

# **UNDERSTANDING AND MEASURING CONTINUITY OF CARE IN STROKE**

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of PhD**

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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My contribution to the work has been the management and coordination of the overall research programme, and the design and conduct of the studies of continuity of care reported in this thesis. I also undertook the analyses of qualitative and quantitative data with the exception of the structural equation modelling. I interpreted the results with the advice and guidance of my supervisors and finally wrote up the research. The details of other contributions to the work are acknowledged at the appropriate points in the text.

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## ABSTRACT

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### Background

This study investigated care for patients following an acute stroke. The focus was on the patient's experience, with particular reference to their impressions of the continuous and discontinuous aspects of care. The study aimed to explore the meaning of continuity of care for stroke patients, the feasibility of measuring patient-perceived continuity of care in stroke, and to examine its effect on outcomes.

### Methods

A mixed methods approach was used, starting with a systematic review of the literature and a qualitative exploration of patients' experiences of care. A case note review was also conducted. An existing quantitative measure of patient-perceived continuity was applied in a sample of patients [N = 310]. Two new measures of continuity of care (one patient-centred and one record-based) were developed and tested in a further sample [N = 178]. Finally, a qualitative study examined the views that stroke care professionals held on communication and continuity of care.

### Results

Accepted models of continuity of care did not readily transfer to the type of care or the services received by stroke survivors. Patients could, either directly or indirectly, comment on the quality of the individual elements of care they had received, and rate their feelings of satisfaction or dissatisfaction with them. They could not distinguish the overall process of care. "Achieved care" and "perceived care" could be measured quantitatively by including components of the physical, psychological and cognitive status of the patient in addition to the two new indices. An association between the measures of care and outcomes was found. Patterns of care were identified that indicated that care networks exist in stroke services. The findings suggest that it is the connectedness of individuals within these networks rather than the longevity or predictability of individual relationships that delivers good care.

### Conclusions

Continuity of care is a professional concept focused on the provision of statutory services. Current ideas of continuity privilege factors such as relational continuity (seeing the same person) in primary care; managerial continuity in acute care and informational continuity in areas like mental health which emphasises care planning not consultant led care. In measurement from the patient's perspective, continuity is intimately linked to related concepts such as quality of care and patient satisfaction.

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## List of Abbreviations

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<b>#</b>	Study ID Number
<b>BI</b>	Barthel Index
<b>BP</b>	Blood pressure
<b>CFA</b>	Common Factor Analysis
<b>Chao PC</b>	Chao Perception of Continuity Scale
<b>CHD</b>	Chronic Heart Disease
<b>CHSRF</b>	Canadian Health Services Research Foundation
<b>CoC</b>	Continuity of Care
<b>CPN</b>	Community Psychiatric Nurse
<b>CST</b>	Community Stroke Team
<b>FAI</b>	Frenchay Activities Index
<b>FIM</b>	Functional Independence Measure
<b>GHQ_28</b>	The General Health Questionnaire (28 Item)
<b>GP</b>	General Practitioner
<b>HRQoL</b>	Health-Related Quality of Life
<b>I_T Analysis</b>	Item Total Correlation Analysis
<b>ICT</b>	Intermediate Care Team
<b>JCMT</b>	Joint Care Management Team
<b>MDT</b>	Multi-disciplinary Team
<b>MLM</b>	Multi-Level Modelling
<b>MMSE</b>	Mini Mental State Examination
<b>NCCSDO</b>	National Coordinating Centre Service Delivery and Organisation
<b>NSF</b>	National Service Framework
<b>OT</b>	Occupational Therapy (or Therapist)
<b>PCA</b>	Principle Components Analysis
<b>PEG</b>	Percutaneous Endoscopically-guided Gastrostomy
<b>PPCI</b>	Patient-Perceived Continuity Interview
<b>PSE</b>	The Present State Examination
<b>PT</b>	Physiotherapy or Physiotherapist
<b>QSOS</b>	The Qualitative phase of the Stroke Outcomes Study
<b>RMI</b>	Rivermead Mobility Index
<b>RMSEA</b>	Root Mean Square Error of Approximation
<b>SALT</b>	Speech and Language Therapy (or Therapist)
<b>SAP</b>	Single Assessment Process
<b>SEM</b>	Structural Equation Modelling
<b>SF_36</b>	The Medical Outcomes Study short-form instrument (36 Item)
<b>SnL</b>	Snakes and Ladders Index
<b>SOS2</b>	Stroke Outcomes Study 2: The impact of depressive symptoms on outcomes for stroke patients
<b>T1</b>	Cohort Study Time point 1 (Baseline: 2 to 6 weeks post-stroke)
<b>T2</b>	Cohort Study Time point 2 (6 to 10 weeks post-stroke)
<b>T3</b>	Cohort Study Time point 3 (12 to 14 weeks post-stroke)
<b>T4</b>	Cohort Study Time point 4 (6 months post-stroke)
<b>T5</b>	Cohort Study Time point 5 (12 months post-stroke)
<b>TIA</b>	Transient Ischaemic Attack
<b>WHO</b>	World Health Organisation

## INTRODUCTION

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### A. Continuity: The cornerstone of care?

Demands on health care systems throughout the developed world are rising, and have added impetus to the drive to improve efficiency and reduce the costs of care. While advances in medical science have resulted in certain aspects of care becoming specialised and highly technical, nevertheless the need for routine and supportive care remains and is a major commitment for health care budgets. Acute hospital beds are expensive settings in which to care for patients with long-term disabling conditions like stroke but discharge to less specialised care providers can result in gaps in follow-up medical care and rehabilitation. Maintaining quality care that satisfies a population with growing expectations therefore presents increasing challenges.

Continuity of care has been described as the “cornerstone of care” and an “essential element” of general practice. (Cabana and Jee, 2004, Freeman *et al.*, 2003).

Notwithstanding the acknowledged significance of continuity as an important aspect of care in these settings, it is unclear whether continuity of care is a generic concept, and if it is, how it might be interpreted in chronic conditions. Definitions of the concept of continuity of care among care providers are varied and sometimes vague and little is known of what patients understand by continuity in the delivery of their care. Indeed, few definitions of continuity of care have attempted to incorporate the patient’s perspective in their formulation.

Over the last two decades continuity of care has come to the fore as an international research priority. In the United Kingdom the NHS Service Delivery and Organisation (SDO) Research & Development initiated a research programme dedicated entirely to the study continuity of care. Further afield researchers in North America, notably the Canadian Health Services Research Foundation (CHSRF), and in other European countries, have also pursued this topic. When it was first established in 1999, the SDO aimed to provide the evidence base for the development and modernisation of health services in the UK as a response to the Government’s agenda for the new NHS, which promised improved efficiency and better care for patients. The SDO commissioned a listening exercise with patients and health care professionals, followed by a scoping exercise and report. (Freeman, 2000) The CHSRF quickly followed on from the SDO report with an expert workshop that brought together health service researchers from a variety of backgrounds to brainstorm the concept further. (Reid, 2002) These two

exercises produced a multi-axial, working definition of continuity, which set the scene for a series of commissioned projects. These projects would seek, over the next several years, to explore the concept of continuity in a range of health care settings, and evaluate its association with outcomes for patients.

On the global stage, the World Health Organisation (WHO) has taken up the theme of continuity in a broader context. The WHO definition of health states:

*"Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."*

(WHO, 2006)

The WHO agenda for world health calls for better integration of health and social care in Europe and North America in order to reduce health inequalities, and for the provision of joined-up government policies that will facilitate the spread of good health and medical practices to developing countries; thus promoting better health for the people that live there.

In the United Kingdom and elsewhere, progressive medical technologies and interventions, and financial re-structuring have contributed to an increasing specialisation and compartmentalisation of health services. Consequently there is a growing requirement to organise services in a way that enables them to work together to deliver quality care. This thesis will focus on care for one chronic condition: Stroke. The next section of this chapter considers why continuity of care is particularly important in stroke, and outlines the research questions that underpin the work reported in this thesis.

## **B. Continuity of care in stroke**

### ***i The nature of stroke***

Stroke differs from other chronic conditions in a number of ways:

- Firstly it is a condition mainly of older people; patients may therefore present with multiple co-morbidities. There are also social issues that can impact on stroke care in the elderly arising from isolation in old age and declining cognitive and physical function;

- Secondly, stroke is an acute event of sudden onset and is treated in the initial stages as a medical emergency. It is unlike many other chronic diseases which have a more gradual course with an extended period of deterioration;
- Thirdly, it differs in the focus and objectives of treatment which in stroke are aimed at improving function and secondary prevention rather than the suppression of symptoms;
- Finally, multiple agencies are often involved in delivering stroke care, more than might be the case in other conditions, with the exception of mental health and (some) palliative care.

Improvements in acute stroke care have helped more people to survive the initial event but, while mortality has been reduced, this has only served to highlight the fact that stroke is a major cause of disability. Half of the survivors of the initial stroke event (about one third of all acute strokes) are left with some degree of disability, which can range in effect from moderate to severe. The more severely affected may be dependent on formal (statutory services) or informal (family or friend) carers for their day to day needs. Although some post-stroke disabilities are less apparent, they are nonetheless important: even mild cognitive impairment can make some of the tasks of daily living difficult, and loss of role and physical function can have profound psychological effects on stroke survivors. Thus, while stroke is ranked in third place (behind cancer and heart disease) as a cause of death, it is the primary cause of disability in the UK.

The nature of onset and the disabling after-effects of stroke have economic implications for care providers. The provision of stroke care represents a large proportion of spending from the NHS annual budget, accounting for around £2.8 billion in direct costs in 2002, which is almost £1 billion more than Coronary Heart Disease. When informal care and indirect costs are taken into account this figure rises to just over £7 billion. (Saka *et al.*, 2005) It is, therefore, not only the diverse and complex nature of stroke as a chronic disease of (mainly) older people that makes it a challenging condition, but also the economic and financial demands that providing effective and high quality stroke care impose on health service providers.

As the National Service Framework (NSF) for Older People, Standard 5 states:

*“Stroke has a major impact on peoples’ lives. It starts as a medical emergency, presents complex care needs, may result in long-term disability and can lead to admission to long-term care.”*

(DOH, 2001)

Hence, although stroke is a single disorder, it is a complicated, heterogeneous condition with complex and enduring sequelae. It is also increasing in incidence as a consequence of the growing population of elderly people. The nature of stroke disease therefore creates particular challenges for continuity of care in an ageing society, and is an interesting and important condition in which to study this phenomenon.

## ***ii Acute stroke care***

Fewer stroke patients are now treated in the community. Most people who experience a stroke will be admitted to hospital at some stage; the only likely exceptions being very minor strokes and transient ischaemic attacks (TIA), and some elderly patients with more severe stroke who are already resident in long-term care. Once admitted to an Acute Stroke Unit or a Stroke Specialist Ward patients receive an evidence-based, protocol-driven package of care which has many aspects that are not contingent on the severity of the index event nor on the health status of the patient. Every patient will routinely have regular blood pressure monitoring and temperature checks, blood sugar and cholesterol tests, swallowing assessment, and an early CT scan to determine the aetiology of the stroke event in order to assess the appropriateness of anti-coagulation therapy. In their book *“The Gold Standard: The challenge of evidence based medicine and standardization in health care”* published in 2003, Timmermans and Berg propose that care pathways and protocols effectively act as a co-ordinating device for health care professionals delivering care. (Timmermans and Berg, 2003) In the case of stroke, although the timing and sequence of these routine investigations may vary, continuity of care is generally well assured in the acute care phase as a consequence of adherence to established and standardised care pathways.<sup>1</sup> There are, of course, deviations from optimal hospital care for some patients with stroke, and the causes and consequences of these for continuity of patient care were encountered in the course of this research. These will be discussed at the relevant points in the ensuing chapters of this thesis.

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<sup>1</sup> An example of a stroke care pathway is not reproduced here but for reference can be found on page 70 of the NSF for Older People.

### ***iii Stroke rehabilitation***

After the initial stroke event has settled and the patient's condition has been stabilised, evidence shows that early assessment of disability, and intervention with targeted therapy, are a positive aid to functional recovery. (Paulucci *et al.*, 2000) At this post-acute stage of care patients are already beginning to diverge in terms of the type of care they require, and the location in which it will be delivered. Much depends upon the nature and level of disability that they have experienced, but some aspects of care may also be determined by their pre-stroke health status and social circumstances. A proportion of patients will remain hospitalised for in-patient rehabilitation, some will be discharged home with or without out-reach therapy and some will enter long-term residential care. Continuity of care thus begins to take on different meanings for patients in this phase of their illness trajectory, and standardised pathways become more difficult to define because of the diversity of care and the means of its delivery. Furthermore, continuity cannot be characterised simply by the type of rehabilitation or supportive care required because much depends on the availability and provision of appropriate services at a given place or time-point. In long-term conditions like stroke, informal care is also an important consideration for continuing care as, in many cases, it is often the family of the stroke victim (or those with other chronic conditions) who provide the majority of support with the activities of daily living. Together these factors present interesting challenges for researching continuity of care in stroke.

### ***iv Longer term care for stroke survivors***

Since the National Service Framework for Older People (NSF) was published in 2001 the Department of Health has promoted improvements in stroke care in order to meet the key milestones that this policy document proposed. One significant objective of the NSF for Older People initiative was that all general hospitals should have a specialised stroke service by April 2004. The National Audit Office Report "*Reducing Brain Damage: Faster Access to Better Stroke Care*" showed, however, that as late as 2005 this target had only been met by around two-thirds of service providers. (NAO, 2005) It must be acknowledged that improvements to acute stroke care are only part of the journey to recovery; and it is often after the patient leaves hospital that gaps in care occur and input in terms of rehabilitation therapy decreases or stops completely. Although the NSF Standard 5 included milestones for stroke care in the community, none of these referred specifically to rehabilitation nor to the need for different health care agencies to join-up to deliver integrated, stroke-specific services after discharge.



Longer term care for stroke is actually dealt with by the NSF for Older People under the more general heading of Standard 2: Person-Centred Care. (DOH, 2001)

Consequently, while much has been done to modernise acute stroke care and to prevent new and secondary strokes by promoting healthier lifestyles, raising public awareness and improving the monitoring of risk factors in general practice, there has been less emphasis on post-acute and post-discharge care and the services required to provide it. Given that care pathways that extend to cover longer term care are difficult to design when needs are unpredictable and non-linear in emergence, this is perhaps less surprising. Care provision for conditions like stroke is further complicated when, as previously noted, service provision varies locally and frequently involves both health and social services whose organisational structures and systems are totally separate and function independently. Local initiatives, such as Joint Care Management, have been designed to try and address some of the problems that arise from cross boundary working and the transfer of care between agencies, but these have met with mixed success. These issues arose in the discussions with stroke care professionals in the final phase of the study, and will be discussed in Chapter 5.

### **C. Aims and objectives of the thesis**

Continuity of care has long been regarded as important in general practice but it remains unclear how the concept of continuity translates into disease-specific settings. Moreover, little is known about the way in which patients perceive and understand it. Ostensibly continuity would seem to represent a desirable concept in the care of people with any long-term condition and, not least, to be beneficial to those with a disabling condition like stroke. The main aim of this research therefore was to study the phenomenon of continuity of care in a stroke care setting and investigate how the recipients of care perceive it. In order to formulate an approach to these problems the following questions emerged:

- What is already known about continuity of care?
- What methods of measuring it have been devised?
- What is the meaning of continuity of care for stroke patients?
- How do patients' and professionals' understanding of continuity differ?
- Can continuity of stroke care be measured?

This research study was designed to try and address some of the gaps in the understanding and measurement of continuity in the context of care and rehabilitation for patients with stroke. In order to achieve this overall aim the thesis had four specific objectives:

- 1) To study the experience of stroke care from the patient's perspective and develop a description of patients' views and understanding of continuity in their care;
- 2) To develop methods of quantifying continuity of stroke care (or modify and adapt existing methods) to produce a patient-centred measure that reflected the patient's view of continuity of care, and a health service record-based measure;
- 3) To apply quantitative assessments of continuity of care in a cohort of stroke patients in order to examine its impact on functional and psycho-social outcomes for survivors;
- 4) To seek professional views on the aspects of service organisation that are relevant in determining continuity of care.

## **D. Structure of the thesis**

### ***i Study design***

A mixed-methods approach was used in a series of inter-linked studies. Qualitative methods were used where appropriate to derive, clarify or check hypotheses and quantitative techniques applied to test or evaluate them. The studies were conducted in a cross-sectional design in order to explore the process of stroke care during the year following an acute stroke event. The work did not involve the delivery or testing of an intervention that affected or modified patient care, and thus did not require any process of randomisation.

In addition to undertaking a part-time doctoral degree, the author (KH) was the project coordinator for a cohort study of early depressive symptoms in stroke and their effect on outcomes for patients: the Stroke Outcomes Study, which had the acronym SOS2. This doctoral research study of continuity of care for stroke was conducted in parallel with the SOS2 study which, with the permission of the principal investigators, provided

an opportunity to share resources in the conduct of some phases of work. The study support team provided administrative assistance by despatching postal questionnaires, entering data and transcribing audio-tapes. The research assistants helped with the recruitment of patients to the cohort study, and collected baseline and follow-up data for SOS2. Helen Brooks, the research nurse assisted with the case-note reviews and interviews for Studies 4a and 4b and with the focus groups and interviews in Study 5. The author (KH) was responsible for the overall conduct and management of the research programme, and supervised all stages of work. KH also recruited and interviewed participants for all phases of the research, designed and managed the databases, analysed the data (with the exception of the structural equation models) and interpreted the results. The contributions of others are acknowledged at the appropriate points in the text. A summary of the SOS2 Study, including the study schedule and outcomes measures, can be found in Appendix A on page 272.

The work was undertaken in the Leeds Teaching Hospitals NHS Trust and the Bradford Hospital NHS Trust. Approval was sought from each of the three Local Research Ethics Committees responsible for the areas where the research was carried out, and permission was granted to conduct the successive phases of work.

## *ii* **Study structure**

The study began with a review of current evidence:

**Study 1:** A systematic review of the literature to identify existing work, concentrating on the definition of continuity of care and the measurement of continuity of care, particularly in relation to stroke.

This was followed by a succession of studies conducted in three strands of research. Participants for each phase of work were either specifically recruited for the study of continuity of care or drawn from the parallel cohort study (SOS2).

The first strand of research studied the patient's experience and recruited longer term stroke survivors from database records in the two centres:

**Study 2a:** An exploratory qualitative study to investigate the meaning of continuity of care for stroke patients and how they experience continuity in their care;

**Study 2b:** A full review of hospital and community clinical care notes to find out how recorded episodes of care provide a model of continuity of care, and how this relates to the patient's experience reported during the interviews.

The second strand of work investigated whether continuity of care can be quantified and drew patients from the parallel cohort study (SOS2):

**Study 3:** A pilot study of a published measure of continuity (identified from the literature review in Study 1) to establish whether it would be suitable, or could be adapted, for use in stroke patients.

**Study 4a:** A second case-note review, informed by Study 2b and using a measure of continuity to extract information recorded in the patients' full complement of clinical case-notes;

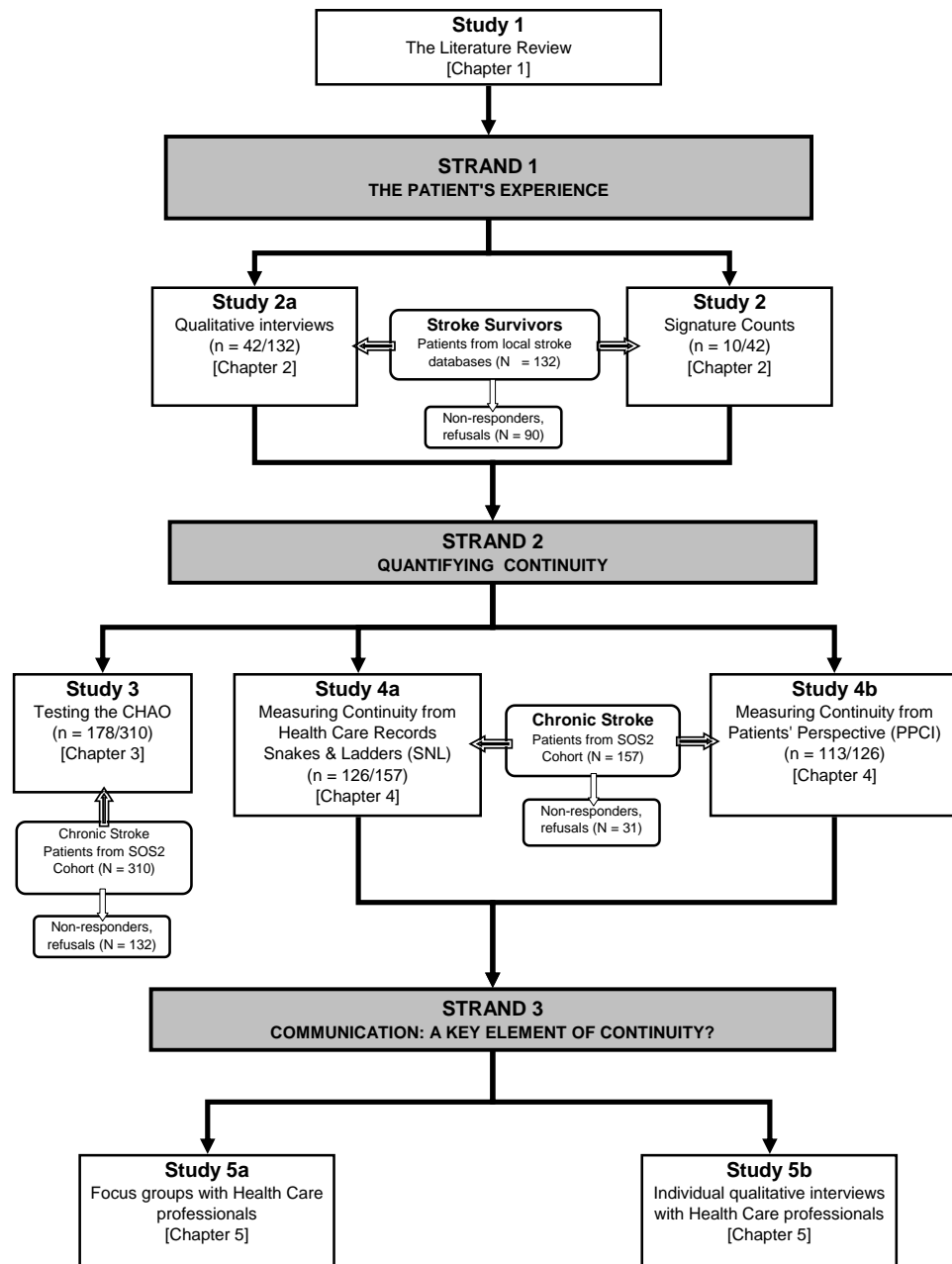
**Study 4b:** A quantitative study of experienced care using a patient-centred measure developed from the information collected from the qualitative interviews (Study 2a) and the findings of the pilot study of an existing measure in Study 3.

The third and final strand of research explored stroke care professionals' views of continuity of care, recruiting participants from local stroke services:

**Study 5:** A qualitative study of communication between health professionals delivering care to patients with stroke.

Figure I.i gives an outline of the study structure showing the three main strands of research which comprise the thesis, and the studies and processes that each of these strands included.

Figure I.i Outline of the study structure



### ***iii Structure of the thesis***

The first chapter of this thesis reports the review of current concepts of continuity of care in the published literature and how they relate to stroke care (Study 1). The measurement and operationalisation of continuity in previous studies is also discussed. The applicability of different methods of measurement in a stroke setting is examined, and candidate measures of continuity for use in the second strand of research (quantifying continuity) are identified.

Chapter 2 describes the first strand of work that started with an empirical qualitative study of stroke patients' experiences exploring the patient's perspective of continuity of care (Study 2a). The first case-note review study (Study 2b) is also reported in this chapter.

The second strand of research is reported in Chapters 3 and 4. Chapter 3 describes how an existing patient-centred measure, The Chao Questionnaire, was tested in a stroke setting (Study 3). (Chao, 1988) This study and the preceding work informed the development of two new methods of measuring continuity: one patient-centred, and the other based on information extracted from formal records of care. The application of the new measures in the stroke cohort and an evaluation of the effect of care on outcomes (Studies 4a and 4b ) are discussed in Chapter 4.

Chapter 5 describes how the work developed into a study of communication between healthcare professionals in the third and final strand of research.

In the last chapter the findings are discussed, and their implications for ways of thinking about continuity of care are considered.

The methods applied in the conduct of the various phases of work, and their limitations are discussed in the relevant chapters.

## CHAPTER 1 A Review of Continuity and its Measurement

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### 1.1 Study 1

#### 1.1.1 *Aims and objectives*

In the first study undertaken for this thesis a review of the published literature and other relevant evidence about continuity of care and its measurement was conducted. This review built on two important reports that had been published in the preceding year that together provided a comprehensive summary of the literature surrounding continuity of care. These two documents, the scoping report commissioned by the NHS National Coordinating Centre for Service Delivery and Organisation (NCCSDO) and the report generated by Canadian Health Service Research Foundation (CHSRF) workshop, covered not only continuity in primary care but also in other care settings, thus providing a useful starting point from which to undertake a reappraisal of the literature in relation to stroke care. (Freeman, 2000, Reid, 2002)

The specific intention of this review was to extend the NCCSDO scoping report and the CHSRF review by supplementing them with more recently published papers (if these were found), and to focus the search on care for stroke and other chronic conditions. Importantly, the main emphasis would be on methods of measuring continuity from the patient's perspective. The aims for this phase of the work were therefore twofold:

- To review the background to the concept of continuity in healthcare and explore how it has been defined and conceptualised in health care settings, with particular reference to stroke care;
- To describe the approaches that had been taken to measuring continuity of care specifically those that had incorporated patient evaluations of care, and to identify any measures appropriate for application in the cohort study of stroke survivors.

This phase of the work was conducted by the author (KH) in collaboration with Dr. Patricia Constantino (PC), an overseas Health Economist interested in the role of social capital in relation to stroke rehabilitation, and with Karen Smith (KS), a librarian at the Hull–York Medical School, who advised on databases and search strategies.

### **1.1.2 Methods**

Continuity of care has been defined using an extensive lexicon and described in widely diverse settings (although predominantly in primary care and mental health services). This review therefore required a broad-sweeping search in order to capture the different terminologies and find all the relevant work in this area. The initial search strategy was designed for the MEDLINE database and mapped search terms to MeSH trees and sub-headings, adding keyword searches in a systematic approach. The first series of search criteria contained terms for:

- a.) different aspects and models of care;
- b.) team working;
- c.) patient experience of care.

The second series included terms that related to different descriptions of continuity and experience of continuity in the care process. Finally, a third series of search terms related specifically to stroke and stroke rehabilitation. For PC's review a fourth series of search terms was devised, relevant to and incorporating the concepts of social capital, social support and social networks. The overall search was designed in stages to facilitate the combination of different terms for the two separate parts of the review: those relating to continuity of care (for KH) and those to social capital (for PC). Details of the full MEDLINE search history are shown in Appendix B, pages 275 - 276.

The initial search strategy was also adapted for application in additional databases where relevant literature might have been found. Table 1.a on the following page lists all databases employed in the search and shows the number of unique hits contributed by each of them after duplicate papers had been removed.



**Table 1.a List of electronic databases**

Database Name	No. of hits
Medline	1047
CINAHL	10
PsycINFO	0
British Nursing Index (BNI)	6
ASSIA	152
The Social Science Citation Index (MIMAS)	0
EMBASE	175
The Cochrane Database (CDSR)	0
TRIP	0
The Health Management Information Consortium (HMIC)	0
DARE	0
HTA	0
ECONLIT	0

Tasks related to the review were allocated in the following way: KS executed the searches in the various databases assisted by KH and PC, who were responsible for defining the search terms. Retrieval and appraisal of the papers and the extraction of data from them was the responsibility of KH (Continuity of Care) and PC (Social Capital). In order to supplement the published papers from peer-reviewed sources that were the product of the electronic searches of bibliographic databases, information was also obtained by several other methods:

- a.) The Internet was searched via Google using the simple search terms: “continuity of care + measur\$” and “stroke”;
- b.) “Pearl growing” searches were made of citation lists to identify papers which had not been found in the database searches;
- c.) Expert opinion was sought from health professionals involved in stroke care.

### **1.1.3 Data extraction**

The initial Medline search produced a total of 1047 hits. Searches in the additional databases found a further 343 papers when the duplicates had been removed. The abstract of each potential review paper was scanned or read independently by KH and PC, and the full text articles were obtained if it was agreed that one or more of the three following criteria were met:

- Described a concept, theory or definition of continuity of care (applicable to both reviews)
- Described a method of measuring continuity of care using a new or existing instrument (KH Review)
- Discussed social support or social capital in relation to stroke care (PC Review)

Screening for the inclusion criteria reduced the number of full-text articles to be examined to 191, of which 98 were finally included in the KH review. A combined data extraction form was designed by KH and PC to retrieve information about the conceptualisation of continuity of care which was of relevance to both reviews, and supplemental information about its measurement (KH review) and its relation to social support and social capital (PC review).

The literature review conducted for this thesis initially sought to examine how theories of continuity of care had developed, how the patient's view of continuity had been represented and how continuity had been interpreted in the context of chronic illness. The second stage was to identify any relevant methods of measurement. The enquiry therefore went beyond the professional debate surrounding continuity of care, which is firmly grounded in the provider domain, and was facilitated by the collaborative nature of the work which introduced the role of social networks and social capital in care. The original search was completed at the beginning of the study and was subsequently updated. Information has therefore been supplemented where appropriate.

#### **1.1.4 Data synthesis**

The method of data synthesis used for this review was qualitative; papers were read and theories, concepts and definitions identified and categorised. Measures of continuity were considered in the same way since meta-analytical techniques could not be applied due to the heterogeneity of the included studies. The combined search strategies found many of the same papers that had been identified in the NCCSDO scoping report and the CHSRF review but, consistent with the different aims, evidence relevant to stroke care was also extracted. As the context of this review emphasised the service user rather than the service provider, the process of synthesis required some disaggregation of the current findings in an effort to reconstruct the evidence and ideas from a different perspective.

## 1.2 Concepts of continuity in health care

The first references to continuity of care as a desirable principle in the delivery of healthcare appeared in the nursing literature in the late 1940's, although decades earlier E. A. Codman (1916) had touched on the theme of continuity in a privately published book "*A Study in Hospital Efficiency*". (Codman, 1916) Codman's thesis, which informed Donabedian's later work on evaluating quality in health care, proposed that standards of care could be raised by studying the process of care. This included the undertaking of regular reviews of medical and nursing practice, developing guidelines for care and monitoring the outcomes of treatment. Effectively, therefore, his "*end result system*" was a means of evaluating and maintaining the quality of care, in which the role of continuity was implicit, if not explicitly defined:

*"...every hospital should follow every patient it treats long enough to determine whether or not the treatment was successful, and to inquire "if not, why not," with a view to preventing similar failures in the future."*

(Codman, 1916)

However, it was not until the mid-sixties that continuity of care really emerged as a separate concept. The publication of three influential reports in 1966, known colloquially as the Folsom, Millis and Willard Reports, led directly to the establishment of the American Board of Family Medicine three years later. Although independently convened, these three working groups had produced remarkably similar recommendations, which centred chiefly on access to health care services, the competencies of practitioners and continuity of care. The Folsom Report, commissioned by the American Public Health Association and the National Health Council, recommended that every American should have their own personal physician to provide continuity in their care:

*"Every individual should have a personal physician who is the central point for integration and continuity of all medical services to his patient. Such physician will emphasize the practice of preventive medicine... He will be aware of the many and varied social, emotional and environmental factors that influence the health of his patient and his family... His concern will be for the patient as a whole, and his relationship with the patient must be a continuity one"*

(Folsom, 1966)

The Millis Report and the Willard Report, commissioned by the American Medical Association, emphasised the need to train family medicine practitioners in the

immediate future, and made recommendations for the structure and content of training programmes. (Millis, 1966, Willard, 1966)

The Millis Report stated the need for:

*“A physician who focuses not upon individual organs and systems but upon the whole man, who lives in a complex setting...and who knows that diagnosis or treatment of a part often overlooks major causative factors and therapeutic opportunities.”*

(Millis, 1966)

The concept of continuity of care was thus founded in a primary care setting within a heterogeneous health system where eligibility for, and access to care were not guaranteed by a National Health Service.

From the early seventies, continuity of care became a central factor in community service development. Becker *et al.* (1974) regarded continuity as a fundamental factor in community medical care and stated that:

*“The need to provide continuity of care is a basic public health and medical care tenet....and a sine qua non to what is currently viewed as “good” medical care.”*

(Becker *et al.*, 1974)

Later, as concepts and definitions of continuity of care began to appear and the relevance of continuity in different care settings was considered, two distinct conceptual categories in thinking about continuity started to emerge:

- a “*seamless service*” - residing in the organisation of care and the structures and processes that support it. (Potentially relevant in primary, secondary and tertiary care settings).
- a “*continuous, caring relationship*” - residing in the interpersonal contact between patient and care providers. (Mainly applicable in primary care settings).

### **1.2.1 Continuity in care processes**

It is convenient to distinguish between the two conceptualisations of continuity simply by reference to the context of care in which they are most relevant but they represent two essentially different approaches to understanding continuity of care. The first of

these, the “*seamless service*”, refers to the way in which diverse health care processes are joined-up to deliver a package of care to the patient. The number and extent of these processes is determined by the nature of care, be it a single referral, a series of interventions of fixed duration or complex, long term care for a chronic condition. The second conceptualisation is clearly more subjective in nature but does imply a patient-centred approach to care, involving the patient rather than casting them as the passive recipient of care.

Early conceptualisations of continuity of care were process based and defined continuity in terms of the connectedness of services and the linkages between them. Wolkon studied mental health patients in a community setting and looked at their up-take of follow-up care after discharge from hospital using hospital attendance records. (Wolkon, 1970). Bass and Windle also studied continuity of care in mental health services in the early seventies, and operationalised their definition of continuity in terms of communication. (Bass and Windle, 1972) Their study used the written (letters and memos) and verbal communication links (direct and telephone conversations) between health care professionals, as indicators of continuity within the same service or across different services and agencies. Continuity in the context of this paper was defined as:

*“the relatedness between past and present care in conformity with the therapeutic needs of the client”*

(Bass and Windle, 1972)

In 1976, Stephen Shortell used data taken from a national study of health services utilisation in the USA to study patterns of care and produced one of the first definitions of continuity that referred to the overall organisation of care, characterising it as part of the care process, and defining it as:

*“...the extent to which services are received as part of a coordinated and uninterrupted succession of events consistent with the medical care needs of patients”*

(Shortell, 1976)

Shortell’s definition has two distinct parts: the first, in common with other early definitions of the term, describes continuity in the context of linkages and a “*seamless service*”, while the second part, which refers to patient needs, brings in another dimension of care, “*appropriateness*”. This is an important distinction when considering how a definition of continuity of care might be operationalised in an evaluation study.

Given that successive episodes in any care setting should ideally be relevant to the patient's needs, it must also be acknowledged that continuity and coordination per se could still be present when care is inappropriate. A misdiagnosis, for example, could lead to a series of unnecessary investigations or interventions, all of which occurred in a timely and joined-up sequence but were entirely inappropriate. Appropriateness therefore implies another dimension to care, one which is more consistent with the quality of the care delivered, and requires an element of judgement.

Early indications of the overlap between continuity and quality of care in the organisational definitions of continuity of care are important to note because the association of continuity of care with quality is a recurring thread running through the literature, both implicitly and explicitly. As research in this area has progressed, studies of "continuity of care" and those of the "care continuum" have moved in different directions. Studies of care processes have generally evaluated services in terms of the quality of care delivered rather than their continuity. In this research context, continuity of care is often cited as one of the components of quality care rather than as a stand-alone concept. In comparison, studies of "continuity of care" more often use the inter-personal conceptualisation of continuity as a theoretical framework. Outcomes are conventionally measured in relation to patient satisfaction by both types of study. It is perhaps an interesting reflection on this overlap between continuity and quality that Shortell's more recent work has focused on quality improvements in care, and integrative care models.

