core category is shown in the figure below.

Figure 6.3 Technology – overall coding structure



6.3.1 Computer literacy (second order theme)

As we have mentioned in earlier chapters, stroke tends to affect older people more than the young. However, the consensus from the informants that were spoken to appears to be that age need not be a barrier to the use of technology. In fact, what has been broadly termed computer literacy may be higher than is perceived in wider society and respondents generally thought technology had an important role to play in improving patient information provision and patient involvement in care. However, in order to make these potential improvements a reality for stroke patients, there first needs to be a change in people’s perceptions outside of the healthcare providers’ network. On the issue of age and technology, a neuro-rehab manager thought that the stereotype of the elderly not being effective users of technology was dated and needed to be challenged:

I think it's an evaporating stereotype [that technology poses a problem for the elderly], in the sense that most people...the proportion of [older people] now that have the web and have mobile phones is growing massively (Neuropsychologist 3)

The stroke academic made the same point, saying that the proportion of older people with computers is continuously increasing. Furthermore, giving the specific example of telemedicine and the response of older patients to cameras, a stroke nurse had this observation to share:

*That's one of the worries that we had when we started the telemedicine. We thought that [older] people might be a little bit freaked out by the idea of having a camera at the bottom of the bed and speaking to a consultant remotely, but that's not been the case. You know, **they seem to embrace it just as quick, really, as somebody who's young** (Stroke nurse 3)*

Finally, one stroke consultant recounted an experience which reinforced their view that the elderly need not have difficulty embracing new technology:

I had a 91 year old lady on Wednesday who asked me to turn the page on her iPad and I didn't know how to do it because I don't have an iPad. She however was far better than I was and I had to go and find a member of nursing staff who knew how to work it (Stroke consultant 14)

However, a number of participants did sound a cautionary note making clear that technology adoption amongst the very elderly is by no means universal at present and that its widespread, routine use would be something very much for future generations. For example, one stroke doctor had this to say when asked if they thought easier informal access to clinicians, via email, could help patients receive the information they needed in a more timely manner:

*Yes, but not everybody's got access to email. This is something we discussed yesterday, about ease of information that in a couple of generation's time, everybody, even people in their 90s, will be going on the internet and getting information etc, but **we're still living in a time when the older people can't do it and they don't always have families that can access it for them.** So that is, okay, you might get 80% of the population, but, yes, you're going to have 20% that won't get it (Stroke consultant 2)*

Similarly, a senior occupational therapist pointed out that whilst the use of technology may have a place in improving some patients' access to information, it is not yet a routine part of the therapy they deliver for the following reason (actual question; "in terms of online material, is that well-received by patients?"):

*That [the use of online material] would not be something that I would routinely do with everyone, it would be dependent on the age and the background of the patient, whether that's something they would be having...so **it's not something I would routinely do.** I think that a lot of the patients are big emailers, do all their internet shopping online and they seem to respond to it really well and they seem to pick up things, things on the internet about their condition anyway, so I think they're the group that responds very well to it (Occupational therapist 1)*

6.3.2 Audio-visual delivery of information (hospital) (second order theme)

The second theme which emerges from the data is the idea that use of audio-visual technology within hospitals may enhance the provision of patient information and may be beneficial in encouraging greater patient involvement in decision making. One participant, a stroke physician, felt that bedside televisions are an underused resource and could prove to be a considerable asset in improving the delivery of information to stroke patients. This is what they had to say:

*Lots of hospital beds now have a television system set up. The trouble is that they're privately run, and it's quite difficult to patch into them as a resource. It would be fantastic if at some point in the future the bedside IT system that the patient is paying for, could provide, part of the quid pro quo would be that there's a **multimedia stroke information element**, but he's not been really able to set up anything like that, because they're private companies, and they're only interested really in making a profit out of what they're providing. **It's almost a wasted resource**, it's clearly something that one is aware of, because potentially they're a rich mechanism for presenting information that's not being exploited at present (Stroke consultant 13)*

The stroke consultant then went on to explain how one could go about implementing such a system (in terms of contracts and obligations) and the challenges that would have to be overcome (chiefly, conducting the negotiation of such a contract at the trust-level rather than the local hospital level):

*The stuff that's provided at the bedside is already there. **It is really a matter of the Trust renegotiating a contract** with these people to say, a component of the contract is that there must be, freely available on your system, the following multimedia presentation. A company wouldn't really resist that, if they knew that's how they were going to get the contract. [It's not as though] patients are not going to bother viewing films. It's very unlikely that the fact that they can access 20 minutes' worth of multimedia presentation about stroke is going to put them off, so I think that it would be a perfectly reasonable thing to build into a future contract. But it would have to be done at that level. **The local negotiation attempt to get into the system has been fruitless**. We're aware that we don't have a suite of multimedia materials that might make presenting information a lot easier, and make it easier for patients to access their own information (Stroke consultant*

Agreeing that bedside televisions could help to improve patient information provision, a senior physiotherapist described them as “underused” whilst a specialist stroke nurse tied the matter in with how patients generally prefer to receive information, in her view:

If there's a telly on, people watch the telly rather than pick up a book or a leaflet. So I do think audio-visual is... it captures you more, and actually... I don't know whether it takes up less or more cognitive processes, but it's easier to do. It's less labour-some, isn't it, for the person? (Stroke nurse 4)

The use of multimedia tools, such as iPads, was also discussed with the participants. The data support the idea that these types of audio-visual devices may have a significant role to play in improving patient information and involvement. One speech and language therapist, an expert in patient communication with experience of using iPads with patients, said:

*We are experimenting with iPads and we also made an aphasia app. Our idea is that eventually someone with aphasia could use this to explain what aphasia is to another person. We have shown that to a lot of our new patients, because people with aphasia are doing quite active, participative things in it. **We're showing it to people earlier on as a way of giving them some hope and it very much promotes the local self-help group.** So we have used that as a way of giving some people information, but mainly I work with the iPads using them as **therapy or communication tools.** But it is, potentially, a really **powerful way of giving information**...[we're] trying to get people to realise that [iPads are] not just about an individual being more able to express themselves, **it's about you giving them information in a way they're going to understand and be able to digest** (SALT 1)*

This same speech and language therapist went on to explain the problems with attempting wider implementation (mainly, incompatibility between Apple's software and the NHS') and also cautioned against viewing the device as a replacement for effective, natural communication between provider and patient:

*Well, our main obstacle [to wider implementation] is that **we cannot use the iPad with the NHS computing system**, a really annoying thing that is limiting its use. Lots of places around the country are having the same experience, so we're actually in negotiations with our IT security people, to try and overcome that problem. But because these devices are becoming more and more mainstream, it's going to be easier for more people to have access to one. Another barrier, though, is **people's expectations are maybe too high** of what the iPad can do. And people are always saying to me, oh, if so-and-so had, you know, an iPad, they could communicate so much better, and I often say, you could communicate better with them (Speech and language therapist 1)*

A stroke academic and physician thought that iPads could be used as a decision making tool and could encourage greater patient involvement in decision making, particularly around thrombolysis:

*[iPads have] potential; it's certainly something that's been looked at for decision making by a Newcastle group. **They've developed a visual tool for decision making**, primarily for doctors, but I can see that being used for patients because it shows a really individualised – the benefits ratio – and I could potentially see that being used to **show the patient's chance of recovery with thrombolysis and help them make a decision** (Stroke consultant 1)*

6.3.3 Social media and online material (home) (second order theme)

The third and final theme identified from the data is the idea that patients and family accessing social media and other online material at home could be another way technology is used to improve patient information provision and involvement with care. There are also some interesting implications of the rise in online sources of information for the PPR, which will be considered in greater detail in the analysis to follow and the discussion chapter too.

A stroke doctor and an occupational therapist saw potential in using the internet to improve information delivery by connecting stroke patients to one another, and to their health provider, from their own homes:

*I wonder about social networking; are there tele – solutions to some of this? I've certainly seen some very interesting examples in the area of supported living, where there are **internet ready touch screen televisions in the patient's house** used for keeping in touch. I don't mean Facebook, but **maintaining social networks in somebody who is perhaps not as mobile as they used to be**, would be very relevant for many stroke patients, and also is **a way to put stroke patients in contact with each other** [for peer to peer information sharing], where perhaps there is a geographical distance, or there's difficulty in transport (Stroke consultant 7)*

Yes, technology certainly does have a role in improving patient involvement, and also perhaps even being able remotely to give information to people. A friend that I was speaking to recently does goal-setting by Skype. When he's reviewing a patient that has been discharged from hospital, he is able to speak to them over the internet or even by email. [It is useful] being able to send some appropriate information to them that way, or being able to show them different things on Skype (Occupational therapist 4)

Several respondents also noted the rise in “self-help”, where patients are using the internet to access information for themselves. Overall, this was deemed to be a positive trend and was actively encouraged by many as a way of improving the delivery of information to patients and helping patients to be more involved with their care. However, a significant minority of respondents were concerned that patients were accessing incorrect information. Perhaps in response to this, several interviewees felt that more should be done to create high-quality websites that patients and relatives could be directed to. Below is a table of key excerpts illustrating these findings.

Table 6.3 Social media and online material (home) excerpts

Interview excerpt	Interviewee
<i>I suppose in a more technological age, I think there is something there about how people can access information themselves as well</i>	Physiotherapist 3
<i>A young guy had a stroke who's coming back a year on and I said, what were you told about this stroke? And he said, nothing, no one tells us anything ... but clearly they were told stuff. We've got an electronic record about it. They said it was only when they got an invite for a study that they went on Google and had a look at Lacunar stroke and they started to understand</i>	Stroke consultant 18
<i>I'd also encourage people to access the internet to look up things, direct them to sites that I think will be helpful. But I'm a firm believer in people doing that for themselves when they can, other than me just force-feeding them information. It might get them a bit off direction and then we'll talk the next time we meet about what they've discovered and what they've learned and what</i>	Neuropsychologist 2

<i>part... areas of confusion still exist</i>	
<i>I've seen a major increase in the last couple of years with regards to thrombolysis. People go on the internet and access information and are prepared to challenge you now. Unfortunately, some of the information they do gain from the internet isn't appropriate and they're obviously not able to look at that rationally. But it is good that they're accessing this information. They have some knowledge in order to [participate], they're interested about their health and about the care that they're receiving</i>	Stroke nurse 7
<i>I've used computer software with lots of patients, not necessarily just aphasic material but just in terms of sharing information, so interactive tools like the Stroke Carers website with diagrams and so on. I try to explain what's happened, educate a bit more rather than just here's a leaflet, go off and read it</i>	Occupational therapist 1
<i>[We can improve information delivery with] virtual learning environments and personal learning networks, and I think increasingly trying to think about how to make accessible patient appropriate materials on the web, that can help people navigate the systems around them. Increasingly people have access to computers, so really making available good quality stuff there is very important</i>	Neuropsychologist 3
<i>One of the things that I found quite mystifying was that these same relatives would go into their own internet search and actually find incorrect information and that comes back to us, perhaps, dealing with an individual who's just upset and is finding it hard to cope. But, yes, having really good websites that you can direct people to with confidence ... would be a good plus</i>	Speech and language therapist 1

The same speech and language therapist felt that in addition to traditional patient information websites, social media sites could also have a part to play in both improving information delivery and particularly in encouraging greater patient participation, particularly by engaging those patients that have a low level of interest in their care. She also stated her intention to use such social media channels “more and more” going forward. Several other interviewees agreed with this view. For example, one neuro-rehabilitation manager cited LinkedIn as a portal for peer-to-peer patient information exchange and ultimately improved information provision, whilst one stroke academic saw potential in using social media networks for improving the delivery of patient information:

*One of the things I've been lurking on and I'm a great fan of is Linked-In, where for example there are forums there, the brain injury forums around education and advocacy, which has hundreds of people from all over the world, and patients post up their kind of queries, and **advise each other and cheer each other on. And I think that's very powerful** (Neuropsychologist 3)*

*In terms of other social media like Facebook and Twitter and those sorts of things, I think that's got **a huge role and will become increasingly important** (Academic 1)*

6.3.4 Summary of key points relating to technology as a core category

In the view of the majority of professionals interviewed, advanced age need not be a barrier to the use of technology, with computer literacy amongst the older patient probably likely to be at higher levels than is commonly perceived. Therefore, technology has a potentially important role to play in improving stroke patient information provision and involvement in care, particularly as it is not yet a routine part of therapy.

Furthermore, bedside televisions are generally thought to be an underused resource in the opinion of those interviewed and therefore could prove to be a considerable asset in facilitating the improvement of information delivery to stroke patients.

In addition, whilst the interview data support the idea that audio-visual devices (e.g.iPads) may have a significant role to play in improving patient information and participation, one must be careful not to view such devices as replacements for effective, “natural” communication between the provider and the patient. Finally, several respondents also noted the rise in “self-help”, which they felt has coincided with increasing access to technology.

Once again, we will revisit parts of the literature to place the research findings pertaining to RQ2 in their proper context. Unlike the purely descriptive findings already presented, here we aim to analyse the study's results in light of what is currently known.

A reminder of the second research question is show below:

RQ2: How do health professionals think patient information provision and involvement can be improved in stroke care?

As we have seen, the answer to this question broadly follows the three core categories delineated above in this second findings chapter; namely, service configuration, inter-agency workings and the PPR outside hospital, and finally technology.

6.4 Suggested improvements in service configuration

The system in which professionals work appears to have various shortcomings and, therefore, opportunities for improvement. One such area for improvement is the allocation of resources so that current shortages in adequately trained staff (particularly neuro-rehabilitation experts) and time constraints on existing providers are less severe. The idea of disinvesting in certain parts of a service to boost funding to more cost-effective areas which may increase the likelihood of longer-term patient involvement (such as psychological care for stroke patients) is supported in the literature (Pearson and Littlejohns 2007), although their work was not specifically aimed at stroke.

The difficulties patients encounter navigating the stroke pathway, and the inability of patients to access information and resources at key points along it, is also an important area for improvement.

Furthermore, current performance measures need to be reassessed as the use of poorly considered targets negatively influences how services are aligned and the emphasis placed on the various aspects of the stroke care system. The reassessment of performance measures must result in a change towards a set of targets more closely matching patients' interests, rather than those of the service providers, in order to improve information provision and patient participation. The literature is equivocal on the broader issue of performance measures in the NHS, with some arguing that targets have done more harm than good (Gubb 2009), whilst others have taken the opposing view (Bevan 2009). It is beyond this study's remit to engage in this more general debate; suffice to say that the more balanced view is the consensus amongst participants here in the specific case of stroke i.e. targets in stroke care are fine so long as they are the *right* targets for *both* the service and the patient.

Greater communication training for stroke doctors, improved time management and alternative communication strategies (e.g. an alternative to the ward round) were all put forward as potential ways of improving patient information provision and involvement. Although necessary, these initiatives (along with the centralisation of information to ensure consistency in its delivery) may be difficult to implement without further government-mandated funding for patient information provision. What can be achieved at minimal cost, however, is the provision of more information to patients as to what they can expect to receive from the stroke services they use. This would reinforce the notion of the patient as a consumer of care, thereby making their active participation in the process more likely (Edwards and Elwyn 2009).

6.5 Inter-agency workings and the PPR outside hospital

The patient's transition from the hospital to home environment is an opportunity to improve patient information provision and involvement, since acute interventions and time restricted interactions are seldom features of community care. To take full advantage of this, however, there needs to be better integration between medical and social care providers – the barriers to which (e.g. professional identities and differential power relationships between newly integrated services and professionals) have yet to be fully overcome (Glendinning 2003).

For maximum effect, this integration agenda must go hand-in-hand with improved post-discharge planning and continuity of care outside the hospital. For, as noted previously, it is not necessarily the length of time in a hospital setting (or community setting) which determines total levels of patient involvement and information, but rather the depth of integration between the hospital and community settings, where boundaries still exist preventing the pathway from being as seamless as it could be, particularly from the older patient's perspective (Lewis 2001; Glasby 2004).

Promoting the deinstitutionalisation of hospitals also appears to be a potential way of more smoothly preparing patients for their transition from hospital to home – thereby also increasing the possibility of patient participation throughout the care pathway. Another important area for improvement would be to remedy the continuing difficulties encountered when sharing information between different trusts, which results in inconsistencies in patient information delivery and care (Booth 2003).

6.6 Using technology to improve patient information provision and involvement

The use of technology is thought to be a key area for encouraging greater patient participation in care and improved delivery of information to patients. Advanced age need not be a barrier to the use of technology; computer literacy amongst the older patient may be higher than is commonly perceived and new skills can be learnt in much the same way as within a younger cohort (Broady, Chan et al. 2010). Therefore, technology has a potentially important role to play in improving stroke patient information provision and involvement in care, particularly as it is not yet a routine part of therapy.

Bedside televisions are underused, yet they could significantly facilitate the improvement of information delivery to stroke patients. Similarly, audio-visual devices (such as iPads) may have a considerable role to play in improving patient information and participation, particularly in stroke rehabilitation (Seminara, Anderson et al. 2013). However, one must be careful not to view such devices as replacements for effective, “natural” communication between the provider and the patient.

The rise in “self-help” (that is, patients and their relatives accessing information on the internet for themselves) is a trend with the potential to improve patient involvement. Similarly, social media and peer-to-peer exchanges online are to be encouraged as avenues for improved patient information and empowerment. However, high-quality online materials and tools must be made available to stroke patients (and adapted to make them accessible to those with aphasia, for instance) to take full advantage of this movement and counter the risks of misinformation through this medium (Kerr, Hilari et al. 2010).

The major ways in which professionals thought patient information provision and involvement can be improved are summarised and presented in the table below.

Table 6.4: A summary of the response to the second research question

Service reconfiguration	Inter-agency workings and the PPR outside hospital	Technology
Reallocation of resources aimed at achieving better psychological care (recruit more specialist staff in this area)	Increase awareness of issues surrounding patient transition from hospital to community care, to take advantage of the empowerment patients often experience once home	Change in perception needed to remove stereotype of age being a barrier to technology use in the elderly
Greater communication and time management training for stroke doctors	Encourage early discharge whenever possible as shift in PPR (i.e. patient becomes more information hungry and demanding once home) presents opportunity to improve patient-centred care	Bedside televisions are an underused resource and could be considerable asset in improving patient information delivery
Explore alternatives to the traditional ward round for improved communication	Encourage moves to deinstitutionalise hospital experience	Use of audio-visual multimedia tools and devices, such as iPads, should be encouraged as they may potentially have a significant role to play in improving patient information and involvement in decision making
Coordination and centralisation of information for consistency in delivery	Delay certain information until such a time that the patient wants it/is more able to absorb and actively discuss it; often this point is arrived at only once patient is home	Encourage more patients and families to access social media and other online material at home
Clarify pathway for patients so that their options are known, information is easier to access and general navigation is better	Greater integration between hospital and community workers and care systems	Increase the use of remote therapy sessions between patient and provider using software such as Skype
Involve patients in pathway redesigns	Greater integration amongst healthcare providers working at different sites e.g. better communication between stroke units	Encourage the trend which is seeing increasing numbers of patients using the internet to access information for themselves and the associated rise in “self-help” approaches to care
Reassess current performance measures and change targets to be more closely aligned with interest of patient, not service providers e.g. ensure auditing does not cause information to be giving for the sake	Remove boundaries between health and social service systems to make pathway less disjointed wherever possible	Recognise the dangers of patients accessing incorrect information on the internet; do more to create high-quality websites that patients and their relatives can be directed to

of “ticking boxes” only		
Centrally mandate, with funding, further provision of patient information	Greater longer term planning (beyond 6 months) and more continuity of care post-discharge, including increasing the ability for Trusts to share information with other Trusts and community services	Increasingly view social media sites and networks, (e.g. Facebook, Twitter and LinkedIn) as important portals for peer-to-peer patient information exchange and a way to encourage greater patient involvement
Recognise that audits do not give an indication of the <i>quality</i> of the information provision process; a way of assessing this should be implemented in future	Trusts should collaborate with the DoH to provide better public education on stroke so that patients and relatives are more likely to know what questions to ask providers	
Provide more information about what a patient can expect from the service they are using		

Note: The three columns represent each of the core categories previously identified as relevant to RQ2. Several second order themes tie in with the first research question also (e.g. communication and information sharing between stroke units), as we have previously discussed.

These ideas for improvement form an important aspect of the study’s practical contribution, as we shall see in the conclusion chapter to follow. Lessons from the suggestions displayed above have also been used to inform the theoretical discussion, as we shall see in Chapter 7. There, we will highlight the areas of thematic overlap alluded to in these findings chapters and develop the relationships between core categories. The complex interactions will be shown in the discussion chapter to follow through the use of abstract illustrations, ultimately leading on to the study’s main contribution to understanding.

6.7 Conclusion

In this chapter we have presented the main findings relating to the second research question. Once again, three core categories were generated according to the techniques previously outlined in the methods chapter (chapter 4). These categories (service reconfiguration, inter-agency workings and the PPR outside hospital, technology) were then examined in detail, along with their associated themes and concepts, using supporting excerpts from the

interview data. Finally, we returned to parts of the literature to place the study's findings and analysis pertaining to RQ2 in light of what is currently known in this field of research.

One of the key ideas emerging from this chapter concerns integration with other agents (itself stemming from the second core category, inter-agency workings and the PPR outside hospital). In this chapter we have shown that integration encompasses many concepts, such as the idea of providing more consistent patient information through having a stroke team working closely together – a topic which has been researched before according to the stroke literature and is confirmed in this study. However, as we shall see in the next chapter, where this study's notion of integration with other agents differs from the existing literature is in its recognition that the provider team (and therefore the PPR itself) extends beyond the hospital's MDT to include, in particular, social workers in the community and health professionals at other sites and hospital trusts.