Fundamental to the concept of a seamless service model of continuity is the movement of the patient through the health care system. This concept can be operationalised in terms of transitions or transfers of care from one setting or provider to another, the approach originally advocated by Shorr and Nutting. Their study examined care for prevalent diseases in a North American Indian population, and used the screening, detection, treatment and follow-up evaluation of a series of tracer conditions (coronary heart disease and late-onset diabetes) as a set of representative care processes. Their definition brings in another dimension of care, that of *timeliness*, something which, like appropriateness, could also be considered to be a characteristic of quality care:

*"the rates of transition between the major clinical elements."*

(Shorr and Nutting, 1977)

A recent review by Cotter *et al.* (2002) discussed the importance of transitions in care and urged health care providers to “*see the system as a whole rather than a grouping of organisational components*”. They concluded that transitions in care were “*the next major quality improvement challenge*”. (Cotter *et al.*, 2002) Contemporaneous with this work, an unpublished review by colleagues in the former Nuffield Institute for Health at Leeds University also considered the role of transitions in relation to stroke care. (Robinson, 2002) They identified issues specific to stroke and sought to identify “hinge points” (transitions) in the care process that could be used as potential indicators of continuity of care. The Nuffield Institute study also reviewed working practices and service models designed to expedite stroke care as well as proposing ideas for future service development.

Notwithstanding the fact that transitions in care are vulnerable points at which discontinuities in care can arise, the predominant focus of the “continuity of care” literature has been the inter-personal element of continuity. The theme of transitions in care has been pursued in a divergent literature, which examines the continuum of care, and the organisational structure and processes that support it.

The search for published studies that have considered continuity of stroke care uncovered no new definitions of continuity of care specific to stroke. In the acute care setting, the introduction and evaluation of specialist stroke units and acute care pathways have been the focal points of research into the organisation and delivery of stroke care. Dancer’s 1996 study reported the design of a patient-care trajectory for acute stroke by a multi-disciplinary team in a US hospital setting. The goal was to improve patient and staff satisfaction, improve resource utilisation and smooth the transition of patients between different elements of the service. Input from patients and carers was incorporated in the validation and revision process of the study; an exercise which highlighted the problems that could arise once patients were discharged home. Overall, this study concluded that the establishment of better communication links between acute and rehabilitation services, facilitated by the introduction of the redesigned care pathway, was the major factor in improving coordination of care and ensuring referrals to appropriate services. (Dancer, 1996)

Fagerberg *et al.* evaluated the longer term (post-discharge) effects of specialised acute stroke unit care integrated with continuing care on a specialist geriatric stroke unit. The enhanced care package was compared with conventional care on a general ward for older people in a randomised trial. (Fagerberg *et al.*, 2000) The study found that the

only measurable benefit was in three month mortality rates, no other significant differences were found, neither in the number of patients living at home at one year nor in functional or quality of life outcomes. Acute stroke units do therefore save lives, as the Fagerberg study and others have shown, but the effect of organised specialist hospital care on longer-term outcomes is less certain. (Sulch *et al.*, 2000, Stroke Unit Trialists' Collaboration, 2004)

While the findings of Fagerberg *et al.* may have been the result of the older age of the participants as the authors suggest, it can also be conjectured that continuity of post-stroke care may be dependent on more than high quality hospital care alone. Several other studies of post-discharge stroke care have investigated the facilitation of ongoing services for stroke patients and the role of care coordinators and health visitors in continuing care. Outcomes have been varied and although reference is made to continuity of care as a beneficial factor in studies of this type, none have sought specifically to characterise or evaluate it. (Burton, 1999, Geddes *et al.*, 1997)

Discharge from hospital is frequently highlighted as a critical transition point in care, and a Cochrane Review of randomised trials of discharge from hospital to home undertaken in 2000 showed that discharge planning can contribute to better outcomes for patients. Discharge planning and arrangements are undoubtedly the most widely studied of care processes, particularly in the context of care for older people, but the review by Parkes *et al.* showed that the main aim of discharge planning, which is to bridge the gap between hospital and home, was rarely addressed by the trials they studied. (Parkes and Sheppard, 2000) Needless to say, in terms of patient satisfaction with care, studies have shown that discharge arrangements are by far the greatest source of discontent with hospital services. (Hickey *et al.*, 1996)

Wolkon's early definition of continuity of care (Wolkon, 1970) and its successors share a common concept of continuity residing in transitions in care, which is firmly located in Donabedian's structure, process and outcome paradigm. (Donabedian, 1966) None of these definitions of process, however, incorporate any element of patient-centeredness in their conceptualisation. Patients' views of health care processes and what they recognise or define as continuity in their care are rarely discussed. Given that modern health care is complex, and specialist knowledge may be required to understand its organisation, the associated difficulties of incorporating a lay perspective are perhaps explicable. As a result, continuity of the care process remains almost exclusively a professionally centred concept.



### 1.2.2 Continuity of care provider

The concept of continuity as a continuous, caring relationship between care provider and patient is often typified as the “Dr Findlay” model of care. For many years this model has been tacitly accepted as a pre-requisite for good general practice because of the trust that is built up in a long-term, stable doctor-patient relationship. It has also been described as the “cradle to the grave” model of care and can be regarded as the basic tenet of the concept of relational continuity.

Advances in modern health care have created recognised barriers to maintaining interpersonal contact in the highly specialised environment of acute care. Diagnostic investigations may lead to a succession of medical, therapeutic or surgical interventions which are carried out by teams in a range of different disciplines. The concept of continuity of care provider could therefore be construed as more relevant in a primary care setting. General practitioners are at the front-end of health care, and consequently they are called upon to deal with all types of health problem by the patients attending their surgeries. Hence it is likely to be true in any number of circumstances pertaining to primary care that accumulated knowledge of a patient could be beneficial.

Banahan and Banahan’s concept of continuity (1981) was developed in a North American family medicine setting and incorporated two underlying constructs: “*trust*” and “*responsibility*” in its definition. Both are considered to be desirable and advantageous in the relational model of continuity. The Banahans’ definition, in which continuity of care is described as an attitudinal contract, is based on the maintenance of an ongoing caring relationship between the patient and the provider of care.

*“Continuity of care is a phenomenon that exists when the patient perceives a dependency on the physician for medical care, and the physician perceives a responsibility for the patient’s medical care. When either attitude ceases to exist, continuity ends.”*

(Banahan and Banahan, 1981)

The essential characteristics of continuity in an attitudinal contract are described as: “(1) a beginning point, (2) an end-point, and (3) quality”. Thus, once again, quality emerges as a theme in continuity of care. Three types of continuity (A, B and C) are proposed in the Banahans’ paper, each of which includes the essential characteristics of continuity but is distinguished by the duration of the relationship between patient and physician: Type A being the relationship of longest duration and Type C the shortest.

The first of these, Type A continuity is the Dr Findlay model of “*care throughout the life course*”, with the physician-patient relationship spanning periods of illness and periods of well-being, and including major life-cycle changes. Type B also covers periods of illness and well-being but does not necessarily cover a large proportion of the life-span because of its shorter duration, and Type C is described as extending only across a single illness episode.

Banahan and Banahans’ paper represents their opinion based on an interpretation of the published literature in the context of extensive personal experience of family and community medicine. It is not based on a new or empirical study, and was not therefore derived from the experience of patients. It is of interest in this review because their definition attempts to incorporate an element of the patient’s perception of continuity and because it has close parallels with ideas about social capital. In Robert Putman’s frequently cited book “Bowling Alone”, the decline of social capital in America and its causes and implications for society are discussed. (Putnam, 2000) In Putnam’s conceptualisation “trust” and “reciprocity” are fundamental to a theory of social capital which relies on the connectedness of individuals and the building of social networks. Reciprocity or the willingness to do things for others is directly comparable to the Banahans’ definition of responsibility in the doctor-patient relationship.

Other studies have sought to understand continuity in family medicine from both the patient and provider viewpoint. Sturmberg conducted focus groups with Australian GPs and derived a definition based on their experiences which had three essential elements:

*“Firstly, it requires a stable environment, secondly good communication to build a responsible doctor-patient relationship and thirdly the goal of achieving an improvement of the patient’s overall health”.*

(Sturmberg, 2000)

Sturmberg’s definition is also analogous to ideas of social capital where connectedness is achieved through good communication and reciprocity, creating a mutually beneficial relationship. The GP’s represented in this study clearly recognised the need for teamwork within practices, and valued coordination as the key to successful continuity of care.

In seeking to operationalise the definition of continuity of care provider, many studies have focused on contacts between patient and provider, evaluating continuity

specifically in the context of patient uptake of services or their preferences for services. Early indicators were based on the number, frequency and sequencing of visits by the patient to the care provider but not on the nature or quality of the relationship they shared. These operational definitions of continuity of care provider have underpinned many of the studies which have attempted to derive continuity metrics, and the outcome measure most frequently associated with them has been patient satisfaction. This is discussed further in Section 1.8 of this chapter (pages 53 – 55) which deals with the outcomes of care.

### 1.3 Continuity as a multi-dimensional concept

As efforts to define continuity in health care progressed, the dichotomy that had emerged in the conceptual models of continuity of care during the eighties created growing confusion rather than a synthesis of opinion. Ideas of multi-dimensional models of continuity that brought together aspects of timeliness, communication and the development of trust were already in circulation. In the mid-seventies Hennen had described four dimensions of continuity in family practice: “*chronological, geographical, interdisciplinary, and interpersonal*”. (Hennen, 1975) While Mary-Anne Test’s multi-dimensional model for continuity in mental health care incorporated a further, cross-sectional, element:

*“At any given time-point in a chronically mentally ill person’s treatment, the person must be involved in a system of care that is comprehensive and integrated”*

(Test, 1979)

In 1980, Rogers and Curtis acknowledged the lack of consensus in the emerging conceptual frameworks by publishing a review of the many different phenomena in the care process to which the term “*continuity*” had been applied. (Rogers and Curtis, 1980) They acknowledged that the term continuity was being used in different ways by different researchers and called for “*the establishment and agreement of a definition*”. However, their re-examination of the issues did not solve the problem, and this may be the reason why their paper is less frequently cited than the editorial by Barbara Starfield that appeared in response to it. (Starfield, 1980) “*Continuous Confusion*”, pleaded for a standardisation of terms, and for clarity in their use and application when describing the concept of continuity. In particular she argued for the distinction between “*continuity*” and “*longitudinality*” that had been made by Rogers and Curtis in their paper. Longitudinality, Starfield proposed was:

*“...a phenomenon involving both the availability of a regular source of care (place or professional) and a decision, by the patient, to seek care from that source whenever care is needed.”*

(Starfield, 1980)

In this definition, longitudinality implies the establishment of a long-term relationship that is independent of a specific health problem; achievement and maintaining longitudinality is under the control of the patient. Continuity is thus separated from longitudinality and characterised as a structural element of care, largely controlled by the care provider, which provides *“a mechanism to ensure that problems are adequately followed up from one visit to the next”*. Starfield’s proposals were aimed at clarifying the focus of research in order to move things forward and, although based on the nature of family practice, they do attempt to draw in wider provision beyond the primary care sector by specifying that continuity should extend to *“those aspects of secondary and tertiary care that involve management of an illness”*.

Leona Bachrach’s conceptual analysis of continuity in relation to care for chronic mental health patients did not separate longitudinality and continuity in the way in which Starfield had proposed. (Bachrach, 1981) It did, however, continue the theme of continuity as a multi-dimensional concept and included a longitudinal aspect as one of its elements. Her paper, published in 1981, has become one of the seminal “continuity of care” papers. In it she proposed a seven dimensional model based on a systematic observation of records of admissions to psychiatric services in one area of the USA over a period of several years. By summarising and explaining how basic elements of continuity could be defined with specific reference to chronic mental services, she too hoped to reduce the confusion that had been described by Starfield (and Rogers and Curtis) a year earlier. The seven dimensions proposed by Bachrach were the temporal dimension (*longitudinal continuity*), *individuality; comprehensiveness; flexibility; relationships; accessibility and communication*. However, whether the extra dimensions of continuity led to greater clarity is debateable, and her actual definition of continuity was in essence very similar to that of Stephen Shortell (Page 29).

*“Continuity of care may be understood as a process involving the orderly, uninterrupted movement of patients among the diverse elements of the service delivery system”*.

(Bachrach, 1981)

Further conceptual reviews appeared in the eighties but without any emergent consensual agreement, and this trend continued throughout the nineties bringing with it a plethora of definitions. Many of these were operationalisations of existing concepts in relation to measurement and, while there was commonality in their terminology, there was considerable divergence in the various aspects of care to which the terms were applied. Needless to say, no real progress towards developing a consensus in the understanding of continuity in health care was achieved despite the plea for clarity that Starfield's earlier editorial had made.

At the end of the 20<sup>th</sup> century, the NCCSDO scoping exercise sought to synthesise all the existing ideas and concepts by conducting a full review of the evidence. The output of this work was the Freeman model of continuity, a multi-axial definition which draws to a large extent on the multi-dimensional models of Hennen and Bachrach. (Hennen, 1975, Bachrach, 1981) It is reproduced here, (in Figure 1.a below), as it was presented in the final report to the NHS NCCSDO. (Freeman, 2000)

**Figure 1.a The Freeman model of continuity of care**

<b>Scoping Definition of the elements of continuity of care</b>	
At a minimum a definition of continuity of care should include the following elements.	
1	The experience of a co-ordinated and smooth progression of care from the patient's point of view ( <i>experienced continuity</i> ).
To achieve this central element the service needs:	
2	excellent information transfer following the patient ( <i>continuity of information</i> )
3	effective communication between professionals and services ( <i>cross-boundary and team continuity</i> )
4	to be flexible and adjust to the needs of the individual over time ( <i>flexible continuity</i> )
5	care from as few professionals as possible consistent with other needs ( <i>longitudinal continuity</i> )
6	to provide one or more named individual professionals with whom the patient can establish and maintain a therapeutic relationship ( <i>relational or personal continuity</i> )."

The ongoing debate about continuity of care gathered momentum and, shortly after the publication of the Freeman report, the Canadian Health Services Research Foundation (CHSRF) Workshop provided another forum for discussion. The product of this

exercise was the CHSRF report which further synthesised the ideas that had emerged from the SDO scoping exercise. The successor to the Freeman report emulated Starfield's plea to reduce the confusion that was still apparent in the conceptual framework of continuity in healthcare. The workshop resulted in a proposal for a new model of continuity of care which comprised three types of continuity (see Figure 1 b below) with two core elements: that it is **received and experienced by an individual**, and that **care is provided over time**. (Reid, 2002)

**Figure 1.b The CHSRF model of continuity of care**

**Informational Continuity:** the transfer and use of information, and accumulated knowledge

**Managerial Continuity:** the provision of timely, complementary and responsive services

**Relational Continuity:** the maintenance of patient-provider relationships and consistency of personnel

A number of smaller reviews have been published since 2001 which have built on the CHSRF conceptual model, some have focused on one particular aspect of continuity of care. Krogstad *et al.* for example based their 2002 definition on the informational dimension of continuity and the way it is integrated within the structure and process of care:

*“Continuity behind the scenes is based on shared information and responsibility, and it is structurally supported by implementation of routines such as shift reports, written guidelines and regular meetings.”*

(Krogstad *et al.*, 2002)

Saultz took the theme of interpersonal (relational) continuity as a basis for his review, and offered a hierarchical definition based on three levels of continuity of care: Informational; longitudinal and interpersonal. (Saultz, 2003) These were intrinsically the same as the three types of continuity that had been proposed in the CHSRF report. However, he attested the importance of interpersonal continuity as fundamental to his model, based in family medicine, as this he argued was the means by which the other aspects of continuity were achieved. However, other researchers have questioned whether models of continuity based on interpersonal relationships are sustainable in

modern general practice. The emergence of larger group practices, flexible work patterns and more GP specialisation for example all contribute to a shared model of care in which the maintenance of relational continuity becomes harder to achieve.

## 1.4 Agency Theory

Divergent from the Freeman and Haggerty-Reid models of continuity is the novel approach put forward in Molla Donaldson's doctoral thesis. (Donaldson, 2001) She hypothesised that continuity of care could best be understood in terms of agency theory or, more precisely, as:

*“a means to reduce agency loss for the patient and thus increase the likelihood of desired outcomes”.*

(Donaldson, 2001)

Health care agency in this context is described by Donaldson as the interaction between the patient and the service providers (the agents), and the gathering (and transfer of) information, which then in turn can be used for the benefit of the patient (goal alignment). This view of continuity incorporates some elements of patient involvement in care if it is assumed that the goals referred to are always identified and negotiated with the individual patient beforehand. This is an important distinction because, while other definitions may refer to patient needs, the majority have been operationalised using medically or service defined terms.

Donaldson's work is less often cited by other reviewers in the field. Its publication post-dated the NCCSDO review, and was only shortly before the CHSRF work appeared. It has not, however, featured in some of the more recent reviews. One explanation for this may be that it uses a different conceptual framework within which to understand continuity, and from which it is harder to derive an operational definition for the measurement of continuity. Another explanation is that it is based on one specific health care delivery system (North American), which differs from the UK system where care is organised at a national level, and is also different from some other European models. It does however have resonances with the concept of continuity in a network of care, an idea which emerges later in this thesis, and is discussed in Chapter 5.

## 1.5 Continuity from the patient's perspective

As researchers took up the theme of continuity in the nineties, greater emphasis was placed on understanding continuity from the patient's perspective. Qualitative studies were conducted to identify the factors that patients perceived as important in their care. Preston *et al.* (1999) elicited the views of UK patients who had experienced referrals from their General Practitioners and received outpatient or inpatient care from secondary care services as a result. They also included experiences of discharge arrangements and aftercare. They interviewed 33 patients (some individually and some in focus groups) and 8 individual carers and derived five themes: “*getting in*”; “*fitting in*”; “*knowing what's going on*”; “*continuity*” and “*limbo*”. (Preston *et al.*, 1999) Although these themes reflect an interaction across a specific health care boundary they also correspond to certain of the Bachrach dimensions such as access to services (getting in), relationships and flexibility (fitting in), information and communication (knowing what's going on).

Norma Ware's study used an ethnographic approach (a qualitative research method traditionally used in anthropology) in a positive attempt to understand both the patients' and the health care providers' perspectives of continuity in mental health services. (Ware *et al.*, 2003) This method used not only the narrative reports of participants in the study but also the direct observations and field notes of the researchers. Ware *et al.* proposed six mechanisms for continuity of care which were labelled as “*pinch hitting*”; “*trouble shooting*”; “*smoothing transitions*”; “*creating flexibility*”; “*speeding up the system*” and “*contextualising*”. In contrast to the work of Preston *et al.*, which described interacting with care processes from the patient's point of view, Ware's descriptions of the mechanisms of continuity are focused on the activities of the care providers in the process of care delivery.

The search conducted for this study found no papers that had explored the issue of continuity of care in depth specifically from the stroke patient's perspective. A postal survey of the experiences of care by stroke survivors was undertaken on behalf of the Stroke Association in 2001. This study found that up to a quarter of the patients surveyed reported that they had not received the rehabilitation services they felt they needed and over 30% felt they had not had contact with stroke care specialists. Some problems were also highlighted with regard to information provision, either in terms of accessing the information they required (22%) or experiencing delays in receiving it



(10%). (Stroke Association, 2001) Although this survey covered issues of relevance to continuity the primary focus was on patient satisfaction with care.

## 1.6 Summary: Concepts of continuity

A multiplicity of terms have been used to describe continuity in health care systems both in studies of professional and lay concepts. Wider reading suggests that there is considerable overlap in these, and that many definitions refer to the same or essentially similar aspects of continuity but use different terminology, while others use the same or similar terms for different phenomena. Notwithstanding the many conceptualisations of continuity of care that have been proposed, few seem to be directly relevant to stroke care.

In many acute and chronic conditions like stroke the ideal of relational continuity cannot be readily applied as care is provided by multi-disciplinary teams of professionals depending on the specific care needs of the patients. In chronic conditions therefore it might be considered more appropriate to frame continuity in terms of the coordination of care-giving either through the monitoring and review of care or by the provision of appropriate referrals and transfers of care throughout the care process. However, reducing these to a single quantifiable definition such as rates of transition as Shorr and Nutting proposed does not capture adequately the complex nature of stroke. (Shorr and Nutting, 1977) A more useful framework in which to understand continuity in stroke care may be that provided by the multi-dimensional model of Bachrach:

*“Continuity of care may be understood as a process involving the orderly, uninterrupted movement of patients among the diverse elements of the service delivery system”.*

(Bachrach, 1981)

Needless to say, operationalising Bachrach’s definition in complicated, chronic care settings where care is driven by changing circumstances is not straightforward. Care is often far from orderly and frequently interrupted by changes in the patient’s physical condition or social circumstances.

Seemingly therefore, despite the development of various conceptual frameworks, there is still no universal consensus about the generic nature of continuity of care, nor how it may vary by disorder or stage of care. Moreover, even less is known about the experience of continuity or how it is understood by the users of health care services.

Against the background of Starfield's continuous confusion, the search for methods of measuring this elusive concept in the context of health care has proceeded apace. The next sections of this chapter describe the approaches to measurement that have been applied in different settings, and review the applicability of existing instruments and scales in relation to evaluating continuity in stroke care.

## **1.7 Measuring continuity of care**

### **1.7.1 *The background to measurement***

The premise that continuity of care is a desirable and beneficial concept in health care carries with it the notion that the presence of continuity should confer advantages for patients that result in favourable outcomes. This hypothesis cannot be proven (or even investigated) without a method of assessing and evaluating continuity of care. A number of theoretical definitions of continuity of care have previously been described (in Sections 1.2 to 1.4, pages 27 – 39), and as research into the measurement of continuity has progressed many operational definitions have also appeared, less complex in nature, but equally diverse. This reflects the wide variety of usage in the term "*continuity*", and the way it has been applied to different aspects of care. This study aimed to review methods of measurement of continuity and to identify a measure that could be applied in a cohort of stroke patients. The focus therefore was upon identifiable index measures of continuity of care. The review did not attempt to cover the whole spectrum of ways in which continuity of care has been defined in research studies.

An early attempt to operationalise continuity of care for measurement (1967) pre-dates published conceptual definitions, and took readmissions and transfers between psychiatric in-patient units as a metric for continuity. (Pugh and MacMahon, 1967) Other measures of continuity, for example using questionnaires or interview survey techniques, or the audit and collection of data from patient records have been developed since the mid-seventies. Nevertheless there is some lack of consistency in the way continuity of care has been evaluated over the last three decades and, with the exception of modifications to certain indices, few attempts have been made to build on existing methods of measurement. Researchers have frequently used opportunity indicators which could easily be identified and measured without reference to their theoretical basis. The CHSRF workshop had a specific remit to study the measurement of continuity and review the operational definitions that had been used.

The measures that were in existence in 2000 were classified in the CHSRF report into four categories. This categorisation is described in Table 1.b below.

**Table 1.b CHSRF classification of measures of continuity**

Category	Operational definition
Chronological	Duration and intensity of affiliation with regular or usual provider Concentration of care among different providers Sequential care from the same of different provider
Relational	Inter-personal relationships; Affiliations i.e. strength of relationships between patient and provider
Informational	Information transfer; Uptake and use of information
Management plan	Prescribed follow-up; Consistency of care

From the table above it can be seen that there is some degree of interaction between these categories. Information transfer, for example, is likely to be a factor in the planning and execution of an effective management plan, and affiliative relationships could influence duration or uptake of care where patient choice plays a role.

The original literature search for the current review, conducted in 2002, found no papers that reported the development of a new measure of continuity of care, other than those that had already been identified by the Freeman report to the SDO and Reid's CHSRF report. (Freeman, 2000, Reid, 2002) However, since the search for this review was completed, new instruments have been developed in response to research programmes funded by the NHS NCCSDO and the CHSRF. These measures have been designed for use with specific diseases or conditions and include an instrument for mental health settings, (Adair *et al.*, 2005); for diabetes (Dolovich *et al.*, 2004), and for chronic heart disease. (Kowalyk *et al.*, 2004) Added to these can be recent measures in mental health (CONTINUUM), (Burns, 2007) diabetes (ECC-DM) (Gulliford *et al.*, 2006) and cancer care. (King *et al.*, 2006) All seek to assess continuity from the patients' perspective either by using self-report questionnaires alone or by an integrated assessment, which includes a component that is completed by the patient. Scrutiny of the included items however suggests that there is some overlap with

perceptions of quality and satisfaction with care, particularly in the chronic physical disease questionnaires.

In addition to specific continuity of care scales, there are a number of instruments designed to assess the quality of primary care that contain items and domains associated with documented dimensions of continuity of care. The Components of Primary Care Instrument (CPCI) for example measures aspects of the affiliation between the patient and provider such as trust, seeing the usual physician and the value of feeling known. (Flocke, 1975) The PCAT-AE has similarities with the CPCI, and the Primary Care Assessment Survey, which also features sub-scales for interpersonal relationships, trust and “*feeling known*”. (Safran *et al.*, 1998)

The Adult Primary Care Assessment Tool (PCAT–AE) consists of seven scales representing five domains that are comprised of service factors relevant to primary care (Shi *et al.*, 2003):

- First contact domain: (i) accessibility and (ii) use
- Longitudinal domain: ongoing care
- Coordination domain: coordination of services
- Comprehensiveness domain: (i) services available and (ii) services received
- Derivative domain: community orientation

At least four of these domains cover aspects of care that are directly related to continuity as described in Bachrach’s seven dimension model, (Bachrach, 1981) and other multi-dimensional conceptualisations of continuity of care.

Table 1.c on the following page lists the measures that have been developed specifically as indices for measuring continuity. It includes the more recent measures described above, updating the findings of the 2001 CHSRF report. It does not include empirical studies that have explored continuity using patient satisfaction surveys (typically one or two items related to continuity) or qualitative techniques alone.

**Table 1.c Papers reporting measures of continuity of care**

ID	Year	Author	Name and Acronym (if any) of Measure	Setting	Conceptual Model
1	1975	Breslau <i>et al.</i> , 1975 and 1976	Usual Provider Continuity Index (UPC); Most Frequent Provider Continuity (MFPC)	Paediatric Care	Provider Continuity "Seeing the same person"
2	1976	Shortell, 1976	Number of Providers Seen (NOP) based on 2 indices of concentration (CON and GINI)		
3	1977	Bice & Boxerman, 1976	Continuity of Care Index (COC) adapted from The Rae Index of Fragmentation (FRAC)		
4	1979	Steinwachs, 1979	Sequential Continuity Index (SECON); Likelihood of Continuity Index (LICON) Likelihood of Sequential Continuity Index LISECON	Medical Outpatients: Hypertension	
5	1981	Wall, 1981	Duration of relationship; Rate of provider turnover		
6	1981	Godkin & Rice, 1981	Modified Continuity Index (MCI); Family Mean Continuity Index (FMCI); Family Continuity of Care Index (FCOC)		
7	1982	Breslau, 1982	Three-Item Continuity Scale	Paediatric Care	
8	1985	Ejlertsson & Berg, 1985	Known Provider Continuity Index (K Index))		
9	1987	Magill & Senf, 1987	Modified, Modified Continuity Index (MMCI)		
10	1988	Chao, 1988	Perception of Continuity Scale (PC)	Primary Care	Banahan & Banahan's Attitudinal Contract
11	1993	Murata, 1993	Family Care measure (FC)		Provider Continuity
12	1993	Anderson & Helms, 1993 Anderson & Hill, 1994	Referral Data Inventory (RDI)		Information Transfer (Records)
13	1997	Citro, Ghosh <i>et al.</i> , 1997	The Fundamental Continuity of Care Index (FCCI)		Provider Continuity
14	2000	Bull, Luo <i>et al.</i> , 2000	The Care Continuity Instrument (CCI)	Elderly Care: Hospital Discharges	Information Transfer (Interpersonal)
15	2001	Lou, 2001	Alpha Index (Clá)		Provider Continuity
16	2003	Ware, Dickey <i>et al.</i> , 2003	CONNECT: Interpersonal Interactions in Mental Health Services	Community Mental Health Care	Interpersonal Processes
17	2004	Dolovich, Nair <i>et al.</i> , 2004	The Diabetes Continuity of Care Scale (DCCS)	Specialist Diabetes Care	CHSRF "Three Element Model"
18	2004	Kowalyk, Hadjistavropoulos <i>et al.</i> , 2004	The Heart Continuity of Care Questionnaire (HCCQ)		
19	2005	Adair, McDougall <i>et al.</i> , 2005	Alberta Continuity of Services Scale for Mental Health Services (ACSS-MH)	Community Mental Health Care	
20	2006	Gulliford <i>et al.</i> , 2006	Experienced continuity of care in diabetes mellitus (ECC-DM)		Freeman's Multi-Axial Model
21	2006	King <i>et al.</i> , 2006	Patient and close persons questionnaire booklets including items covering satisfaction with care, mood, symptoms, health-related quality of life and spirituality	Specialist Cancer Care	
22	2007	Burns <i>et al.</i> – Unpublished report	CONTINUUM	Mental Health Care	

### 1.7.2 Index measures of continuity

Primary care and mental health services have led the way in the development of measures of continuity. The first scales to emerge for primary care settings were predominantly based on service usage, which was expressed as contact with the providers of health care. Continuity scores were calculated either as a proportion of visits to the same (known) provider, or the extent to which visits were dispersed between different providers. In the main the care provider has been defined as the doctor in this type of measure, usually the family care physician. One of the first to appear, and perhaps one of the most widely used in other studies, was Naomi Breslau's Usual Provider Continuity Index, (Breslau and Reeb, 1975) later modified to become the Most Frequent Provider Continuity Index. (Breslau and Haug, 1976) The formula from which it is calculated is given by the equation:

#### Equation 1.a Most Frequent Provider Continuity Index

$$MFPC = \frac{\text{Max}(n_1, n_2, \dots, n_M)}{N}$$

Where:  $N$  = total number of visits  
 $n$  = number of visits to each provider  $j$   
 $M$  = number of possible providers

Another early, and frequently cited, measure of continuity is Bice and Boxerman's Continuity of Care Index (COC). (Bice and Boxerman, 1977) This was adapted from Rae and Taylor's original fragmentation index, a measure developed in the political sciences and designed to show that increased "fractionalisation" among legislators delayed the speed with which they reached agreement. (Rae and Taylor, 1970) The COC Index was originally developed to operationalise Shortell's conceptual definition of continuity of care (Page 29) (Shortell, 1976). Bice and Boxerman's formula measures the distribution of visits among usual, referred or unreferred care providers to derive a quantitative score of continuity, and is given by the following equation:

#### Equation 1.b The Continuity of Care Index

$$COC\ Index = \frac{\sum_{j=1}^s n_j^2 - n}{n(n-1)}$$

Where:  $n$  = total number of visits  
 $n_j$  = number of visits to provider  $j$   
 $s$  = number of unreferred providers

In 1979, Steinwachs introduced a formula that incorporated the sequencing of visits to known care providers (i.e. the order in which care providers are seen in addition to the frequency). (Steinwachs, 1979) This was designed to address some of the limitations of the simpler provider continuity indices and was followed by other derivative indices, for example the LICON, LISECON and the later FCCI and Alpha Index, which used the same fundamental approach (see Table 1.c, page 45, for references). The SECON and associated indices are based on similar formulae to Breslau's MFPC and Bice and Boxerman's COC index but are more complicated to calculate in practice because of the difficulty in quantifying the sequence of visits. They are based on the theory that consistently seeing the same care provider should produce a higher (better) continuity score. However these, like other similar indices, are potentially confounded by variations in patient characteristics and patterns of care; the associations between which are likely to be complex and difficult to control for as both clinical and social factors could influence the need for, and compliance, with services.

Given *et al.* undertook a comparative review of the three principal indices which were available in the mid-eighties: the MFPC, the COC and the SECON. (Given *et al.*, 1985) They used retrospective attendance data from five family practice sites and applied the measures to all visits made to them. They also studied a sub-group of visits made for four specific diagnoses: Upper respiratory tract infection; hypertension; mood and anxiety disorders; and ante-partum care. In an effort to evaluate external validity they computed three measures of laboratory usage (number and rate of laboratory tests ordered per visit). They found that the continuity scores calculated for each site were very similar for each of the three instruments, and were related to the number of return visits prescribed. Patients with the four tracer conditions all had better (higher) continuity scores than the general patient population visiting the practices but they found no association between the continuity scores and the level of laboratory service usage. The authors concluded that this finding was related to the low severity of the conditions and the absence of need for continuing care. An alternative explanation however could be that a simple index measure based on the number of visits to health care providers is not sensitive enough to capture elements of service usage that can detect differences and discriminate adequately at either the patient or practice level.

Subsequent indices of continuity identified in the published literature have been variants on the existing measures of density, distribution or sequencing of visits to care providers. Murata's Family Care Measure for example was based on a three part operationalisation of family care (frequency of visits, number of members in the family

unit, number of providers), which claimed to “*translate a family's pattern of health care into an easily interpreted index*”. (Murata, 1993) However, both this and earlier measures of family care proposed by Godkin and Rice in 1981 were variations on the COC and SECON indices previously described. (Godkin and Rice, 1981) Citro *et al.*, in a later study, also took the concept of usual provider continuity but incorporated the duration of the interaction between patient and provider in order to derive the Fundamental Continuity of Care Index (FCCI). (Citro *et al.*, 1997) They examined the pattern of visits to a primary care clinic over a three-year period in a large data set of electronic patient records and applied complex statistical modelling to generate an optimum value of the mean time of doctor–patient interaction. The main aim of their index was to offer a practical tool with which to analyse resources and thus to improve efficiency in primary care provision. Maximal continuity, it was proposed, could be achieved (given acknowledged resource constraints) by the effective management of clinic schedules. No element of individual patient variation was included in the model except for age (the sample was stratified into 5 age groups) and, in this mathematical solution, continuity was taken as a product of the total duration of interaction between the patient and the primary care provider, relative to a standard value derived from their stochastic models. Other objective measures of continuity have used audit data such as referral letters (the RDI) or discharge summaries as indicators of continuity of care but are subject to similar limitations. (Anderson and Helms, 1993)

A recent up-date of the search identified a full systematic review of index measures of continuity published in 2006. (Jee and Cabana, 2006) This comprehensive paper updated previous reviews by re-examining the early indices of continuity and provided a full description of all index measures of concentration, fragmentation and continuity of care, including the methods and formulae used for their calculation. The review focused on measures that had been applied in out-patient settings to assess both adult and paediatric care, and used two criteria to define a method of measuring continuity: firstly that the measure accounted for continuity of care at the provider level and secondly that it determined the patient-provider relationship over a time frame longer than one visit. Measures were characterised into five conceptual categories: *duration*, *density*, *dispersion*, *sequencing* and *subjective* but, as the focus was primarily on quantitative measures of continuity derived mathematically, the evaluation of the subjective measurement of continuity was limited. Measurement of continuity from the patient perspective implies a subjective evaluation of care, and the subjective assessment of continuity by the patient is therefore of particular relevance to this



review. Measures that have attempted to address this aspect of continuity of care are described in the next section.

### **1.7.3 Subjective measures of continuity**

Quantitative measures of continuity have conventionally used indicators based on information from service providers. Nevertheless, these are sometimes described in the literature as measuring the “*relationship*” or “*affiliation*” between patient and care provider despite being based solely on the duration of the relationship or the number of visits that have been made to the specified provider. Moreover it has been proposed by some researchers that such methods of measurement of continuity can be representative of other attributes of the patient/physician relationship such as the strength of affiliation (how well individual patients are known) and the extent to which families are seen and treated by a doctor with knowledge of the family unit. (Murata, 1993, Citro *et al.*, 1997) Banahan and Banahans’ typology of continuity, based on the duration of the patient-provider relationship, offered a theoretical basis for this approach. (Banahan and Banahan, 1981)

Ian McWhinney on the other hand maintained that “*continuity was not only a question of the duration (of relationship)*”. (McWhinney, 1989) In a comparative study investigating the patterns of movement of patients in 17 family practices in south-western Ontario, hypertension was used as a tracer condition to demonstrate that treatment was maintained for 90% of patients over the five-year study period despite a relatively mobile population. (McWhinney *et al.*, 1988) Notwithstanding the limitations of the study design, mobility for example decreased with age but the incidence of hypertension is known to increase, it can still be argued that strength of affiliation is a more subtle construct than some of the preceding studies suggest. Strength of affiliation implies a quality judgement by one or other of the partners in the relationship under scrutiny and, as McWhinney contends, cannot be represented simply by duration of relationship alone.