The discussion chapter will build on this finding to illustrate how this is an important departure from how the stroke PPR is typically conceptualised and may have implications for how it is researched also, since it is the first time that this concept has been associated with the PPR in stroke or any other condition. It may be important for future studies to consider incorporating the views of social workers to derive a more comprehensive PPR model that is not purely medically driven, depending on the age and circumstances of stroke patients involved.

Other noteworthy findings include the need for improved training of stroke professionals to equip them with better communication skills. Aside from improved training for existing practitioners, the shortage in psychological expertise – highlighted as an area for improvement by some of the interviewees – has been an undocumented issue in the prior research. This may be an issue specific to the UK, but consideration should be given to how

resources may be reallocated to achieve better psychological support for stroke patients. These are areas of health policy and practice with significant implications for stroke care, as we will see in the next chapter.

Similarly, in terms of service configuration, the suggestion from this chapter that professionals may feel obliged to prioritise and/or balance stroke patients' needs with those of the wider service (particularly around thrombolytic therapy) and therefore compromise their interaction (from an information provision and participatory perspective) with patients could be a reason to reassess the NAO's thrombolysis targets. For instance, as a result of time-based treatment targets, interviewees cite that they often do not feel they can engage with the patient and carer(s) about the merits and risks of thrombolytic treatment as much as they would like.

Relating to this, the findings in this chapter imply that service and thrombolytic therapy audits must be able to assess better the quality of stroke patient information provision, in order to guard against a potential "tick-box" culture. For instance, the fact that a trust can point to evidence that a leaflet was given to a patient or carer about their treatment or discharge options should not be taken as a sign that the information was actually understood. We will return to these topics in more detail in Chapter 7.

Other practical measures emerging in response to RQ2 here include providing more information to the stroke patient and their family about what they can reasonably expect from the service they are entering. This was perceived to be one of the main ways in which the pathway could be clarified for stroke patients and was seen as a way of boosting their likelihood of participating in care decisions.

Additionally, greater priority should be given to the production of high-quality online material to complement the existing offline offering, in recognition of the increasing trend for

stroke patients (and their carers) to access information in this way. Similarly, audio-visual ways of delivering information should be explored more fully, with particular emphasis placed on the potential exploitation of pre-existing technologies (most notably bedside televisions) as an inexpensive but effective information provision strategy. Another related finding is the potential benefit of remote access technology and teleconsultations to take full advantage of what we have termed the empowered-by-home phenomenon, which sees stroke patients asking more questions and demanding more say in their care outside the hospital environment. This has implications for the argument that the stroke PPR is greatly affected by where the patient is when they are receiving information and making decisions, as well as implications for the use of such technology, which is discussed in the final chapter.

Chapter Seven – Discussion

Discussion

7 Introduction

This chapter will build on the analysis presented in the findings sections. The bulk of the discussion will follow on from the responses to the research questions we set out to address at the start of the study. The responses, as presented in the previous two chapters, lay the foundation for the theoretical, and other contributions, shown here.

We set out to understand the processes of patient information provision and patient involvement in greater detail, with the aim of applying this knowledge to ultimately achieve improvements in both, leading to increased patient satisfaction. To do this, it was decided that factors currently affecting patient information provision and patient involvement in decisions about their care had to be identified. As we saw from the literature review, a number of factors had already been suggested. Some of these have been confirmed as being important here. However, several other factors that had not received much attention in the literature have also been noted in this study, as demonstrated in the analysis in the findings chapters. Moreover, exploring *how* some of these factors impact patient information provision and involvement has resulted in new implications for the PPR in stroke, which we shall turn to later.

As described in the findings chapters, a number of important factors from the stroke literature are confirmed by the data here. However, there are also some differences in how certain factors are seen to be having an impact. For example, in the stroke literature, early-supported discharge is shown mainly to affect involvement, whereas here we find evidence that it affects information provision also. Furthermore, several other factors that appear in the

general literature (but not the stroke literature) have been identified here, along with another factor that does not appear in either the general or stroke-related literature, but for which evidence emerged from this study. A summary of the main similarities and differences in the factors affecting information provision and involvement between the stroke literature and the data here are shown in the table below:

Table 7.1: The main similarities and differences in the factors affecting information provision and patient involvement between the stroke literature and the data from this study

Similarities found in these factors	Differences found in these factors
Auditing	Early-supported discharge (5.4.3)
Patient capacity	Discharge co-ordination (5.5.6)
Tailoring/sources of information	Patient-specific impairment(s) (5.5.1)
Dynamic information needs	Patient personality/characteristics (5.4.1)
	Government policy (5.4.4)

The discrepancies and the extent to which the similarities are comparable have been explained in previous chapters. A discussion of all these differences, with possible explanations for why they might exist, can be found in the sections shown in parentheses and therefore will not be repeated here.²²

In order to move the discussion beyond this, we must compare table 5.8 with tables 3.3 and 3.4. By doing so, we are able to deduce that there are four stroke-specific factors from the data here affecting patient information and involvement, which have not previously been

²²However, later we will select two of the factors where differences were found (“patient-specific impairment(s)” and “discharge co-ordination”) to illustrate a separate point about the “how” component of RQ1.

identified in the stroke literature. They are technology, training, resources/sources of information and neuro-psychological shortages. The first three of these have been described in the general literature only (i.e. they have not been mentioned as factors affecting patient information and involvement in stroke specifically until now). The fourth factor is “new” as a stroke-specific factor (having been described in neither general nor stroke literature), but rather being identified from the data in this study.

The more comprehensive the list of factors generated from research, the more informed the debate can be and, therefore, ultimately the more complete our understanding of this area will become. For this reason, the recognition of these four factors in this way should be seen as a contributing step towards increasing knowledge in this field. They also have implications for policy and practice, as will be seen in 7.2.3.

As shown in Table 7.1, the place where any given factor is seen to be having its main effect can often differ, as can the level at which the factor is acting, i.e. organisational, social/political versus individual – together, part of the “how” component of RQ1.

Take, for example, “patient-specific impairment(s)”; some parts of the literature suggests that involvement is equally impacted by patient-specific impairments (such as aphasia) and that the effect may be at an organisational level (Gordon, Ellis-Hill et al. 2009). This is in contrast to the data here, which imply the effect is mainly on information provision, at an individual level. As described before, one key study showed that aphasia results in asymmetric interactions which hinder the formation of a partnership approach to care, with stroke nurses controlling the topic and flow of conversations (Gordon, Ellis-Hill et al. 2009). The reason for this difference in emphasis may be that this research considers settings outside of hospital

too (through interviews with community professionals, for instance, where we find a patient is more likely to be engaged with decision making), involves a broader range and number of professional perspectives (not solely nurses) and does not include patients' views directly.²³

Another example of a discrepancy between the stroke literature and the data in how a factor is seen to be having its impact on patient information provision and involvement is found in “discharge co-ordination”. Some parts of the literature suggests that it is mainly patient involvement that is impacted by a lack of discharge co-ordination and that the effect is at an individual level (Koh, Barr et al. 2014). This is in contrast to the data here which imply that the degree of integration between health providers at (and beyond) discharge mainly influences patient information provision, at an organisational/social and political level.²⁴

The reason for this discrepancy may be due to a different participant mix (Koh et al asked for stroke patients' views only, here we have interviewed a range of health professionals), the fact that Koh's paper is based on research carried out in a Singaporean hospital (where culturally/politically authors may be more reluctant to blame organisational failings), the paper's focus on patient participation in particular or a combination of these.²⁵ As discussed, many of the professionals interviewed felt that patients were empowered to be more involved once discharged and that is possibly the reason we see this entirely “post-hospital” factor having its greatest impact on information provision, rather than involvement.

²³As mentioned before, outside the hospital setting, professionals report patients seeming more in control and therefore more participatory also. In their view, this is largely attributable to the lifting of a sense of “powerlessness” that comes from being “institutionalised”.

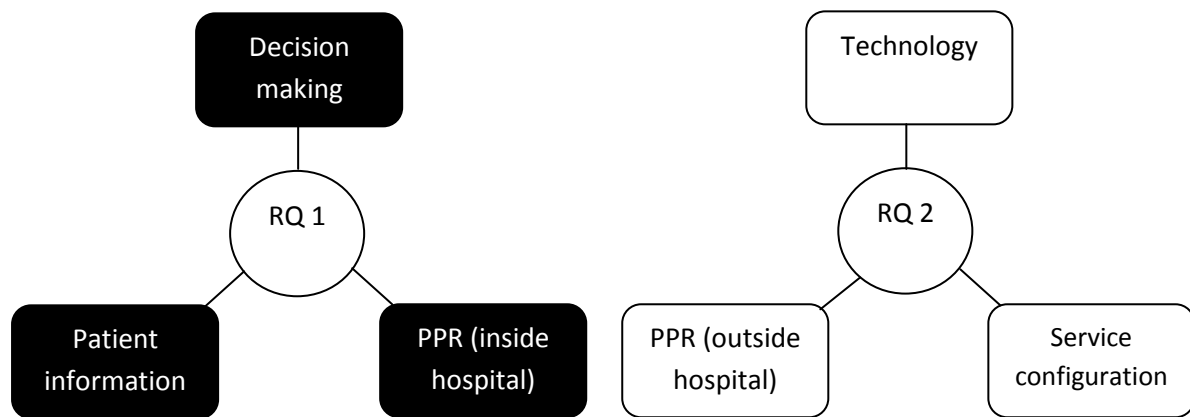
²⁴It is important to note that the Koh paper does not consider the impact of discharge co-ordination on the PPR specifically, whereas this research does.

²⁵The methodological implications of this for research in this area are considered in 7.2.2.

7.1 Building a new model of the patient-provider relationship in stroke care

In answering each of the research questions, certain core categories emerged, as shown in the figure below. For the first research question the three core categories were PPR, decision making and patient information (shown in black). For the second question they were technology, service configuration and inter-agency workings and the PPR outside hospital (shown in white).

Figure 7.1: The study's core categories



NB: Decision making and patient information are *not* presented here as factors/answers to RQ1. They are simply the core categories/headings under which the factors in response to RQ1 have been categorised.

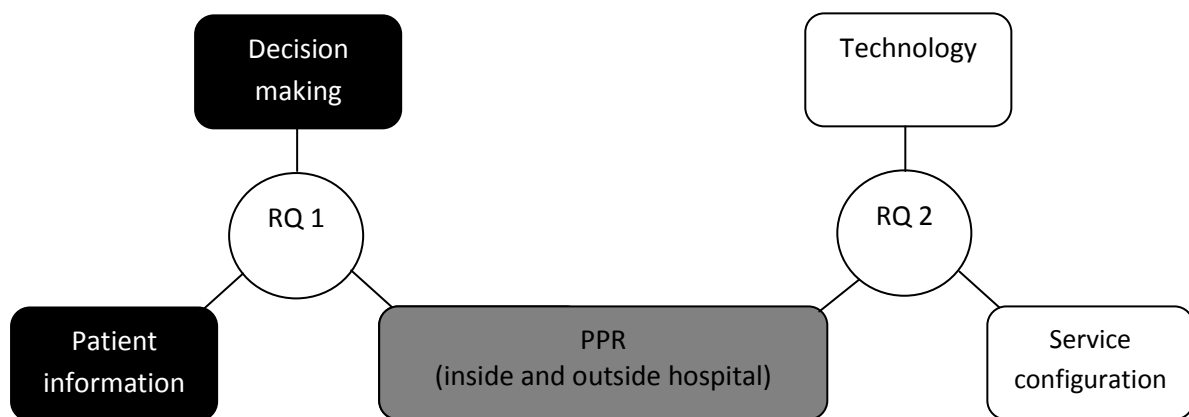
These are not neatly demarcated categories that have relevance to only one of the research questions, but instead there is overlap and inter-relatedness. Factors identified as having an influence on patient information and involvement will concurrently, by a change in said factor, be a way in which health professionals think patient information and involvement can be improved.²⁶

²⁶Moving one step beyond this, the literature shows that patient information provision and involvement are often inter-related themselves (Maclean, Pound et al. 2000; Smith, Forster et al. 2008; Murtagh, Watson et al. 2012). The findings have also confirmed this, which is the reason factors have been categorised as mainly affecting one or the other (and, indeed, often impact both information and involvement) in the analysis.

For instance, resource availability was shown to be an important factor in information provision and involvement of patients by professionals and better allocation of resources has been put forward as a way of improving information and involvement. By way of analogy, speed could be identified as an important factor in influencing road-traffic collisions (RTCs) and a reduction in speed could be put forward by road safety experts as a way of improving RTC figures.

An understanding of this inter-relatedness and the way in which concepts, themes and categories tie together that leads to the study’s central contribution to understanding. Once again, the core categories from the first findings chapter pertaining to RQ1 are shown in black; those from the second findings chapter associated with RQ2 are in white. Where there is an overlap, the category is shaded grey.

Figure 7.2: Establishing the PPR as the key core category



Overall, we can say that for some stroke patients information is synonymous with participation, whilst for others information is necessary but not sufficient for participation and that an individual patient’s feeling on the matter may even vary depending on psychological factors, the timing of information and other variables. A similar conclusion is reached in a Swedish paper studying 15 “frail elderly” patients’ preferences for participation in their care during hospitalisation (although only 2 of the participants were stroke sufferers) (Ekdahl, Andersson et al. 2010).

As we can see, the only shared core category is the patient-provider relationship. Unlike the other four core categories, the patient-provider relationship is a central component to the answer to *both* research questions and therefore merits particular attention. This commonality not only ties the work together, but also offers the opportunity to bring a fresh perspective to what is currently theorised about the PPR.

As shown in the literature review, the historical model put forward and most frequently used for studies in this area in the past often involved no more than the provider (usually a doctor) and the patient. Over time, this has been extended to include other care professionals (such as nurses and therapists) and sometimes the patient's family (Charles, Gafni et al. 1997). Many other influences have also been acknowledged. For example, the impact of technology and the internet, in particular, on the relationship dynamic between provider and patient.

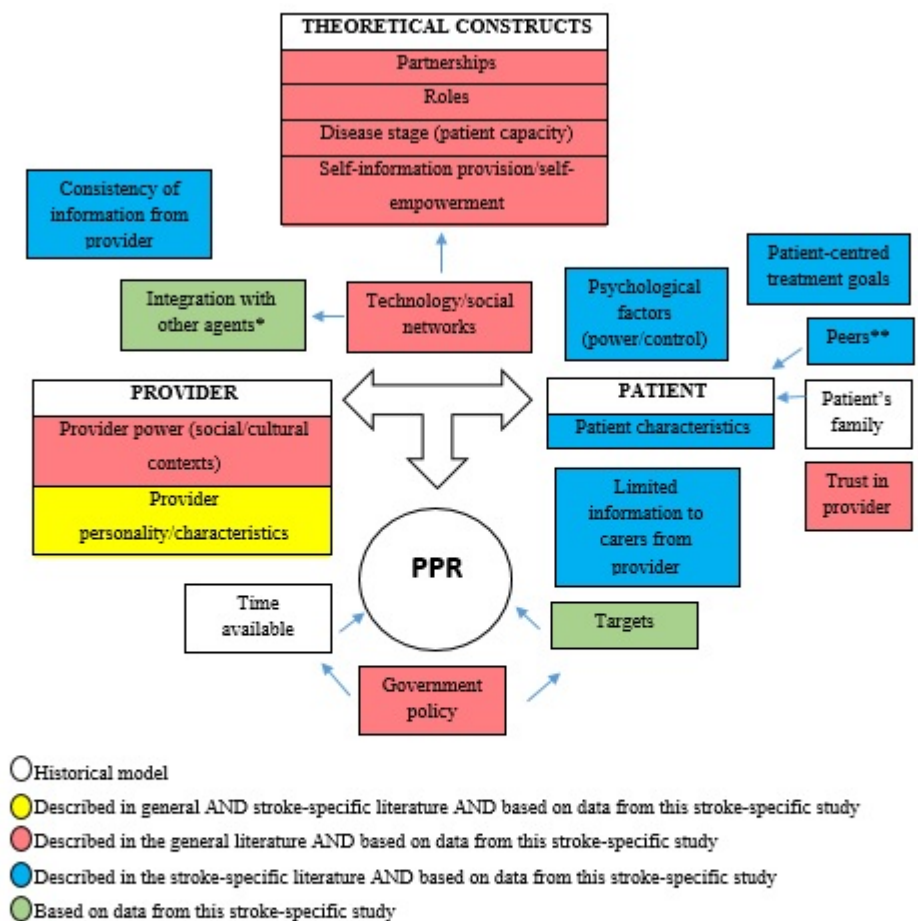
Organisational settings have been viewed as having a significant impact on patient-provider interactions for many years, particularly when the patients concerned are elderly (Haug and Ory 1987). However, the stroke PPR is still usually only studied in the narrow context of a single, specific hospital or primary care setting, with acute versus non-urgent interactions only occasionally being categorised separately. Additionally, the stroke PPR is often looked at without full consideration of the impact a patient's home environment, for example, could have on the interaction.²⁷

Therefore, here we propose a revised model for the stroke PPR, based on several factors that this study has shown to be important in influencing patient information provision and participation in stroke care decisions. The revised model also includes other components that

²⁷ Whilst this research was not conducted in patients' homes, the impact a patient's home setting has on the relationship was asked about in the interviews and the issue also emerged in response to other questions about the stroke PPR.

have previously been shown in the general literature to be important to the PPR, such as internet use in a digital “era” (labelled in red as part of “technology/social networks” in Fig. 7.3 which follows), but as of yet have not been incorporated into the concept in relation to stroke (Lo and Parham 2010). The revised model is equally applicable and relevant to contexts inside and outside of the hospital, as shown in the figure below.

Figure 7.3: The revised PPR model for stroke - factors affecting, and related to, the PPR according to the literature (both general and stroke-specific) and the data from this stroke-specific research



*most significantly, social workers in the community and other hospital trusts

**although fellow stroke survivors in hospital are mentioned in the stroke-specific literature as potentially impacting the PPR, the data from this study demonstrates that peers can have an effect on the relationship outside the hospital also

The revised model shown above has been generated through a synthesis of Tables 3.5 and 3.6, together with the data from the interviews (particularly that shown in Figures 5.3 and 6.2, which deal with the stroke PPR specifically).

The factors shown in red are found in the general literature but they have not previously been applied in the specific context of stroke. Those in green are not found in the general or stroke-specific literature i.e. this is the first time they have been explicitly applied to the PPR either generally or in the particular case of stroke. This is in contrast to those in yellow which have been described in the general and stroke literature and are now confirmed by the data here. Finally, the elements in blue are those that have been mentioned in the stroke-specific literature and are confirmed by the data in this research. As the model shows, the factors impacting the PPR in stroke are varied, but inter-connected. To illustrate some of the more important links based on the evidence here, arrows (in blue) have been added to the figure. This way key connections between, for instance, “technology/social networks” and “self-information provision/empowerment” or “government policy” and “targets” are emphasised.

The revised model for the patient-provider relationship can be applied to clinical and non-clinical stroke care settings in and out of hospital (for example, to include a consideration of the effect on the PPR of a patient’s home environment, once discharged). It is important to note that the revised model is for the PPR in stroke from the health professional’s perspective only. To demonstrate its applicability to other conditions and capture patients’ views directly, further research is required. Additionally, even though studies have hinted at the potential implications for the PPR of the rise in technology and social network use (McMullan 2006; Stevenson, Kerr et al. 2007), researchers have not fully explored the topic in stroke nor have these elements been incorporated into a revised PPR model as they are here, despite calls from some authors for this to happen (Wald, Dube et al. 2007).

Moreover, it is interesting and significant to note that under this study's proposed stroke-related PPR model the provider is now not the only, or even most important, source of information for the patient. Similarly, in the revised model, the ability of the patient to participate in care decisions is no longer as heavily determined by the level of involvement judged suitable by the provider. That is, other external factors (e.g. targets derived from government policy) are exerting more influence on the relationship dynamic than is suggested by the traditional PPR construct, with the provider increasingly adopting the role of *passive facilitator* of involvement rather than *active adjudicator* of it. This appears to more accurately reflect the reality of the patient-provider relationship within stroke care today.

Indeed, the types of changes in the relationship dynamic suggested by the extended model here would appear to indicate that stroke patients are becoming more empowered, or at least have the opportunity to be, whilst providers are perhaps becoming disempowered. Along the same lines, some in the general literature believe that socio-technological changes have led to a role convergence between patients and providers, in what has been termed the *doctor-modern patient* relationship (Buetow, Jutel et al. 2009). Whilst this is thematically close to part of the contribution to understanding here (as we shall see below), the authors stop short of proposing a revised model for the PPR and, indeed, are not commenting on the specific case of stroke as we are here. The merits or otherwise of these, and similar, lines of argument could form the basis for future work in this area and will be explored in the final sections of Chapter 8. Before then, we will expand on this study's contribution to our understanding of the PPR in stroke and its potential impact on policy and practice relating to the PPR in stroke care.