Assessments of primary care services summarised briefly in Section 1.7.1 (on page 44) frequently operationalised the concept of affiliation as the degree to which the patient “*feels known*” by or the extent to which they expressed “*trust*” in their health care provider. (Flocke, 1975, Safran *et al.*, 1998, Shi *et al.*, 2003). These measures use the subjective ratings of patients and are not based on service usage data alone but are primarily designed as measures of quality of primary care. The literature search

undertaken for this study identified only three measures that had been specifically designed to measure the patient's perspective of continuity of care: Breslau's Three Item Continuity Scale (Breslau, 1982), the Chao Perception of Continuity scale (Chao, 1988) and the Care Continuity Index. (Bull *et al.*, 2000) The earliest subjective index measure of continuity identified in this review was that described by Breslau in 1982. This short scale was developed for a paediatric care setting and contained three items which were rated by the parent in order to describe continuity of physician:

- *"My child hardly ever sees the same doctor when he or she goes for medical care."*
- *"If more than one family member needs medical care, we have to go to different doctors."*
- *"My child sees the same doctor just about every time he or she goes for medical care."*

This concise scale was followed by the Perception of Continuity questionnaire, a 23-item instrument, developed Dr. Jason Chao in 1988 to survey patients' views on continuity of family care. The full questionnaire is reproduced in Appendix C, page 277 from which it will be seen that Breslau's three items (above) are included and have simply been adapted for an adult primary care setting by re-wording. Chao's aim was to test the concept of continuity as an attitudinal contract between patient and care provider, originally hypothesised by Banahan and Banahan (1981), in an empirical study. The Chao PC questionnaire focused on the structural and interpersonal aspects of the relationship, including a rating of trust, between the patient and the physician in a primary care setting. Unfortunately only rudimentary tests of internal validity were conducted, which explored the basic correlations of items. These proved to be non-significant for several items, which is not surprising given that they cover a broad range of perspectives on family care. Furthermore, a number of individual items in the Chao measure are not confined to single constructs rendering the questionnaire less compliant with psychometric testing methods. It should be noted that satisfaction with care (also assessed in the Chao study) showed a high correlation with the perceived continuity scores; however no association was found with an external rating of the economic cost of care.

Margaret Bull's Care Continuity Index (CCI) was developed from a qualitative study of older patients' views of care. It was based on the effectiveness of information transfer around the time of discharge of elderly people from hospital care and contained 13

items rating various aspects of information provision by care providers and the attitudes of patients to information seeking. The items were rated on a seven-point Likert scale with scores ranging from 1 (least) to 7 (best). It was used in conjunction with a physical health subscale from a geriatric assessment instrument: Lawton's Philadelphia Geriatric Center Multi-Level Assessment Instrument (Lawton *et al.*, 1982) and, cognisant of the findings of Chao (1988), also included a patient-rated satisfaction scale (The Client Satisfaction Questionnaire). Bull *et al.* used a more sophisticated approach than Chao to exploring the psychometric properties of the CCI and reported both an item-scale correlation matrix and exploratory and confirmatory factor analyses of the instrument. The item-scale correlation matrix showed some discriminatory properties for the items, but the confirmatory factor analysis, which used computerised modelling with LISREL software to examine model fit, only weakly supported the four-factor structure of the instrument's original sub-scales. A principal components analysis had identified these in an earlier qualitative study as information about care management, information about services, provider continuity (seeing the same doctor) and conflicting information. (Bull, 1994) Like the Chao study, Bull *et al.* found that continuity of care scores assessed by their CCI measure and satisfaction with care were significantly correlated. The CCI scores were not, however, associated with the measure of physical health used in this study.

Alternative methods of assessing continuity of care from the patient's perspective have used patient preferences for care as a subjective evaluation of continuity. Schers *et al.* operationalised patient-provider continuity in terms of patient preferences for seeing their own General Practitioner. (Schers *et al.*, 2002) 875 patients from 35 general practices were surveyed in the Netherlands, and achieved a high response rate for a postal questionnaire, particularly from older patients. This study found that patients would prefer to see their own GP for serious problems but thought it less important for minor problems. The reasons most frequently cited by patients for their preferences were the doctor's knowledge of medical and family history. However, their analyses showed that only two factors: a serious life event in the preceding 5 years or having children, were significantly associated with a perceived need for continuity. The majority of patient and practice characteristics assessed including age, gender, presence of chronic illness and frequency of attendance, accounted for only a small amount of variance between responders.

### **1.7.4 Measuring continuity in mental health**

It is not only in primary care settings that practitioners and researchers have pursued the measurement of continuity. The evaluation of continuity of care for people with mental health problems has progressed too but with an emphasis on service functioning rather than the use of specific indices to calculate a continuity score. In this setting, where patient compliance with treatment and monitoring can often be a barrier to continuing care, the discontinuities and gaps in care have often formed a basis for assessment. One of the earliest attempts to assess the effect of continuity in this setting used the proportion of in-patient transfers and subsequent re-admission to a different hospital as indicators. (Pugh and MacMahon, 1967) Other measures in mental health care have been based on access to on-going services such as referrals to community care facilities; the uptake of services and compliance with follow-up by patients; and contact with a case manager. (Tessler, 1987, Shern *et al.*, 1994)

The original literature search conducted for this study found one review that had examined the conceptualisation and measurement of continuity in mental health. The paper, by Johnson *et al.*, described eight separate methods by which continuity had been assessed in mental health care using relatively simple definitions of continuity. Some of the studies included in the Johnson review also reported associations between continuity of care and outcomes for patients. In view of this, Johnson *et al.* concluded that, given the relative lack of useful measures of care process, continuity of care could provide “*an important focus for the development and application of process measures.*” (Johnson *et al.*, 1997)

Two more recent reviews by Adair *et al.* and Joyce *et al.* were identified when the search originally undertaken for this review was up-dated. (Adair *et al.*, 2003, Joyce *et al.*, 2004) These offered a newer perspective and provided a useful source of reference on this topic. The Adair review concluded that the measurement of continuity remains haphazard, the association with outcomes is not proven and that little progress has been made in the development of instruments. Objective methods of measuring continuity that have “*utility across service interfaces at multiple levels of the health care delivery system*” were thus still required. Interestingly they advised that the incorporation of patients’ and carers’ perceptions should be treated with caution until more evidence could be produced for the validity of subjective measures. They also made the important point that the conceptual boundaries between continuity of care

and other aspects of service evaluation such as quality and patient satisfaction with care are not clear, and that this hinders measurement.

Joyce *et al.* had a different focus for their review, the objective of which was to clarify the construct of continuity of care. They used qualitative methods to examine the definition of continuity of care, both in the literature and from interviews with mental health patients, their families or carers. From these data they sought to identify the key attributes of the construct of continuity. The information that was derived from these two reviews was combined and used to develop the items for a self-report measure of patient-perceived continuity, the Alberta Continuity of Services Scale for Mental Health Services (ACSS-MH). The psychometric properties of this instrument were evaluated in a field trial and reported in a later paper which they co-authored. (Adair *et al.*, 2005)

## 1.8 Continuity of care and outcomes

If continuity of care is to be considered a key factor in health care it is important to understand its effect on patient outcomes. The development of measures of continuity has been driven largely by the desire to use them as a means of evaluating the effects of interventions or to compare different models of service delivery and organisation. Thus the effect of continuity of care has become a topical issue and the subject of wide debate, not only in the mental health literature, where the emphasis has been on continuity as a measure of process, but also in the primary care sector where objective measures of continuity have focused on the number and nature of contacts between patients and providers of care.

In addition to the reviews of continuity in mental health services that were discussed in the previous section, continuity in relation to outcomes in general practice has also been subject to review. Saultz discussed methods of measuring continuity in primary care in a conceptual review, (Saultz, 2003) and went on to produce two subsequent papers that examined the links between continuity and patient outcomes. In 2004 (with Albedaiwi) he explored the association between interpersonal continuity and satisfaction with care and found a trend towards a positive association between satisfaction and continuity as measured in the reported studies. (Saultz and Albedaiwi, 2004) However, the absence of standardised measures of continuity and the diverse methods used to assess satisfaction with care made direct comparisons difficult and thus limited their findings.

In 2005 (with Lochner), Saultz went on to review the effect of continuity on clinical outcomes. Continuity was measured using a variety of methods in the studies reviewed, and a positive association between continuity and better clinical outcomes was indicated in 63% of the outcomes assessed. Better resource usage was also found to be associated with continuity of care but again the authors commented that their findings were limited by the wide range of methods used to measure continuity and the emphasis on service-based, rather than patient-centred, outcomes. (Saultz and Lochner, 2005)

The relation between outcomes and continuity in primary care was considered in a systematic review by Cabana and Jee. (Cabana and Jee, 2004) They used the criteria for “*sustained*” continuity of care (provider continuity measured over a period of time); one of the conceptual categories of continuity that had been described in their preceding review of indices. (Jee and Cabana, 2006) From the 18 papers that met their inclusion criteria they found no reports of negative associations between sustained continuity and quality of care but again comparative analyses were constrained by the relatively small number of studies included and the heterogeneity of methods and outcome measures. Based on their analysis of the included papers they suggested that better continuity was associated with increased patient satisfaction, decreased hospitalisation, fewer visits to the emergency department and better uptake of preventative medical services. Only two studies were reviewed that had examined the costs of care, and these had shown conflicting results. Notwithstanding that Jee and Cabana’s review was carefully done, it must be acknowledged that there are limitations in their interpretation of the findings. Decreased hospitalisation and less emergency room attendances for example could have been associated with higher provider continuity measured over a period of time if patients were being treated by their GP or community physician instead of accessing secondary care services. Similarly those taking up preventative services might well be attending more frequently, while dissatisfied patients would be less likely to go back.

In general the reports on mental health services have been less positive about the association between continuity of care and outcomes. Adair *et al.* (2003) found only 5 papers among the 305 included in their review that had investigated the effect of continuity on outcomes. In common with reviews in other health care settings, they were unable to draw any conclusions from this small sample of papers due to the inconsistency with which both continuity and outcomes were measured. Their findings served mainly to highlight the fact that standardised methods of measuring continuity

are required in order to facilitate more research into its effect on the outcomes of patients' care.

## 1.9 Summary: Evaluating continuity

The literature review reported here was undertaken to achieve the following objectives:

- to review the conceptual framework for the measurement of continuity of care (although not to undertake a re-conceptualisation)
- to identify an existing measure or measures that would be suitable for application to patients after stroke.

Until recently, the measurement of continuity has consistently been operationalised in a pragmatic way, using simple models of care driven by the data that was available. Indicators of continuity have thus been mainly opportunistic: for example counting episodes of care such as attendances in clinics or the number of contacts with specified carers have often stood as proxy measures of continuity. The standardised measures available at the outset of this work therefore were almost exclusively provider-centric measures that had been developed and used in primary care or mental health, and were not readily applicable in complex conditions like stroke, where care may be provided at different stages of care by specialist providers with different types of expertise.

### 1.9.1 Formulating an operational definition of continuity

The major difficulty in understanding the effect of continuity of care on outcomes is that “*continuity*” is difficult to define. Firstly, there is a problem with language: the dictionary definitions of continuity, which can be considered relevant to health care, seem to suggest that continuity is a description of a process:

**noun** (pl. **continuities**) 1 the unbroken and consistent existence or operation of something;

(Collins English Dictionary, 2001)

**noun** (pl –ties) 1 logical sequence, cohesion, or connection. 2 a continuous or connected whole.

(Oxford English Dictionary Online, 2007)

Secondly, there is the perspective: prevailing concepts and theories of continuity present a predominantly professionally orientated view which renders it difficult to differentiate what continuity is (the “seamless” process experienced by the user), from how it is achieved (the structures of the “joined-up” services that deliver it), and whether or not it is desirable (the outcome for users). Where patients’ perspectives have been taken into account there seems to be confusion with overlapping concepts of satisfaction with care and subjective ratings of quality of care.

Thirdly there is the inconsistency with which the terminology is used throughout the health care system and the way it is applied to different aspects of care.

Finally there are the limitations of the methods of measurement, many of which focus on a narrow spectrum of available information and thus restrict the utility of measures because those that are specific to the service in which they have been developed are less easily generalised in other settings.

Wider reading suggests that care processes have certain characteristics. These were described by Donabedian as structure, process and outcome in his seminal model of care. Building on Codman’s theories, (Codman, 1916) Donabedian offered a framework for quality health care assurance and measurement. (Donabedian, 1966) Notwithstanding these earlier characterisations of care, no definition or theory of continuity emerged from the literature that equated to a description of the mechanisms that deliver care (the professional perspective) or the ways in which continuity of care is achieved (the patient perspective).

As a starting point for this work, therefore, continuity has been considered principally as an attribute of the care process and a programme of work was designed that endeavoured to investigate the structures that are set up to deliver continuity of care processes from the patients’ and the providers’ perspectives. In formulating a strategy for measuring continuity of care, the definition to which this evaluation might be considered to be most closely aligned is that of Shortell:

*“...the extent to which services are received as part of a coordinated and uninterrupted succession of events consistent with the medical care needs of patients”*

*(Shortell, 1976)*



Given that the “appropriateness” of care referred to in this definition is considered to be a separate and distinct concept, this study will focus on an evaluation of the three key elements of continuity as proposed by the CHSRF model of continuity of care (managerial, informational and relational) against the structures that are set up to deliver continuing care processes in stroke, and to explore the ways in which these are perceived by patients.

### **1.9.2 Understanding the patient's perspective**

In the main the conceptualisation and measurement of continuity of care has been pursued from a service-orientated, clinician-centred perspective. Provider continuity has been a persistent theme in the assessment of continuity, and many of the early objective measures were based on this idea of continuity; something which may have misled researchers in the past, privileging as it does one particular aspect of care. Although a few early researchers sought to include the views of patients this too has often been accomplished by evaluating their expectations of, or satisfaction with, “*seeing the same (or personal) doctor*”, an approach which takes a lead from the service-orientated quantitative measures. In certain care settings, such as primary care, the relevance of provider continuity can be understood but a focus on this aspect of continuity alone limits the versatility of measures. It fails to take account not only of the various types of care that patients, particularly those with chronic conditions, may need to access but also the changing face of health care delivery.

While professional definitions of continuity can be found that offer a simple, linear view of continuity grounded in a medical perception of care, none of these easily translate to the diverse experiences that characterise longer term care for people with stroke. The move towards operationalising the multi-dimensional definitions of continuity and evaluating them from the patient's perspective has been a relatively recent development. Only three studies were revealed by the original literature search that had attempted to make a quantitative assessment of continuity of care from the patient's perspective. None of these had been conducted exclusively with the chronically ill (although more recent measures for specific patient groups now exist).

Furthermore it is interesting to note that while some quantitative indices of continuity have been used as predictors of outcomes of care in a number of published papers, the majority of the outcomes considered have been limited to clinical or service indicators; few have attempted to examine the effect of continuity of care on patient-

centred outcomes. Only the two studies that had used patient-centred measures had incorporated patients' subjective ratings of their health (Bull *et al.*, 2000) or their satisfaction with health care (Chao, 1988). As a result, published reviews that have attempted to synthesise the findings relating continuity of care to patient-centred outcomes have been inconclusive due to the heterogeneity of the small number of studies from which evidence could be drawn. It is only in recent years that the importance of understanding the service users' view of continuity has come to the fore as a research priority. As Fulop and Allen wrote in their report of the listening exercise that laid the foundations for the Freeman scoping study for the NCCSDO:

*“Continuity matters to those who use the health services”*  
(Fulop and Allen, 2000)

In an editorial for the Journal of Health Services Research and Policy, Sheppard and Richards described continuity as “*a chameleon concept*” and put forward a case for a better understanding of the patient's perspective, calling for a shift in focus away from the organisational and administrative systems of care. (Sheppard and Richards, 2002) Since little is known about what continuity of care means to stroke patients in particular, there seemed to be a persuasive argument for an empirical approach to the problem. It was therefore decided to begin this work by undertaking a qualitative exploration of continuity with stroke survivors, and the lay and professional people involved in their care. This study is reported in Chapter 2 and uses an investigative and analytical thematic framework based on the Freeman multi-axial definition and the CHSRF model of continuity. The empirical study was designed to establish firstly whether the lay concept of continuity could be framed in the same way that the existing reviews implied, and secondly to derive a patient-centred definition of continuity that could be used to design a method of measurement which incorporated the patient's perspective.

### **1.9.3 Existing measures of patient-perceived continuity**

A secondary aim of this review was to identify an existing measure of continuity of care that could be tested in a cohort of stroke patients. Quantitative indices that incorporated the subjective assessments of service users into measures of quality of care were found but only one: the Chao Perception of Continuity Questionnaire (Chao PC) provided the scope to evaluate managerial, informational and relational continuity; the elements of continuity taken as a paradigm from the CHSRF model. (Chao, 1988) The Breslau measure was not only too brief and specific to paediatric care but was, in

any case, subsumed in the Chao questionnaire. (Breslau, 1982) The CCI measure devised by Margaret Bull and colleagues was of interest but focused almost entirely on information transfer, and the patient's satisfaction with that process. (Bull *et al.*, 2000) The Chao measure also offered scope for further investigation of its factor structure as this was not examined in the original report of the scale.

The preceding review was up-dated throughout the course of the present study. As a result it contains references to later works, which, although they may have informed discussion of the findings reported in later sections of the thesis, were not available when the work was started in 2002. For example, since the original search was instigated new instruments for measuring continuity have begun to emerge, including instruments for mental health, (Adair *et al.*, 2005, Burns, 2007); for diabetes, (Dolovich *et al.*, 2004, Gulliford *et al.*, 2006); for chronic heart disease (Kowalyk *et al.*, 2004) and for cancer. (King *et al.*, 2006) All are designed as self-report questionnaires that seek to measure the patient's view of continuity but were not available for testing while the active phase of cohort study work was in progress. Consequently the measure of continuity of care selected for evaluation of an existing instrument had to be drawn from the very small selection of patient-perceived measures of continuity of care that could be accessed at the time.

### **1.10 Strengths and limitations of the review**

Extensive reviews of the conceptualisation of continuity of care, and its measurement, had been completed shortly before the work for this thesis was undertaken (Freeman *et al.* 2000, Reid *et al.* 2001). Repeating the work already covered would have had little point as it would not have added much to the existing evidence. The basis of the review undertaken in Study 1 therefore was not a systematic review of the conceptualisation of continuity but a re-examination of the literature in the context of chronic illness, something that had not previously been done. Current theories of continuity of care were developed primarily in family medicine and mental health care settings; this review considered the various concepts of continuity of care identified in the Freeman and Reid reviews in the context of stroke care, and sought to identify methods of measuring continuity that could be used or adapted to a stroke setting.

Over the years the conceptualisation of continuity has dichotomised into definitions based either on the coordination of care processes or the continuity of care provider. The Freeman and Reid reviews attempted to aggregate the diverse concepts of

continuity into a multi-axial model of continuity but the components of continuity that made up the model were not discrete, and some overlap was evident between them. A limitation of both reviews was that too little is known about the interactions between the elements of the multi-dimensional definitions of continuity to comment on the extent to which the models derived were robust. Subsequent work has shown that the nature and importance of continuity changes in different health care settings, and this has implications for its definition and measurement. This review discussed how the existing theories and models could be applied in stroke and found that they did not translate easily in a chronic care setting. Longitudinal continuity, for example, is defined as care from as few health professionals as possible but in stroke care this may not be beneficial in the acute phase when access to a range of highly skilled professionals is required to deliver advanced care procedures like scanning and thrombolysis. Moreover the focus on continuity of care provider has resulted in an emphasis on relational continuity that does not correspond to care delivered by multi-disciplinary teams, nor indeed into the provision of the type of longer term care that may be required after stroke. Team working is more important in this context than care from an individual in order to provide and maintain the services that people recovering from an acute stroke (or other acute exacerbation of a chronic illness) might require. This has implications for measurement because standard index methods of measuring continuity, based on the number of care providers or the frequency of visits to them, are difficult to apply.

Communication between all the stakeholders involved in patient care, and the continuity of information transferred between them, is one of the components of continuity that seems both important and applicable in a range of situations. Some form of communication or information transfer is often the link between care settings that facilitates transitions through the care process. In practice, this can be interpreted functionally through the role of a care coordinator, a named nurse or a key worker. It is also good communication that underpins a consistent approach to the management of a patient by ensuring that all the care providers involved are aware of the management plan and the patient's preferences for care. Continuity of information transfer can therefore be seen as having a role in several components of the current definition of continuity and thus offers a potential method of measuring the continuity of formally recorded care. It is less useful as the basis of a patient-centred measure however because the patient is not party to all aspects of the communication and information transfer process that may occur in the course of their care.

It must be acknowledged that the use of stroke related terms in this review would have been a serious limitation without the benefit of the pre-existing work on the conceptualisation and measurement of continuity. Few papers were identified that focused on the topic of continuity when searches were limited to papers in a stroke care setting; an indication of the paucity of evidence on continuity of care in stroke that was available at the time the searches were conducted. The searches were up-dated throughout the course of the present study and new papers found which, although they may have informed the discussion reported in later sections of the thesis, were not available when the work was started in 2002. For example, since the original search was instigated new instruments for measuring continuity have begun to emerge, including instruments for mental health, (Adair *et al.*, 2005, Burns, 2007); for diabetes, (Dolovich *et al.*, 2004, Gulliford *et al.*, 2006); for chronic heart disease (Kowalyk *et al.*, 2004) and for cancer. (King *et al.*, 2006) All are designed as self-report questionnaires that seek to measure the patient's view of continuity but were not available for modification and testing in stroke care while the active phase of cohort study work was in progress. Consequently the measure of continuity of care selected for evaluation of an existing instrument had to be drawn from the very small selection of patient-perceived measures of continuity of care that could be accessed at the time.

The qualitative, essentially descriptive, method that was applied to analyse the findings of this review might be considered a further limitation but this approach was indicated due to the nature of the material that was generated. Meta-analytical techniques were not possible because the included papers were heterogeneous. At the time it was conducted, no prescribed method of qualitative synthesis had been established but the purpose of the review was clear at the outset and a robust scrutiny of the papers was supported by the involvement of two independent researchers in the selection and data extraction process. The methods used for searching and selecting of papers were systematically applied, and the benefits of working as part of a team, which included an experienced medical librarian, undoubtedly enhanced the quality and scope of the review.

## CHAPTER 2 The Patient's Experience

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### 2.1 Study 2a: A qualitative study of the experiences of stroke survivors

#### 2.1.1 Background

Stroke rehabilitation and recovery are complex processes and evidence suggests that patients' views of the rehabilitation process and its various stages may differ from those of health care professionals involved in stroke care, particularly in patients' expectations of functional recovery. (Doolittle, 1992, Folden, 1994, Dowswell *et al.*, 2000 ) This is not a unique phenomenon as disparity has also been identified in other lay and professionals' assessments; for example in ratings of quality of life in cancer. (Slevin *et al.*, 1988) In order to strengthen the overall design this study used a mixed methods approach and derived evidence of continuity of care from a number of sources applying different techniques:

- Qualitatively, from the patient's account of their care;
- Quantitatively, from the formal clinical records kept by the care providers;

This chapter reports the two studies that were undertaken in this first strand of research work.

#### 2.1.2 Study design

Little is known about how patients understand and experience continuity in the processes of stroke care, nor in a wider context, how health service users understand and experience continuity of process in other healthcare settings. Moreover, as Hafsteinsdottir and Grypdonck highlighted in their 1997 review, relatively few qualitative studies have described patients' experiences of physical, psychological and social changes after stroke. (Hafsteinsdottir and Grypdonck, 1997) As many of the current methods of measuring continuity of care have been derived from professional theories of continuity that have been mapped onto definitions without reference to the patient, a qualitative exploration of perceptions of care with stroke survivors offered a good starting point. In this way the research could be firmly grounded in the patients' understanding of continuity of care before embarking on any attempt to measure it.

This phase of the work aimed to use a patient-centred approach to explore, in an empirical qualitative study, how people who had suffered a stroke experienced their care, and whether they would recognise and describe elements of continuity in its processes. Individual interviews were chosen as the primary method of data collection because they afforded the confidentiality for frank and open discussion. They also enabled severely disabled and housebound patients to participate because the interview could be conducted at home. Focus groups and interviews with stroke care professionals were used to collect background material and supplementary information for confirmation and verification of some of the findings but were not a primary source of data.

## **2.2 Methods**

### **2.2.1 Participants**

The patients who participated in the first qualitative phase of the study were recruited from the Leeds Stroke Database. Permission was obtained from the local research ethics committee for a sample of 100 patients who had been hospitalised with a diagnosis of new or recurrent acute stroke between twelve and eighteen months earlier to be selected at random from the database. Patients were contacted by the database manager, by letter, to obtain consent for their names to be released to the researcher (KH). Initial consent was sought from them to be approached directly in order to explain the project before asking for second stage consent to participate in the qualitative study of patient experience of stroke. Those that replied and agreed [N = 28] were contacted by KH to arrange an interview.

The initial sample was later supplemented by a purposive sample [N = 14] from the Bradford area selected to be representative in age and gender of the wider stroke population. The Bradford patients were drawn from a cohort of stroke survivors who had previously participated in a local study and had agreed to be contacted in connection with future projects. Each participant was given a written information sheet, and the nature and purpose of the study was explained to them in detail before written consent was obtained and the interview commenced. Recruitment and interviewing was conducted by KH. The SOS administrative support team provided assistance with correspondence and appointments. The study received full approval from the Local Research Ethics Committees in Leeds and Bradford.

The initial interviews [n = 5] with patients were used to pilot the topic guide and refine the mode of questioning. These first interviews were therefore excluded from the analysis. Eighteen patients (9 from the Leeds sample and 9 from the Bradford sample) either changed their minds when the study was explained in more detail, or could not be contacted to arrange an interview. Thus from 114 potential participants only 24 patient interviews were finally obtained for analysis. Interviews were not conducted exclusively with the patient participants as many patients recognised that they had poor recall of events during the early stages of their stroke. It was not unusual for married patients to request that spouses remain and contribute to the interview. This was also true of patients who lived alone some of whom asked for close relatives or friends to be present during the interview. In some circumstances patients would ask them for supplementary information or verification of their accounts. Patient #17 below, talked about initial admission, and illustrates how stroke patients often remember little of the first week in hospital.

*“.....I was in casualty and then I err..... and I can't remember a right lot. Because I mean I don't know but I was so surprised when they told me that I'd had a stroke.....”*

Patient #17

Two interviews were conducted specifically with carers. In one case, a patient with total aphasia was unable to respond so the interview was conducted with the spouse (the main carer) in the presence of the patient. In the other case, the interview was conducted with the spouse of a younger stroke patient (at the specific request of the patient) because she felt it would be too upsetting to recount her experiences personally.

In addition to the individual interviews, four focus groups were also convened with patients and carers. Three of the groups comprised volunteers from a Stroke Association support group, some of whom had major post-stroke disability. These focus groups took place at the regular meetings of the support group in breakaway sessions. The fourth focus group comprised patients drawn from the longitudinal SOS2 cohort study, which was studying the effect of depressive symptoms on outcomes after stroke. This focus group was conducted in a day room on a stroke rehabilitation ward at a local Hospital.

Stroke care and other health care professionals were also consulted in this early exploratory phase of the study. This enabled an appreciation of the organisation of



local stroke services to be developed, which in turn aided the understanding and interpretation of the patients' accounts of their care. These interviews were not audio-taped as it was not intended to use this data in a formal analysis but contemporaneous notes were taken for reference. The interviews took place during the same time frame as the qualitative study with patients. They were conducted with the following health care practitioners:

- 3 Hospital Consultants
- 3 General Practitioners
- 4 Acute and Rehabilitation Stroke Unit Ward Sisters
- 1 Stroke Nurse Specialist
- 6 Senior Therapists (Physio-, Occupational and Speech Therapist)
- 2 Intermediate Care Team Managers

All the individual interviews with patients and professionals were conducted by KH. The focus groups were led by KH assisted by the research and administrative support team from the SOS programme. The limitations of the sample studied and the method of selection are discussed in Chapter 6, Section 6.5.3 (page 259).

### **2.2.2 Characteristics of the patients**

Patients in the interview sample ranged in age from 48 to 95 years old with a median age of 75, which is slightly older than the UK median age for stroke (72yrs). The sample comprised 13 males (54%) and 11 females (46%). The majority of patients interviewed (15) lived at home with their spouses; 2 lived permanently in the homes of their adult children. Five patients lived alone in their own homes, one lived in sheltered accommodation, one in a nursing home.

It should be noted here that this sample only included patients who had had a hospital admission related to their stroke event and did not draw patients from the estimated 500 to 600 patients per year who are treated in this area by generic services in the community. This does not represent a serious omission firstly because a hospital admission was a criterion for recruitment to the parallel cohort study (from which the outcomes data would be drawn in the later stages of the study) and secondly because longer term survivors were recruited for this phase of the study. It could be surmised therefore that continuity of interactions with community services would be adequately represented in this post-discharge, predominantly community-dwelling sample.

The patients who comprised the sample had post-stroke functional deficits that ranged from mild to severe. Four patients had minor post-stroke or co-existent age-related cognitive impairments, and three had speech and language deficits (one, for whom a proxy interview had to be conducted with the spouse, had total aphasia as previously noted). Major cognitively impaired patients were not able to participate in the interviews and, as no proxy interviewees were forthcoming, these patients could not be represented in the qualitative study.

### **2.2.3 Study procedures**

A qualitative approach was chosen to collect information for Study 2a because this method can provide essential insight into the types of phenomena studied in health and social sciences research. While quantitative studies are outcome-orientated and examine causal relationships, qualitative methods are useful for revealing and understanding concepts. (Bryman, 1988) From the outset, the interviews with patients were intended to be open and flexible in order to develop a framework for exploring continuity from the patient's perspective in a later study. Qualitative methods were therefore ideal for this form of empirical enquiry.

A structured approach was adopted to gather information about the experiences of stroke care from patients and their carers. The interviews used open questions about care initially based around the Freeman multi-axial definition of continuity of care, and information from other relevant sources as indicated below:

- Current evidence and ideas about continuity of care
- Insight gained from conducting a parallel cohort study in stroke (SOS2)
- Insight gained by talking to local stroke care practitioners
- Personal knowledge of hospital and community care for chronic disease

Questions and prompts were related to everyday aspects of care processes that patients would recognise. The interview began by seeking a narrative of the patient's experience of care with an open question: "*Tell me what happened when you had your stroke...*" It moved on to explore relationships with health care staff and informal carers; views about communication; information transfer (between patient and

professional, and between agencies) and the co-ordination of care. The topic guide is shown in full in Appendix D, pages 279 - 280.

All the individual interviews were audio-recorded and later transcribed for analysis using QSR NVivo Version 7. (QSR International Pty Ltd, Version 7, 2006) The SOS research support team transcribed the interviews. Recordings were made of the focus group discussions but the background interference at the two venues used made transcription impracticable. As only the contemporaneous notes were available these data did not form part of the formal analysis. The interviews with stroke care professionals were not transcribed as they were conducted for background information and did not form part of the formal analysis. Thus only the transcripts of the individual patient interviews were subsequently imported into an NVivo database for the thematic analysis.

### **2.3 Analysis**

The most widely known method of qualitative analysis is Grounded Theory, an analytical technique developed by Glaser and Strauss, which adopts a totally empirical approach to interrogating qualitative data, allowing themes to emerge from its context and theory to be generated from the findings.(Glaser and Strauss, 1967) Grounded theory has subsequently been modified by Strauss in association with Juliet Corbin to permit the use of proven or valid *a priori* assumptions thus alleviating the requirement to revisit every topic from a totally grounded standpoint. (Strauss and Corbin, 1990, Strauss, 1998) Grounded theory and modified grounded theory formed the basis for the development of Framework analysis, a technique which allows a qualitative study to be designed and analysed in the context of a known (or hypothetical) conceptual framework. (Bryman, 1988, Ritchie and Spencer, 1994)

The use of grounded theory was considered as an analytical method for this study but an abundance of conceptual categories had already been established by previous researchers. It was therefore rejected in favour of a "Framework" approach which, with the assumption of prior knowledge of the phenomenon being studied, can be used where existing theories lack clarity (as seems to be the case in continuity of care). The analysis was conducted by KH using NVivo Version 7 as the analytical tool.

### 2.3.1 *Framework analysis*

Framework analysis was developed in an independent social policy research institute but has proved to be a method applicable across a wide range of studies. It follows a systematic process of interrogation and organisation of the material collected using a set of *a priori* issues. In this study the analysis of the individual interview transcripts and a review of the notes taken during the focus groups facilitated the process of immersion in, and familiarisation with, the data. Familiarity with the data had also developed naturally as the study progressed because the material was collected and analysed by a single researcher (KH). Given the iterative nature of qualitative work the data had also been subject to continuous review throughout the whole process of data collection.

The objectives of the study were predominantly contextual and the enquiry used the phases and transitions in care as markers in the care trajectory in order to explore the nature of stroke patients' experiences of care and to identify their attitudes to, and perceptions of, continuity in their care. The thematic framework for the investigation was derived from the dimensions and elements of continuity identified from both the NCCSDO and CHSRF reports. (Freeman, 2000, Reid, 2002) The data were later condensed into an analytic framework based on the three element model of the CHSRF because it emerged as a logical format in which to interpret the results as the analysis progressed. The transcripts were indexed in QSR NVivo 7 software using the thematic framework to define the tree nodes.<sup>2</sup> These were supplemented with additional nodes which represented relevant emergent themes and categories as they arose during the process of analysis. The thematic index is shown on the following page in Figure 2.a.

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<sup>2</sup> *Node is the term used to describe the headings under which information is collated in the NVivo software package.*

**Figure 2.a Thematic index for the qualitative analysis**

<b>1. Patterns of care</b>
1.1 <i>Experience of a co-ordinated and smooth progression of care</i>
1.2 <i>Experience of flexibility of care and adjustment to the needs of the individual</i>
1.3 <i>Availability and accessibility of services</i>
1.4 <i>Changes in care over time</i>
<b>2. Patterns of communication</b>
2.1 <i>Experience of information provision</i>
2.2 <i>Knowledge of information transfer</i>
<b>3. Patterns of relationships</b>
3.1 <i>Understanding of the roles of health care professionals</i>
3.2 <i>Nature of relationships</i>
3.3 <i>Changing relationships over time</i>

## 2.4 Results

The pilot interviews [n = 5] which were conducted at the beginning of the study assisted the process of finding the best phrasing for questions and prompts to explore patients' views about continuity of care processes. A glossary of related terms was used during this stage. Although some patients were comfortable with hearing and using the word "continuity", the form of words which seemed to elicit the best responses were "joined-up" and "co-ordinated". Notwithstanding the fact that the nature and purpose of the study had been fully explained, the most striking and consistent finding in all the individual interviews was that interviewees never referred to continuity spontaneously when discussing their care. It was only by specifically prompting patients that any discourse about continuity of care processes could be achieved.

### 2.4.1 Narratives of care

One important finding was that almost all patients could give a very good account of their care regardless of their physical condition or frailty. They could also relate how they felt about it, although it was apparent both during interviews and from later correlations of the narratives with clinical records that, while the accounts were very

accurate in detailing events during episodes of care, they were often chronologically misplaced. It must also be accepted that due to the nature of stroke and, in some cases, to age related cognitive factors, several patients did have some difficulties recounting details of the early part of their hospital stay, in particular the admission period. However, this can be regarded as providing more insight into the unique nature of stroke care rather than detracting from the quality or value of the data that was collected.

The qualitative interviews therefore provided useful information about the differences between patients' views of their care and the service-orientated perspective obtained, for example, through formal records of care. They also highlighted the challenges that these differences could present in the measurement of continuity in care processes. Overall it became apparent that lay interpretations of continuity did not easily fit into the existing professional models of continuity of care. The professional perspective of continuity is informed by a special knowledge of the stages of care, which is based on a personally assumed, professional concept of optimal care and an ideal pathway for stroke sufferers. By contrast the patient perspective derives from personal experiences, attitudes and expectations about care that can influence their views and the way they express them. Many terms derived from the Freeman model of Continuity (See Figure 1.a, page 37, (Freeman, 2000)) were used to explore the responses that patients gave during their interviews, and to introduce themes like flexibility and adaptability of services. However, for clarity the findings of the qualitative were analysed and reported under the headings of the three types of continuity proposed by the CHSRF: Managerial; Informational and Relational Continuity. (Reid, 2002) See Figure 1.b, page 38. These three elements subsume all the dimensions of continuity in the Freeman multi-axial definition, and provided a logical framework in which to interpret the findings in relation to the process of care.