7.2 This study's contribution

We will look in turn at the research's contribution to:

- (i) understanding of the PPR in stroke care
- (ii) methodology in stroke care research and that relating to the PPR in stroke care
- (iii) policy and practice in stroke care and that relating to the PPR in stroke care

7.2.1 Understanding of the patient-provider relationship in stroke care

Figure 7.3 is a useful way to visualise the main findings pertaining to the PPR in stroke and therefore provides an effective basis for discussion of how our understanding of it has been enhanced. As we can see, there are two elements that are based on the data from this study only. Namely, “integration with other agents” and “targets” (both shown in green). It is the first time that these areas have been associated with the PPR, in stroke or any other condition. Taking the first of these (“integration”), we see from Fig. 6.2 that it is closely related to the idea of providing more consistent information to patients by having a stroke team working closely together. This, in fact, is an area which has been researched according to the stroke literature. How “integration with other agents” differs, however, is in its recognition of the provider team (and therefore the PPR itself) extending beyond the hospital's MDT to include (in particular) social workers in the community and health professionals at other sites and hospital trusts. This is an important departure from how the stroke PPR is typically conceptualised and may have implications for how it is researched also e.g. future studies may consider incorporating the views of social workers to derive a more comprehensive PPR model that is not purely medically driven. Other contributions to methodology are considered in section 7.2.2 below.

Secondly, “targets” have not been researched with respect to their impact on the PPR specifically in stroke (or any other condition). This finding is related to the stroke-specific literature which calls into question the usefulness of audit targets as tools for improved patient outcomes (Sudlow and Warlow 2009), but differs in connecting such targets directly to the relationship between the provider and patient. It furthers our understanding of the stroke PPR by highlighting the need to position seemingly external, government-driven matters (such as thrombolysis targets) at the centre of the interaction between professional and patient. The finding therefore also has implications for practice and policy relating to the PPR in stroke, as we shall see in 7.2.3.

The elements shown in red and blue in Fig. 7.3 are factors which arise from the general and stroke-specific literatures respectively and which have also been confirmed by the stroke-specific data from this study. While those in yellow are derived from both the general and stroke literature and the data here. Demonstrating these different aspects of the model helps to place the stroke PPR in the context of what is already known about the PPR more broadly. Additionally, in the case of the blue factors, it illustrates that many points arising from an array of PPR stroke studies (e.g. different countries, different health systems, those that include patients directly etc.) are confirmed here, thereby suggesting a universality to many stroke PPR notions – the extent of which might not have been appreciated previously.

7.2.2 Methodology in stroke care research and that relating to the PPR in stroke care

As we have seen in this discussion of some of the factors which impact patient information provision and involvement in Table 7.1, the design of the research, the differing approaches

and the predetermined focus of the particular study (whereby researchers often only find what they set out to look for) may result in a different emphasis being placed on similar findings.

Having said that, it is important not to overstate this point. For, as Table 7.1 also shows, many of the same factors are confirmed by studies where researchers adopt a range of methodological approaches (e.g. interdisciplinary studies) within different health systems (such as Singapore, Australia and North America), suggesting that a diverse set of approaches to research in stroke care often yield very similar results and are therefore likely to be equally valid.

This study shows that when researching the PPR in particular, it is important to initially take an holistic approach and view. That is, to help the researcher tease out and differentiate what is known more generally about the PPR from what is known in the specific case of the condition under investigation, the study must first look at issues broadly and only then become more narrowly focused. If this is not done, then important components of the PPR (particularly the theoretical constructs which inform our understanding of the relationship, both historically and now, as shown in Fig. 7.3) cannot be fully considered and therefore the validity of the condition-specific findings would have to be questioned for their lack proper context and depth.

Secondly, this research demonstrates that our understanding of the stroke PPR can be furthered, despite only considering stroke professionals' views. Indeed, as we have noted in the discussion around the factors influencing information provision and involvement above, occasionally it is precisely this approach that has highlighted certain novel findings that might otherwise have remained obscured. This is likely because some issues might require an

“insiders” perspective to be fully elucidated, such as the impact of targets on the PPR in stroke. Having said that, on other occasions, and in other aspects, it is reasonable to assume that only considering the professional viewpoint will limit findings, an issue we return to in the final chapter.

7.2.3 Policy and practice in stroke care and that relating to the PPR in stroke care

The research potentially makes a contribution to the development of stroke policy and practice by identifying four factors that are either only mentioned in the general literature (i.e. not the stroke-specific literature) or, in the case of neuro-psychological shortages, in neither. Indeed, the latter is of particular importance in the improvement of stroke care and highlights where practice in the UK is currently deficient. It follows that stroke patients may benefit from policies placing a greater emphasis on the importance of mental health in stroke care and which draw attention to, and take steps to counter, the current shortfall in neuro-psychological support. The improved training of stroke professionals to equip them with better communication skills (in particular) is another area highlighted in this research with implications for stroke policy and practice.

In terms of PPR research, the finding that targets have an impact on the stroke PPR has implications for policy and practice also. The suggestion that professionals may feel obliged to prioritise and/or balance stroke patients’ needs with those of the service in some way (particularly around thrombolytic therapy) and therefore compromise their interaction with patients (from an information provision and participatory perspective), appears to be yet another reason to reassess the NAO’s thrombolysis targets. Interestingly, this finding and recommendation comes at a time when an investigation into the appropriate use of Alteplase

is already underway, a review having been announced by the UK Medicines and Healthcare Products Regulatory Agency (MHRA) in 2014 (Cohen and Macdonald 2014), and therefore should be included in the current debate around future practice directions in this area. Moreover, future policy reports and guidelines in stroke should recognise the importance of social workers and others in the community (as well as encourage greater integration with stroke colleagues at different sites and trusts) in response to the finding that inter-agency integration also has an effect on the PPR in stroke. Implications for stroke practice are considered in further detail in 8.2.

7.3 Summary

In this chapter, we have discussed the research findings in relation to the current literature and presented the responses to the two research questions asked at the beginning of the study. In the process of answering these research questions, we have also considered the contributions that have been made to our understanding of this area. The methodological and practice/policy implications of the research has also been presented. The principal limitations of the study, and a consideration of the future directions in which the research may be taken, will be presented in the final chapter.

Chapter Eight – Conclusion

Conclusion

8 Introduction

In this final chapter, the implications for practice and policy that arise from answering the research questions will be considered in further detail. As part of this, we will explore the potential implications for health practitioners, alongside possible areas for future research. Firstly, however, the limitations of the work will be discussed.

8.1 Limitations

8.1.1 Wider applicability of results

Since this study focuses on the specific context of stroke care, it is not easy to generalise the findings here to other settings and patient populations (for instance, stroke disproportionately affects the elderly whereas some other conditions may not). For, as we have seen, the stroke patient's journey along the care pathway is particular to the condition itself and indeed the individual impairment(s) they have suffered as a result of the event. Similarly, stroke professionals have backgrounds, skills, attitudes and targets to meet that may differ markedly from health providers treating other conditions.

Having said that, stroke shares many common aspects with cardiac care; most notably, the aetiology of the two conditions is often the same (i.e. thrombus or clot formation), as is the therapeutic intervention (i.e. thrombolysis). Therefore, it is conceivable that some lessons from this study may be applicable to cardiac care too. Indeed, one natural extension to this work may be to explore the factors influencing cardiac patient information provision and involvement.

However, in the case of this single study, examining the factors influencing these two processes concurrently across multiple care settings, and in numerous health conditions, would have necessarily diluted the findings to such an extent as to render them invalid. For this reason and other reasons already described, it was decided that this work should be conducted within the narrower confines of stroke care alone.

An additional, and related, limitation is that the case study here was based entirely within the UK's NHS. As a result, several of the factors identified as having an impact on patient information provision and involvement may be specific to the NHS (e.g. overburdened staff). This raises concerns about the transferability of some of the study's findings, so caution will need to be exercised before applying the data here to non-NHS contexts. With that said and as we have discussed, many of the factors identified in this study maintain their relevance in settings outside of the NHS.

8.1.2 Grounded theory

As has been alluded to previously in the methodology chapter, the work here is inspired by grounded theory only, rather than strictly conforming to its precepts. An example of this is the way in which some of the initial participant questions were informed by a literature review which had already been carried out ahead of the first interview taking place. However, since questions for subsequent interviews were formulated by responses from previous participants in an iterative process taking place over a period of months, the effects of the departure from the strictest interpretation of grounded theory were minimised.

Indeed, even the first proponents of the grounded theory method acknowledge that no researcher can completely erase from their minds any literature they may have read or any other *a priori* knowledge they may have (Glaser and Strauss 1967). Furthermore, while concepts consistent with findings in the extant literature did emerge, these only account for a

small element of the study's final contributions. This stands as evidence of theory development based on the systematic analysis of data, as prescribed by grounded theory, rather than a reliance on preconceived notions from the literature.

Overall, notwithstanding the problems with the grounded theory approach mentioned here, the exploratory nature of the study, the complexity of the phenomena under examination and the explanatory contributions we sought to make at the outset, made this method the most suitable for the work.

8.1.3 Balance of participants

As we have seen from the summary of participants in the methodology chapter earlier, there is an imbalance in the representation of stroke professionals – with the vast majority of interviewees being drawn from the more senior, clinical roles (e.g. stroke consultants and stroke nurses) rather than managerial and academic disciplines. At first glance, this may appear to unnecessarily skew the study's findings. However, as the focus of the work is on stroke practitioners' interaction with patients, this was a deliberate strategy and is consistent with the non-probability sampling approach outlined in the methodology chapter already. The reason for not recruiting junior doctors, for instance, is also explained in more detail there. Indeed, as we have seen, the probability sampling techniques used for quantitative studies are rarely appropriate when conducting qualitative research (Marshall 1996). Instead, we chose to use purposeful (judgemental) and theoretical sampling here; that is, forms of non-probability sampling.

8.1.4 The views of health professionals only

As highlighted in the discussion, the four stroke-specific factors which have not previously been identified in the stroke literature (technology, training, resources/sources of information

and neuro-psychological shortages) emerge from research that considers the professional's view only. Since a professional may be better placed than a stroke patient to comment on professional training issues and neuro-psychological shortages, for example, and since these types of issues are often best viewed from "the inside", it is perhaps unsurprising that such factors have been overlooked in other stroke research, which rarely focuses exclusively on the professional's perspective. Patient inclusion is considered in the future work section, 8.3.2.

8.2 Implications for practice

At the outset, the literature review and the case study background made it clear that a fuller understanding of the processes driving patient information provision and participation in stroke is needed. This not only fills a theoretical void, but it also facilitates the implementation of the government's more patient-centred care vision and thereby forms one of the study's main practical contributions.

Identifying the factors which affect patient information and involvement in stroke allows us to implement better the policies designed to improve the PPR and potentially improve stroke care. Indeed, it is only by identifying the influencing factors, understanding how these factors play their role and finally considering what steps professionals think can be taken to improve the current situation, that we may begin to meaningfully inform the debate around the optimal strategy for policy implementation.

Putting government policy into action in this area is important as better information provision and increased patient engagement have been associated with improved overall patient satisfaction levels, as shown previously in the literature review.

Some of the study's main practical implications are taken directly from the suggestions for improvement in response to RQ2. For instance, the psychological sequelae from stroke are well researched and their impact on decision making has also been noted (Mukherjee, Levin et al. 2006). However, what is not documented is the shortage in psychological expertise; suggested as an area for improvement by some of the interviewees here. Practically, therefore, consideration should be given to how resources may be reallocated to achieve better psychological support for stroke patients.