#### **2.4.2 Continuity in the management and organisation of care**

Managerial continuity can be regarded from a professional perspective as especially important in chronic or complex diseases like stroke because care for these conditions may involve a combination of several specialist and non-specialist providers working together to deliver a multi-disciplinary package of care. Ideally, therefore, it would involve a coordinated approach to care using shared protocols and cooperative planning to facilitate the delivery of care in a complementary and timely manner. However an appreciation of a formal, "managed" view of health care was not readily

elicited from the lay respondents in this study, and very few of the stroke patients interviewed could talk objectively about aspects of their care in these terms unless, like the retired GP who participated in the study, they had some special knowledge or insight. There was no overall concept of care as managed or organised in a systematic way other than a rather vague overarching idea of the consultant “*being in charge*”.

*“Well I got the impression....I only mentioned this to someone you know I said ‘...don’t forget this bloke he’s got the Infirmary, St James’s, he’s got Chapel Allerton, there isn’t much going on that he doesn’t know’, now we’re lucky if we’re under him because he’s got the lot.”*

Patient #3

*“He (Consultant) was the key person as far as I was concerned.”*

Patient #20

Different opinions were also elicited as respondents interpreted this line of questioning in a variety of ways. In contrast to the view of the consultant as the principal agent of care came the response of a younger, male patient who felt he had taken primary responsibility for the management of his own care.

*“I think because I’m such a determined person and used to working for myself I made it happen – you know I forced things to happen.”*

Patient #132

Yet another interpretation of the managing agent of care was in the context of the person who had initiated admission to hospital. One patient described his son as the person he felt had “organised” his care but his extract also illustrates how difficult it sometimes was for people to recall events in the early stages of their stroke event:

*“I just don’t remember, and apparently my son organised everything, he realised something was wrong. It had happened before, but I’d never paid much attention because it passed, you know you would suddenly read a paper and you couldn’t put together what you was reading and you tried to pronounce something and you knew what you wanted to say but it wouldn’t come out right. I mean that had happened over a period of once every six months perhaps, not every six months but occasionally and I had mentioned it to my own doctor, you know. I think he took some samples or something and I was on the stuff – rat poison – what do you call it...? (Interviewer: Warfarin?)....I carried on and I was all right and then apparently this, I don’t know whether it was a weekend but my son came, he realised something was wrong and he came back again later on and got the doctor and as I say I was three days in Jimmy’s and I didn’t know anything about it. In fact I think I was in three wards and I don’t remember the first two wards, they found me wandering about one night in the middle of the night, I think I fell or something. I must’ve had speech therapy because I had been out of St James’s for about five or six weeks when the*

*phone rang and this was Miss somebody or doctor somebody, Speech Therapist you know to make the arrangement as we'd said and I said well I don't even remember seeing you. Of course I kicked that into touch because there was no point and so that's all I can tell you about what happened."*

Patient #11

It was common too for episodes of care to be described by patients as a series of separate and unrelated events. This phenomenon was particularly marked in patients with multiple morbidities, who would talk often about their care in relation to the condition for which they had been treated. On the whole respondents seemed very comfortable with this disjointed view of care, sometimes even qualifying their responses for the benefit of the interviewer to distinguish between stroke and other care. Only one carer of a stroke patient with end-stage renal failure expressed any discomfort (not shared by the patient) with seeing care delivery in this way:

*Carer: "You know there are that many things wrong with him and when he does get anything - it's serious. I think they just focus on that to get him right.*

*Because there's so, he's so much wrong with him.../ I do I think that's what it is because he is such a wreck, he's so, he's you know - / he really is.*

*Patient: As long as you keep going that's the main thing.*

*Carer: ...but I know they do keep changing his tablets and I mean I don't know whether I'm coming or going."*

Patient and Carer #133

In the same way that patients frequently related their care in terms of separate episodes or related to specific conditions, there was also a marked tendency for patients and carers to regard the service providers as distinct and separate, and to refer to them in ways that reinforced this view. References to *"the Hospital"*, *"the Social"*; *"the Housing"*; *"the District Nurses"* were made occasionally but more often the differentiation was more obscure and in general patients did not name the agencies that had been involved in organising aids, adaptations or services, for example:

*"Well when I came home that was.... Oh yes they got it all organised, that, the wheelchair. Somebody had been into the flat and made sure that the doorways were all nice and smooth so that I could...I wouldn't fall – trip over them."*

Patient #20

Although recognising that different agencies had been responsible for organising care, neither patients (nor carers) readily made links between them. They did not express views about how these agencies interacted to deliver care or about how they coordinated their activities and, when specifically asked what they thought about how this happened, their responses were often ambivalent.



*“.....Well yes – and, but as I say whether they’re working together basically as a team I don’t know, you know and to honest I don’t, I don’t really care because what they’re doing for me individually is working, or it has been you know and umm – and like my wife says we don’t, we don’t – we’re not the type of people who say ‘oh I’ve got a cold I must go to the doctors’ you know.....my doctor never knew me.*

Patient #121

They were vague too about the origins of the services they received after leaving hospital and it was clear that patients did not normally make these links when thinking about their care:

*“Interviewer: Who organised for them (Home Care Team) to come? Do you know?*

*Patient: Unless it were, would it be your Mum (to Granddaughter)?*

*Granddaughter: Was it arranged in hospital before you came home? Do you think they might have.....?*

*Patient: Honestly I don’t know.*

*Granddaughter: I think it might’ve been discussed at the beginning you know before you came home.”*

Patient and Carer #183

Thus there was a tenuous theme running through the accounts that suggested an idea of information being passed on in some way between agencies to deliver on-going care but this was not explicitly expressed and often hard to elicit.

### **2.4.3 Continuity in relationships**

Conversations with patients and carers, and later reviews of the data revealed that, inter-personal relationships with health care staff were clearly important to them. Nevertheless, they had difficulty identifying the individuals involved in their care, and did not easily recognise the different roles of hospital or community staff. From the patients’ perspective, most professionals in hospital were divided into two broad categories: nurses and doctors, with the consultant generally being the only figure to stand out or be most frequently named by patients. In community care, with the exception of the GP, visiting health care staff were often referred to by gender: “*the girl(s)*” or “*the lad that comes*”. Only District and Practice Nurses were more frequently identified, but rarely by name, and with the terms used interchangeably. These findings are perhaps not surprising given the nature of stroke, and could be interpreted as imperfect recall due to the type of condition or the older age of this group of patients. It is interesting however that a review of maternity care services found a similar

mismatch between pregnant women's accounts of the midwives and other practitioners involved in their care compared with the clinical records. (Green *et al.*, 2000) In this patient group cognitive impairment or deficits would seem an unlikely explanation for failure to recall their health care staff contacts accurately.

The general hustle and bustle of hospital was remarked on by many patients as a barrier to developing relationships with staff. This was perceived as a problem not only for the most elderly patients in the sample but also for the younger patients too, as this 65yr old female patient explained when asked about the different people who had looked after her in hospital.

*"I don't know there was so many backwards and forwards that I think the only one that I really think and talked to me was (Doctor's name) then and I think that was when they decided that they were going to take me to Chapel Allerton then. But it's a bit hard trying to remember (of course) you know and the thing is as well there was so many people coming and going in the end you didn't know who was what there. I mean it was nice that they come and say this is doctor so and so. But it's too quick."*

Patient #33

A number of examples of positive bonds with staff both in hospital and after discharge were also described and, in the patients' view, these had often aided their recovery or helped them come to terms with life after stroke.

*"The lad that was training me, that was sort of in-charge of that gymnasium there he was very good – he would give me a job to do you see and he'd say 'now you've got that'.. 'yes'...'right carry on' and then after a bit he'd say 'well do it again' and 'you are walking down that straight line aren't you?'...'well yes I think I am'...'just do it again' and I would do it again. We got on very well."*

Patient #3

Negative examples of inter-personal relationships arose too, however, and a few incidences were related that had involved clashes of personality or evoked impressions that staff were "too busy" or "didn't listen".

*"– wait a minute now – (Trying to remember name) ....getting there... / she were with me all the time, well she were with me all time but another one – I won't mention her name it wouldn't do and she started doing a lot of mouthing and I couldn't do with mouthing because I always say when she said 'you can, you can, you can' and I used to turn round and I used to say 'I \*\*\*\*\* well can't, if I could I would so \*\*\*\* off' and she went, I never saw her again."*

Patient #133

There were several examples of supportive relationships with fellow patients in the ward but these were very rarely maintained after discharge with only one or two

accounts of ongoing contact by telephone or visits. Once home, families and friends were the most prominent persons to feature in patients' accounts of ongoing emotional and instrumental support. Among statutory services the Intermediate Care Teams were highly praised by all the patients who received care from them in the early days after discharge. They were often perceived as having more time than the staff in hospital and were generally regarded as good sources of information. This view could be accounted for by the likelihood that community staff were reinforcing the information that the patient had already been given in hospital but had been less able to understand or assimilate at that time due to the nature of their condition. However, as with hospital staff, the names of community care staff were not easily remembered and roles were often confused.

*“Yes especially the intermediate nurses taking over from – looking after me when I got out of hospital. They were a Godsend when I knew they were coming, you know. Because they were so good, if they could help at all, they would do and they were able to talk. They would tell me things about strokes you know.”*

Patient #15

Talking to patients about the people who had cared for them after their stroke elicited many examples of how they had related to them on an inter-personal level. These were expressed in a wide variety of ways, such that it is difficult to typify their responses. However, it was very obvious that the patients' accounts challenged the professionally held views of how patients perceive relational continuity. No examples were found, even when prompts about the issue were given, of patients referring to or expecting that they would be cared for by a provider that knew them, or would continue to be involved with their care longer term. Furthermore, while patients undoubtedly valued the therapeutic relationships they developed with health care staff in all care settings, no anticipation was expressed of any form of continuity in relationships. On the whole patients seemed to have no expectation of the “Dr Findlay” model of care that relational continuity seems to espouse. Many of the patients interviewed were registered with group practices and were used to seeing different GPs, particularly those who had been in good health before their stroke and were not regular attendees at the GP's surgery. A young stroke victim (a full-time teacher before her stroke) described her relationship with her GP providers as follows:

*“Yes, well in fact my doctor, there are four doctors at the Clinic and two had left and so the doctor I was registered with had left and, I think there was one doctor there that I knew from, you know, before that time so I'm afraid that's just a picture of what it is like at the moment, you know, with GPs and, you know,*

*they're very short aren't they. There is now a doctor that I could – since registered with but the system that they run is, if you phone up for an appointment you'll have what they can see there is with any of the ..what they've got and I think they've got two permanent doctors and someone else on supply, it's not called supply is it? that's teaching terms. (A locum?) A locum that's right. So that's the system they run but when I – I phoned up and said, you know, 'I've not had any contact with the clinic, shall I come down for a blood pressure test' and I went down to see the clinic nurse and she put me in touch with Dr (Name) and I've forgotten it. Anyway the doctor I saw I registered with because she'd got the information and she seemed, you know..., to have a nice manner, you know, and after a couple of meetings she seemed to understand, you know, what my needs – difficulties might be. So otherwise I've not had any contact with them."*

Patient #2

The provision of intimate personal care was the only aspect of care in which patients expressed a preference for having the same people involved. Here it was sometimes regarded as a means of maintaining dignity. One elderly widow explained how she had found it reassuring to have the same people from the Home Care Team involved who had come to look after her husband following his stroke because she didn't have to "get used to different people". Just a few examples arose where older patients made indirect comparisons to care in the past as being more likely to have a relational component. An example of this was the view expressed by a carer who felt that her husband's stroke care had been disjointed. She compared his present care with that received for another condition in the past:

*"well you feel, you don't, you don't see the main consultant – I mean when he had his kidney problem, that, that consultant he stayed with us. but now – you see sort of – well it says on your appointment 'see Mr so and so or his team, a member of his team' and you never see, they're all young umm – and obviously in the time you have you can't go through the – the history. I mean, obviously, his hospital notes are like this you know."*

Carer for Patient #139

Overall there was an implicit perception of care being "passed on" to different health care professionals both in hospital and in the community. In the case above this was perceived as being achieved through record keeping in the hospital notes but in general the way in which this occurred was not discussed, nor was it often criticised. Spontaneous references were never made to team working and, even when expressly asked about it, patients did not readily identify it as previously described in Section 2.4.2 (pages 70 - 73).

In general, therefore, the same nebulous perception of relational continuity was held by patients as had been apparent in discussions about management, organisation and planning of care. The theme of care as episodic and separate was also present to some extent in the patients' views of formal carers. They too were regarded as separate, providing care for different things, at different times. Clearly, given the past emphasis on provider continuity, these findings have implications for assessing continuity of care from a stroke patient's perspective, and this is a theme which will be returned to in later chapters.

#### **2.4.4 Continuity in information**

Information was the theme which most patients easily recognised and could interpret in relation to their care. It had links to relationships with staff, and patients often mentioned people who were “*good at telling you things*” or “*had time to talk*” when relational aspects of care were discussed; a quality that patients obviously valued. Discussions with General Practitioners after discharge were also frequently mentioned, and by and large it was evident that patients found their GP to be a major source of information and support after their stroke. GPs were often individually described as “*a good communicator*” and many examples of how they had explained “*all about strokes*” were related. Nonetheless, when the idea of continuity in respect of information transfer was explored with patients, exactly the same pattern of responses that had been identified in regard to other aspects of care was found. There was a vague impression that providers of care “*knew about things*” but how this had been achieved, and whom or what the agent of communication had been, was obviously something that patients had not really considered.

It must be acknowledged that despite the response to this line of questioning about informational continuity, the ideas elicited were the most consistent of any that arose from the themes of continuity of care that were discussed with patients. The following extract is a fairly typical quote from a patient and carer:

*Interviewer: What about your own doctor your GP was he aware of the stroke and what had happened to you?*  
*Patient: yeah he was yeah.*  
*Interviewer: Do you know how that had come about? / (indistinct discussion between patient and carer concerning contact between GP and hospital) / Had he had a letter from the hospital? Do you know?*  
*Carer: We haven't heard anything about that....I don't know really.”*

Patient and Carer #133

There was a similar impression of other care providers in the community having been given information by the hospital but, in the same way, the initiators, and mode of transfer, were unclear:

*“I mean, like I say doctor didn’t come to see, you know they say when you come out of hospital your doctor will come and see you when they get this letter, we’ll fax them and that, but I mean, practice nurse came so ....I suppose he must have passed it on”.*

Patient #128

Numerous examples were found of both positive and negative views of the information that had been given to patients some of which arose from general discussion in the interview. There were instances of apparently conflicting information, as illustrated by the extract below about how a patient, unable to get upstairs, was managing at home without sanitary facilities on the ground floor of her house:

*“I don’t really..... The social workers came and said ‘well we’ll put your name down for this.... the council and things like that and as it happens there’s a flat I wouldn’t mind, well I wanted to go just a few weeks ago and somebody has got it obviously I haven’t heard anything. I’ve to resign me myself again to living, staying here and so I psych myself up to move and then not getting it because the housing list is difficult. In hospital she said, she said she’d seen the Council and I was second on the list for the disability and when I ring up about it they don’t have lists, it’s first come first served sort of thing so I missed that flat down there.”*

Patient #128

The perception of the information they received was thus highly subjective and no predominant view emerged from patients. Not unexpectedly, they would choose to interpret how the topic of information related to their care in diverse ways, just as had been encountered when talking to them about other aspects of continuity. As a result the sources and types of information described were very varied and the main theme to emerge from the patients’ accounts of information was dissatisfaction; sometimes with the way information had been given, but more often with the content especially where it concerned waiting times for service provision or follow-up after discharge. The two following examples illustrate the views of patients with regard to the waiting time for community therapy services:

*“Well it went from every day again to nothing. It was about 12 weeks actually, which they did tell us it would be before they got things organised and I felt it was quite strange to go from having an hour’s physiotherapy every day to nothing.”*

Patient #2

*“I just came in here and I think I wept, I just – how can they say wait six months. I mean to me, all right I know what she was sort of saying, but you need some help until that six months don’t you. I mean, with other...., when you’ve had an operation they usually explain and sort of, but, strokes it isn’t an ordinary operation if that’s the right word, it isn’t straight forward is it. I should imagine...., it affects different people different ways doesn’t it?”*

Carer for Patient #139

There also emerged related themes around the necessity for seeking out information oneself:

*“We respect the professionalism of others but will ask questions and want to know what’s going on so if somebody had been depending on information being volunteered I think they would have known a damn sight less than we...”*

Carer for Patient #2

Although all the patients interviewed wanted to know about care and service provision, their attitudes to information related to the actual stroke were varied and individual. Some perceived a lack of information about their stroke while others felt they didn’t want to know too much. Written information leaflets had been given to (or obtained by) most patients at some stage but these were criticised by some for giving too much information:

*“Because there was that one about....do you know when you’re fed up and depressed and you’re reading about...I had one about telling me all, you know side effects on tablets are enough to put you off taking them. But they’re a lot of trouble, I’ve had so many tablets and they must all have side effects.*

Patient #15

In contrast, seeking information either in written form or from the internet was described by some patients as *“therapeutic”* and *“like taking control”*.

Notwithstanding that the transfer of information between health care professionals was far less frequently described or recognised by stroke patients, it did conform, albeit obliquely, to a notion of a common thread linking care from one provider with another. Inter-professional information was not often identified explicitly as linking different health care episodes or events, a finding which seems to reinforce the patients’ perceptions of care for different conditions as separate and unconnected, but there did seem to be an underlying theme of some method of communication or the passage of information acting as a means of maintaining continuing care.

### 2.4.5 Perceptions of continuity

Where it was deemed appropriate, patients were asked to try and describe (in their own words) what continuity of care meant to them and whether or not they felt that there had been continuity in care processes for their stroke. Language and terms were used that were appropriate and relevant to the individual patient to explore these concepts, as has previously been described in the methods (Section 2.2.3 of this chapter, page 66). This line of questioning revealed that, almost without exception, patients would affirm at the outset that they understood the term “continuity of care” and its associated idioms. Nonetheless with even minimal probing it was apparent that participants struggled with the abstract concept of continuity. Their responses were generally subjective, frequently vague, contradictory or confused, and contained virtually no temporal dimension.

When patients were asked to describe what they thought continuity meant in relation to their own care, the context in which they chose to explain it varied widely. Some chose to interpret continuity in relation to the quality of specific aspects of the care they had received, some to their satisfaction with the services that had been available to them in hospital or after discharge and some to their recovery. There was no consistent pattern to the examples that patients chose to give except that care, as had become increasingly apparent throughout the interviews, was generally described in terms of its particular properties rather than in the way it had been coordinated or joined-up. In-patient care was marginally the most frequent example given by patients in response to questions about continuity in their own care, either in terms of access to a specialist service in the acute stage of care:

*“Maybe I was fortunate in having a stroke because there’s the Stroke Unit being set up for a specific purpose and it has got a specialist in there – devoting most of his time to it so that really it’s a special unit really. They’ve not got these stroke units at every hospital have they?”*

Patient #1

Or in the way that they valued the type of care they had received:

*“You know people want different things, I mean a patient will go into the hospital and you can have the most marvellous service from doctors and then... they’ll complain about the food. They don’t think to themselves well lets leave it; we’re not bothered about the food as long as someone’s looking after me, making me better... Which I mean I’d never think about...I wasn’t bothered about the food things. You want people looking after you....”*

Patient #33



There were also interpretations of continuity in relation to ongoing care or help received after leaving hospital:

*“I’ve not asked for any help really so – I mean when I’ve needed it I’ve got it, like the second lot of physiotherapy, she came – and - - and that’s all really just, I don’t have any other help I mean home care seven days a week but I don’t really bother about that.....”*

Patient #128

Two elderly widows talked about the Christian faith groups with whom they were associated in this context, and the support they had received from them in order to continue their normal activities including help with transport and holidays. They also felt emotionally supported by these groups. Organisations like the Stroke Association support groups and the Freemasons were also mentioned during interviews although not in a way which directly associated them with the continuing care process. Finally a few patients chose to interpret continuity in terms of their recovery and made reference to “getting better” or “getting back to how they were before”.

#### **2.4.6 Positive and negative views of continuity**

When patients were asked whether they thought their care had been “well joined up” or “coordinated”, seventeen patients were able to make an assessment of this aspect of their care. Eight out of the seventeen expressed positive perceptions of the coordination of their care.

*“Interviewer: Tell me how joined up do you think your care seemed overall?”*

*“I think it was nicely joined up as far as their targets were concerned, and then all these people coming to see me when I was back here.”*

Patient #20

Only one patient, who gave a very traumatic account of her admission during her interview, had a persistent theme running through her narrative of disappointment and dissatisfaction with all the care processes she had received:

*“Well there’s no continuity at all. nobody seems to know – it doesn’t seem passed on, anything – I mean like one day I had, this lady come occupational therapist and she said to me ‘I’ll be seeing you everyday and seeing if you need any aids for when you go home to help you’ But I didn’t see her again.”*

Patient #140

The remainder of the interviewees said that they didn't know or couldn't say how joined up or coordinated their care had been, or they were equivocal, relating an assortment of views about different stages of care.

*"So no problems, but if there had there been, I'm not entirely sure that there would have been – I mean there would have been anybody who would've been onto it really."*

Patient #2

The carers (n = 5) who contributed to an assessment of continuity presented a different, and sometimes contradictory, perspective. More negative views of continuity were expressed by the carers of stroke patients than by the patients themselves. However the ways in which the participants in this study, both patients and carers, qualified their ratings were extremely variable, and only two carers were purposively interviewed. It was not possible therefore to make further, formal comparisons between these groups.

## 2.5 Supplementary qualitative data

After the patient and professional interviews were completed, and while the qualitative analysis was in progress, four focus groups with stroke survivors were conducted. The composition and format of these has been described previously in the methods section of this chapter (Section 2.2, pages 63 - 67). The participants in the focus groups (n = 18: 8 male/ 10 female) ranged in age from 50 to 82 years old. Length of time since acute stroke ranged from 6 months to 12 years. The groups comprised between 4 and 6 patients, and were conducted as a means of corroborating the findings from the individual interviews. They also provided a test-bed for the theories and hypotheses that were beginning to emerge from the qualitative interviews with patients.

Unfortunately, the audio-recordings that were made during the focus group sessions proved to be of very poor quality due to the locations in which the meetings were conducted (a hospital day room and a community centre), thus no transcriptions could be made but detailed contemporaneous notes, taken by the facilitator (KH), were available.

It was interesting that the focus group discussions with the stroke support group members, although conducted using the same framework, were different from the individual interviews. The participants in these focus groups were, at times, very critical of the care they had received. Many expressed dissatisfaction and

disappointment with care, and said that they felt “*medically dumped*” after their stroke. In contrast, the patients in the focus group drawn from the SOS2 cohort study were generally more satisfied with their care, and far less critical overall. In this respect their impressions of care were closer to those of the patients in the interview group. All focus group participants were keen to compare their experiences with one another and express their opinions about the health care services they had received. This may account for the fact that, while many of the general themes were the same, a more judgemental view of stroke care services emerged from the group discussions than had been the case in the interviews with individual patients.

With regard to organisation, there was a general view that after care for stroke was too short in duration, that resources were stretched and there was too much bureaucracy. The participants resented some of the other patients on the ward whom they termed “*bed-blockers*”, and also felt strongly about delays in discharge while waiting for services to be put in place.

Interestingly they did not generally feel that there was any ageism in the care they had received but they did articulate the view that there were no links between health and social care agencies. Relational aspects of care processes were discussed mainly in the context of intimate personal care, and a preference for the same people to be involved (something which had come out of the individual interviews) was expressed. In common with the individual interviewees, these views were related to “*keeping your self-respect*” and “*maintaining what little dignity you’ve got left*”.

Informational processes were described as “*too much too early and too little, too late*”, and there was a general view that information giving had been poor although, consistent with the findings from the individual interviews, no view was formed about information transfer between health care professionals and agencies. When asked about the meaning of continuity of care, the focus groups conducted with the stroke support group members described it as “*Non-existent*” and “*Meaningless, because it can’t keep up with the extended stroke recovery process*”. The hospital-based focus group expressed a less clear view of continuity and related vague and subjective interpretations similar in nature to those elicited from the individual interviewees.

Several interpretations can be inferred from the differences in the findings of the two sets of focus group participants. One possible explanation is that the majority of support group members had had a much longer interval between their stroke and

attendance at the focus group. They were also resident in a different area and thus service configurations differed, a factor which could also have accounted for some differences in their experiences of care. The group dynamics were also different since members of the support group met regularly, and the presence of opinion leaders was obvious. By contrast the participants in the hospital focus group, recruited from the stroke study cohort, were complete strangers who had come together for the first time in the focus group setting.

## **2.6 The impact of the researcher: a reflexive account**

Qualitative research generates a large volume of information much of which is complex and can be interpreted in many different ways. While the reliability of quantitative tests can be assessed in terms of the number of observed events and the types of variables used in the calculations, qualitative analyses cannot be evaluated according to the same criteria. Unlike quantitative data analyses, qualitative analyses are subjective by nature and standardised tests that yield repeatable results cannot be applied. The nature of qualitative work means therefore it is important to consider the factors that might have influenced both the collection of the data and the subsequent analysis in order to assess its validity. Elliott *et al.* (1999) recommended guidelines applicable to both quantitative and qualitative studies in psychology. By addressing the following factors (specific to qualitative research), potential biases in the reporting of work could be explicitly reflected on:

1. Owning one's perspective
2. Situating the sample
3. Grounding in examples
4. Providing credibility checks
5. Coherence
6. Accomplishing general vs. specific research tasks
7. Resonating with readers

They acknowledged however that qualitative methods are dynamic and thus recommended that their guidelines be considered evolving rather than static.

With regard to objectivity, the researcher's own assumptions and values must be considered particularly relevant as the choice of what to include, and how to explain the findings, is the researcher's prerogative. This section of the thesis will focus on an

assessment of the validity and reliability of the interpretive judgements made by the author in the course of analysing the qualitative components of this thesis. It will reflect on how KH's background, personality and experience may have influenced the research process by applying Henwood and Pigeon's (1992) concept of reflexivity. In order to do so effectively the next section of the thesis will depart from the passive voice.

### **2.6.1 Reflections on the research process**

As a biological scientist I am aware that at times I may be highly protocol driven. I have had 17 years experience of research in three areas of medicine, 8 years of this time was spent working on various aspects of clinical trials in respiratory medicine. Considering this background I may have adhered to my topic guide too firmly and not always allow the interviewees space to expand on aspects of the care that were more abstract. In this respect I may not have explored some topics in sufficient depth. I am also aware that my reading and background study prior to the interviews had shown the confounding effects of satisfaction with care in the measurement of continuity. A principle aim of the qualitative work with patients was to find indicators of continuity that patients recognised and which could be incorporated into a patient-centred measure of continuity. With this in mind I may have biased my enquiries to avoid issues of preferences for care and chosen to privilege examples in the data that described patients' experiences of the process and how they viewed critical points in the care pathway rather than their attitudes to the outcomes of care. Inevitably issues of choice and preference did arise in the course of the interviews, particularly with patients whose care experiences had been poor. It is possible that the analysis does not sufficiently reflect these issues because of the focus on process and the search for meaningful indicators of continuity.

A large proportion of my time in respiratory medicine was spent on the wards at Killingbeck Hospital and the Leeds General Infirmary. In order to work effectively it was essential for me to develop a rapport with the nursing staff and to integrate my research activities into the ward routine. I regularly attended multi-disciplinary meetings, and used the seminars and training days provided for junior medical and nursing staff to learn about respiratory diseases and their effects on patients. Concepts of continuity of care described in the literature, whether defined in the context of coordination of process or interactions between care providers and recipients are centred on a professional view of care both in the coordination. My early career

environment and the type of training I underwent my have influenced my perspective of care and given it a professional bias.

Participants in any type of research study can be selective in the information they want to share in response to either an interviewer's line of questioning or a self-completed questionnaire. In this study I may have been perceived by some participants as having a connection to care service providers and hence being 'one of them'. While carrying out the study I did not get the impression that the interviews were substantially inhibited or restrained by this factor. I was exploring the care experiences of patients, and some participants used the interview to discuss not only their care but also their needs and how these had or had not been met. I found both positive and negative examples of care experiences, and patients did not seem to be reticent when talking to me about their care. I cannot comment on the extent to which attitudes to care services may have affected participation in the study because people are not obliged to give a reason for refusing to take part in a research. A large proportion of the original random sample selected did not respond to the initial mailing. It can be conjectured that a variety of factors could have influenced the non-responders including dissatisfaction with care and mistrust of anyone associated with health care in general.

My aim is to use a conversational style when I conduct interviews in order to create an atmosphere that helps the patient to feel more comfortable but I am aware that my work is time limited and too much inconsequential chatter can impede the ultimate aim of the research interaction. Time pressures were a major issue in the conduct of the SOS2 cohort study to ensure that both recruitment targets and follow-up schedules were maintained. Work-related appointments or demands would often intrude into the time I had allocated to interviews and this was possibly detrimental to a fully reflexive approach to the qualitative elements of the work. I kept field notes in which I mainly recorded background information about the interviewee but these did not constitute a full reflective diary or a retrospective review of the overall interview process. If I were to undertake further qualitative work I would definitely ensure that I kept a diary of this type in order to monitor my own subjectivity more effectively.

Gender did not seem to have any impact on the way participants responded to the interview. As a female interviewer it is possible that I might have talked to males and females in different ways or they may have responded differently to me but I was not aware of this. The gender of health care professionals did arise on the subject of personal care but no gender differentiation was apparent in the participants' accounts

of overall care delivery. The gender of the interviewee was more relevant in terms of the quality and content of the information that could be elicited. It was not uncommon for carers to be present during the interview, many at the specific request of the patient. This did not interfere with my enquiry because the nature of stroke means that many patients have limited or muddled recall of the first few days (or weeks) after their stroke. My primary aim was to identify elements of continuity in the accounts of care and hence I did not reject carers' perspectives but allowed their contributions to supplement the data where appropriate. Two interviews had to be conducted specifically with carers because in one case because the patient had experienced total speech loss following the stroke and in the other because the patient refused to participate herself but nominated her husband as advocate.

### **2.6.2 Reflections on the methods**

My research questions were designed to support the development of a patient-centred measure of continuity but as data were accumulated, it became increasingly apparent that meaningful indicators of continuity were not emerging from the patients' accounts of care. My interview strategy thus changed over time as I adapted to the realisation that the concept of continuity of care was difficult for patients to grasp and that a degree of abstraction was necessary to separate care from the overall illness experience. Not all the participants were capable of this and my questions may therefore have privileged some aspects of care and patients' views and experiences above others and meant that I did not probe certain areas in sufficient depth. Moreover the focus on continuity and the search for measurable aspects of care may have blinded me to other emergent themes and led me to over interpret some of the data in the context of continuity. All of these factors could potentially have biased my execution of the interviews, and my reading and interpretation of data.

As a relatively inexperienced qualitative researcher my interview technique will have influenced the interview process. A more experienced interviewer using another style might have found that different results emerged as a consequence. My approach may not have provided sufficient opportunities for participants to talk about things they would otherwise have revealed. I am also aware that the interviews changed during the data collection period in response to my increasing confidence in the conduct of them and as I began to realise that the conceptual basis of the topic was not one with which the participants could easily be engaged. The extensive topic list originally proposed was therefore considerably curtailed and the interviews were allowed to

develop from the opening account of the patient's experience of care. This approach enabled a diversity of experience to be accommodated as it became clear that many of the questions in the topic guide were neither universally relevant nor applicable.

Demographic data were provided for the sample interviewed and certain background details for case studies and other examples cited. In this way I hoped to assist the reader to judge how well the account presented might be representative of more general attitudes and experiences of stroke care. In the qualitative analysis I have used direct quotes throughout the results section to allow the voices of the participants to support my interpretation of the data and to show how the findings were derived. Different themes would undoubtedly have emerged if a grounded theory approach had been applied but I chose to structure my enquiry and interpret my findings in the framework of the three CHSRF elements of continuity: management, information and relationships in care. I read the transcripts carefully to identify these themes in the narratives and selected quotations that illustrated how patients had described aspects of continuity in their care in the course of the interview.

Study 2a provided a vast amount of data on patients' experiences of the stroke care process and how they made sense of it. The challenge for my analysis was that the themes of continuity, derived from the accepted models of continuity, could not easily be elicited from patients. Participants did not express unequivocal views about continuity nor did they recognise many elements of the care process. In this respect, knowledge of the care process was useful as it enabled a better understanding of the data in some cases. On the other hand it is possible that my background knowledge led to an over professional interpretation of some accounts of care without sufficient emphasis on the patient's viewpoint. Notwithstanding the limitations set out above, the research presented in this study was conducted in accordance with guidelines of good practice in qualitative research (Elliott et al. 1999).

### **2.6.3 Reflections on the validity of the findings**

Qualitative methods yield large amounts of data and it is incumbent on the researcher to decide which quotations or case studies they will use to illustrate their interpretation of the subject. My intention for the qualitative study was to give an objective account of the care process and the events that occurred from the patient's point of view. On reviewing my analyses, I am aware that my focus on process may have conveyed the impression that I had not always given the patients' choices and preferences sufficient



consideration. For example, in Case Study #553 my report of a patient who took his own discharge and subsequently missed out on follow-up and rehabilitation therapy could be construed as implying that this was the patient's own fault. In the case of Patient #2, I interpreted the patient's attitude to seeing different doctors at the practice in terms of negotiating her ongoing care but an alternative explanation could be offered in terms of making a positive choice for a certain type of interpersonal relationship.

My writing and presentational style may also contribute to an impression of professional bias, particularly my use of language. An example of this is the word "*compliance*" (see pages 47, 52, 177 and 225) which, in all probability, is a hangover from my clinical trials work where compliance is often used to describe a participant's adherence to the trial protocol. In my analysis of Case Study #531, (page 177) the word "*compliance*" was intended to describe cooperation with care rather than a preconceived notion that patients should assume a submissive attitude to care provision. On reflection I could have balanced the consequences of uncooperative behaviours on the quality of care delivery with an account of the views of patients who complained about staff attitudes and behaviours, and the quality of care they received. There were examples to draw on in my data such as Patient #17, an elderly lady who talked about some of the nursing staff being "clever" at avoiding certain tasks like toileting patients when they rang for assistance. There were also numerous other references to lower standards of care and cleanliness in hospitals, and complaints about lack of privacy on wards. Older patients in particular lamented the passing of the matron's daily ward rounds, regarding matrons as the upholders of standards in the hospital. (It should be noted here that this study was conducted just before the role of the modern matron was fully established in hospital). Furthermore, as I was aware that patients do not understand the care process in the same way as professionals do, I could have paid more attention to the relevance of certain care events to patients. Case #531 is a good example: the input offered may have contributed to the poor outcome for this patient because it did not address her declining cognitive state adequately and failed to meet the family's expectations of care.

In the analysis of Study 2a I was able to discuss the data and my interpretations of it with my supervisors. Professor Allan House has extensive experience of stroke and Professor Jenny Hewison has in-depth knowledge of qualitative techniques. Both are highly skilled in health services research. With regard to the coherence of the data, many of the participant's narratives resonated with my own experience of a close family member with severe stroke. Moreover, as the cohort study progressed, my experience

of effects of stroke grew and I found that the issues that had emerged in the early qualitative study reflected the broader range of experiences that arose in the wider study population.

## **2.7 Discussion: The patient's experience of care**

### **2.7.1 Qualitative methods**

Studies using qualitative research methods are often criticised for lack of scientific rigour and precision but their role in health care research is acknowledged to provide important understanding of patients' experiences, perceptions and behaviour, as Britten explained:

*“the clinical task is to fit the problem into an appropriate medical category....in a qualitative interview the aim is to discover the interviewee's own framework of meanings”*

(Britten, 1995)

Many of the current methods of measuring continuity have been derived from professional concepts of continuity and mapped onto definitions without reference to the patient. This work aimed to use a patient-centred approach to explore how people who had suffered a stroke had experienced their care, and what elements of continuity they recognised within it. The individual interview method was therefore chosen as the main method of qualitative data collection because it allowed patients to talk freely about their stroke care and also about their attitudes to care if they wished to do so. Focus groups provided an alternative approach, and were used to collect some supplementary data for this study. They were not used exclusively because this method might have constrained the expression of participants' views and in practical terms would have been difficult to organise for the severely disabled patients, and impossible for the housebound.

The reliability of qualitative research can be difficult to demonstrate in the traditional biomedical research paradigm. In this study, the interviews with patients and health care professionals were conducted in accordance with the recommendations of Mays and Pope. (Mays and Pope, 1995) No more than two interviews were done on any single day, and meaning and completeness was checked by the interviewer (KH) through summarizing (where appropriate) during interviews. Audio-recordings of interviews were made and subsequently transcribed. This is generally regarded as the

most reliable method of ensuring that data from interviews is accurately recorded and reported but even this method can be criticised for inadequacy. It is inevitable that some of the details and nuances in accounts will not be captured, especially if the interviewee moves away from the topic being investigated. Deviation from the topic is common in interviews, and can be a particular marked when interviewing elderly or chronically ill people. In an attempt to lessen this effect, field notes were also taken during the interviews and supplemented the recorded data when they were required. Notes from each interview were checked against the audio-tapes and if necessary, corrected, following interviews. No internal standardisation of the analytical procedures was necessary as they were conducted and analysed by KH without assistance.