The study's data suggest that audits must be able to assess better the *quality* of stroke patient information provision, in order to guard against the "tick-box" culture that is becoming more pervasive across the NHS.

Other practical steps emerging in response to RQ2 include providing more information to the stroke patient and their family about what they can reasonably expect from the service they are entering. This was perceived to be one of the main ways in which the pathway could be clarified for stroke patients and was seen as a way of boosting their likelihood of participating in care decisions.

Additionally, greater priority should be given to the production of high-quality online material to complement the existing offline offering, in recognition of the increasing trend for stroke patients (and their carers) to access information in this way. In fact, more providers are

now encouraging patients to do this in what has been dubbed “internet prescriptions” by some in the literature (McMullan 2006), so it is vital that stroke patients can be directed to high-quality websites and online learning tools also. Similarly, audio-visual ways of delivering information should be explored more fully, with particular emphasis placed on the potential exploitation of pre-existing technologies (most notably bedside televisions) as an inexpensive but effective information provision strategy.

As implied above, practical implications can also be drawn from the more theoretical aspects of the work. For instance, in recognition of the finding here that stroke patients are generally more likely to seek information and be more involved with their care once they have been discharged home, strategies for sustaining this sense of empowerment outside hospital in the longer-term could prove useful. Some see the primary care setting as an ideal mechanism for this (Hare, Rogers et al. 2006). However, data here suggests that increased integration between hospital and community stroke workers (through shared training, rotational work and pooled budgets for instance) and remote consultations from home would be more beneficial.

This fits in with the revised PPR model for stroke presented here, which emphasises the importance of the patient’s location to the interaction, in contrast to other concepts of the stroke PPR, that do not make this distinction explicitly. Indeed, we argue that the stroke PPR is greatly affected by the where the patient is and recommend the increased use of remote access technology and teleconsultations to take full advantage of the *empowered-by-home* phenomenon, which sees stroke patients asking more questions and demanding more say in their care. This is one example of how a better theoretical understanding of the PPR in stroke may enable us to improve both information provision and patient engagement with their care.

8.3 Future work

8.3.1 Potential case study of a London HASU

This study has included participants from a wide range of geographical areas – in fact, each country within the UK has at least one representative here. Therefore, as a next step, it may be beneficial to complement this breadth with a detailed case study of one location regarded as a centre of excellence in the delivery of stroke care. Extending the work in this manner will allow us to assess how this study's findings on the PPR apply in what is regarded as a centre of excellence and whether new avenues for exploration arise.

As we have seen, stroke continues to be a leading cause of disability with significant human and financial costs. National Sentinel Audits in 2004 and again in 2006 reported that London had a lower overall standard of care than the remainder of the country. This instigated a major change to the way acute stroke care was being delivered. The single largest aspect of this transformation was the establishment, starting in February 2010, of 8 HASUs across Greater London. These specialist acute stroke units now provide 116 monitored beds, offering equitable, 24/7 access to stroke specialists, investigations, imaging and (if deemed necessary) thrombolysis.

Early results from this service reconfiguration were encouraging, with an increase in thrombolysis rates for London from 3.5% in February-July 2009 to 12% over the same time interval a year later (Davie and Rudd 2011). The Sentinel Audit of 2010 showed that 5 of the top 6 stroke centres in the UK were London HASUs. Since then, increases in HASU thrombolysis rates have continued to accelerate, with the percentage of all stroke patients given thrombolysis (all stroke types) now ranging from 12.8 to 22.4, according to the 2015 SSNAP data. This compares favourably with the national average, which stands at 11.6%.

Across the capital, soon after the reconfiguration, the average length of stay for stroke patients dropped to an average of 19.4 days, compared to the national average of 24 days (Davie and Rudd 2011), a trend which then continued (Morris, Hunter et al. 2014) The dramatic change in the way stroke services are delivered in London has not been matched by any other global city and makes it a particularly interesting context for research in the form of a case study. From this, lessons of excellent care may be drawn and an assessment could be made of how the changes in performance are impacting the PPR in stroke and the information requirements of stroke patients.

8.3.2 More quantitative approach and the inclusion of stroke patients and their carers

As already mentioned in the methods chapter, clinicians and other healthcare professionals are understandably concerned about investigators wanting to approach vulnerable patients, such as those who have suffered from a stroke, for research purposes. Similarly, speaking with stroke patients' relatives comes with its own host of sensitivities and access issues, making large-scale recruitment difficult.

We did, however, manage to conduct a preliminary background interview with one family member who had cared for a relative for a number of years. A direct quotation from that interview has been used in the work's introduction to highlight some of the current difficulties being encountered within stroke care. The issues the relative raised are relevant to this area of research – therefore, future work may look to include more carers.

As discussed in Chapter 4 and Appendix V, we also considered using a quantitative approach in evaluating information provision, decision making and the stroke PPR. This would have involved using the SASC and OPTION scale, as outlined in section 4.1.3. A more quantitative study could form part of a larger-scale stroke study. Furthermore, as part of a more quantitative approach, patient information could be formally categorised for analysis

into the multiple possible sub-variants²⁸ that might arise in a complex context such as stroke care, as mentioned in the literature review.

8.3.3 Economic case for improved patient information and involvement

This study has accepted the normative view that improving patient information provision and involvement is a desirable objective. Indeed, evidence in support of this position often includes arguments associating better patient information and involvement with increased patient satisfaction. This line of reasoning has already been evaluated and reported on extensively earlier in this work and shall not be repeated here.

However, one key aspect that this study has not fully explored is the economic argument in favour of improving patient information delivery and participation. Unfortunately, a thorough consideration of the economic case for better patient information and involvement was beyond the scope of this work; however, approaching the subject from an economic perspective would certainly provide a useful extension to the research here.

8.3.4 Professional disempowerment and patient provider role convergence

The types of changes in the relationship dynamic suggested by the revised model in this study would appear to indicate that stroke patients are becoming more empowered, or at least have the opportunity to be, whilst providers are perhaps becoming disempowered. Indeed, as we have previously noted, some in the general literature think that socio-technological changes have resulted in a role convergence between patients and providers; the so-called *doctor-modern patient* relationship (Buetow, Jutel et al. 2009). A fuller appraisal of these, and similar lines of argument, could form the basis for future work in this area. In carrying out

²⁸There are many aspects of information provision, for example when it is delivered, by whom, how often and in what format. As a result, it follows that there are many different types of information and different ways in which information can be provided to patients, for example using social media or audio-visual tools. Other possible categories could be medical knowledge (about stroke, its treatments and aftercare), information about patient experience, information about patient services and accessing those services, amongst others.

this additional work, particular attention should be paid to the transition period from hospital to home, as the results here demonstrate that it is during this phase that the greatest increase in patient empowerment is often observed. This future research could also assess the PPR in stroke beyond the acute (6 month post-stroke) phase studied here.

8.4 Final thoughts

In the last two chapters, we have considered the theoretical and practical contributions arising from answering the research questions. As part of this, we have looked at the stroke PPR in detail, and placed it in the context of what is already theorised about it in the literature. Based on this we propose a revision of the stroke PPR is needed to more fully take into account the external influences acting upon it, which are likely to grow in importance with time. We have also looked at the study's main limitations and proposed a series of possible future directions for the work.

In spite of significant moves by policymakers to inform and empower patients in their care, implementation has only been achieved with limited success. Part of the problem stems from an insufficient understanding of the processes underpinning the policy drive in the first instance and particularly how these fit in the specific context of stroke. This study goes some way to providing a solution to this problem by deepening our understanding of the factors affecting information provision and involvement of stroke patients in the light of a revised model for the stroke patient-provider relationship that more comprehensively conveys the health service practice environment in the UK today.

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Appendices

Appendix I: Categorising the literature

Ref	Level	RQ	Empirical context	Key theoretical constructs	Variables	Method	Quant/Qual	Contribution	Implications for my research/potential research questions
Basslet 2011	Individuals within organisation	Is use of online social networks amongst physicians and physicians-in-training the same as that of the general population? Do patient-doctor interactions take place within OSN? Who initiates these interactions? Will OSN interactions compromise patient confidentiality?	National survey of US med students, resident physicians and practicing physicians	The nature of patient-doctor boundaries in the digital age. Nursing the between public and	Name	Random, stratified mail survey of US physicians and physicians-in-training	Quant: INOVA and Fisher's exact tests	Creation of a validated survey tool for the topic OSNs may lead to new kinds of doctor-patient interactions - raises questions about appropriate professional boundaries	Understanding how patients feel about physician interactions within OSNs would complement these findings and help us to understand patients' motivations behind these interactions
Bergmo 2005	Individuals within general practice setting	Does electronic patient-provider communication offset office visits and telephone consultations in primary care?	A primary care clinic in Norway	The use of technology to enhance communication between doctor and patient and improve provision of patient care in general practice	Access to secure messaging system. Outcome measures: no. of online and telephone consultations, office visits	200 patients recruited for a longitudinal RCT. Split into intervention and non-intervention groups	Quant: analysis using Mann-Whitney U-test	Electronic messages can act as a substitute for office visits, but not for phone consultations. The reduction in visits was all linked to the time saved by avoiding travel. First RCT to report this improvement. Results contrast with later et al's findings that email represent an 'add on' to existing workload in primary care	From our patient-provider communication promises to improve efficiency and effectiveness of clinical care. All patients chose had access to internet and mobile telephone, implying a bias towards technology acceptance that may not be as pronounced in generally older stroke patients. Age and technology use is therefore a theme to explore
RCP 2012	National clinical guideline for	N/A	N/A	N/A	N/A	N/A	N/A	Provides a comprehensive framework of care, with over 300 specific recommendations covering almost every aspect of stroke management. It outlines 20 key recommendations which (if followed) will greatly enhance stroke care in UK	Key messages include the recognition of the importance of psychological care after stroke, the importance of individualised care for patients and the importance of involving patients and their carers with the management of their condition from the outset. The report also recommends that carers be viewed as additional sources of important information about the patient both clinically and socially. The report thereby confirms that my research involves central aspects of current UK stroke policy
Epstein 2005	Mixed: theoretical, conceptual, consensus with practical applications	What is patient-centred communication (PCC) and how do we measure it?	N/A - theory paper	Instruments should measure contributions of relationships, health systems and patients to PCC. PCC is both a trait and a state. i.e. context influences expression of PCC behaviour e.g. communication style for critically ill patients is non	None	Literature review & analysis: theoretical development & practical considerations	N/A - theory paper	Seeks to define theory for PCC that is empirically testable and clarify measurement issues within PCC literature and operationalisation of PCC process; principles for choosing methods to assess PCC	Paper focuses on PCC - communication among clinicians, patients and family members but not other health professionals although it is acknowledged that similar issues would apply to them. Acknowledges the role of context and the overall health system plays in influencing patient communication. In particular highlighting the differing needs of critically ill (such as hyper-acute stroke sufferers vs non-critically ill patients). Paper lists factors influencing patient-centred communication into 4 areas: patient factors (incl. personality), health system factors (incl. e-communication), relationship factors and clinical factors (eg clinical 'personality'). Paper is theoretical - not based on an empirical study so it will be interesting to test in practice
Jones et al (2007)	Discussion paper	How involved in decision-making are stroke patients? How does the process of shared decision-making occur? What are the obstacles? Can 'perceived control' improve rehabilitation for stroke patients?	N/A	In view of the processes used as part of treatment require patient involvement?	N/A	N/A	N/A	Reconsideration of the meaning of empowerment in the context of stroke rehabilitation and the patient-pharmacist dynamic.	There are variations in personal responses to rehabilitation, specifically how individuals re-integrate into society. Factors influencing involvement are cited as the health system itself, 'top-down rehab regimen', the hospital setting, power/knowledge dynamic. Paper looks at physio. only and rehabilitation, not hyper-acute/ thrombolytic stages. Presumption that everyone would benefit from greater involvement is overoptimistic. Psychological factors such as 'perceived control' may also reduce 'powerlessness', therefore needs to be explored