### **2.7.2 Interpreting the data**

Qualitative studies of process are important adjuncts to developing an understanding of stroke care; to establish what works (for patients and caregivers); to examine why it works and to understand how care processes are perceived by them. As Dowswell *et al.* identified there is a need for more qualitative research in stroke because:

*“while a great deal has been written about stroke recovery, there has been relatively little theoretical work examining the process from the point of view of patients and caregivers.”*

(Dowswell *et al.*, 2000 )

As a starting point for this work qualitative methods offered a means of obtaining empirical evidence about the meaning of continuity of care for people with stroke, an area which had not been previously studied. This enabled the subsequent phases of the study to be firmly grounded in the patient’s perspective. The Freeman multi-axial definition and the CHSRF conceptual model provided a comprehensive framework for the interview topic guide enabling a full exploration of the topic at the outset of the study. However, in the subsequent analyses, only the three elements from the CHSRF model were used for the analytic framework as it became evident that this model provided the most logical format in which to interpret the processes of stroke care from the emergent data.

Initial recruitment to the study proved to be difficult, something which could perhaps be due to the indirect method by which first contact with the target sample of patients was made. However, it was a stipulation of the Ethics committee approval that patients had to be approached in the first instance by the hospital database manager for permission

to release their details. Fortunately those patients who did agree to be contacted were willing and able to talk about their experiences of care, and also how they felt about the care they had received following their stroke. The qualitative interviews and focus group discussions thus provided a rich and detailed insight into the ways in which people perceived their stroke care. The narratives obtained from the patients and the information derived from interviews with the health care professional who participated in the study also revealed that care after stroke can be delivered in diverse ways. Various combinations of lay and professional agents were described by participants throughout their recovery period. Together, these different perspectives enabled a good impression to be gained of the way stroke care in this area is organised.

Notwithstanding the ability of the participating patients to describe their care, it became increasingly evident as the study progressed that few, if any, had more than a vague idea about the mechanisms and processes that contribute to care. While the concept of continuity was tacitly recognised, relating it to the organisation of care required an understanding of care that was outside the experience of most of the patients in the sample. Instead they recounted a wealth of information about their lives after stroke, their strategies for coping and the various ways in which they managed their day to day activities. The role of informal care in stroke was often foremost during this part of the conversation and this is not surprising as the importance of informal carers in stroke (and other chronic conditions) has long been recognised. (Anderson, 1988, Parker *et al.*, 2002) The overall impression to emerge from the interviews therefore was that the personal and social circumstances of the individual on the whole determined how their continuing care was organised and maintained. This reflected the findings of Pound *et al.* in their earlier study of stroke care. (Pound *et al.*, 1998)

### **2.7.3 Limitations of the findings**

The extent to which the findings of Study 2a may be limited can be examined in the context of other qualitative work on patients' perspectives of care. Interpersonal continuity of care for example did not feature strongly in stroke patients' accounts of care yet a recent review has shown that patients attach strong values to the relationship with their doctor in primary care settings. (Pandhi and Saultz, 2006) One explanation for this inconsistency is the difference in the care delivered in acute and primary care settings, and the extent to which the patient retains control and the ability to exercise choice. A patient admitted to hospital following acute stroke is unlikely to have a choice of the location of their initial care. Nor is it likely that they will know the

care providers or exercise preference in deciding who will provide their care. There is a vast literature on patient satisfaction, information giving and perceptions of quality of care but few qualitative studies have documented patients' views of acute stroke care. This almost certainly reflects the patient's condition during this phase of care and the practical difficulties of conducting such research. However, retrospective studies have reported high levels of satisfaction with acute stroke care. (Pound *et al.*, 1995; Thomas and Parry, 1996)

Perceptions of recovery and the differences in priorities between patients and professionals have been more widely studied in stroke. The synthesised findings of a systematic review by McKeivitt *et al.*, 2004 clearly resonated with the findings of the qualitative study (Study 2a): for example the unwillingness of some patients to accept or use aids and adaptations. Attitudes to goal setting and the outcomes of recovery were also highlighted in the McKeivitt *et al.* review as an area where discrepancies between patients' and professionals' views could occur. Conversations with patients in Study 2a revealed that, by and large, they expressed higher expectations of recovery than their health care providers, and preferred goal setting in the context of return to previous activities and function rather than the shorter-term, more specific aims favoured by professionals. Views about poorly coordinated care services and gaps in the provision of personal care in the community were reported in this thesis and also emerged from several papers included in the systematic review. Moreover, these findings were also endorsed by the patient centred study reported later in this thesis, when similar themes arose in the context of measuring continuity of care.

Notwithstanding the similarities in findings, some differences were also revealed. Longer term rehabilitation, for example was reportedly viewed by patients as providing continuity of care after stroke, something that did not emerge from the qualitative accounts of the patients in Study 2a. Specific information requirements and deficiencies were also described in the review whereas participants in the qualitative study had expressed much vaguer views of information needs and information transfer. These differences may reflect the open style of questioning that elicited few spontaneous references to care processes or continuity of care from patients. The information that emerged from later interviews, using a more specific, and structured schedule in the study of patient perceived care, would tend to support this explanation.

## 2.8 Summary: Study 2a

The qualitative data analysis showed that the accounts of care given by patients did not map readily onto currently recognised elements of continuity. The only partial exception to this was with regard to information transfer and communication, which patients were able to relate to in their care and to which some tenuous links with continuity could be inferred. This finding presents problems for pursuing an evaluation of the continuity of care processes with patients, particularly in the context of the dimensions proposed by both Freeman and the CHSRF, as ultimately no specific patient-centred indicators of continuity could be derived from the patient accounts.

Good practice in any scientific enquiry is to seek evidence from different sources in order to check and corroborate findings. This process of triangulating data is accepted as strengthening study design particularly in observational or qualitative research where no randomisation procedure is possible. Where findings from different methods are complementary they lend weight to the argument that the hypothesis being studied is true, when contradictory they may signpost new avenues of exploration through which an answer can be pursued. Notwithstanding the findings of Study 2a, a further enquiry had been planned and was conducted as part of the first strand of research.

In addition to seeking the patients' perspectives of care this study also planned to explore how continuity might be assessed from recorded care. Throughout all sectors of health and social care it is considered good practice to record episodes of care and the procedures and processes associated with them. This provides a history for the patient that is used for monitoring and reviewing care or as a source of information if new health problems arise. As records are regularly passed between care providers in all health care settings, many past studies have based the measurement of continuity of information derived from care records. However, while records of care form an important repository of knowledge about an individual patient they cannot in themselves deliver continuity of care.

At the outset of this study it was hypothesised that a profile of care could be obtained from formal health and social care records, and that this would be reflected in the patient's account of care. Together these two sources of information would enable an understanding to form of how continuity of care was achieved in stroke care. The case note reviews therefore formed an important part of the first strand of research.

## 2.9 Study 2b: The case note reviews

### 2.9.1 Study design

The objectives for the second study were firstly to explore how continuity in stroke care processes was represented in formal records of care, and secondly to examine a method of evaluating it. As the literature review conducted in Study 1 had shown, many examples could be found in published papers that described methods of measuring continuity which based assessments on service provider records of the process of care. Examples of these included calculating continuity from entries in care notes by counting the number of referral letters or the number, frequency and sequence of visits to care providers. (Anderson and Hill, 1994, Bice and Boxerman, 1977, Steinwachs, 1979) For the purpose of this study a method of assessing care providers was chosen that had previously been used by Professor George Freeman to count the care providers delivering care in a study based in primary care. (Freeman, 1987) It had also been used to assess the number of midwives involved in pre and post-natal care in a study of continuity in maternity care by Farquhar *et al.* (1996).

Given that care after stroke can often be protracted applying this method of assessment meant that the total number of care providers that had contact with the study patients during the whole period of their acute stroke care, rehabilitation and after care had to be assessed. In order to quantify care providers, and capture the multi-disciplinary nature of stroke care, the signatures of all health care professionals who had made entries in the hospital and community care notes were therefore counted for a sub-sample of patients in the qualitative study.

### 2.9.2 Methods

The sample was selected from the Leeds Stroke Database and recruited as described previously in Section 2.2.1, page 63. A full review of the medical, nursing, therapy and social care notes was undertaken for 10 patients (6M/4F) whose stroke had occurred up to 12 months previously, and who had completed a qualitative interview as part of Study 2a. The median age of the sample was 82 years (Range 48-95). The review included general practitioner records and any community care or district nursing notes, in order to identify the type and timing of all care delivered. The individual signatures against entries in the care notes were counted and categorised, and the number and type of care-givers involved in delivering stroke care was calculated.

### 2.9.3 Results

The original intention was to complete the signature count review for all 23 patients who had participated in the qualitative interviews. However, it soon became apparent that the number of health care professionals involved during the acute, post-acute and rehabilitation phases was not only extremely variable but also exceedingly high in cases of severe stroke. Table 2.a (below) summarises the signature count and the other variables in the process of care that were assessed.

**Table 2.a Variables associated with care process**

Variable	Median	Range
Number of signatures	59	16 to 111
Length of stay (days)	34	6 to 73
Number of Wards in residence	3	1 to 4
Number of OP Follow-up visits	1	0 to 3
WHO Performance Status	1	0 to 4

In the main, a count of signatures present in notes indicated that nearly all members of a particular team would be involved with a patient, especially if their stay in hospital was prolonged or they had multiple identified care needs. This applied to ward nurses, medical and therapy staff alike, and was replicated in the community setting by the Intermediate Care Team (ICT) where all or most of the team members were involved with patients with complex needs. Accordingly a decision was made to limit the reviews to a purposive sample of ten patients, selected to represent a range of age groups, gender, acute stroke severity and residual functional deficits. Mild cognitive deficits were present in some patients who had participated in Study 2a but those with severe cognitive impairment, either pre-existing or post-stroke, were not represented as previously described in Section 2.2.2, page 65.

Signature counts were found to be significantly associated with length of hospital stay ( $r = 0.94$ ) and the number of wards on which a patient was treated ( $r = 0.83$ ). For admissions of more than 10 days, it was almost always the case that the whole complement of ward or unit clinical staff had made entries in the medical records at some stage. Albeit less strong, there was also an association between signature numbers and the WHO performance status in this small group ( $r = 0.58$ ).



**Figure 2.b Cases studies**

Patient #17	Patient #26
88 yrs, widow, living alone.	63 yrs male, living with spouse
WHO PFS = 4	WHO PFS = 0
Retired	Full-time employment
<i>Significant cardio-vascular disease with history of multiple admissions</i>	<i>No significant medical history or co-morbidity.</i>
Admission: 73 days followed by transfer to long-term care	Admission: 6 days followed by discharge home
111 care-givers hospital and nursing home	16 care-givers
26 Investigations	4 Investigations
38 N/H staff accounted for 659 entries in care notes	No formal community care
No stroke specific follow-up	Follow-up by stroke specialist nurse

In this small sample it was not possible to draw statistically valid inferences from the mathematical correlations but, as Figure 2.b shows, using an illustrative case study approach it can be seen that the patient with the poorest function also had the highest count of signatures. (See Appendix E for WHO Performance Scale categories on page 281).

The count of signatures thus revealed an association with duration of care, which could also be regarded as a proxy measure for severity of stroke. There was no apparent relationship with any of the accepted dimensions of continuity. Furthermore, nothing can be inferred about the nature or sequence of contacts using signature counts alone. As the two case studies described in Figure 2.b illustrate, simple comparisons of care in stroke are not straightforward on account of the range and diversity of patients and post-stroke effects. However, these results did show that it was possible to map patients' stroke care from their medical records, and to gain an overview of the care processes they had received, and the transitions between them. This information was useful to identify potential indicators of continuity in processes and to ascertain their likely sources as Table 2.b on the following page shows.

**Table 2.b Transitional stages in care<sup>3</sup>**

<b>Stage</b>	<b>Potential Process Indicators</b>	<b>Source</b>
Admission	Mode of admission	Medical notes
Acute Care	Care needs identified Tests and investigations completed Appropriate management planned – active or palliative Functional status assessed – therapy as appropriate Care needs addressed Progress reviewed: subjective and objective Explanation/information given to patient/carer	Medical notes Stroke proforma Nursing notes Barthel Index
Rehabilitation	Functional status assessed Goals negotiated and identified Progress recorded Secondary prevention discussed	PT/OT/SALT notes Barthel Index
Discharge/Death	Discharge planned with patient Home visit completed if necessary GP informed Named contact given to patient/carer Information about voluntary groups given Delays in discharge	Medical notes Nursing notes
Community care/support	Care needs identified Aids/adaptations requested and received Referral to ICT if >65 Referral to Social Care services Contact with voluntary groups	OT/PT notes Nursing notes ICT notes CST notes
Residential care	Long term care discussed with patient Referral to Social Services Placement arranged Placement reviewed Outcome of placement	Medical notes ICT notes CST notes DSS notes
Out-patient therapy/Community rehabilitation	Ongoing need for therapy identified Referral for OP appointment OP care commenced Progress recorded Follow-up by specialist/GP/specialist nurse if <65	Medical notes Nursing notes  Hospital/GP notes
Independent living	Carer support services if required	GP

<sup>3</sup> The stages of care were based on the type and content of information that was found during the review of hospital, primary care, and community health and social care records.

## 2.10 Discussion: Counting caregivers

### 2.10.1 Methodological issues

A number of operational difficulties were encountered in the process of applying signature counting as a method of enumerating care providers:

- **Accuracy**
  - The total number of signatures was hard to determine precisely because the caregivers making entries in the notes often used initials that were difficult to decipher.
  - In the nursing notes and multi-disciplinary notes of the ICTs in particular, the entries rarely included staff designations or grade.
  - Countersignatures occurred frequently in nursing notes due to the requirements for supervision of junior staff, and for the purpose of cross-checking the administration of medicines.
- **Reliability**
  - Traditionally nursing and medical notes are kept separately during admission, and the nursing notes filed sporadically in a special section at the back of the notes. Some types of care or therapy services also keep separate records within the same hospital: physiotherapy and speech therapy services are two examples. Evidence of service input could therefore sometimes only be found as a referral in the main medical record.
  - Multi-disciplinary case-notes were only present in specific units.
  - Entries did not necessarily represent the caregivers actually involved with the patient. For example: Day Hospital (DH) attendances were usually recorded only by the senior grade on duty although in many cases another member of the Day Hospital staff would have most contact with the patient during their visit.
- **Consistency**
  - Although a basic format for patient record keeping exists, there was no way of knowing what was missing from the notes. Different wards and specialties used different documentation and recording practices as did different primary care providers even those practices that used electronic records.<sup>4</sup>

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<sup>4</sup> *The Primary Care Trusts in the areas studied had a choice of four alternative systems which could be customised to suit individual practices' preferences.*

- **Gaps in records**

- Many of the stages in the actual process of care were not fully documented in the notes, and it was also apparent that relevant forms were not always filed.
- Referrals, or handovers made by telephone, were rarely recorded, and transfers and discharges were not always formally noted. Advice about post-discharge services given to relatives and carers during visits to the ward, for example, was almost never recorded.

### **2.10.2 Continuity and caregivers**

Green *et al.* showed that continuity in the process of maternity care did not necessarily mean continuity of carer to women. (Green *et al.*, 1998) In the small sample of case-notes reviewed for Study 2b there did seem to be some evidence that this might also be true for stroke patients. No association was seen between the number of care givers and the nature of the stroke care received. For example, the patient with the greatest number of care givers had received no stroke specific follow-up after discharge.

Notwithstanding that the most dependent patients are likely to require more assistance with day to day activities; it has been suggested that in some cases, having more carers increases the dependency of patients. In stroke this has been shown to act as a set-back to rehabilitation effects being maintained or progressed. (Dennis *et al.*, 1997) In caring for the elderly too larger numbers of caregivers could mask the onset of the symptoms of reversible medical conditions. Clearly therefore cases could arise where an increase in perceived need could lead to a compensatory increase in input, which in turn could result in certain types of problems remaining untreated. If successful treatment were given for underlying medical conditions, increased input could be avoided or withdrawn, and greater independence restored. If these hypotheses are indeed valid then it would be counter-intuitive to regard the number of care-givers as a potential metric for measuring continuity.

Undoubtedly the information collected during this phase of the study indicated that counting the number of signatures was more likely to be proportional to staffing levels, length of admission and degree of dependency of the patient than to indicate relational or managerial continuity in their care. No evidence was found to support further testing

or to justify signature counts as a method of assessing continuity in stroke care processes.

### **2.10.3 Care records and communication**

Based on the findings of this study, signature counting was rejected as a valid method of assessing continuity. The role of care records in maintaining effective care processes was nevertheless evident from the reviews. Hospital care was the most vulnerable to errors or inefficiencies when records were missing and, although the findings were not specifically quantified, several examples were found of tests and investigations that had been repeated when no records were available. There was also evidence of the difficulties that medical staff faced in the management of patients with complex medical histories who frequently had hospital case-notes that were multi-volume and not sequentially filed. This, and the problem of missing case-notes, could result in delays in treatment or referral especially if patients were admitted acutely to different specialties.

Missing, inaccurate and out of date information were issues that related particularly to contact details for patients. There were a number of examples of follow-up clinic appointments, hospital appointments for tests and investigations, and transport pick-ups that had been missed when letters had been sent to the wrong address or because telephone numbers were incorrect or missing. In one set of case-notes four different address labels were found for the same patient; in another set of notes there were address labels for another patient with the same name, but a different address and date of birth. Clearly these are simple errors but when compounded they contribute substantially to reduced effectiveness and efficiency, and increase the costs of care. Written records seemed to work better in the community care teams. In the area studied, Intermediate Care (ICT), the Community Stroke Team (CST) and Home Care maintained two patient files during their intervention period: one in the patient's home and one at the office base. Each practitioner involved in a patient's care was responsible for making entries, as appropriate, in both sets of records whenever they visited the patient. The two files were merged, and stored at the office, when community care input was withdrawn.

Most general practices in the area surveyed used an electronic records system for patients' notes. These had many observable advantages for the accessibility and storage of information or data that had been entered. There is a drawback to present

systems however as they were very slow at retrieving and viewing any form of external correspondence or documentation that had been scanned in. This was noticeable during the actual reviews and confirmed by one of the GPs interviewed, who described his practice's electronic management system (EMIS) as "*great for consultations but a pain when you're looking for hospital letters.*" As most information between primary and secondary care is still currently transferred by letter or fax, this flaw in the system can be regarded as problematic, and many practices were found that had retained their old system for filing and storing any external correspondence received.

#### **2.10.4 Developing indicators of continuity**

Complex care requires collaboration between different practitioners, working independently or in separate teams. Communication between them, the individual people and the teams delivering care, is important if uninterrupted care processes are to be maintained and appropriate and timely interventions ensured. Much of the information related to these processes is passed on by telephone or face to face conversations and not formally recorded, therefore the written or electronic patient records do not necessarily provide a full assessment of all the care processes that have occurred. Nonetheless, although provider continuity cannot be assessed from counting signatures, the medical, nursing and therapy notes and community care records do provide the best available record of formal care.

The knowledge gained from the reviews of care records proved useful in starting to develop a framework for assessing continuity of inpatient care from the provider perspective. Table 2.b on page 98 outlined the stages of stroke care and shows possible indicators of continuity for the various stages of care based on the themes of management and the communication of information both from professional to professional and from professional to patient. Using this format a checklist for continuity of care processes was formulated that aimed to assess how the processes and transitions in care had been achieved. The checklist and the study in which it was applied are described fully in Chapter 4.

### **2.11 Summary: Study 2b**

The first strand of research took the patient's experience of care as its primary theme. It began with a qualitative exploration of stroke patients' experiences of care in an effort to interpret a patient-centred concept of continuity of care. This empirical approach

grounded the work firmly in the patient's perspective. A method of measuring continuity was also investigated using formal service-based records of care.

Forty-two stroke survivors and several carers participated in the interviews and focus groups undertaken in Study 2a, the exploratory qualitative study. Thirty-two of these interviews were subject to detailed framework analysis; the remainder could not be transcribed or were not adequate for analysis. Notwithstanding the wealth of data obtained, sufficient key, patient-centred themes or indicators could not be derived from which to construct an easily quantifiable measure of patient-perceived continuity. Aspects of continuity could, however, be identified implicitly in the patients' narratives. Study 2a thus showed that a self-reported checklist of care could not be designed at this stage and a different approach was therefore considered. This led to the development of a structured interview schedule which would eventually be used to assess the process of care in Study 4b, using the patient's personal accounts of their experiences of care.

The case-note reviews conducted in Study 2b showed that continuity in the process of stroke care could not be evaluated simply by counting signatures in order to quantify input from care-givers. This was due not only to the complex nature of stroke but also to the confounding factors which arose from the dependency or physical status (stroke and non-stroke related) of the patients, as well as to the quality of entries in the care records. This method of assessment was therefore rejected. The findings from Study 2b provided useful information that was applied to the development of a checklist based on the phases and transitions of stroke care. In the second strand of research the checklist was tested alongside the patient-perceived measure of care as a means of quantifying care from formal records.

## CHAPTER 3 Testing a Measure of Continuity

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### 3.1 Study 3: Evaluating the Chao Perception of Continuity scale

#### 3.1.1 Study objectives

The objectives for Study 3 were threefold:

- To determine the feasibility of using an established measure of continuity in a new patient group by studying its meaningfulness and usability with stroke survivors;
- To explore the factor structure of the Chao PC scale and to examine the underlying constructs that it measures;
- To explore associations with physical and psychosocial outcomes for patients in the longitudinal cohort study to determine its potential for wider use in that context.

#### 3.1.2 Study design

At the planning stages of this research it seemed logical to locate any existing measure or measures of patient-perceived continuity and to test their application and performance in a cohort of stroke patients. If a suitable standardised measure could be found it would be unnecessary to embark on the design of a new measure of patient-perceived continuity. The literature review conducted at the outset of this study had identified many measures of provider continuity, such as the COC Index or the UPC, which used service provider data. However, at the time of the original review only a few studies had attempted to measure continuity from the patient's perspective. Only two candidate measures were therefore available for consideration for this study: the Chao Perception of Continuity (PC) Scale and the Care Continuity Index (CCI). (Chao, 1988, Bull *et al.*, 2000) The third patient-centred measure found had been designed for paediatric care and consisted of only three questions assessing the parent's perspective of care for their child. (Breslau, 1982). The Chao PC measure has been described by its author as:

*“measuring patients’ attitudes to care to define continuity and provide information which is distinct from provider continuity formulas”.*



It was designed in a questionnaire format to test Banahan and Banahan's attitudinal contract, and included a range of items that sought to evaluate aspects of the patient's interaction with primary care services and service providers. (see Appendix C for a copy of the full scale, pages 277 - 278). By comparison the majority of items in the CCI focused on aspects of information giving, and were assessed in terms of patient satisfaction with that process. The CCI had also been subject to analysis of the factor structure whereas the Chao PC scale had not. Testing the questionnaire in this study thus offered the opportunity to examine its underlying constructs, and contribute further to the general pool of knowledge about measuring continuity of care.

### **3.1.3 Validity of the Chao Perception of Continuity Scale**

In view of the limited number of patient-centred measures of continuity that were available the Chao PC scale appeared to offer the best choice for testing in the SOS2 cohort. Its face validity was not strong given that it was developed in the United States, where care is differently organised, and had originally been designed for use with primary care patients, albeit only with adults. However, on inspection of the items it was clear that only a few related to methods of primary care delivery and the majority focused on attitudes to care that would be independent of the setting: for example: seeing the same doctor, and perceptions of trust, knowledge and the strength of personal ties. The SOS2 cohort had been recruiting steadily by the time Study 3 was planned and many patients had index stroke events that had occurred in the previous year. A target survey group of patients living at home was thus available, all of whom had completed therapy and stroke-specific follow-up, and were under the care of their own General Practitioner.

The population in which the Chao PC scale was first tested had a range of conditions but a stroke specific measure was not an option for this study as none could be identified. The nature of the items on the Chao PC scale suggested that they would be relevant regardless of the nature of the patient's condition, and there was no reason to assume that patients with stroke would be unable to rate them. It could be hypothesised that stroke patients (or any population with a chronic condition) might generate a different profile of scores from a mixed, primary care population but this did not present a problem for the analysis as no external comparisons of scores was planned.

The format of the Chao PC scale matched the planned design for Study 3. It had also previously been administered to patients in two ways: directly for self-completion and as a postal survey. Furthermore it was quickly and easily obtained direct from the originator Dr. Jason Chao, and without copyright restriction other than acknowledgement of the source.

The construct and content validity of the Chao PC scale had been subject to limited testing only in the original report. Applying the measure in the stroke study thus presented the opportunity to explore the properties of the scale further as well as testing its application in a different population.

## **3.2 Methods**

### **3.2.1 Participants**

As described in the introduction (pages 18 -19), this study benefited from access to a cohort of patients who were already participating in a parallel, longitudinal, prospective study. The Stroke Outcomes Study (SOS2) examined the impact of early depressive symptoms on outcomes for patient in the year after stroke, and collected a range of physical and psychosocial outcomes assessments at baseline and four follow-up points. (See Appendix A for a full description of SOS2, pages 272 - 274).

SOS2 recruited patients sequentially with new or recurrent stroke. Potentially eligible participants were identified within the first weeks following admission to two acute trusts in the West Yorkshire region. Admitting wards were checked weekly. Only patients with transient ischemic attack, subarachnoid haemorrhage or severe cognitive deficits were excluded. The criteria applied for entry to the cohort study were broad and aimed to be as inclusive as possible in order to permit the recruitment of a range of stroke severities. Details of the specific criteria are shown in Figure 3.a below.

**Figure 3.a** Criteria for inclusion in the stroke cohort study (SOS2)

INCLUSION CRITERIA	EXCLUSION CRITERIA
Patient has survived a first or recurrent stroke and is fit to be seen at 2 – 4 weeks. Patient is aged 18 years old. Patient is able to give informed consent. MMSE (Mini Mental State Examination) score of 23 or above (Borderline scores between 20 and 23 to be accepted if physical or speech deficits impair scores.)	Severe cognitive impairment Sub-arachnoid haemorrhage Transient ischemic attack Non-English speaking No concurrent major illness the management of which is likely to predominately determine care.

Those patients who had reached the one year follow-up point of SOS2 provided a target sample of patients with whom the Chao PC scale could be piloted. Further details of SOS2 recruitment procedures are given in Appendix A (pages 272 – 274). The Chao PC Scale is reproduced in Appendix C (pages 277 - 278). The limitations of the sample selection method and the final sample studied are discussed in Chapter 6, Section 6.5.3 on page 259.

### 3.2.2 Study procedures

The author (KH) was project coordinator for the overall programme of stroke outcomes studies and benefited from access to the SOS2 outcomes assessments and also from the assistance of the research support team working on SOS2. A team of research assistants, supervised by KH, were involved in the recruitment of patients and the collection of the outcomes data across the whole timescale of the cohort study. They also delivered a proportion of the Chao PC questionnaires directly to patients as part of the final SOS2 follow-up visit. The support team assisted with the administration of the postal survey that was conducted, and with data entry for this study (Study 3). KH undertook a number of visits with patients in order to complete the Chao PC scale and also collected the SOS2 cohort study assessments at the same time. KH was responsible for the conduct and management of the overall study programme, and for all data management and analysis.

The Mini-Mental State Examination was used as an initial screening tool for assessing the cognitive function of potential participants in the cohort study. (Folstein, 1975) A cut-off score of 25 was applied, although some flexibility was permitted around the cut-off point to allow patients to be included whose low scores were clearly not due to cognitive impairment but to general frailty or to a specific communication deficit; and with whom sufficient communication could be established to complete the necessary study procedures. A description of the SOS2 cohort study including the visit schedules and outcome measures used can be found in Appendix A, pages 272 - 274.

The Chao Perception of Continuity questionnaire (Chao PC) was given to a sample of 310 patients in the SOS2 cohort study who consented to complete the additional questionnaire. It was delivered by the interviewer completing their final (one year) follow-up visit, or at a time-point towards the end of the one year follow-up period if it could not be delivered at the same visit. The nature and purpose of the additional questionnaire was explained to patients and they were given the opportunity to opt out by not completing it if they chose. It was also sent to a sample of patient who had already been followed-up for a year. Two modes of delivery were therefore used: those actively participating in the Stroke Outcomes Study cohort (N = 110) were given the option to complete the Chao measure as part of their routine assessments; those participants who had completed the final follow-up for the cohort study but had given consent to contact for future research (N = 200) were sent the postal questionnaires.

Items on the questionnaire are rated on a standard Likert type 5-point scale; Table 3.a shows the distribution of the scores in the scale and their descriptors, which are different for each of the two sections of the questionnaire:

**Table 3.a Chao PC scoring system**

Section 1	Section 2	Values
Definitely True	Agree Strongly	1
Mostly True	Agree	2
Uncertain	Uncertain	3
Mostly False	Disagree	4
Definitely False	Disagree Strongly	5

Active participants in the cohort study were surveyed first and were encouraged to comment on or query any aspect of the questionnaire, either verbally or by writing on the form. This assisted with the design of the postal survey as the first round of

interview delivered questionnaires showed that the absence of a “*Not Applicable*” rating was causing some difficulties and was the source of numerous queries. The postal forms were therefore modified by the inclusion of an additional category for “*Not Applicable*” to address this issue as they would be completed without an interviewer present.

The data collected from the completed questionnaires was entered into an SPSS database and scored according to the author’s prescribed method. Scores for questions 1B; 1D; 1F; 1H; 2A; 2D-E; 2H; 2J-O were rescaled by subtracting the values from 6 to convert them to the same order as the other items. Thus, when rescaling was completed, a higher score always indicated a “better” score. No weighting was applied to items and an overall mean score was calculated for the 23 items.

### **3.3 Results**

#### **3.3.1 Comprehension and utility**

Data was collected from 108 of the 110 patients approached at interview (98%). Only two participants refused to complete the questionnaire, although a number rated items “*Not Applicable*” and could not score them. Data retrieved from the forms delivered by post were (not unexpectedly) much less comprehensive: only 68 (34%) out of 200 forms were returned fully or partially completed. This gave a total of 178 completed questionnaires representing 54% of the total eligible survey population. Combined, these 178 patients, of which 104 were male and 73 female, formed the sample used for the analysis (1 respondent from the postal sample was of unknown gender due to a minor clerical error in coding the forms); median age was 69 years (Range 33 to 94 years).

Feedback from patients was most frequently given verbally, or inferred by requests for assistance or explanation, during completion at interview visits. A total of 45 comments were written on questionnaires by respondents (or by the interviewer in response to verbal comments and queries). The interpretation of certain questions caused the most difficulty (24 comments) and 17 comments were made about the relevance of the items. The remainder (4 comments) concerned specific post-stroke deficits, and were not directly relevant to the questionnaire. Only five items out of the total of 23 (1D; 1E; 2E; 2J and 2O) did not give rise to comment by patients. The remarks on the remainder (18 items) were mostly “*Odd question*” or “*What does that mean?*” The

items not fully understood were often left blank; and the four questions most often noted in this category were:

- 1F *“My medical care improves when the doctor has seen me before”*
- 2D *“The doctor knows a lot about the rest of my family”*
- 2F *“The doctor doesn’t know about my family problems”*
- 2K *“My doctor would take care of me if I had to go to the hospital”*

Problems with comprehension thus resulted in 29% missing items in Section 1 (Range 1 to 8 items left blank) and 35% in Section 2 (Range 1 to 15). Five questionnaires had insufficient data for analysis. Descriptive statistics for all the Chao PC variables in the order in which they appear in the questionnaire are shown below in Table 3.b.

**Table 3.b** Descriptive statistics

Item No.	Chao PC Variable Descriptor	N	Mean	SD
1A	Different Doctors	141	3.45	1.742
1B	Past Medical Problems	159	2.74	1.494
1C	Location	164	3.16	1.749
1D	Medication	171	4.80	0.590
1E	Same Doctor	170	3.59	1.498
1F	Prior Knowledge	161	3.42	1.253
1G	Unknown Problems	168	4.54	0.984
1H	Care For All Problems	167	3.90	1.291
2A	On-going Relationship	167	3.74	1.312
2B	Unrelated Medical Problems	160	3.78	1.228
2C	Personal Problems	162	3.67	1.440
2D	Knowledge of Family Members	155	3.21	1.405
2E	Ease of Communication	169	4.20	1.061
2F	Knowledge of Family Problems	139	3.33	1.332
2G	Poor Explanations	165	3.83	1.310
2H	Emergency Care Preference	165	3.38	1.524
2I	Waiting For Own Doctor	161	2.73	1.409
2J	Referrals	165	4.18	0.939
2K	Provides Pre-admission Care	159	2.92	1.276
2L	Provides ER Care	163	3.49	1.259
2M	Trust Recommendations	166	4.34	0.760
2N	Recognition	169	3.48	1.381
2O	Trust Personal	167	4.38	0.916

Mean scores were used for some analyses but in order to facilitate description of the data and to interpret the initial findings, the mean scores were also grouped into 5 “continuity” categories based on the distribution of scores for the summed

questionnaires. The categorical ratings reflected the individual item response categories. They are shown in Table 3.c below.

**Table 3.c Continuity categories based on Chao PC mean scores**

<b>Continuity Category</b>	<b>Patients (n)</b>	<b>Percentage</b>	<b>Mean Score Range</b>
Very Good	15	8%	4.5 and above
Good	99	56%	3.5 to 4.49
Adequate	56	31%	2.5 to 3.49
Fair	3	2%	1.5 to 2.49
Poor	0	0%	0 to 1.49
Missing	5	3%	Insufficient data
	178	100%	

### 3.3.2 Exploring associations

The outcome variables measured in the SOS2 cohort study can be divided into two main categories:

- **Measures of function:**
  - WHO performance index: (World Health Organisation)
  - Barthel Index (BI): (Mahoney, 1965)
  - Frenchay Activities Index (FAI): (Wade *et al.*, 1985)
  - Functional Independence Measure (FIM): (Hamilton, 1994)
- **Measures of mood and health related quality of life (HRQoL):**
  - Present State Examination (PSE): (Wing, 1974)
  - General Health Questionnaire (GHQ\_28): (Goldberg and Hillier, 1979)
  - Medical Outcomes Study (SF\_36) Questionnaire: (Ware, 1992)

As a preliminary analysis, selected baseline variables were compared with the categorical ratings derived from the Chao PC scale in a cross-tabulation, and Chi-square statistics calculated. The aim was simply to assess the performance of the Chao measure in this sub-sample of the main cohort and not to draw any conclusions about the effect of continuity of care measured in this way on outcomes.

In view of the large difference in the response rates for the postal questionnaire and interview sample, the two groups were also examined for characteristics that could be a potential source of bias. No significant differences were found.

No associations were detected between any of the measures of physical function and Chao PC Questionnaire scores. The only significant association found in this analysis was with the psychosocial assessments: poorer Chao PC scores were reported by patients with higher levels of anxiety or depressive symptoms at baseline (i.e. those scoring 12 or more on the GHQ\_28 on entry to the cohort study). This was explored further by examining subsequent GHQ\_28 scores for these patients but no significant associations were found between GHQ scores at any other time-point in the follow-up schedule of the cohort study and the Chao scores. This finding could be explained by the tendency for high initial positive responses to the GHQ to decrease over time as patients report their symptoms to be "*the same as usual*" at follow-up. There also remains the possibility that as multiple tests of significance were performed for this analysis, the significant p-value of 0.04 detected for GHQ caseness could be a chance effect.

Demographic, social and co-morbidity data were recorded for participants in the cohort. Males and females are known to respond differently to self-reported assessments of health, and this varies by age. (Eriksson *et al.*, 2001) Likewise this could be true for their perceptions of care. Age could have other effects: care patterns may differ or younger people might be more critical of care delivery than their elders, who had experienced health care before the introduction of a national health service.

The statistical tests were run to examine these possibilities but no differences were found on the basis of any of the demographic characteristics of the sample, nor the mode of questionnaire delivery. The results are shown in Table 3.d on the next page.



**Table 3.d Comparison of baseline characteristics with Chao scores<sup>5</sup>**

Baseline (T1) Variables	Distribution	$\chi^2$	p-value <sup>(i)</sup>	Sign <sup>(ii)</sup>
Gender	Male (n = 105; 59%)	6.11	0.41	NSD
Age over/under 65 years	>65 yrs (n = 112; 63%)	5.45	0.14	NSD
Dependent/Independent	Dependent (n = 52; 29%)	1.84	0.61	NSD
Interview/postal	Interview (n = 110; 62%)	4.98	0.17	NSD
GHQ case <sup>(iii)</sup> / non-case	Cases (n 38; 22%)	8.33	0.04	SD

A descriptive analysis of responses to individual items proved more informative as it provided an indication of patients' attitudes to their care. Item by item analyses showed that patients trusted their doctor (Question 2O: 90% of respondents agreed with this statement to some extent) and 67% agreed they had an ongoing relationship with their own doctor (Question 2A). However, with regard to emergency care (Question 2H), only 38% of respondents preferred to wait to see their own doctor; 4% were uncertain and 58% would see any doctor in an emergency. These findings were consistent with those of Freeman's 1993 study in general practice which had investigated patients' views on seeing the same doctor. (Freeman and Richards, 1993)

### 3.4 Exploring the constructs

The Chao Perception of Continuity scale was originally designed to test the Banahan and Banahan concept of continuity, in an empirical study conducted in a USA primary care setting. (Banahan and Banahan, 1981) The Banahan's conceptual theory proposed that continuity be viewed as an attitudinal contract; a mutual relationship in which the doctor assumes responsibility for care and the patient relies on, and trusts, the doctor. These ideas, which echo those of some theories of social capital, (sic Putnam, 2000) have underpinned a number of operational definitions of provider continuity found in the literature. In this context it is assumed that duration of relationship between patient and provider leads to greater acceptance of responsibility for care on the part of the provider, and thus confers better continuity of care as a result.

<sup>5</sup> Table 3d: Notes

(i) Significant at 5% level

(ii) NSD = No significant difference identified; SD = Significant

(iii) Total Score  $\geq 12$  = a case: Cases report lower (poorer) Chao scores.

The Chao PC was developed specifically to measure components of this type of doctor-patient relationship in family medicine and attributes like trust, knowledge and satisfaction with care. However, within the 23 items there are also some which can be construed as addressing other elements of continuity. For example Item 1C: *“I receive my medical care at more than one location”* implies measurement of a geographical component rather than a relational one, and Item 1F *“My medical care improves when the doctor has seen me before”* could be interpreted as a judgement of the quality of care. Other items in the questionnaire can be highlighted that measure information giving (2G); management of care (1D) or which have a degree of ambiguity in their construction (1H). Nevertheless, the univariate analyses reported previously in Section 3.3.2 (page 111) had found no associations between the Chao PC scores and physical function or other variables that could be hypothesised to have an impact on the care received. This suggested that, despite the inclusion of items such as 1C and 1F, the discriminatory properties of the Chao measure were low with regard to assessing the process of care.

The multi-dimensional aspect to the items had partly contributed to the decision to choose the Chao PC for testing in this study. Further investigation was therefore warranted to explore how the measure factored out and to determine whether any constructs could be identified that corresponded to the current multi-dimensional models of continuity. The sample size for Study 3 was more than 100, which was adequate to undertake a factor analysis as it provided the required minimum of approximately 8:1 ratio of observations to variables. Although there was a trend for scores to be distributed in the three higher categories in a number of variables, with fewer at the lower end of the scale, no marked ceiling effects were noted.

Variance is an important consideration when undertaking factor analysis. The process uses a series of statistical computations based on the correlations between the variables to examine the patterns that are present in the data set. Unless the items within a given set are totally uncorrelated, the underlying constructs that a questionnaire (or any other set of variables) is measuring can be extracted.

## 3.5 Methods

### 3.5.1 Factor analysis

Factor analysis is a multi-variate statistical technique designed to examine the structure of correlations or inter-dependence in a set of variables based on their variance or statistical distributions. It has two main objectives:

- To identify patterns in the data.
- To reduce the number of variables for analysis.

Two basic models were available to derive factors from the data set: common factor analysis (CFA) and principle components analysis (PCA). They differ mainly in the way they use variance in the factor matrix but both methods are widely used and, in practice will often yield identical results. The first of these (CFA) can generally be regarded as the most applicable method for examining the overall structure of the data and identifying latent constructs, while the aim of PCA is to summarise the data into the least number of dimensions that contribute most to the variance in the data under scrutiny. Given that the overall aim of this analysis was to identify the constructs underlying the Chao questionnaire, common factor analysis could be argued to be the most appropriate method. However, CFA makes more restrictive assumptions and bases computations only on common variance whereas the PCA method includes the variability that is unique to a specific variable and not shared or explained by others. Given that there was a degree of heterogeneity in the items covered by the Chao questionnaire reflecting the multi-dimensional nature of the concept of continuity of care, the author therefore considered PCA to be the most appropriate method for exploring the factorial structure of the Chao questionnaire. The PCA analysis was undertaken by KH unaided using SPSS software as an analytical tool, and guided by the principles of Hair *et al.* (1998). The main drawback of using SPSS for this type of analysis was that the actual method of computation of the factors is not always explicit in the output generated by the software.

### 3.5.2 Process of analysis

A principal components analysis was carried out using SPSS Version 14 software. This method reduces the data to the least number of dimensions or characteristics that contribute most to the variance in the data. The first stage of the process was to examine the correlations between the Chao PC questionnaire items to establish

whether adequate co-linearity was present to allow the analysis to proceed. A correlation matrix for all the variables was generated showing the correlation coefficients of each of the variables. The results are shown in the full matrix table, which for a 23-item questionnaire is a large table and is therefore reproduced in Appendix F (page 282).

The SPSS package uses the Kaiser-Meyer-Olkin (KMO) test as a measure of sampling adequacy, a test which quantifies the degree of intercorrelations in the data. Values over 0.5 indicate the appropriateness of applying factor analysis. For this data set the KMO value was 0.751. Other assumptions about the data such as the presence of a conceptual linkage between the items (all the questions were related to perceptions of health care delivery) and the homogeneity of the sample (all subjects were post-acute stroke patients) were also satisfied. However it must be acknowledged that certain items did not conform ideally to psychometric questionnaire design as they were not confined to single ideas or statements. Ratings for these items could therefore be conflicted.

### **3.5.3 Deriving the factors**

The Chao questionnaire contained 23 items for inclusion in the analysis. Descriptive statistics for all the variables under investigation, are shown in Table 3b (page 110) and are presented as number of respondents (N), mean and standard deviation (SD). This table shows that item 1D “*The doctor has a list of all the medications I am taking now*” had the highest mean score, and was therefore the most highly endorsed item. However no importance can be attached to that finding at this stage particularly in a questionnaire that had not shown high discriminatory properties in the earlier analyses.

In the second stage of the analysis factors were extracted from the correlation matrix based on the correlation coefficients of the variables. Table 3.e on the next page shows all the factors extractable; their eigenvalues (the percent of variance attributable to each factor); the cumulative variance of the factor and the previous factors. The Chao questionnaire, which was developed in 1988, pre-dated the models of continuity of the Freeman review and the CHSRF report that had formed the *a priori* framework for the design and analysis of this and the preceding two studies. Therefore, although the working hypothesis was that three constructs would emerge, no limit was placed on the number of factors to be extracted in this analysis.

**Table 3.e Factor analysis: Total variance explained by the extracted factors**

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	5.475	23.803	23.803	5.475	23.803	23.803	2.963	12.884	12.884
2	2.411	10.484	34.287	2.411	10.484	34.287	2.890	12.567	25.450
3	1.694	7.367	41.655	1.694	7.367	41.655	1.973	8.578	34.029
3	1.453	6.318	47.973	1.453	6.318	47.973	1.829	7.951	41.980
5	1.274	5.539	53.512	1.274	5.539	53.512	1.700	7.392	49.372
6	1.174	5.103	58.616	1.174	5.103	58.616	1.681	7.308	56.680
7	1.097	4.768	63.383	1.097	4.768	63.383	1.542	6.703	63.383
8	0.941	4.093	67.476						
9	0.886	3.852	71.328						
10	0.803	3.493	74.821						
11	0.720	3.131	77.952						
12	0.689	2.996	80.948						
13	0.642	2.790	83.738						
14	0.617	2.682	86.421						
15	0.534	2.321	88.742						
16	0.483	2.099	90.841						
17	0.458	1.993	92.835						
18	0.407	1.768	94.603						
19	0.321	1.397	96.000						
20	0.290	1.262	97.262						
21	0.243	1.059	98.320						
22	0.205	0.892	99.212						
23	0.181	0.788	100.000						

Extraction Method: Principal Component Analysis.

It can be seen from Table 3.e that seven component factors had eigenvalues greater than 1, although only the first two factors were substantially more than this value. Factor 1 accounted for 23.8% of the variance, the second factor only 10.5%. Overall only 63.4% of the total variance in the questionnaire was accounted for by the seven significant factors suggesting that the remaining factors, accounting for almost 40% of the variance, were less strongly correlated. Table 3.f below shows the communalities in the data. Communality indicates how much variance in an individual variable can be accounted for by the factors extracted in the analysis. A higher value in the extraction column means that a greater proportion of the variance in that variable has been explained; for example 81% of the variance in “*Provides pre-admission care*” was accounted for by the extracted factors in this analysis compared to only 46% for “*Seeing the same doctor*”. Lower values for communalities are not evidence that the data do not fit the hypothesis under examination but are an indication that the variables in the data are uncorrelated, and have little in common with one another.

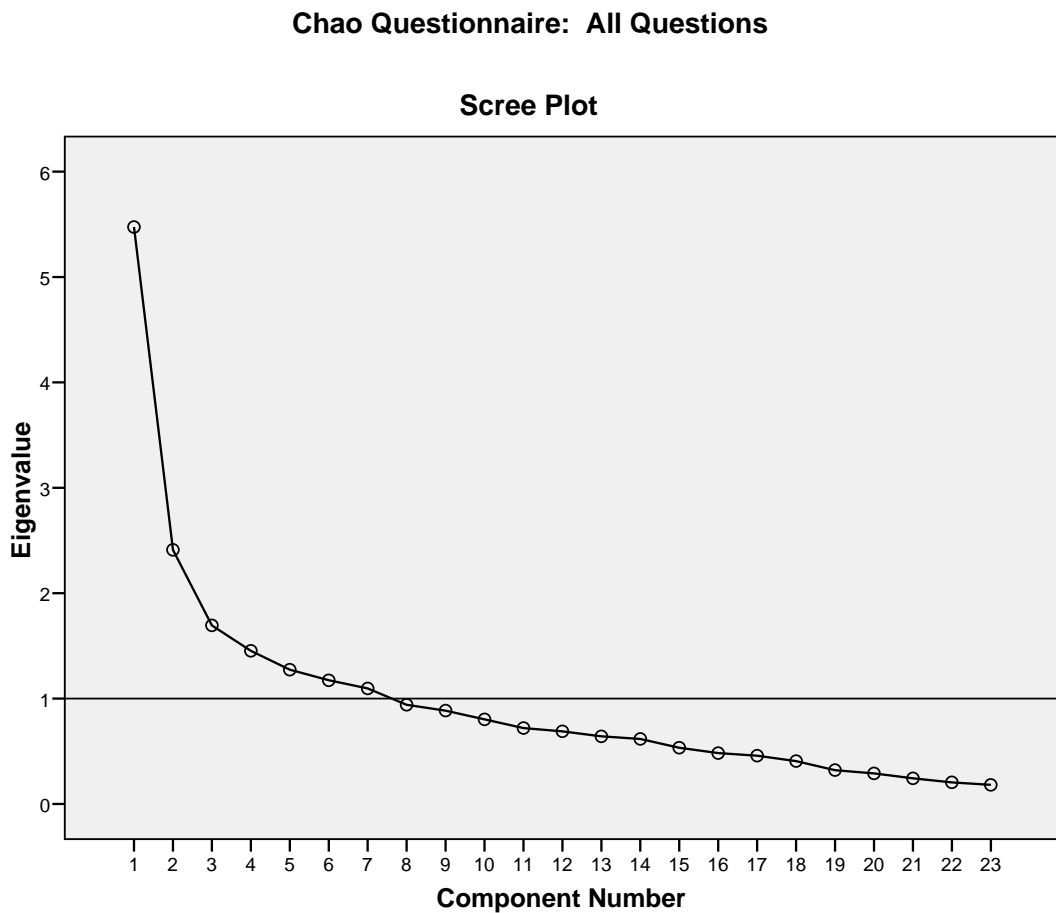
**Table 3.f Factor analysis: Communalities**

	Initial	Extraction
Provides Pre-admission Care	1.000	0.810
Knowledge of Family Problems	1.000	0.769
Personal Problems	1.000	0.744
Trust Personal	1.000	0.724
Recognition	1.000	0.724
Knowledge of Family Members	1.000	0.714
On-going Relationship	1.000	0.674
Provides ER Care	1.000	0.673
Emergency Care Preference	1.000	0.670
Waiting For Own Doctor	1.000	0.669
Unrelated Medical Problems	1.000	0.656
Referrals	1.000	0.652
Prior Knowledge	1.000	0.623
Different Doctors	1.000	0.596
Poor Explanations	1.000	0.596
Location	1.000	0.590
Care For All Problems	1.000	0.583
Trust Recommendations	1.000	0.582
Ease of Communication	1.000	0.573
Medication	1.000	0.556
Past Medical Problems	1.000	0.545
Same Doctor	1.000	0.462
Unknown Problems	1.000	0.394

Extraction Method: Principal Component Analysis.

Figure 3.b below shows a Scree Plot which gives a graphical representation of the eigenvalues plotted against all the component factors. The point of interest on a plot of this type is the point where the curve starts to flatten. In this plot it can be seen that the curve flattens noticeably after factor 4 and becomes more or less a straight line thereafter. The reference line indicates the cut-off point of 1 which is the value taken as significant for eigenvalues. Note that factor 8 has an eigenvalue of less than 1, so seven factors were retained from this analysis.

**Figure 3.b Factor analysis: Scree plot**



The table on the following page (3.g) shows the loadings of the 23 variables on the factors extracted. The higher the absolute value of the loading, the more the factor contributes to the variable. The gaps on the table represent loadings that were less than 0.5, which were suppressed in the output to simplify the interpretation of the data.

**Table 3.g Factor analysis: The component matrix**

	Component						
	1	2	3	4	5	6	7
Different Doctors							
Past Medical Problems							
Medication							
Prior Knowledge						0.523	
Unknown Problems							
Unrelated Medical Problems							
Emergency Care Preference							
Waiting For Own Doctor				0.559			
Provides Pre-admission Care							0.533
Provides ER Care							
Location		0.623					
Personal Problems		0.518				0.551	
Trust Personal	0.835						
On-going Relationship	0.707						
Recognition	0.630						
Care For All Problems	0.626						
Knowledge of Family Members	0.619						
Poor Explanations	0.614						
Trust Recommendations	0.605						
Knowledge of Family Problems	0.596						
Referrals	0.585						
Ease of Communication	0.546						
Same Doctor	0.523						

Extraction Method: Principal Component Analysis.

a. 7 components extracted.

In the final stage of analysis, the factors were rotated in order to maximize the relationship between the variables and some of the factors. The purpose of rotation is to make the interpretation of the analysis easier by reducing the number factors on which the variables under investigation load. A rotation which requires the factors to remain uncorrelated is an *orthogonal* rotation, while others are *oblique* rotations. Oblique rotations may achieve a simpler structure but can be more complicated to interpret. Rotating the data does not alter the model fit, and in practice different methods of rotation may yield very similar results. For this analysis an orthogonal (varimax) rotation was selected thus minimising the number of factors and maximising the sum of variances of the loadings.

The table (3.h) on the next page shows that all the variables related to trust and interpersonal relationships were substantially loaded on Factor (Component) 1. Variables measuring knowledge and information load on Factor 2 (with some overlap with Factor



1), while the remaining variables, which measure other aspects of care were dispersed across Factors 3 to 7, and were less easily categorised.

**Table 3.h Factor analysis: The rotated factor matrix<sup>6</sup>**

	Component						
	1	2	3	4	5	6	7
Past Medical Problems							
Medication							0.687
Care For All Problems							
Unrelated Medical Problems						0.661	
Personal Problems						0.830	
Ease of Communication							
Poor Explanations							
Emergency Care Preference					0.805		
Waiting For Own Doctor							-0.758
Provides Pre-admission Care				0.881			
Provides ER Care				0.544	0.555		
Different Doctors			0.693				
Location			0.544				
Unknown Problems			0.516				
Knowledge of Family Members		0.811					
Knowledge of Family Problems		0.740					
Prior Knowledge		0.565					
Referrals	0.746						
Trust Recommendations	0.710						
Same Doctor	0.598						
Trust Personal	0.558						
Recognition	0.504	0.574					
On-going Relationship	0.500	0.511					

### 3.5.4 Interpretation

Given that the Chao PC Questionnaire was originally designed to test Banahan's Attitudinal Contract theory of continuity, it was not unexpected that attitudes like trust and relationships would be prominent in the factor structure of the measure. In that respect the questionnaire met its stated aim: Factor 1 contains variables that can be broadly categorised under the heading of "Trust". While some items in this category are clear statements of trust (for example Item 2O "I trust my doctor"), others are more ambiguous. Item 2J "My doctor provides appropriate referrals to other specialist" for example is one item which requires two separate judgements as it asks not only about

<sup>6</sup> Table 3.h: Notes

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization

Rotation converged in 12 iterations.

Values below 0.5 have been suppressed

the provision of referrals but also the “appropriateness” of them. This implies an assessment of the quality of the referral or the confidence that the patient has in it which, in turn, could of course be construed as a measure of trust or respect for the doctor’s decision.

Items 2A “*I feel that I have an ongoing relationship with a doctor*” and 2N “*My doctor would know me by name if we met in the street*” are present in both Factor 1 and 2 but are slightly more weighted to Factor 2, and indeed fit well with this factor which appears to represent the depth of knowledge that resides in the doctor-patient relationship.

Factor 3 is more difficult to interpret but appears to capture items in the questionnaire which measure consistency of care like seeing the same doctor, the location in which care is received and the depth of knowledge that the doctor has of the patient. Beyond Factor 3, the remaining significant eigenvalues fall below 1.5, and lie close to the cut-off point. They each contain only two items in the rotated matrix. Factors 4 and 5 have items related to acute care, and share one item in common. Factor 6 has two items which refer to problems (medical and personal) and Factor 7 has two apparently unrelated items: “*The doctor has a list of all the medicines which I am taking now*” and “*I would rather see a doctor right away, instead of waiting a day or two to see my own doctor*”

These findings support a three factor structure for the Chao questionnaire in this sample of stroke survivors, although together the first three factors account for only 41% of the total variance.

## **3.6 Discussion: Testing a measure of care**

### **3.6.1 Contextual issues**

The Chao PC questionnaire was designed for use in a primary care setting but this did not seem to be problematic for the patient group in this study, all of whom completed the questionnaire in the post-acute stage. The patients were at home at the time of the survey and were asked to rate the questions in relation to their General Practitioner. Notwithstanding this, it should be noted that the wording of some items was confusing for patients, and it was sometimes unclear whether they were rating responses in respect of hospital medical staff or their GP. This was particularly apparent when questions referred to hospital care, since all the respondents had been

hospitalised as a result of their stroke in the preceding 6 to 12 months, and were being seen in the context of a stroke-focused cohort study.

The Chao PC was developed around Banahan's specific model of continuity. Content validity cannot therefore be judged against the multi-axial definitions of Freeman and the CHSRF, although certain items in the questionnaire allude to aspects of continuity found in the three element model derived by the CHSRF. There are references to the informational and managerial elements of continuity, for example Question 1D: "*The doctor has a list of all the medicines I am taking now*" and Question 2J: "*My doctor provides appropriate referrals to other specialists.*" In the main, however, the questions are focused on the patient's satisfaction with, and trust in, their relationship with their doctor. Many of the questions could also be construed as representing ratings of the quality of their care.

A chronological context is implied in the Chao measure but it is ill-defined and items do not differentiate between care received at different time-points or for different stages of an illness. This may have contributed to the confusion of patients, especially as they were used to a different type of health care system from that for which the questionnaire was originally designed. It also means that the measure lacks a temporal element, which is found in more recent Freeman and CHSRF definitions of continuity of care.

In the stroke sample, differing family circumstances may have accounted for some discrepancies in responses because, while a wide age range was represented in the study sample, many of the patients were older (median age 69 years) and some lived alone. As a consequence the questions about family medical care such as Questions 2D and 2F (see Section 3.3.1, page 109) were confusing as even married couples did not necessarily attend the same GP surgery, and few patients in this sample had dependent children living with them. Given that this cannot be a difficulty that is unique to stroke, it is an area that would require revision if the questionnaire were subject to wider use.

Specific problems with the format of questions in this study, identified from the patient feedback, arose either as a consequence of the different healthcare system (USA) for which the Chao measure was originally developed, or because the sample was drawn from an older population. The items about family care (2D and 2F) have already been mentioned in this context and those about hospital and emergency care (Questions 2K

and 2L) were not easily interpreted by patients familiar with a national health care system. Wider application of this measure would require the wording of these questions to be adapted in order to clarify them for a UK NHS patient population.

### **3.6.2 Scoring the questionnaire**

The data collected from the postal survey, in particular, had a high proportion of missing values and this, combined with the effects of inconsistent rating of the intermediate values reported by patients, was an obvious source of bias. In particular, the use of “*uncertain*” as the label for the mid-range value (3) in the format of the original questionnaire was unhelpful when summing the data. Patients frequently used this option when they were not sure what the question meant rather than meaning (as intended) that they were not sure about their response. In view of this a further recommendation for the modification of this questionnaire for wider application would be an amendment of the response categories, either by re-labelling the intermediate value “*neither...nor*” or by creating an additional missing value option for “*not applicable*” or “*not sure*”. The latter was the approach piloted in the postal survey conducted in Study 3 in an attempt to reduce data loss.

### **3.6.3 Factor structure of the questionnaire**

An exploratory analysis of the underlying structure of the Chao PC using Principal Components Analysis revealed the presence of several significant factors. When the items contributing to these factors were examined the two strongest factors could be interpreted as representing the two concepts of “*Trust*” and “*Inter-personal knowledge*”. This would correspond with the original purpose of the questionnaire, which aimed to operationalise continuity of care in terms of Banahan’s attitudinal contract. This concept of continuity as a mutual relationship in which the doctor assumes responsibility for care and the patient relies on the doctor for their care could be envisaged as having trust as its core component, and that trust might be established or enhanced by mutual knowledge and understanding. A third weaker factor had two items which related specifically to care delivery and a third which could be indirectly associated with personal knowledge. This factor could be labelled as “*consistency*” of care but could also be fitted into the “*Inter-personal knowledge*” category. Overall however, the three stronger constructs contributed to only 41% of the variance in the phenomenon being measured.

The four weaker factors were harder to interpret and contained items representing other facets of care, some of which could be aligned to aspects in the accepted models of continuity of care, and others which were less clear in their associations. The bias introduced by missing data, lack of clarity and inapplicability of certain items may have exacerbated this ambiguity in the findings to some degree. When combined with the three stronger factors, 63.4% of the variance in the total measure was accounted for but a large proportion remained unexplained. It is reasonable to assume therefore that many items within the measure corresponded to unrelated aspects of care.

### **3.6.4 Reliability, validity and sensitivity**

The original Chao study reported high internal consistency and reliability for the Chao PC scale but extensive testing of the psychometric properties of the questionnaire has never been undertaken. It was tested for external validity against the Continuity of Care and Usual Provider Continuity indices but only a modest association was found with these measures. (Reid *et al.*, 2001) Neither was any association shown with other external factors like the economic costs of care in the original study. The Chao PC scale did however show a strong association with patient satisfaction. (Chao, 1988)

In Study 3, the results suggested that the Chao measure was not particularly sensitive to those factors that might be expected to drive care patterns, for example differences in respondents' ages or levels of dependency. Only those outcomes assessed by the mental health dimensions of the instruments used in the cohort study showed any association with the Chao scores. Moreover, given that this questionnaire is a self-report measure the results suggest that it is mood responsive; a finding which would be consistent with a questionnaire that measured satisfaction with relationships rather than one that described care itself (Kressin *et al.*, 2000).

There were also items in the questionnaire that contained more than one idea or concept; for example Question 1F: "*My medical care improves when the doctor has seen me before*" and Question 2J: "*My doctor provides appropriate referrals to other specialists*". In quantitatively assessed questionnaires psychometric design guidelines advise that items contain single constructs in order to facilitate analysis and reduce bias in the responses.

The factor analysis carried out in Study 3 identified trust, inter-personal knowledge and consistency of care as the principle constructs measured by the Chao PC scale. Given

that it was designed to measure the Banahans' Attitudinal Model of Continuity, the major portion of which relates to mutual trust and responsibility, this finding suggests that the construct validity of the questionnaire remained fairly robust in this stroke population. However, the three major factors identified accounted for less than half the variance in the overall measure and four weaker factors, comprising miscellaneous items, suggested that the content validity of the overall measure may be questionable. Unfortunately, the presence of multiple concepts within individual items hindered factor analysis and an accurate evaluation of the underlying structure of the Chao PC scale.

The Chao PC clearly has some potential for measuring relational continuity but would require a process of refinement to create a modified instrument based on the observations of its application in this study, and the factor extraction information. Further testing would then be required. In its current format it does not offer sufficient scope to measure the elements of continuity in the currently accepted model nor to assess effectively the processes of stroke care and the mechanisms that support them. Additional items would need to be incorporated in the measure to address this particular issue. However, given that the Chao PC was designed as a patient self-reported instrument, and that Study 2a had shown that indicators of managerial and informational continuity that patients would recognise were not easily identified; further work to modify the Chao PC was not considered a practical option for the next stage of this study.

### **3.7 Summary: Study 3**

The second strand of research for this thesis was undertaken to investigate the evaluation and quantification of care. The first study to explore this research theme (Study 3) took an existing measure of continuity of care (the Chao Perception of Continuity Scale) and evaluated it in a cohort of stroke survivors. As the Chao questionnaire was designed for a primary care setting, only patients who had been discharged home following their stroke event were surveyed in order to determine how continuity of care might be perceived in the post-acute stroke phase. The Chao PC questionnaire proved to be mood responsive and did not discriminate between patients on the basis of any physical or illness characteristics that might influence the care they received.

The factor structure of the Chao PC was then explored in a Principal Component Analysis. The model derived suggested a three factor structure: *trust; inter-personal*

*knowledge and consistency of care.* At least two of these factors could be considered to correspond with the Banahan's concept of continuity that the measure was designed to test. A further confirmatory factor analysis would be required to explore this finding further. Nevertheless, although the Chao PC has potential for the measurement of relational continuity, it does not have the scope to measure managerial or informational continuity. Consequently it was concluded that it did not provide a method of evaluating continuity which was consistent with a definition of continuity residing in the process of care.

It was not possible to derive an entirely patient-driven measure of continuity from the empirical qualitative data that was the output of the first strand of work, and no simple available measure was found that could be used "*off the shelf*". Therefore in the next phase of this strand of research two new instruments were developed: one of which used information recorded in the care notes and the other an interview, which was designed to assess patients' views and perceptions. Each measure used the *a priori* framework of managerial, informational and relational continuity derived from the CHSRF model, and was structured around the main phases and transitions in the stroke care process: admission, acute care, post-acute and rehabilitation care, discharge, community rehabilitation, nursing and social care.

## CHAPTER 4 Quantifying Continuity and Evaluating Care

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### 4.1 Developing the measures

#### 4.1.1 *A checklist to evaluate records of care processes*

The organisation of stroke care is complex and patterns of care vary depending on the configuration of services in the area in which a patient resides. Factors like the age at which someone suffers a stroke, for example, may determine how and where they will be cared for. The main focus of measurement of continuity in this thesis was patient-centred and the qualitative study (Study 2a) had shown that the CHSRF model of continuity was the most useful framework in which to interpret the patients' accounts of care. This three element model was therefore chosen to underpin the development of the continuity checklist.

Key stages and transitions in the care processes of stroke patients in the locality where this study was carried out were identified by reviewing formal records of care in Study 2, and by listening to patients' narratives. The stages of care, and potential process indicators and their source, are shown in Table 2.b (page 98). Guided by the data points collected by the Sentinel Audit, aspects of the stroke care process were then selected that were hypothesised to be both important for good quality stroke care and relevant to the elements in the CHSRF definition of continuity of care. (Gompertz *et al.*, 2001, Reid *et al.*, 2001) Consideration also had to be given to the sort of information that would be recorded routinely either in the hospital or community case notes. The items were organised to represent a longitudinal pathway through care and to cover aspects of management, (records of assessment and monitoring procedures) and evidence of information transfer (discharge summaries and referrals) in the various phases. However, operationalising an assessment of continuity of care providers from case note records carried out in Study 2b. (See Section 2.9, page 95) had proved unsuccessful due in part to the nature and complexity of stroke care. The number of care providers and frequency of contact were driven by the level of dependency of the patient. Hence the relational element of continuity was addressed in the checklist by recording changes in consultant in charge of care and the provision of a named contact on discharge.

In order to assess the extent to which aspects of the stroke care process had contributed to continuity of care for the patient, indicators were either scored as present



or absent, or rated on a three point scale: positive (+1); negative (-1) or stable (0). Modifying variables were also included in the checklist, for example early discharge and age less than sixty-five years, to allow adjustment for factors which were known to influence care processes. The scoring criteria, which were designed to apply to both the checklist and the patient-centred measure, are shown in Table 4a, (page 132). Derivation of scores will be discussed in more detail in Section 4.1.3 (page 131).

The new measure was called the Snakes and Ladders (SnL) Index because it described the sometimes perilous journey through inpatient care, with the potential for both progress and setbacks. The checklist was piloted and refined on a sample of case notes. A final version of the SnL Index can be found in Appendix G (pages 283 - 285).

#### **4.1.2 A patient-perceived measure of care processes**

A quantifiable assessment of care from the patient's perspective requires a set of clear, consistent indicators that the patient can rate. First attempts to construct a questionnaire to enable the self-reported assessment of patient-perceived continuity in the process of stroke care failed because it was not possible to derive patient-centred indicators from the accounts of care. A different approach was therefore required, and this led to the adoption of an interview format. Questions were asked about the patient's views of different stages and processes of care, based on the themes and stages of care which, from the findings of the qualitative study, it was known patients could recognise

A number of standardised psychiatric assessments, including for example the Present State Examination (Wing, 1974) and the Structured Clinical Interview for Depression (Spitzer *et al.*, 1990), are interview-based. Patients are asked a series of questions about psychological symptoms, the responses to which are rated against specific criteria in order to ascertain clinical diagnoses of mood, anxiety and psychotic disorders. Correspondingly, the patient-centred measure (PPCI) employed a semi-structured interview to ask questions that patients could answer about their experiences of care. This permitted a flexible approach to measurement which allowed for individual variations in the accounts of care. Notwithstanding that a patient-centred measure should ideally be self-reported, this method offered the best option for extracting quantitative ratings from a set of incongruent and sometimes complex data. A patient-derived definition was lacking and therefore specific indicators could not be

formulated for patients to rate themselves. Using the interview approach it was also possible to include an assessment of informal care, which is never formally documented or recorded, and can only be evaluated through the accounts of patients and others close to them. Only two interviewers conducted the PPCI assessments, the author (KH) and Helen Brooks (HB), who was trained and supervised by KH. A continuous monitoring and standardisation of the ratings was maintained throughout the data collection period to avoid interviewer bias.

Developing and using the interview method was an extended process. A programme of testing and refining the schedule was required before it could be applied to the patients that were steadily accruing to the parallel SOS2 cohort. Interview methods are more time consuming to apply than a checklist style measure, and using interviewer ratings means that it is necessary to allow time for the review of tapes and the rating of interview responses. The original plan to rate items generated during the interview on a Likert scale proved impracticable due to the variation in input of care given and disparity in the type of care processes to which patients had been exposed. Generic scales could not be formulated that could be applied in a standardised way across all patient narratives. A different approach to scoring was required, one that enabled a more flexible scoring system to be applied. In order to achieve this, the patients' responses generated from the interview were rated against a set of pre-defined criteria using similar methods to those used for other standardised interviews. The criteria and scores are detailed in Table 4a (see page 132); the allocation of scores was made according to the same system as that used for the SnL Index. This is discussed further in the next section.

At the end of each interview, patients were asked to complete a short, self-report questionnaire section consisting of ten items. The first four items (adapted from the McGill Existential Well-being questionnaire (Cohen *et al.*, 1995)) were related to patients' perceptions of self in terms of recovery, dependence on others, control and enjoyment of life. Attitudes that could have an effect on the way patients perceived their care. The remaining six items were ratings of their perceptions of services. This second set of items was based on subjective judgments about care, which it was theorised might be confounding factors in measuring perceived continuity, for example quality of care and patient satisfaction. Elements were also included that were present in the existing and accepted models of continuity, and which it was known from the qualitative work that most stroke patients would recognise, such as coordination of care, level of input, information transfer and trust. During this part of the interview each

item was self-rated by the patient on a 10-point linear analogue scale using polarised descriptors at each end of the scale. Lower scores indicated a poor or negative rating for each of the items and higher scores a better (positive) response.

It was necessary to pilot several versions of the interview before a schedule was available that could be applied in the cohort study. This, and the initial protracted development phase, reduced the numbers available for inclusion in the final study group. The ultimate version of the instrument, called the Patient-Perceived Continuity Interview (PPCI), was used in the next stage of the study and can be found in Appendix H (pages 286 – 291).

### **4.1.3 The scoring system**

A measure of continuity in care processes required not only rateable indicators but also a method of quantifying the different types of rating to be applied to the processes of care. In this way there was the potential to derive an overall score for continuity in the care process. As mentioned above, items were initially rated on a 5 point Likert scale, using descriptors relevant to the variables being measured. This type of measurement was piloted in the initial version of the PPCI and used in the first 32 interviews. This method of rating proved difficult to apply to the type of responses generated by the PPCI, as it was not always possible to differentiate the data generated from the patients' interviews in order to attribute a rating on a 5-point scale with any degree of precision or reliability.

The SnL checklist data presented similar problems to the researcher using Likert scale ratings. This was due mainly to the difficulty of differentiating scores on the basis of the information or detail that was available from the cases notes. As a consequence a simpler quantitative approach was taken in place of a Likert scoring scale. This method attributed each item (or discrete experience) as having a positive (+1), negative (-1) or stable/no change (0) effect on the patient's overall progress through care. Using this approach meant that the same scoring system could be applied to both measures with the exception of the self-rated items, which were scored on a visual analogue scale as described previously on pages 131- 132. The criteria for attributing scores to checklist indicators and patient accounts are detailed in Table 4.a on the following page. No weightings were assigned to any specific aspects of care.

**Table 4.a Scoring criteria for the SnL Index and the PPCI schedule**

<b>Positive Score (1)</b>	<b>Negative Score (-1)</b>	<b>Stable (no change) Score (0)</b>
<p>Characterised by a deliberate or managed change in the care process perhaps representing an increase in specialist stroke care input or evidence of preparation for a progressive onward stage in the process of care.</p> <p><i>For example:</i> Named contacts given to patients or carers at discharge, referrals for appropriate out-patient therapy or intermediate care. If no ongoing care or therapeutic needs after discharge then evidence of discussion of secondary prevention. Clinical follow-up by the specialist stroke services or specialist nurse.</p>	<p>Characterised by a long delay, an extended gap in services or total failure in the process of care such as progression to an inappropriate stage in the care process or one that fails to meet the patient’s needs or expectations.</p> <p><i>For example:</i> Waiting times of approximately 6 months are standard for out-patient SALT therapy and, input not currently available from community sources. Difficulties often resolve before therapy is offered. A further example from a patient perspective would be a referral to Day Hospital care that does not meet expectations because of the low level of physiotherapy input offered and the unstructured nature of the care.</p>	<p>Characterised by evidence of appropriate care but transitions which have no positive impact on the progress of stroke specific care.</p> <p><i>For example:</i> Withdrawal of specialist care as a result of a clinical decision to change management.</p>

## 4.2 Study 4: Two methods of measuring continuity of care

### 4.2.1 Study aims and design

The qualitative exploration of patients' perspectives of continuity of care was described in Chapter 2. A full review of entries in hospital and community health care records to estimate the number and types of carers involved in caring for stroke patients was also undertaken. These two studies formed the basis of the enquiries conducted in the first strand of work: the patient's experience. The second strand of research, quantifying continuity, began with Study 3, an evaluation of an existing measure of continuity: the Chao PC measure. Together these three initial studies informed the development of both the Snakes and Ladders Index (SnL) and the Patient-Perceived Continuity Interview (PPCI).