Appendix II: Identifying and categorising key themes from the literature

<p>The importance of setting and context in affecting patient information provision and the extent of patient involvement</p>	<p>Gordon et al (2008) Observational study assessing communication between nurses and aphasic stroke patients. Key findings include: asymmetric interactions with nurses controlling topic and flow of conversations, not helped by patients having to respond to closed questions (communication difficulties make these patients particularly susceptible to unequal interactions as they are less able to steer conversation away from nursing-related tasks, for example). Institutional context found to affect these behaviours; to what extent remains unexplored. Would the same results occur if the work included other HPs, settings and all stroke patients? How can a wider institutional culture of partnership be developed on stroke wards? The study used conversational analysis of videotaped interactions between 14 nurses and 5 patients. The small patient sample is a significant limitation here.</p>	<p>Disler and Wade (2003) The study evaluates the clinical benefits of early-supported discharge (ESD) and rehabilitation at home. The literature shows that there is still no consensus on the percentage of patients who would be eligible for ESD and even less agreement on the percentage of stroke patients who would benefit from such schemes. This Australian study advocates more widespread implementation of ESD citing increased patient empowerment and participation with rehabilitation at home as a key mechanism for improved outcomes and patient satisfaction. The physical and psychosocial elements of the environment influence the patients' ability to perform desired activities and attain the targeted levels of participation during the rehabilitation process. A limitation is that geographical and service system issues, as well as the rehabilitation outcome measures used, may not be applicable to the UK context.</p>	<p>Epstein et al (2005) Theory paper on patient-centred communication (PCC). Communication assessed among doctors, patients and family members but not other HPs (although it is acknowledged that similar issues would apply then). Acknowledges the role context and the overall health system plays in influencing patient communication, in particular highlighting the differing needs of critically ill (such as hyper-acute stroke sufferers) vs non-critically ill patients. PCC seen as both a trait and a state i.e. context influences expression of PCC behaviours e.g. communication style for critically ill patients vs non. Papers breaks factors influencing PCC into 4 areas: patient factors, health system factors, relationship factors and clinical factors. Not an empirical study so will be interesting to test in practice.</p>
<p>The impact of the internet and online information on the patient-provider relationship (PPR)</p>	<p>Wald et al (2007) Review article of the complex effects and occasionally contradictory roles of the internet w.r.t. healthcare delivery and the PPR. The main tangible outcome of the work is a physician guide for effective interaction with "Web-activated patients". The key findings include the emergence of a consumerist model with triangulation of patient-interent-physician and, as a result, the expectation that the PPR will be significantly impacted; potentially positively: to help SDM, make more efficient use of clinical time, to augment patient information provision and patient self-accessing information; potentially negatively: misinformation due to quality variability of online material, exacerbation of socio-economic health disparities and challenging "traditional" medical authority within a changed PPR. A balanced discussion is presented, however the article is not specific to stroke and does not include other HPs or the role of family/carers.</p>	<p>Hart et al (2004) A qualitative study, mainly using semi-structured interviews with 47 patients and 10 HPs, to assess the role of the internet in the PPR. The research was conducted in a primary care setting, specialist clinics and patient homes. The participants all had contact with information/treatment in relation to sexual health matters. Since the paper looks at HPs' and patients' information seeking practices, rather than solely the provision of information to patients by professionals, and in a context outside of stroke care, the focus is not directly comparable to the research here. However, the findings on patients' trust in HPs in particular are interesting. The suggestion being that patients generally have high levels of trust in their providers and therefore few felt the need to access other, or even additional, sources of information such as the internet or family/friends. The extent to which this may be applicable in stroke care should be explored in this work also.</p>	<p>Gerber and Eiser (2001) A general discussion paper which explores the PPR in the internet age and proposes a research agenda calling for future studies looking at the impact of online information on the PPR. The authors argue that the ways in which HPs and patients use online information can influence the PPR and that patients may become more involved in decision-making if they are willing and able to share the "burden of responsibility" for knowledge. Whilst the paper does mention the need for studies of methods to increase access to computer-based information for patients with low computer literacy and cites "variability in patient types", it fails to acknowledge communication and other difficulties a stroke patient may experience as a factor influencing information seeking and retention patterns. The paper also falls short of recognising the role carers/family may play in accessing online material on a patient's behalf and the implications this might have on the PPR.</p>
<p>The importance of the availability of different modes of patient information delivery for shared decision-making in stroke</p>	<p>Flynn et al (2013) This review of 26 decision support, risk communication and patient information tools for the hyperacute, thrombolytic treatment of stroke finds that current tools to support decision making and patient understanding lack comprehensive development processes. The majority of tools (identified from databases, internet searches, survey of UK and North American stroke networks) lacked development informed by theory and were not tested in actual acute stroke settings. Whilst we are not aiming to develop a tool here and we are looking beyond information and decisions during the hyperacute thrombolytic stage, the findings highlight the importance of having stroke work that is theoretically informed by the literature, with practice implications being applied to the context from which they derive. The authors categorised the tools into four types: (i) Brief decision aids (ii) Risk communication tools (iii) Patient information tools and (iv) Standardised information for clinicians. The researchers here identify four tool categories for a single decision point (albeit a vital one) in the stroke pathway, so breaking information types into categories across the whole stroke pathway may not be feasible. However, it is a useful framework to bear in mind and it may be a fruitful way to extend this research in the future. The paper recommends further research into tailoring information (such as outcome probabilities) to individual patients, which they advocate as a way to help patients/relatives make treatment decisions "consistent with their preferences and values." The authors note that only a minority of tools (9/26) use graphical methods to convey probabilistic information to patients on the risks/benefits of thrombolysis. The availability, potential benefits and current obstacles to the use of graphics (and other modes of information delivery) will therefore need to be explored in this research. The acknowledgment of important role relatives play throughout their review is a strength of their work.</p>		<p>Cunningham (2008) A Canadian study presenting a proposed toolkit for stroke assessment and management, with the overall intention of assisting patients and their families in SDM during the 3-hour treatment window for thrombolysis. The author suggests that the proposed outcome wheel could help patients and family in making an informed decision by presenting risk-benefit information visually and intuitively in a "spin the wheel" type fashion. She argues that when the information is presented verbally, it is often less well understood by the general population - citing commonly used but nonetheless problematic terms such as "odds ratio" and "adverse outcome". The usefulness of the toolkit is not formally studied, so the report relies solely on anecdotal evidence for its claims - a serious limitation. Additionally, the merits of visual communication outside of thrombolytic decision-making is not considered and is therefore an area this research could explore.</p>
<p>The impact of an audit/target-driven culture on shaping patient information provision and involvement</p>	<p>Bevan and Hood (2006) The authors outline three main concerns with regulating healthcare by targets in their commentary piece. Namely that it assumes that priorities can be targeted, that the part that is measured can stand for the whole and that what is omitted does not matter. They analyse the star rating system (2001-05) for English NHS trusts, finding (i) star system improved reported performance on key targets (ii) effect on services excluded from star ratings unclear (iii) in some cases data have been manipulated to achieve targets (iv) systems need to be put in place to minimise "gaming" to meet targets and ensure targets are not causing unwanted effects elsewhere (e.g. key target that 100% of patients be offered an appointment to see a GP within two working days resulting in many refusing to book any appointments more than two days in advance). The main limitation is that the three types of targets analysed are unrelated to stroke care (4 hour wait in A&E, ambulance category A calls, waiting times for first elective hospital admission). The extent to which their findings may apply to stroke care is worthy of further investigation as is the theoretical basis of targets for performance improvement in healthcare.</p>	<p>Sudlow and Warlow (2009) A paper presenting an analysis of performance of stroke services in light of the National Audit Office's (NAO) 2007 report emphasising hyperacute stroke care and which concludes that there is a need to greatly increase the proportion of patients being given intravenous thrombolysis. In response, the authors devise their own estimates of the net benefit (in terms of numbers avoiding death or dependency) of the three proved interventions for acute stroke (stroke unit care, aspirin, thrombolysis) at what they consider realistic and optimistic target levels. The assumptions are now dated, as data are estimated from the 2008 national sentinel stroke audit figures. However, the main finding - that it is important to give thrombolysis in an appropriate setting to as many eligible patients as possible, but not at the expense of the many other effective components of a comprehensive stroke service - is an important one worthy of more investigation, particularly in the context of the recent Alteplase investigator where there is some suggestion that the drug may have been too readily given in order to meet such targets.</p>	<p>Grubb (2009) A discussion piece focused on the use of targets in the NHS. The work is not specifically on stroke, so the general observations and arguments made need to be tested in the context of stroke care. The author suggests that targets have done "more harm than good" in the NHS, by ignoring underlying problems important to patient care. He asserts that the most intractable problems in health care, which he sees as "the lack of communication, leadership, and teamwork; the lack of integration; and the lack of any meaningful, patient focused, quality framework" are systemic or cultural and are only made worse by targets, because they "devalue" the patient by focusing attention on an "arbitrary number". Part of the solution according to Grubb may be the adoption of "lean" thinking. Whilst not denying that targets can mean that predetermined goals are met, he argues that the unintended consequences, which often can't be easily seen or measured, outweigh the benefits. He goes on to argue that the preoccupation with hitting targets results in the actual journey an individual patient experiences becoming secondary, with performance being determined against "crude indicators", not the expectations and experience of those using the service. The extent to which this may be borne out in the research here has implications for the PPR in stroke care and patient-centredness and is therefore important to consider.</p>

Appendix III: Consent form

CONSENT TO PARTICIPATE IN INTERVIEW

An evaluation of patient information provision and involvement of patients by health professionals: the case of stroke care

You have been asked to participate in a research study conducted by Fawaz Fram from the Health Management group at Imperial College Business School.