After completion of the design and development of the measures, and the early piloting stages, the SnL and PPCI were tested in a sample of patients participating in the parallel cohort study: the Stroke Outcomes Study (SOS2). The aim was to apply the new measures of care to a sample of stroke patients in order to investigate:

- Firstly the feasibility of quantifying care processes using two different methods:
  - Study 4a: Measuring Continuity from Health Care Records.
  - Study 4b: Measuring Continuity from the Patient's Perspective.
- Secondly, the association between continuity of care processes (as measured by the PPCI and SnL) and outcomes for patients.

### 4.2.2 Methods

Running in parallel to this study of continuity of care was the Stroke Outcomes Study (SOS2) which was investigating early depressive symptoms and their effect on patient outcomes. The cohort study prospectively recruited 592 patients to participate in SOS2, 189 of whom remained eligible for inclusion in Studies 4a and 4b once the measures of continuity of care were prepared and available for testing. The recruitment procedure and eligibility criteria for the SOS2 study have previously been described in Study 3 (Chapter 3; Section 3.2.1: page 106), and in Appendix A (page 272).

SOS2 was longitudinal in design, collecting data at 5 time-points from each study participant in the year after stroke providing a detailed range of outcomes assessments in the year after stroke. The study of continuity of care involved only one research visit with the patient in order to conduct the PPCI interview and collect other relevant data not less than 6 months and up to one year after their stroke. Case note reviews were also completed for each of the patients interviewed either before or after their study interview to extract service data using the SnL checklist developed for the purpose.

The cohort did not include the severest of strokes, because they were either too ill or too cognitively impaired to participate. However, in other ways, for example in gender distribution and age range, the SOS2 cohort appeared to be reasonably broad in its representation of the stroke population.

Patients were interviewed either in hospital, in care homes or in their own residences. It was explained to patients that the exploration of continuity of care was a different research study, and that their participation was voluntary. All participants were given a written information sheet, and the nature and purpose of the interview and the case-note review was discussed with them. Written consent was obtained from patients before any study procedures commenced. The interviews and case note reviews for the study of continuity of care reported in this thesis were conducted by two researchers: KH and HB, under the supervision of KH.

Study 4a therefore involved a full review of hospital and community care notes to extract data using the SnL checklist, and Study 4b, a single structured interview with patients and their carers (if present) using the PPCI schedule. Both studies were conducted no sooner than a minimum 6 months after their acute stroke admission as earlier phases of the study had shown that it was more relevant to assess care processes in the post-acute stage, when a strategy for on-going care had been established. As an upper limit, the majority of patients were seen within 12 months of their index stroke event although a few were seen slightly later than this if interviews could not be arranged within the 12 month period.

### **4.2.3 Characteristics of the sample**

The first 32 eligible patients identified from the SOS2 cohort completed pilot versions of the PPCI. The remainder (N = 157) comprised a group of stroke survivors (82M/75F) with a median age of 72 years (Range 32 to 95 years). The patients presented with

varying levels of post-stroke disability: Barthel scores ranged from 1 to 20, but the median Barthel score of 19 supports the assertion that while it is relatively easy to recruit patients who are fit and well after a stroke, it can be difficult to encourage those who are more poorly or incapacitated to participate. Notwithstanding the fact that all the patients in this group had been recruited to the study of early depressive symptoms (SOS2), further consent to participate in the SOS3 study had to be sought from them and this process resulted in some dropout, details of which are shown below:

- 12 patients completed SOS2 but refused to take part in Study 4
- 19 patients had withdrawn from SOS2 and declined to be contacted again
- 9 patients agreed to case-note reviews but refused the interview (Study 4a only)
- 2 patients were incapable of interview
- 6 patients died before consent could be sought
- 1 patient died after consenting to participate but before the interview was arranged

From the original sample of patients this left 113 (72%) with whom PPCI visits were completed; and 126 (80%) sets of case-notes available for SnL checklist reviews. The limitation of the sample selection method and the final sample studied are discussed in Chapter 6, Section 6.5.3 on page 259.

#### **4.2.4 Plan of analysis**

The analysis plan for the quantitative studies (Study 4a and 4b) was to undertake a series of standard statistical tests:

- To describe the basic demographic characteristics of the sample studied;
- To describe the variables measured;
- To test the internal validity of the new measures;
- To examine the associations between scores on the new continuity measures and the demographic characteristics of the sample;
- To examine associations between scores of the new continuity measures and outcomes;
- To undertake more complex modeling of the data (if appropriate).

The data set contained a mixture of variable types. Therefore descriptive statistics were produced using both medians and ranges, or means and standard deviations, as applicable.

The new measures contained predominantly categorical variables but, in view of the heterogeneous nature of the items in the new measure, testing the inter-item correlations, or the use of split half techniques, would not be meaningful. Item-total correlation tests were thus applied as a measure of internal consistency to indicate the extent to which individual items differentiated between high and low scores for the phenomenon. This method required the calculation of standard deviations for each item as an indication of differentiation. All standard statistical tests were therefore run initially using both parametric and nonparametric methods to check whether the two approaches generated consistent results.

Only minor differences were found by applying the two methods. Therefore parametric statistics were selected as the main reporting method for the data. A clearer pattern of discriminatory characteristics could be shown by presenting mean values and standard deviations. The non-parametric results have not been presented in their entirety as listing both sets of values would have increased complexity without improving the interpretation of the findings. Discrepancies in the two methods have instead been indicated in the foot notes of the relevant tables of results.

Distributions in the data have been illustrated by histograms either in the text or in Appendices J and K. Chi-square or Student T-tests were used where appropriate to test for associations and all statistical tests considered a significance (alpha) level of 5% ( $p\text{-value} = 0.05$ ) as a minimum criterion for rejecting a null hypothesis. The results of significance tests have been given to three decimal places, and confidence intervals reported where appropriate.

After reviewing the characteristics of the data and the results of the basic tests, the analytical strategy was developed with the assistance of an expert biostatistician, Dr Robert West (RW). It was decided to carry out a factor analysis of the two new measures to explore their underlying structure. KH had used a Principle Components Analysis to identify the factors present in the Chao PC scale but RW suggested Structural Equation Modelling class as a more sophisticated approach, which would identify the latent constructs of the PPCI and the SnL. The latent constructs could then be used to calculate latent variables which in turn could be entered into a regression



model to investigate the associations of the new measures of continuity with outcomes for patients.

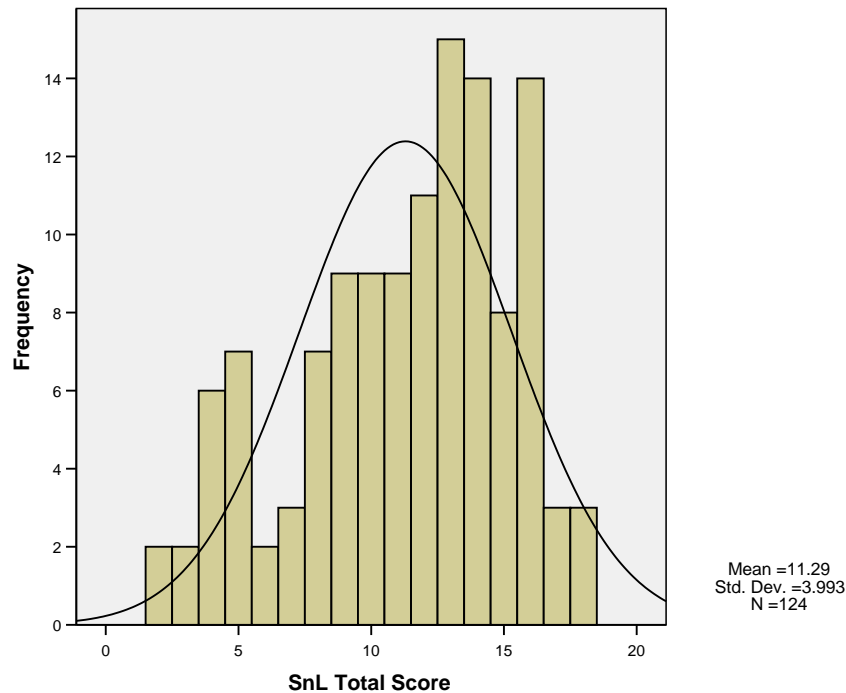
The standard statistical tests described in this chapter were conducted unaided by KH using SPSS Version 14 software; the more complex modelling of the data reported later in Sections 4.9 to 4.12 (pages 178 – 197) required the advice and assistance of, Dr. Robert West (RW).

### **4.3 Study 4a: Measuring continuity from health care records**

The Snakes and Ladders Index was developed specifically for the study as described earlier in this chapter (Section 4.1.1, page 128). It comprised 29 rateable items that used selected indicators to rate care processes from the information that was available in the records. An ordinal scale was used to rate items against pre-defined criteria with values of minus one, zero and plus one to represent:

- discontinuity in the care process (-1);
- no positive effect (0);
- positive continuity of care processes (+1).

This was adopted in preference to an ascending scale starting from 0 or 1, and was designed so that a higher total score would represent better care processes as described in Section 4.1.3, (pages 131 – 133). A simple aggregation of the scores for the 29 items shows a distribution of scores throughout the range of data which is biased towards the higher end of the total score range. Figure 4.a on the following page shows the total score distribution.

**Figure 4.a Histogram of SnL Index total score showing normal curve**

### 4.3.1 Validating the SnL

There was a high proportion of missing data in the variables due to the diverse care needs of the participants. Unfortunately this precluded the option to calculate an alpha value for the index to test associations between the variables. Two researchers (KH and HB) completed reviews of the clinical records and inter-rater reliability was tested by independent ratings of a sample of 10 sets of notes, the scores for which were then compared. No discrepancies were found in the ratings when cross-checked. Quality was maintained by a random check of the SnL forms by the lead researcher on the project (KH) throughout the review period.

No gold standard measure existed against which to assess the validity of the SnL Index. Other record-based measures had been found in the literature search but these focused almost exclusively on single indicators: for example the number of contacts with providers (the CoC Index), (Bice and Boxerman, 1977) or the number and content of clinic letters. (Anderson and Helms, 1993) Therefore, in order to investigate the properties of the SnL Index, an Item-Total correlation analysis (I\_T Analysis) was applied. Each item in the index was deducted in turn from the total score, and the

remaining item totals compared for each category of the excluded item. This method of analysis was used to identify items which showed differential scores between the proposed positive and negative indicators of continuity measured by the SnL Index, thus giving an indication of the internal consistency or homogeneity of the tool by showing how much each item contributed to the overall phenomenon being measured. A value of twice the standard error of the mean score was used to define “meaningful” differences in scores, and thus items which graduated in the same direction could be regarded as measuring the same or related themes.

### **4.3.2 Results**

126 (80%) hospital case-notes and GP medical records were authorised for review by patient consent: 105 sets (67%) were finally completed; 16 sets of hospital medical records could not be retrieved either from the medical records library or by contacting the last known location to which they had been booked out. Access to 5 sets of GP notes was denied by the medical practice at which they were held.

Checklist scores were obtained for 105 sets and total scores calculated. The results showed that division into 3 scoring categories: positive, negative and no change, had resulted in small numbers of patients present in the “no positive effect” and the negative, “discontinuous” care categories. There were none at all in these categories for certain variables. Given that the chosen indicators were selected as markers of optimal stroke care, this result was not surprising as large numbers in the negative categories would be indicative of a service that was failing, something which was clearly not occurring in the localities where the study took place. In view of the distribution of scores therefore it was decided to create a bimodal instead of a tri-modal distribution for the SnL to use in the I\_T analysis.

A reaggregation of the scores was achieved by leaving the variables which only had values for two of the three original categories as they were, and combining categories for others on the basis of “best fit” for the criteria. For example: the categories in the variable *Ward Transfers* were recoded as shown overleaf:

<i>None or specialist transfer</i>	+1	}	<i>None or appropriate transfers only</i>	+1
<i>Medical Assessment Unit or Rehabilitation Transfer</i>	0			
<i>Other ward transfers</i>	-1			

Other variables such as *Stroke Unit Care* were recoded by combining the two lower categories so that only care on a designated specialist stroke unit scored +1. In addition the three items relating to community therapy were combined into “Any community therapy”, a process which reduced the number of rateable items to 26. While there are clearly some limitations to amalgamating items on the checklist, which will be discussed in a later section (see Section 4.4.2, page 145), it can be justified. Information about community therapy referrals was difficult to trace and the outcome of referrals often only came to light from GP records, usually in the form of a discharge letter from the community team. When therapy records were obtained, the review was only able to determine whether community therapy had been delivered (or whether the patient had been assessed for post-discharge input by a community therapy team). No judgement could be made about the appropriateness or otherwise of the therapy that was received by the patient.

The results for the I\_T correlation analysis are presented as means (standard deviations) and summarised in Table 4b on the following page. Some items, such as BP monitoring in hospital and medication review by GPs, were positively scored for all patients and were included in the summary because they were always reliably recorded. On the other hand, items that had been selected as potential indicators of continuity but for which data could not be obtained consistently for a large proportion of patients had to be excluded. Examples of items which fell into the latter category were records of contact telephone numbers being given to patients or carers at discharge, the use of patient-held records and input from a stroke care coordinator.

**Table 4.b The Item\_Total Correlations for the Snakes and Ladders Index**

SnL Items	ITC Totals		Positive Continuity		Sub-Optimal or Discontinuity		Difference Mean X minus Mean Y
	Mean	SEMean	N	Mean (sd) (X)	N	Mean (sd) (Y)	
<b>Section A: Acute and Rehabilitation Hospital Care</b>							
1.) Admission mode	13.10	0.35	36	12.92 (3.79)	69	13.20 (3.43)	-0.28
2.) Ward transfers	12.89	0.32	93	12.91 (3.32)	16	12.75 (3.86)	0.16
3.) Referrals to other specialities	13.14	0.35	34	13.29 (3.98)	68	13.06 (3.32)	0.23
4.) Change of Consultant	14.22	0.34	24	12.96 (3.32)	84	14.58 (3.53)	-1.62*
5.) Medical assessment: Standard	12.91	0.33	85	12.82 (3.42)	22	13.23 (3.60)	-0.41
6.) Medical assessment: Problem-based	12.72	0.33	105	12.79 (3.41)	2	9.00 (1.41)	3.79*
7.) BP monitoring: Hospital	12.85	N/A	105	12.85 (3.31)	0	N/A	
8.) Other risk factor monitoring: Hospital	12.97	0.33	95	12.98 (3.33)	6	12.83 (3.12)	0.15
9.) Stroke nursing assessment	13.11	0.31	70	13.69 (2.94)	37	12.03 (3.35)	1.66*
10.) Rehabilitation therapist assessment	12.95	0.33	84	13.25 (3.13)	12	10.83 (3.01)	2.42*
11.) MDT Review	13.93	0.35	61	14.21 (2.90)	10	12.20 (2.74)	2.01*
12.) Specialist Stroke Unit care	12.85	0.31	97	13.07 (3.19)	12	11.08 (3.65)	1.99*
13.) Documentation transfer	13.34	0.37	74	13.28 (3.19)	2	15.50 (4.95)	-2.22*
14.) Rehabilitation goal setting	14.20	0.58	26	14.38 (2.74)	4	13.00 (5.60)	1.38*
15.) Discharge planning	12.95	0.33	92	13.12 (3.32)	8	11.00 (2.78)	2.12*
16.) Home visit complete (if required)	14.50	0.52	32	14.69 (2.92)	2	11.50 (4.95)	3.19*
17.) Discharge advice to GP	12.19	0.38	99	12.30 (3.98)	16	11.50 (5.02)	0.80*
<b>Section B: Home and Community Care</b>							
	<b>Mean</b>	<b>SEMean</b>	<b>N</b>	<b>Mean (sd)</b>	<b>N</b>	<b>Mean (sd)</b>	<b>Difference</b>
18.) BP monitoring (GP)	12.24	0.39	99	12.19 (4.23)	14	12.57 (3.61)	-0.38
19.) Other risk factor monitoring: Primary Care	12.08	0.39	110	12.07 (4.17)	3	12.33 (5.03)	-0.26
20.) Medication Review	12.00	0.41	107	12.00 (4.25)	0	N/A	
21.) Aids & adaptations received	13.88	0.50	46	14.02 (3.37)	3	11.67 (5.77)	2.35*
22.) DSS Home Care	13.00	N/A	17	13.00 (4.01)	0	N/A	
23.) Day Hospital Care	15.00	N/A	6	15.00 (1.79)	0	N/A	
24.) Any Post-Discharge Therapy	12.58	0.49	62	12.77 (4.21)	7	10.86 (2.34)	1.91*
25.) Follow-up by Stroke Specialist	11.57	0.42	93	11.51 (4.22)	7	12.43 (4.68)	-0.92*
26.) Record of reassessment for targeted therapy at 6mths	13.07	0.67	17	13.76 (3.53)	12	12.08 (3.68)	1.68*

### 4.3.3 Item clusters

The indicators of continuity in care processes that were used in the SnL were chosen to represent the transitions and stages in the process of stroke care. Accordingly they could be aggregated, using consensus grouping, into the seven clusters of items that corresponded to broader categories of care as shown below in Table 4.c:

**Table 4.c Cluster groupings for the SnL Index**

Cluster Grouping	SnL Items
Admission Sub-group	1.) Admission mode 2.) Ward transfers 3.) Referrals to other specialities 4.) Change of Consultant 13.) Documentation transfer
Clinical Care Sub-group	5.) Medical assessment: Standard 6.) Medical assessment: Problem-based 7.) BP monitoring: Hospital 8.) Other risk factor monitoring: Hospital
MDT Sub-group	9.) Stroke nursing assessment 10.) Rehabilitation therapist assessment 11.) MDT Review 12.) Specialist Stroke Unit care 14.) Rehabilitation goal setting
Discharge Sub-group	15.) Discharge planning 16.) Home visit complete (if required) 17.) Discharge advice to GP
GP Care Sub-group	18.) BP monitoring (GP) 19.) Other risk factor monitoring: Primary Care 20.) Medication review
Community Therapy Sub-group	21.) Aids & adaptations received 22.) Community therapist 23.) Outreach Team (Bradford) 24.) Intermediate Care Team (Leeds) 25.) DSS Home Care 26.) Out-Patient Therapy 27.) Day Hospital Care
Stroke Care Follow-up Sub-group	28.) Follow-up by Stroke Specialist 29.) Record of reassessment for targeted therapy at 6mths

Total scores for the clusters were distributed across the range of scores with a similar bias towards higher (positive) scores as had been found in the total scores for the overall index. (Histograms are reproduced in Appendix J: Figures J1 to J7, page 292 - 294). Only two categories: admission scores, which had a normal distribution, and community therapy scores which were biased towards lower scores, differed from this pattern.

Data on demographic, and social and life-style factors were collected at baseline for every patient participating in the SOS2 cohort study. The mean scores for the clusters were compared on the basis of these factors for different sub-sets of patients in the sample using Student T-tests. The aim of this analysis was to investigate the potential for the SnL Index to detect differences in stroke care processes that were associated with certain characteristics of the patients in this sample. Age and area of residence for example were known to determine location and patterns of care in the areas studied; and gender or marital status could affect discharge arrangements depending on the availability and capacity of informal carers.

#### **4.3.4 Demographic factors and scores on the SnL Index**

The comparative analyses showed that the total scores for the SnL Index were not significantly different on the basis of any of the following socio-demographic factors: age, gender, marital, residential status or location (i.e. living in an area covered by the Community Stroke Team). Neither did these factors have a large effect on the cluster sub-scores. No differences were found between the genders for any clusters using parametric methods. One isolated result was found using non-parametric tests (see Table 4.d footnote). Neither was there a difference between scores based on postcode area of residence. The only effect of age was upon follow-up, the cluster for which older patients (>65yrs; n = 85) had lower (worse) scores ( $p = 0.05$ ) than younger patients (<65yrs; n = 33). One explanation for this finding could be that younger patients were more able to attend out-patient appointments than their older counterparts, either because they were fitter or because they had access to their own transport. Attendance for follow-up leads to a greater likelihood of reassessment for targeted therapy at six months thus a lower score on the first component is likely to result in a lower score for the second component of this cluster score. The provision of a stroke specialist nurse for younger patients (those under 65 yrs old) in the area studied, whose role includes recall of patients to her clinic after discharge, may also have had an effect on the number of patients seen for follow-up in the younger age

group. The results of the tests for differences in the mean scores are shown in Table 4.d (page 148).

Admission sub-scores were lower ( $p = 0.02$ ) for those in residential care ( $n = 9$ ) than those living at home or with relatives. This finding is more difficult to interpret because of the small number of patients represented in the residential care group; too few on which to base any sound explanation as the potential for bias is high and the result might have occurred by chance.

#### **4.4 Study 4a: The association of recorded care with outcomes for patients**

The second aim of this phase of research was to examine the association between continuity of care processes (as measured by the PPCI and SnL) and outcomes for patients. A range of outcome data for physical and psychological functioning were collected in the parallel cohort study (SOS2), the protocol for which conducted assessments at baseline and a number of time-points throughout the one year follow-up period. The measures were completed with patients at five time points in the SOS2 cohort study:

- T1: Baseline 2 to 6 weeks post-stroke
- T2: 6 to 10 weeks post-stroke
- T3: 12 to 14 weeks post-stroke
- T4: 24 to 26 weeks post-stroke
- T5: 52 weeks post-stroke

(See Appendix A for further details of SOS2 study procedures, pages 272 - 274).

Access to this series of assessments enabled a range of quantitative statistical tests to examine the associations and effects of continuity of care, as assessed by the new measures, to be applied.

##### **4.4.1 Measures of mood and well-being**

Two measures of psychological status were used to measure emotional outcomes in the cohort study (SOS2): the 28-item General Health Questionnaire (GHQ\_28) and the



Present State Examination (PSE). (Goldberg and Hillier, 1979, Wing, 1974) The PSE uses a standardised clinical interview method to detect the presence of symptoms and their severity. The likelihood of an affective or mood disorder can then be assessed against the ICD\_10 diagnostic criteria.

The General Health Questionnaire, a patient self-reported questionnaire, was developed by David Goldberg as a screening tool for use in epidemiological psychiatry. The original questionnaire contained 60 items but shorter versions have been developed to produce the GHQ\_28 and GHQ\_12. The items contained in the GHQ\_28, sometimes referred to as the scaled version, were derived by factor analysis from the original questionnaire. It is categorised into four sub-scales: somatic symptoms, anxiety, social functioning and depression.

The patients participating in Study 4 were all acute stroke patients presenting with a variety of different of physical states. The aim of this study was to investigate the effects of rehabilitation and recovery over time on both physical health and psychological well-being. For brevity the term mood has been used to describe the psychological status of patients. In the context of this study, mood encompasses a range of psychological, social and somatic symptoms that may be present to a greater or lesser degree, and which collectively may contribute to the diagnosis of a mood or affective disorder. The GHQ\_28 was selected for this study because it has been validated against clinical assessments like the PSE and because it is widely regarded as the best research tool available for the assessment of psychological status in non-psychiatric populations. The GHQ is also more often reported as a numeric variable than the PSE, and given the analysis plan for this study, an overall score for mood status for each patient was more important than the identification of a specific psychological diagnosis.

#### **4.4.2 Scoring methods**

Several methods of scoring the GHQ\_28 can be applied. The two most commonly used are the simple 0 or 1 bimodal scoring matrix that denotes the presence or absence of symptoms, and the 0 to 3 Likert scale scores that indicate not only the presence or absence symptoms but also some measure of severity for each of them. Both methods of scoring were used in analysing different stages of the study thus enabling the data to be used to best advantage in the statistical analyses. A cut-off score of 11 on the bi-modal scoring system, for example, enabled the designation of

“cases” and “non-cases” thus providing categorical data where appropriate for groups of patients and allowing methods of statistical analysis such as Chi-square tests and Student T-tests to be applied. The structural equation modelling reported later in this chapter required the full range of data to be used, and thus employed the Likert scoring system. The chronicity scoring method was not used in this study, although it could be considered as a method for exploring new facets in the data for future research papers. A system for scoring the SnL Index and the PPCI was developed by KH and has been fully explained in Section 4.1.3, page 131.

#### **4.4.3 Post-stroke disability**

The impact of the index stroke on physical function was assessed for the study sample by the change in post-stroke Barthel Index (BI) recorded at baseline from the pre-stroke score. The pre-stroke information was obtained either from the patient (if they were able to supply it) or, if not, then from a proxy rating by a carer or relative, or from health care records (if available). Higher impact was defined as a change of more than 3 points in BI post-stroke. When the effect of stroke severity was examined the results showed that this was the factor which had most effect on scores for the SnL. Cluster sub-scores for MDT care ( $p = 0.012$ ); Discharge ( $p = <0.000$ ); Community Therapy ( $p = 0.004$ ) and SnL Total score ( $p = <0.001$ ) were all significantly higher for patients with higher impact strokes. (See Table 4d, page 148) This finding was supported by the results for early discharge (length of stay  $<7$ days) and continence which revealed an almost identical pattern. Longer admissions and incontinence are both factors which are known to be strongly correlated with acute stroke severity and post-stroke disability.

These findings would be consistent with an index which measured the intensity of care delivered, a factor which had confounded the first assessment of care processes. In Study 2b, episodes of care and the number and types of carer involved in post-stroke care were calculated from case note reviews as reported in Section 2.9, page 95. These were found to be proportional to the physical status of the patient in the post-stroke period. The level of dependence and symptom burden (in terms of the disabling effects of the stroke) would thus seem to be the major determining factors when assessment of care is based on information recorded in clinical care notes.

#### **4.4.4 Mood and psycho-social factors**

All the patients recruited to Study 4a were participating in the longitudinal cohort study (SOS2), a study which investigated the impact of stroke on mood and psychological well-being. Consequently all had assessments of mood made at regular intervals throughout the first year of the post-stroke period. The total scores for the two methods of mood assessment used in the SOS2 study: the GHQ\_28 and the PSE were highly correlated with each other across all time points of the study. The results from Study 4a showed that mood had little effect on SnL cluster scores. No significant differences were detected in mood for any of the cluster sub-scores at any time-point using Student T-tests with one exception: the Community Care scores, which were lower for GHQ cases at the 3 month follow-up point. The difference was significant with a p-value of 0.022. In multiple tests of significance however this isolated finding could have arisen by chance.

Table 4.d (on the following page) shows only the results for the significant findings of the tests for differences in mean scores, reported in the three preceding sections.

**Table 4.d Factors differentiated by the SnL Index scores<sup>7</sup>**

Factor	SnL Variable	Mean difference <sup>(i)</sup> (95% CI)	t	df	p-value <sup>(ii)</sup>
<b>Age:</b> <65yrs old v >65yrs old	Follow-up	0.34 (0.00 to 0.68)	1.99	100	0.050
<b>Residential Status:</b> Residential Home v Living with someone	Admission	0.90 (0.10 to 1.70)	2.25	77	0.027
<b>Stroke Severity:</b> High v Low Impact (Change in BI >3)	MDT Care	-0.90 (-1.60 to -0.20)	-2.55	109	0.012
	Discharge	-0.75 (-1.14 to -0.36)	-3.80	118	0.000
	Community Therapy	-0.71 (-1.20 to -0.23)	-2.95	90	0.004
	SnL total score	-2.71 (-4.34 to -1.09)	-3.32	120	0.001
<b>Early discharge:</b> <7 days v >7 days	MDT Care	1.64 (0.97 to 2.31)	4.85	110	0.000
	Discharge	0.54 (0.14 to 0.95)	2.67	119	0.009
	Community Therapy	0.99 (0.39 to 1.59)	3.30	92	0.001
	SnL total score	3.03 (1.45 to 4.61)	3.79	121	0.000
<b>Continence:</b> Continent v Incontinent	Discharge	-0.68 (-1.10 to -0.25)	-3.17	116	0.002
	Community Therapy	-0.52 (-1.04 to 0.00)	-1.99	88	0.050
	SnL total score	-2.45 (-4.17 to -0.73)	-2.82	118	0.006
<b>GHQ Cases (T3):</b> GHQ >11 v GHQ <11	Community Therapy	0.76 (0.11 to 1.41)	2.33	91	0.022

#### 4.4.5 Pre-test and post-test items

The I\_T correlation analysis that was applied to the data correlated every item in the SnL Index with the total score separately to provide an indication of the degree to which each item contributed to the phenomenon being measured. When the response categories for all the rated items in the SnL checklist were compared, fifteen items were identified with a difference of more than twice the standard error of the mean (one means of assessing whether a difference is meaningful or simply a result of chance). The earlier table (4.b), on page 141 shows the full results of this analysis.

Although these 15 items seemed to have a differential effect, some of the results proved counter-intuitive and certain items showed a trend for negative ratings (discontinuity) to be associated with higher (better continuity) overall scores. For example: the item which rated changes in consultant (hypothesised as a potentially negative continuity effect) was associated with higher overall scores. Two further items

<sup>7</sup> Table 4.d: Notes

(i) Means compared using Student T-tests

(ii) Significance set at a 95%  $\alpha$ -level. Tests for remaining variables were not significantly different.

Results using non-parametric methods (Mann-Whitney Test) were the same except for gender: Females score were better on the Discharge cluster ( $p = 0.04$ ).

demonstrated the same effect: *Documentation transfer* and *Follow-up by Stroke Specialist*. However, since only a very small number of patients (2 and 7 respectively) were represented in the sub-optimal groups for these two items, the results must be treated with a degree of caution. Three broad categories were identified to define the problematic items in the SnL checklist:

- **Items for which it was not possible to collect data consistently from the case-notes:**
  - For example: The provision of contact telephone numbers to patients at discharge, which is done routinely but rarely recorded.
- **Items which were not contingent on health status or stroke severity:**
  - For example: All patients admitted to hospital following a stroke are given a medical assessment and subject to routine monitoring of blood pressure and other risk factors associated with stroke.
- **Items which showed an unexpected relationship to the total scores:**
  - For example: The item “changes in consultant” had a strong association with positive (better) overall scores for the cases that had been under the care of one or more consultants compared to those cases that had remained with the same consultant throughout admission. On review of the data it was clear that one explanation for this finding was that changes were associated with transfer to another specialist. However, although care on an Acute Stroke Unit demonstrated a trend in the same direction, no significant inter-item association with was found. Neither was any significant correlation found between them when tested in a contingency table using a chi-square test of the two categorical variables:  $r = -0.036$  and  $X^2 = 0.134$ . The implications of these apparently anomalous results will be discussed later.

Following a review of the results from the first stage of the Item\_Total correlation analysis, the items which did not contribute to the overall measurement made by the SnL Index were removed. This left a total of 12 items remaining. The I\_T analysis was then repeated for the reduced index. As Table 4.e on the next page shows, the remaining 12 items in the index all contributed strongly to the theme of the overall measure.

**Table 4.e Reduced item structure of the SnL Index**

SnL Items		ITC Totals		Positive Continuity		Sub-Optimal or Discontinuity		Difference Mean X minus Mean Y
		Mean	SEMean	N	Mean (sd) (X)	N	Mean (sd) (Y)	
Item No.	Descriptor							
Section A: Acute and Rehabilitation Hospital Care								
6	Medical assessment: Problem-based	5.45	0.26	105	5.52 (2.65)	2	1.50 (0.71)	4.02
9	Stroke nursing assessment	5.79	0.25	70	6.21 (2.08)	37	4.97 (3.14)	1.24
10	Rehabilitation therapist assessment	5.80	0.25	84	6.14 (2.21)	12	3.42 (2.54)	2.72
11	MDT Review	6.61	0.26	61	6.85 (2.05)	10	5.10 (2.33)	1.75
12	Specialist Stroke Unit care	5.59	0.25	97	5.80 (2.40)	12	3.83 (3.30)	1.97
14	Rehabilitation goal setting	7.43	0.37	26	7.73 (1.61)	4	5.50 (3.51)	2.23
15	Discharge planning	5.74	0.25	92	5.99 (2.37)	8	2.88 (2.36)	3.11
16	Home visit complete (if required)	7.06	0.40	32	7.16 (2.32)	2	5.50 (3.54)	1.66
17	Discharge advice to GP	5.13	0.28	99	5.27 (2.94)	16	4.25 (3.34)	1.02
Section B: Home and Community Care		Mean	SEMean	N	Mean (sd)	N	Mean (sd)	Difference
21	Discharge advice to GP	6.84	0.34	46	6.96 (2.26)	3	5.00 (3.61)	1.96
24	Any Post-Discharge Therapy	5.84	0.33	62	6.05 (2.75)	7	4.00 (1.83)	2.05
26	Record of reassessment for targeted therapy at 6mths	5.97	0.48	17	6.47 (2.37)	12	5.25 (2.83)	1.22

Reducing and rescaling the variables meant that the negative categories rated by each item were now consistently associated with lower overall scores and the positive categories with higher overall scores for the SnL Index. They also showed a correlation between higher mean item total scores and positive (better) care process category ratings and lower mean totals for sub-optimal or negative ratings. The re-defined indicators were thus contributing to overall measurement of the intended phenomenon. On the basis of this analysis the score for the modified 12 item measure was used for the next stage of the analytical process.

Comparative tests were repeated and scores for the modified 12-item SnL Index checklist examined again on the basis of pre-determined factors such as age, gender and marital status. The same criteria were used to define the groups as had been adopted for the preliminary analysis and T-tests were applied to the same clusters of symptoms detailed in Table 4.c (page 142). T-tests were deemed to be justified for this application because the analysis sought only to validate the initial findings rather than to test a hypothesis. However, mindful of the fact that some of the variables were not normally distributed, and some of the comparison groups had fewer cases than others, parallel tests were conducted using non-parametric methods (Mann-Whitney tests) to compare groups and Spearman's rho for measuring correlation between variables. Except where noted, parametric and non-parametric methods produced exactly the same results.

The factor that had the greatest impact on scores for the SnL Index remained disability measured by the Barthel Index, and those factors closely associated with it: length of admission and continence. These findings were significant even if the threshold alpha values were lowered to 99% ( $p = 0.01$ ). This was not surprising given that the items that had been identified by the I\_T correlation analysis as contributing most to the overall phenomenon being measured were those items which were contingent on the functional status of the patient, the degree of post-stroke disability or severity of the stroke event.

Older patients were still less likely to be followed up by a stroke specialist after discharge and living in a nursing home again had a detrimental effect on admission sub-scores. The isolated finding in the mood outcomes data was found again for the T3 (12 to 14 weeks post-stroke) GHQ scores whereby GHQ cases (those patients who had scored a total of 12 or more on the bi-modal scoring system, indicating higher mood and anxiety symptoms) were associated with lower scores for community care.

It must be noted however that this effect of mood was not seen at any other cohort study time-point. It is also important to note that reducing the alpha level to 0.01 meant that these three findings no longer achieved significance in contrast to the results for the functional variables which remained robust.

Overall these results clearly point to the SnL Index being a measure of the intensity of care input rather than a measure of any of the specific characteristics of the process of care. Patients with higher scores on the SnL Index would be likely therefore to be those in receipt of more therapeutic input or supportive care. Based on these findings it cannot be assumed that lower scores indicate a poorer (or less progressive) care process as care is generally proportional to need, and good care does not always necessarily mean higher levels of care.

## **4.5 Discussion: Measuring record-based care**

### **4.5.1 Using information from different sources**

Hospital medical and multi-disciplinary case-notes, GP medical records and other therapy or community care notes can only yield the information that has been entered into them. The format of care records varies according to the setting: in hospital notes for example the medical staff and (some) therapy staff write in the medical section of the notes, nursing notes are kept separately during the admission period and later filed in the patient's case-notes (usually after discharge) whereas notes in primary care are entered sequentially by all staff members including administrative staff dealing with correspondence or referrals. Specifically designated multi-disciplinary team (MDT) notes are found in some rehabilitation wards but, while stroke MDT care notes are good for tracking care within episodes, they function less well generically across different areas of care if they do not get filed with the patient's main hospital record.

Furthermore, although some aspects of the care process are routinely recorded and can be determined from the care notes there are also those which are not: verbal communications, for example telephone contacts with other external agencies or internal departments fall into this category, and are rarely recorded in hospitals although they are sometimes found in primary care notes. Associated written documentation may be generated for an episode of care but faxed referral letters, forms or investigation results are not always filed. In this study therefore, cross referencing between the records held by different agencies proved necessary to rate



aspects of care for which some records were incomplete but outcome was apparent from other sources.