The purpose of the study has been outlined in the informational sheet sent to you previously. The results of this study will be included in Fawaz Fram's doctoral thesis. You were selected as a possible participant in this study because of your experience as a stroke care professional in the NHS. You should read the information below, and ask questions about anything you do not understand, before deciding whether or not to participate.

- This interview is voluntary. You have the right not to answer any question, and to stop the interview at any time or for any reason. I expect that the interview will take about 30 minutes, but no longer than one hour.
- You will not be compensated for this interview.
- The information you tell us will be confidential; however, you may be quoted in the thesis and any publications that may result from this research. No personal information (name/title) will be used that would make you easily identifiable.
- I would like to record this interview so that I can use it for reference while proceeding with this study. I will not record this interview without your permission. If you do grant permission for this conversation to be recorded, you have the right to revoke recording permission and/or end the interview at any time.

This project will be completed by October 2013. All interview recordings will be stored in a secure work space until 1 year after that date. The tapes will then be destroyed.

I understand the procedures described above. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

(Please check all that apply)

I give permission for this interview to be recorded.

I give permission for the following information to be included in publications resulting from this study:

my name (N/A) my title (N/A) direct quotes from this interview

Name of Subject _____

Signature of Subject _____ Date _____

Signature of Investigator _____ Date _____

Please contact Fawaz Fram at fawaz.fram@imperial.ac.uk with any questions or concerns.

Appendix IV: Example of recruitment email that was sent to potential participants

Dear X,

I am part of the Healthcare Management group at Imperial College Business School. I have spoken to your colleagues A and B as part of the study I am conducting and was hoping you would be willing to help me also.

My PhD research (under the supervision of Professor James Barlow and Dr. Steffen Bayer) looks into the patient-provider relationship and the provision of information to patients. I am focusing particularly on stroke care.

As part of the data gathering process, I am seeking to interview a sample of health professionals, including stroke consultants. I would be grateful if you could help me.

The telephone interview should take no longer than 30 minutes and will be a one-off, confidential interview.

I have attached a brief overview of the work I am conducting. If you require more detailed information about the research, please don't hesitate to contact me. I look forward to hearing from you soon.

Best wishes,

Information provision and decision making in stroke care

The aim of this research is to investigate the nature of information provision and its influence on the health professional-patient relationship within stroke care. This will include a consideration of issues such as patient empowerment and information use, as well as the factors influencing the wishes of patients to receive or not to receive information.

In order to investigate the central research question I intend to undertake a detailed case study at a local hospital. This will involve three activities:

(a.) Observations:

I intend to observe interactions between health professionals (clinicians/therapists/nurses) and patients at a local stroke unit. These observations aim to improve our understanding of decision making and the carer patient relationship. In analysing the observation I would like to make use of the ‘observing patient involvement in decision making’ instrument (or OPTION tool) (Elwyn 2010). The OPTION scale is an item based instrument used to facilitate the description of carer patient interactions and is designed to help describe the overall shared decision making process. There is no underlying assumption that more participation in decision-making is indicative of a better relationship. In fact, depending on the context very little participation of the patient in decision-making might be appropriate.

(b.) Patient interviews

I intend to interview a sample of patients shortly before discharge about the perception of their relationship with the physicians/allied health professionals, the experience of their role in the decision processes about their care, and about their information requirements.

During these short interviews I will also ask them to answer the questions from the

²⁹ Difficulties securing ethical approval for the project’s initial vision (alluded to in the study’s limitations and future work sections, respectively) resulted in parts a and b having to be removed from the process. However, the time spent with the i-Health team and the interview with a patient representative, both proved invaluable and went some way to tackling this shortcoming.

validated 'satisfaction with stroke care' instrument (Boter 2003) which relate to inpatient care.

(c.) Interviews with physicians and allied health professionals³⁰

I would also like to conduct short interviews with physicians and allied health professionals about their assessment of the role information plays in the relationship between professionals and patients. Of particular interest will be shared decision making and ideas on improving information provision and patient participation.

Boter, H. (2003). "Clinimetric evaluation of a Satisfaction-with-Stroke-Care questionnaire." *Journal of neurology*

Elwyn (2010). Implementing shared decision making in the NHS. *BMJ 2010; 341*

³⁰ Ultimately, this was expanded to become the main approach for data gathering in this case study.

Appendix VI: An example of some early stage questions used to guide initial semi-structured interviews³¹

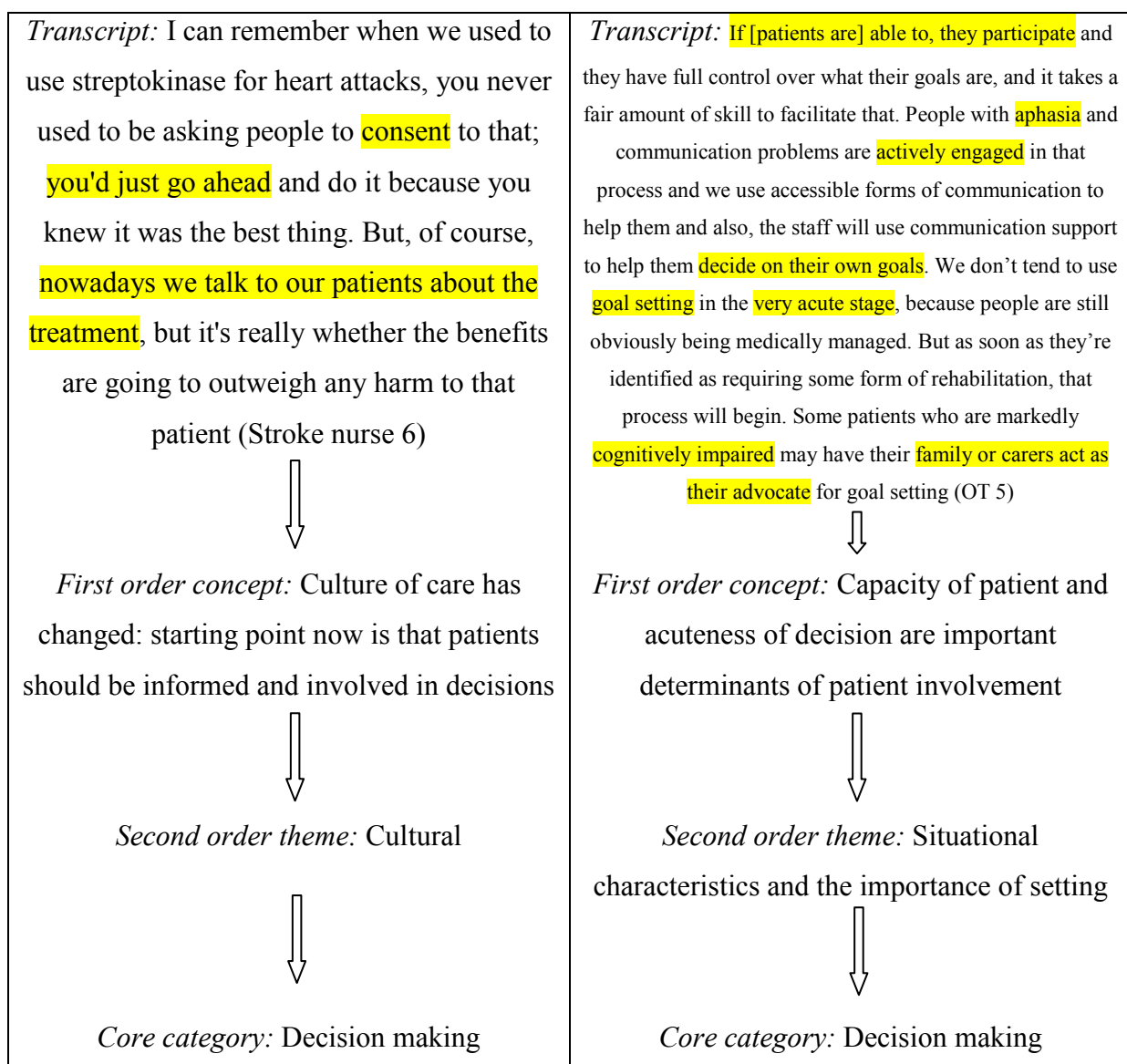
- Briefly describe who you are, what your role is and how long you have been involved with stroke for please.
- Could you please tell me about the decision making process in stroke; I would really like just to hear from you how treatment decisions in stroke are made.
- Is shared decision making an important part of stroke care? Why/why not? What can be done to improve patient participation?
- How would you describe the relationship you have with patients?
- Have you, in your experience/in your time working, seen a shift away from patients perceiving the health professional as the expert?
- I am interested in information provision so I would like you to briefly tell me what types of information you provide patients. What is the mode of delivery? Largely spoken/written/audio-visual (e.g. iPads)?
- Stroke tends to affect the older spectrum of patients, do you think technology is a problem for that category of patient, or not really?
- Retention of information appears to be problematic, especially in the acute phase. Do you have any thoughts on how this can be improved, or any strategies that you might use?
- Are there any information gaps post-discharge and during repatriation between hospitals; is there good integration and continuity then?

³¹ As discussed in the methodology chapter, these questions were not rigidly adhered to as we chose a semi-structured approach. Additionally, as is consistent with GT-inspired research, the questions themselves underwent revisions as data gathered was used to inform subsequent interviews, in an iterative way. Therefore, the questions displayed here are only a sample and should not be taken as an exhaustive representation of questions that participants were asked.

- There is some suggestion that some patients feel a sense of abandonment when going from a very intense/focused setting, like a hospital, and then back to the community or their homes, for instance. Is that something that you come across?
- How do service demands (such as LOS targets) impact patient information provision and involvement?
- Do you feel that information empowers patients to make decisions about their care and treatment? Please explain why you think this is the case.
- Do you feel that enough is done to tailor information to individual patients' needs? e.g. aphasia-friendly materials?
- What triggers information provision? e.g. some information has just become available, or a relative has asked for clarification about something?
- Is the importance of timing information recognized enough? i.e. a patient's information needs might change with time, so that what is relevant in the acute stage is not maybe later on?
- These days there is an increasing emphasis on patient involvement and a lot of that is focused around redesigning services, and not necessarily the therapist-patient relationship. Do you have any thoughts on how that relationship itself can be changed to facilitate greater patient involvement and improved information provision?
- Is there any information or any way of delivering information that could improve patient satisfaction that is not currently part of standard practice?
- Is there anything else that we have not discussed that you feel is important or relevant?

Appendix VII: An example illustrating the formation of analytical constructs

Both excerpts shown below are ultimately giving an insight into how decisions are made. The next level of analysis beneath this overarching idea is known as the second order theme, which may or may not be held in common by the two coded transcripts³². A step closer to the original excerpt reveals a descriptive first order concept, itself formed from the collation of multiple primary open codes (examples of which are highlighted in yellow). Finally, this information is all brought together and summarised in constructs, as shown in the two findings chapter. The overall approach is consistent with that outlined in the methodology chapter previously.



³² Neither the first order concept nor the second order theme has to be shared for both transcripts to fall under the same core category.