Ward nursing notes are comprehensive but often swamped by routine details which render information difficult to retrieve. This problem is exacerbated by the non-sequential filing commonly found in nursing notes that occurs because they are kept separately during admission and later merged with other case-notes. Case-note files may (and frequently do) contain blank forms, either standard forms on which only the patient's name has been entered and no more, or multiple copies of the same types of form which have been started in different wards, or on previous admissions. These add bulk to the records, particularly those of the elderly with multiple co-morbid conditions, but usually add no information and moreover, remain in the notes in perpetuity since no-one has responsibility for maintaining individual patient files. In this study the most problematic reviews were of multi-volume case-notes which had information for related episodes filed randomly throughout.

#### **4.5.2 Rating the SnL Items**

The rationale for selecting indicators and defining the rating criteria was discussed in Section 4.1.3 (page 131). The items found which were straightforward to rate were those which involved the assessment and delivery of standard stroke care procedures. Medical, therapist and nursing assessments were clearly documented and procedures such as BP monitoring and reviews of prescription drugs were consistently evident in the records. Advice and monitoring of other risk factors for stroke such as smoking, poor diet, alcohol consumption and lack of exercise were also routinely discussed and recorded, both in the acute and community care sectors. These are all items which are not contingent on the physical status of the patient or the severity of their stroke event, and are part of the standard care process delivered to all patients admitted with acute stroke.

Records of Multi-Disciplinary Team (MDT) input were less consistent and depended largely on the length of the patient's admission. Early discharges (those who stayed for less than seven days) only had a recorded MDT discussion if they were in hospital on a day when a meeting was scheduled, or if their case required a specific discussion. This item was thus more likely to be contingent on the health and physical status of the patient. For the purposes of this study therefore, early discharges were rated as not applicable for MDT case handling unless they had a Barthel Index score of less than 19

when the item was rated according to actual MDT input. A corresponding approach was adopted for a number of other contingent items which could also only be rated on the basis of need. These related mainly to post-discharge care in the community and re-assessment for targeted therapy. These items were coded and aggregated as previously described in Section 4.3.2 (page 139).

The results highlighted some interesting (but unexpected) anomalies in the rating criteria. The CHSRF model had been used not only to develop items for the assessment of continuity in the stroke care process but also applied to the definition of the rating criteria, producing categories of items and ratings for continuity in managerial, informational and relational processes. One conventional interpretation of “relational continuity” is that it resides with the healthcare professional with overall responsibility for the management of an individual’s care at a particular time; for example the GP in the case of day to day health problems arising in the community setting. In acute care that role could be assumed to lie with the consultant in charge of the condition that had required admission to hospital, and would extend after discharge to consultant-led hospital out-patient care, if applicable. With this in mind one of the indicators that had been selected for the acute care phase was the number of consultants under whose care the patient had been during admission. Change in consultant was rated as a negative continuity event. The I\_T correlation results showed that the majority of the patients had at least one change in consultant, yet this seemed to confer an advantage in terms of their overall scores rather than detracting from them. (Table 4.b, page 141). One interpretation of this finding is that most stroke patients in this study were admitted through Accident and Emergency departments to the medical admissions unit (MAU) and transferred from there to Acute Stroke Units or general wards under the care of a stroke specialist. Thus a change in consultant was usually associated with a benefit to care, and rated as a positive score. This construal is supported by the large number of patients (93) whose transfer of ward was coded as appropriate, in other words transfer occurred mainly for specialist acute care or rehabilitation, under a stroke specialist.

This example plainly shows how simple indicators do not capture the more subtle aspects of transitions in care. Entries in medical records are routinely signed by the doctor who writes them but grades are not generally appended to entries made by senior medical staff. While some junior doctors (Senior House Officers and below) and some registrar grades will do so, others may not be identified in any way. Complicated criteria and a degree of informed judgement or special knowledge would be required by

a reviewer completing a measure like the SnL to determine an accurate rating against criteria framed in this way. This observation highlights one of the drawbacks of applying existing indices like the CoC index (which was developed for general practice), to care for complex conditions, like stroke, that require hospital admission and, in some cases, multi-specialty care.

The item assessing referrals was subject to a similar ambiguity in rating. Referrals to other specialties represent a positive progression in care if made appropriately when on-going health problems exist or new conditions are recognised or suspected. However, finding no evidence of referral does not constitute a failure of the care process unless it is known that a specialist referral was actually required. Clearly, this distinction cannot always be made on the basis of the entries in the notes alone, firstly because of the question of appropriateness and secondly because related information may be missing. To take account of this, a negative category was not used for this item and no referrals meant a score of 0 was allocated, the item scored +1 only if evidence of an appropriate referral was found. Appropriate referrals included referrals for vascular surgery, and other referrals for stroke related, pre-existing or newly diagnosed conditions. This solution was not perfect as it did tend to bias the scores of patients with more health problems and post-stroke complications in a positive direction thus contributing to the overall association of the SnL with physical health status.

Finally, three items proved difficult to rate from the case-notes. These related to contact numbers given to patients or carers at discharge, patient held records and contact with a stroke care co-ordinator (this role was disestablished with changes in joint care management in Leeds, and established in the Bradford area during the course of data collection). As a result, these items could not be included in the aggregation of the results because of the extremely high proportion of missing data (over 90%), and because of the changes in service provision in the two locations of the study during the data collection period.

The SnL Index was therefore subject to an ongoing process of development: trial and error showed how well the indicators performed when applied to this sample of patients' case-notes. Applying the measure showed too how early assumptions on which the SnL Index measure had been based were flawed and how it became necessary to adjust certain item ratings to take account of these. The strategy adopted of combining categories and eliminating variables, although subject to some of the limitations discussed above, enabled the best possible use to be made of the data that

had been collected in this exploratory study of methods of quantifying continuity in stroke from formal records of care.

### **4.5.3 What is the SnL Index measuring?**

The I\_T correlation analysis showed that indicators which measured common aspects of care, like medical assessment and blood pressure monitoring, were routinely done for all patients regardless of health status or where they were treated. They showed no association with the overall score in the SnL Index. Items relating to specialist care such as MDT input, specialist nursing and rehabilitation assessments, and transferring information across care boundaries demonstrated more impact on the overall score. One explanation for this finding is that these are all factors that provide a gateway to continuing services, and that the patients who are exposed to them are more likely to receive additional services, thus adding to their score. Nevertheless, this in itself does not necessarily mean that measuring these items constitutes a measure of continuity of the process of care as these factors also measure care input and intensity. Thus the association of scores for the SnL Index with severity of stroke and post-stroke disability are not surprising as more disability means more dependency and higher levels of care need; and by and large care is given in proportion to need. This finding suggests that the phenomenon being measured by the SnL is not continuity in the process but the nature and degree of the care delivered. A confirmatory factor analysis was therefore conducted to study the phenomenon measured by the SnL Index using more sophisticated methods. This is reported later in Sections 4.9 to 4.12 of this chapter, beginning on page 178.

## **4.6 Study 4b: Measuring continuity from the patient's perspective**

### **4.6.1 Method**

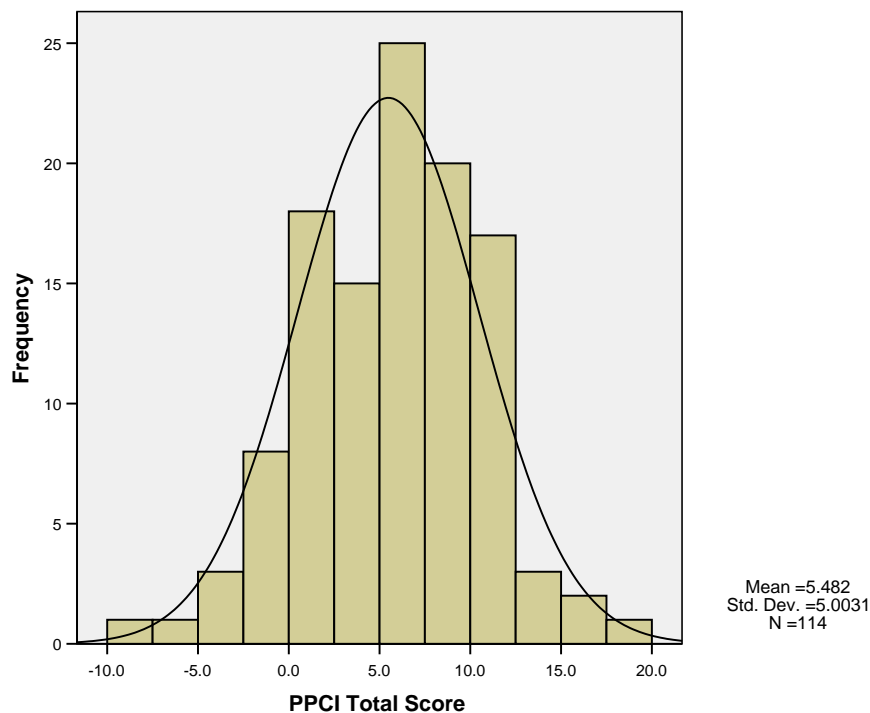
The assessment of continuity of care from the patient's perspective was conducted in the same sample of patients whose case-notes were reviewed using the SnL Index checklist, identified from the SOS2 cohort as described in Section 4.2. The initial sample thus comprised the same group of 157 stroke survivors (82M/75F) with a median age of 72yrs (Range 32 to 95). However, not all the patients who gave permission for their case-notes to be reviewed were willing (or able) to participate in the interview. A total of 113 (72%) interviews were eventually undertaken but, although

126 (80%) patients had consented to the SnL review, missing notes or difficulty retrieving or accessing notes meant that only 105 (67%) were finally completed. This meant a reduced sample of 97 (62%) patients had both a PPCI interview and a complete case-note review (including hospital and community care notes). This serves to highlight the problems of researching chronic illness. Not only can it be difficult to recruit participants in the first instance but samples can diminish gradually through the course of the study for a variety of reasons, most of which cannot be predicted or controlled by the researcher.

#### 4.6.2 Results

The PPCI schedule comprised 19 rateable items with indicators of continuity that were scored by the interviewer, based on the patients' responses to a series of questions. A simple ordinal scale was used to rate items against the pre-defined criteria using the same values as the SnL Index: minus one, zero and plus one to represent discontinuity (-1); no positive effect (0) and positive continuity (+1). The scaling was designed so that higher scores would represent better continuity in the care process. Figure 4.b below shows a normal distribution of total scores for the PPCI when ratings for the 19 items were aggregated.

**Figure 4.b** Histogram of PPCI total scores



The items on the PPCI schedule were structured using the same framework as that applied to the SnL Index but with altered terms of reference which covered themes of contact and relationships with health practitioners, the management of care and information transfer. The semi-qualitative nature of the PPCI schedule meant that it continued to evolve as the study proceeded. 32 patients in the study were interviewed using the final (Version 6) schedule but corresponding data points were retrieved from interviews using earlier versions of the schedule (81 patients). This minimised the amount of missing data that occurred as a result of the ongoing process of development. In addition to the items rated by the interviewer, the PPCI also contained a self-report section which patients completed after the interview. The results for the two parts of the schedule are reported separately because of their differing nature: the results of the interview study are reported first and the self-complete items later in Section 4.7 (page 167).

The interview used a standardised semi-structured method to collect the data. Responses to the questions were rated by the interviewer and given a quantitative value based on pre-defined criteria. This allowed flexibility in ratings to take account of the different patterns of care that had been identified in the preliminary qualitative study. The scoring categories designed for the criteria framework were the same as those used for the SnL Index but they were not combined for analysis in the same way. Although some variables and categories had few cases represented, unlike the SnL, none were present that had no cases at all. There was also a wider distribution of cases through the categories and it was important to preserve this detail in the data. The first approach to analysis was however exactly the same and an Item\_Total correlation analysis method as previously applied to the SnL scores was used. The results are presented as mean (standard deviation) and shown in Table 4.f (page 160). Median scores showed exactly the same pattern of results, as had been the case for the SnL Index.

A definite trend was revealed for negative response categories to demonstrate lower overall mean scores for all the items in the schedule but this effect was more pronounced than that seen in the SnL Index. The nature of the data and the different method of obtaining it offered an explanation for this finding: intermediate categories, for example, were much harder to define for data extracted from case-notes where ratings tended to fall more readily into yes/no; present/absent and done/not done categories. By contrast, it was also possible (in most cases) to explore the events reported in the interview using probes to clarify the responses and thus to obtain more

detailed information to assist the rating of items; something which was not feasible when rating items from clinical or other care notes. Moreover, as it was the patient's view of care that was being assessed by the PPCI, most of the items in the schedule applied to all patients in the sample whereas the SnL checklist contained many items that related to the delivery of services that had not been received consistently by all the participants in the study.

It is interesting to note that the interviews revealed some discrepancies between the services which were recorded as being delivered and the services that patients recognised as having been received. The most obvious example of this was in community care assessment. Referrals to, and visits made by, the Intermediate Care Teams or other community therapy or care services for assessment were recorded as positive indicators of continuity of care on the SnL checklist even if they did not result in a service input. This was considered appropriate because they are indicators of a process of care being applied (assessment), albeit one that does not always result in an intervention being offered. Patients, however, rarely reported care assessment episodes spontaneously and only considered that these situations represented continuing care if actual therapy or other service had been received as a result. Consequently 84 incidents (84% valid cases) of any type of community care were recorded on the SnL Index checklist from the case-note reviews but only 36 patients (31%) reported these type of events in the PPCI (although 80 patients did report receiving or being assessed for an aid or adaptation to their home when specifically asked about it). This has implications for the measurement of continuity and will be discussed in a later section. It also echoes some of the findings from the qualitative study which identified a mismatch between patients' recognition and recall of contact with health care practitioners from professional definitions of episodes of care.

**Table 4.f The Item\_Total correlations for items in the PPCI**

PPCI Items	ITC Totals		Positive Continuity		Some Continuity		Discontinuity	
	Mean	SE Mean	N	Mean (sd) (X)	N	Mean (sd) (Y)	N	Mean (sd) (Z)
1.) Admission	5.36 (4.74)	0.50	37	8.11 (3.73)	29	4.14 (3.64)	24	2.58 (5.18)
2.) MDT meeting	5.54 (4.81)	0.46	26	8.23 (4.08)	58	5.12 (4.78)	23	3.57 (4.51)
3.) Home visit	5.74 (4.78)	0.49	45	7.56 (4.19)	3	0.67 (2.31)	46	4.30 (4.77)
4.) Discharge	5.04 (4.65)	0.44	71	6.97 (3.69)	33	1.94 (4.26)	6	-0.83 (2.71)
5.) Timely provision of aids and adaptations	5.15 (5.39)	0.61	59	6.03 (4.95)	18	2.89 (6.13)	2	-0.50 (0.71)
6.) Pt/family rating of ability to cope	5.16 (0.47)	0.47	60	6.70 (4.29)	42	3.26 (4.74)	5	2.60 (5.94)
7.) GP Housecalls	5.83 (5.05)	0.51	11	7.55 (5.01)	73	6.03 (4.98)	16	3.75 (5.09)
8.) GP Care	5.15 (4.74)	0.46	68	6.49 (4.24)	32	2.75 (4.93)	5	2.40 (2.97)
9.) Experience of follow-up	5.13 (4.82)	0.46	70	5.76 (4.69)	14	4.86 (5.25)	25	3.52 (4.76)
10.) Information giving	5.09 (4.75)	0.46	63	6.22 (4.03)	32	4.50 (4.72)	13	1.08 (5.89)
11.) Information transfer (between agencies)	5.25 (4.85)	0.48	65	6.06 (4.27)	23	4.35 (5.34)	16	3.25 (5.80)
12.) Relationship with GP	4.89 (5.09)	0.53	59	5.97 (5.02)	26	3.85 (4.70)	8	0.38 (4.07)
13.) Community care services	5.97 (5.52)	0.93	26	7.35 (5.13)	7	2.71 (2.14)	2	-0.50 (12.02)
14.) Relationship with community care teams	5.94 (5.59)	0.97	24	7.42 (4.80)	8	1.88 (6.31)	1	3.00 (n/a)
15.) Accessibility (contact) to CC teams	5.83 (5.61)	1.04	24	7.21 (4.67)	1	4.00 (n/a)	4	-2.00 (5.29)
16.) Extent of social support	5.32 (4.83)	0.47	45	7.42 (3.99)	55	4.07 (4.84)	6	1.00 (4.10)
17.) Functionality of social support	4.98 (4.94)	0.48	76	5.75 (4.62)	24	3.13 (5.18)	5	2.20 (6.06)
18.) Extent of social capital	5.62 (4.90)	0.52	29	8.03 (4.04)	33	5.91 (4.09)	27	2.67 (5.25)
19.) Value of social capital	6.04 (5.27)	0.72	19	7.53 (4.38)	13	6.85 (4.70)	22	4.27 (5.95)



### 4.6.3 Item clusters

The items in the PPCI had been themed to coincide with the phases of stroke care. They could thus be aggregated into clusters in a similar way to that applied to the SnL items, although the cluster groupings were slightly different due to the different nature of the items. The clusters and the items contained within them are shown in Table 4.g below together with the mean (sd) scores for the cluster total scores.

**Table 4.g Cluster groupings for the PPCI items**

Cluster Grouping	PPCI Items	Cluster Mean (sd)
Hospital Care	1.) Perception of admission 2.) Awareness of MDT care 3.) Home visit (if needed) 4.) Perception of discharge process 9.) Experience of follow-up	1.13 (2.28)
GP Care	7.) GP Housecalls 8.) GP Care 12.) Relationship with GP	0.99 (1.26)
Community Care	5.) Timely provision of aids and adaptations 13.) Community care services 14.) Relationship with community care teams 15.) Accessibility (contact) to CC teams	1.48 (1.46)
Information Transfer	10.) Information giving 11.) Information transfer (between agencies)	0.89 (1.14)
Social Function	6.) Perceived ability to cope 16.) Extent of social support 17.) Functionality of social support 18.) Extent of social capital 19.) Value of social capital	1.49 (2.09)

Two cluster sub-groups scores (Hospital Care and Social Function) showed a normal distribution of scores but the three remaining clusters had non-normal distribution patterns. GP Care and the Information cluster were skewed towards higher scores, and Community Care was skewed towards the lower end of the scale. (See histograms in Appendix K for Figures K1 to K5, pages 295 - 296).

The same factors examined in the SnL data were used for a comparison of cluster sub-scores and, given the varying patterns of distribution, both parametric and non-parametric statistical methods were applied in the same way.

Mean scores for the clusters were compared for different sub-sets of patients in the sample using T-tests, and medians were compared with Mann-Whitney tests. The results of both statistical approaches were the same except for a few minor differences, which are indicated in the footnotes of the tables of results. Only the parametric test results are reported in full for clarity.

#### **4.6.4 Social and demographic factors and perceived care**

The associations between the PPCI scores and the socio-demographic characteristics of the sample showed a different pattern from that found for the SnL Index scores. Gender for example had shown no association with SnL total or cluster scores, and this was not unexpected as the process of care should not differ greatly for male and female patients. However gender differences in the social functioning cluster of the PPCI were identified, and females scored significantly lower than males in this sub-group ( $p = 0.017$ ). Given the profile of the sample this could be the result of a proportion of elderly widows reporting more isolated existences than their male counterparts but it could also be that the well established trend for women to report poorer self-rated health status than males is reflected in their subjective views of care. (Eriksson *et al.*, 2001).

Marital status was associated with PPCI scores. Patients living alone, either single, widowed or divorced, had significantly lower scores not only for the social function sub-group ( $p = 0.025$ ) but also for GP care ( $p = 0.031$ ); Information transfer ( $p = 0.047$ ) and the overall score for the PPCI ( $p = 0.005$ ). While the effect of marital status on social functioning can be understood, the findings are more difficult to explain in terms of differences in care delivery, although the same factors (lower levels of instrumental and emotional social support) could play a role.

Age and continence showed no association with the PPCI scores in contrast to the results for the SnL Index, where they appeared to act as indicators of stroke severity. Area of residence (within or outwith a community stroke team area) had no association with the scores for either SnL or PPCI, nor for any of the sub-scales.

In common with the SnL results, lowering the alpha level to 0.01 meant that only one of these findings (the association of marital status with the total PPCI score) remained significant. Table 4.h on the next page summarises the significant results.

**Table 4.h** Effect of gender and marital status on the PPCI<sup>8</sup>

Factor	PPCI Cluster	Mean difference <sup>(i)</sup> (95% CI)	t	df	p-value <sup>(ii)</sup>
Gender: <i>Male v Female</i>	Social Function	0.95 (0.17 to 1.74)	2.42	108	0.017
Marital Status: <i>Living alone v Living with partner<sup>3</sup></i>	PPCI Total Score	-2.61 (-4.43 to -0.79)	-2.84	108	0.005
	GP Care	-0.52 (-0.99 to -0.05)	-2.18	105	0.031
	Information Transfer	-0.42 (-0.84 to -0.01)	-2.01	106	0.047
	Social Function	-0.91 (-1.70 to -0.12)	-2.27	105	0.025

#### 4.6.5 Post-stroke disability and perceived care

Severity of stroke and other factors associated with stroke severity, like incontinence, had been found to be the major influences on the SnL Index scores but they had little or no association with the patient-perceived scores. Only early discharge had a negative association with the overall score for the PPCI: patients who had longer admissions reported higher scores than those discharged within a week ( $p = 0.053$ ) although significance was marginal. Early discharge was more strongly associated with the hospital sub-scores: longer stay patients scored higher ( $p = 0.000$ ) than those who left hospital within a week of their stroke, and the same was true for the community care cluster ( $p = 0.033$ ). This finding would be consistent with a longer admission on account of more dependency leading to more care input and thus resulting in more care events to be rated. Some elderly, early discharges said that they felt they had been sent home too soon and this could also have had a negative influence on patient-perceived scores. Moreover, two early discharges represented in this sample had occurred as a result of patients taking their own discharge causing a number of system failures (and consequently low scores) which will be discussed later.

Stroke severity measured by the Barthel Index score (BI) had an association with the PPCI hospital and community care cluster scores ( $p = 0.027$  and  $p = 0.037$ ), and also with scores for information transfer and social function:  $p = 0.014$  and  $p = 0.021$  respectively.

<sup>8</sup> Table 4.h: Notes

(i) Means compared using Student T-tests

(ii) Significance set at 95% level. Tests for remaining variables not significantly different. Results using non-parametric methods (Mann-Whitney Test) were the same except for GP care, which was not significantly different for the marital status groups.

Patients with BI scores equal to or less than 18 immediately after their stroke rated more negative scores on the PPCI cluster scores than the fitter patients but this association was not maintained when severity was measured by change in BI pre and post-stroke (the method that had been used to assess post-stroke disability in the SnL Index analyses). When the impact of stroke was assessed by a change of 3 or more points only the information cluster showed a significant association with stroke severity ( $p = 0.006$ ), no significant differences were found for other cluster scores between more severe strokes and those patients whose stroke had had a lesser impact. This finding seems to suggest that, in this sample, it was residual dependency (and possibly the co-morbidity of patients) that was the physical factor most strongly associated with the PPCI results rather than the severity of the index stroke. Table 4.i below summarises the significant findings.

**Table 4.i Effect of stroke severity on the PPCI<sup>9</sup>**

Factor	PPCI Cluster	Mean difference <sup>(i)</sup> (95% CI)	t	df	p-value <sup>(ii)</sup>
<b>Stroke Severity:</b> <i>Barthel Index <math>\leq 18</math> v <math>\geq 19</math></i> <i>(at baseline)</i>	Hospital Care	0.98 (0.11 to 1.84)	2.25	108	0.027
	Community Care	0.67 (0.04 to 1.29)	2.12	81	0.037
	Information Transfer	-0.54 (-0.96 to -0.11)	-2.50	108	0.014
	Social Function	-0.93 (-1.73 to -0.14)	-2.34	107	0.021
<b>Stroke Severity:</b> <i>High v Low Impact</i> <i>(Change in BI <math>&gt; 3</math>)<sup>(iii)</sup></i>	Information Transfer	0.66 (0.19 to 1.12)	2.78	106	0.006
<b>Early discharge:</b> <i>&lt;7 days v &gt;7 days</i>	PPCI Total Score	-1.99 (-4.00 to 0.02)	-1.96	110	0.053
	Hospital Care	-1.95 (-2.80 to -1.09)	-4.50	108	0.000
	Community Care	-0.83 (-1.59 to -0.07)	-2.16	81	0.033

#### **4.6.6 Mood and psycho-social factors**

In contrast to the findings of the SnL where psycho-social functioning did not show major effects, mood measured by the General Health Questionnaire 28 item questionnaire (GHQ\_28) demonstrated a consistent association with the PPCI. The

<sup>9</sup> Table 4.i: Notes

(i) Means compared using Student T-tests

(ii) Significance set at 95% level. Tests for remaining variables not significantly different.

(iii) Results using non-parametric methods (Mann-Whitney Test) were the same except for Hospital care, which was also significantly different for Stroke Severity groups ( $p = 0.03$ ).

longitudinal nature of the cohort study assessments meant that the effect of mood could also be examined over time, and the total score and the social function component of the PPCI were found to be significantly worse for GHQ-derived cases<sup>10</sup> compared with non-cases at all time points over the one year follow-up period. Patients with higher levels of mood symptoms at one or more time points also reported significantly lower (worse) scores than non-cases on other clusters of the PPCI. These findings are not surprising given that the PPCI is a patient-centred measure as distinct from the SnL Index, which uses a clinical audit type method of data collection. It has been established in a variety of studies and settings that ratings of perceived health care and responses to self-report measures of HRQoL are affected by respondents' mood states. (Atkinson and Caldwell, 1997, Hermann *et al.*, 1998, Kressin *et al.*, 2000)

When the separate domains of the GHQ were examined, a strong inverse association was identified between the PPCI total score and the Social Dysfunction sub-scale of the GHQ\_28 at T1 (baseline); T3 and T5 of the SOS2 Cohort study schedule. The Social function cluster of the PPCI demonstrated the same negative association with GHQ Social Dysfunction at T3 and T5 but not at baseline. A negative association with GHQ social dysfunction was also found for the PPCI GP and community care sub-scales at specific time-points.

The findings related to social functioning are important to note because they suggest that those feeling less connected to others seem to have much poorer perceptions of care may therefore require more support in order to facilitate their recovery after a stroke. This effect has also been recognised in other settings such as maternity care. (Donaghy *et al.*, 2000)

The significant results are summarised in Tables 4.j and 4.k on the following page.

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<sup>10</sup> *Aide Mémoire: Mood was assessed for patients in the SOS2 cohort study at 5 time points in the year following their stroke. Using the bi-modal scoring system, cases are defined as those with symptom scores of 12 or more.*

**Table 4.j Effect of mood state on the PPCI<sup>11</sup>**

<b>GHQ Cases</b>	<b>PPCI Cluster</b>	<b>Mean difference<sup>(i)</sup> (95% CI)</b>	<b>t</b>	<b>df</b>	<b>p-value<sup>(ii)</sup></b>
<b>T1:Baseline</b> <i>2 to 4 weeks post-stroke</i>	PPCI Total Score	4.58 (2.14 to 7.01)	3.73	110	0.000
	Hospital Care	1.68 (0.52 to 2.84)	2.87	108	0.005
	Social Function	1.71 (0.66 to 2.76)	3.23	107	0.002
<b>T2:</b> <i>6 to 8 weeks post-stroke</i>	PPCI Total Score	4.12 (1.49 to 6.75)	3.11	104	0.002
	GP Care	0.71 (0.01 to 1.40)	2.00	101	0.048
	Information Transfer	0.66 (0.08 to 1.24)	2.25	102	0.027
	Social Function	1.73 (0.58 to 2.87)	2.99	102	0.004
<b>T3:</b> <i>12 to 14 weeks post-stroke</i>	PPCI Total Score	5.82 (3.15 to 8.48)	4.33	109	0.000
	Hospital Care	1.38 (0.05 to 2.71)	2.06	107	0.042
	Community Care	1.03 (0.01 to 2.05)	2.02	80	0.047
	Information Transfer	0.64 (0.01 to 1.28)	2.01	107	0.047
	Social Function	2.40 (1.26 to 3.55)	4.15	106	0.000
<b>T4:</b> <i>6 months post-stroke</i>	PPCI Total Score	4.59 (1.28 to 7.91)	2.75	108	0.007
	Social Function	2.65 (1.29 to 4.01)	3.87	105	0.000
<b>T5:</b> <i>12 months post-stroke</i>	PPCI Total Score	4.89 (1.27 to 8.50)	2.68	106	0.009
	Information Transfer	1.11 (0.31 to 1.92)	2.73	104	0.007
	Social Function	2.08 (0.59 to 3.56)	2.77	103	0.007

**Table 4.k Correlation table for social function sub-scales<sup>12</sup>**

<b>Variable</b>	<b>Patients (N)</b>	<b>Pearson coefficient</b>	<b>p-value</b>
PPCI Total Score & GHQ social dysfunction T1	109	-0.28	0.003
PPCI Total Score & GHQ social dysfunction T3 <sup>(i)</sup>	111	-0.25	0.009
PPCI Total Score & GHQ social dysfunction T5	106	-0.24	0.015
PPCI Social Function Cluster & GHQ social dysfunction T3	108	-0.24	0.013
PPCI Social Function Cluster & GHQ social dysfunction T5 <sup>(i)</sup>	103	-0.30	0.002
PPCI GP Care Cluster & GHQ social dysfunction T5	103	-0.24	0.016
PPCI Community Care Cluster & GHQ social dysfunction T1 <sup>(i)</sup>	80	-0.31	0.005

<sup>11</sup> Table 4.j: Notes

(i) Means compared using Student T-tests

(ii) Significance set at 95% level. Tests for remaining variables not significantly.

Results using non-parametric methods (Mann-Whitney Test) were the same except for Information Transfer, which was not significantly different for the T2 groups.

<sup>12</sup> Table 4.k: notes

(i) These association were also significant using Spearman's rho

#### **4.7 Assessing the patient self-rated items**

A self-report section was included in the patient assessment of care processes because the principal measure, the PPCI, was interviewer rated. Incorporating an element of patient-self reported assessment was therefore prudent because it enabled an independent patient-centred rating of care to be obtained against which the PPCI ratings could, to some extent, be explained and validated. This was also useful as no gold standard exists for patient-perceived care with which the new measure could be compared. Full details of the items and scale descriptors for the self-reported section of the patient interview schedule are shown in the PPCI document in Appendix H, on page 286.

Histograms (not reproduced) showed that the distributions of total scores for all items were biased towards the higher end of the scale.

Table 4.1 on the following page shows the mean scores, standard deviations and ranges for each of the patient-rated items.

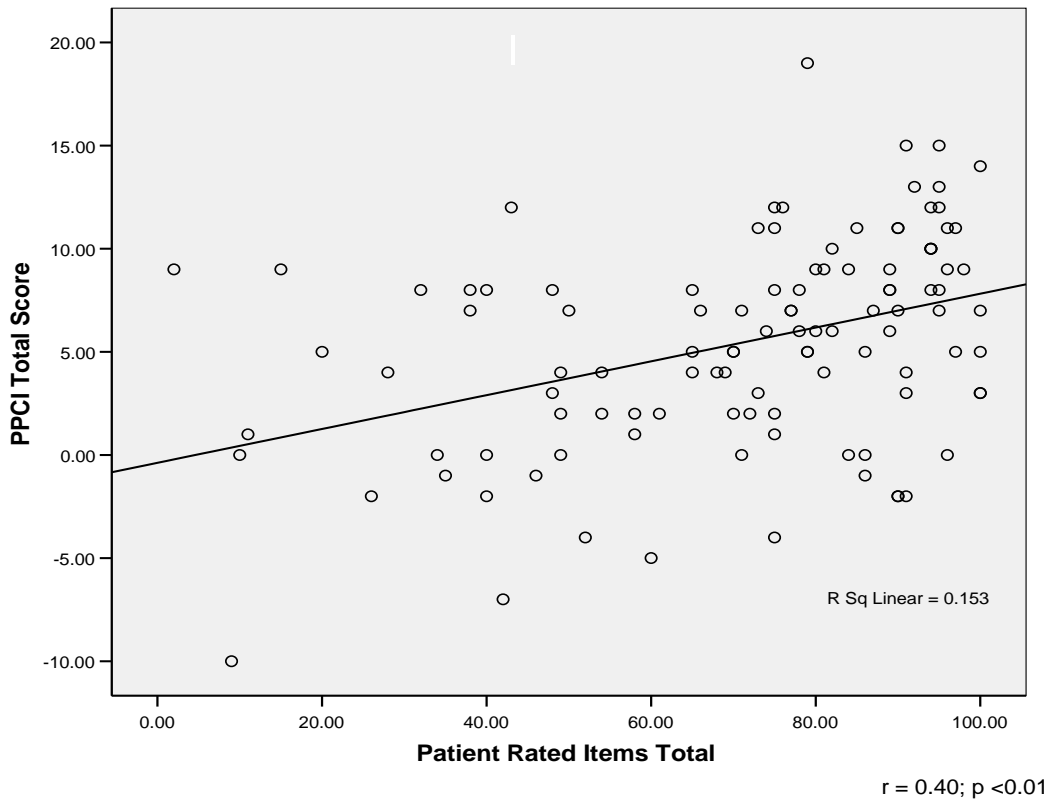
**Table 4.1      PPCI patient-rated variables**

Variable	N	Minimum	Maximum	Mean		Std. Deviation
	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic
Progress with recovery	94	0	10	7.00	0.226	2.190
Control over life	91	2	10	8.23	0.227	2.166
Enjoyment of life	92	0	10	6.99	0.286	2.748
Dependence on others	89	0	10	7.31	0.280	2.640
Sub-Total: Patient Ratings of Self	95	2	40	28.43	0.969	9.443
Standard of care	103	0	10	8.10	0.237	2.403
Trust in carers (professionals)	98	0	10	8.98	0.200	1.984
HCP's knowledge of condition	100	0	10	8.37	0.207	2.073
Coordination of care	97	0	10	8.10	0.265	2.608
Level of service	98	0	10	8.35	0.262	2.589
Satisfaction with service	103	0	10	8.44	0.257	2.607
Sub-Total: Patient Ratings of Services	105	2	60	47.85	1.398	14.322
Patient Rated Items Total	109	2.00	100.00	70.8716	2.31389	24.15770



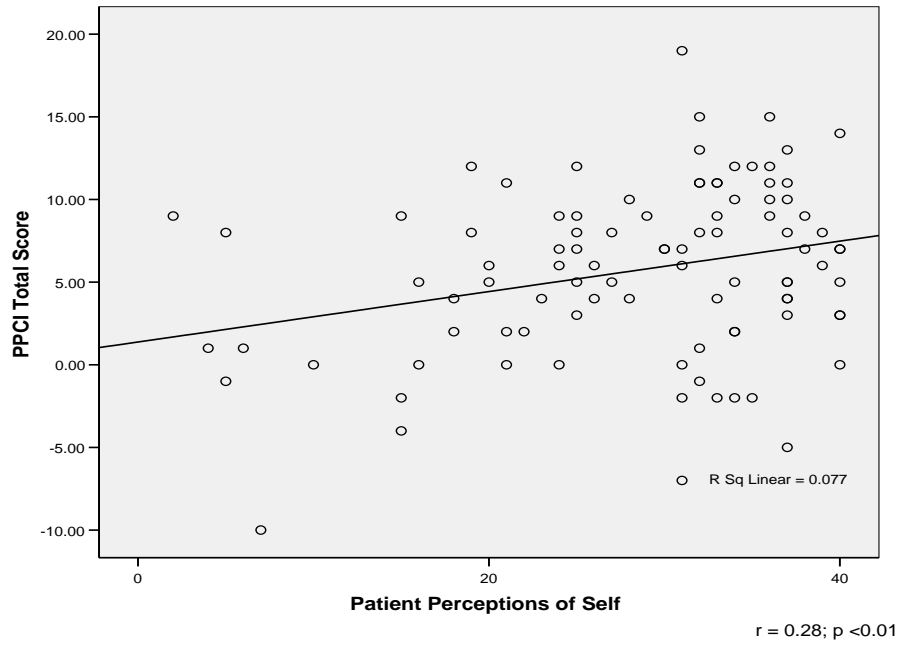
Scores for the patient rated items were found to have a moderately good association with the total score for the PPCI. As Figures 4.c below shows, a significant correlation was found between the PPCI and the total score for all items ( $r = 0.40$ ).

**Figure 4.c Correlation between PPCI and patient-rated Items**

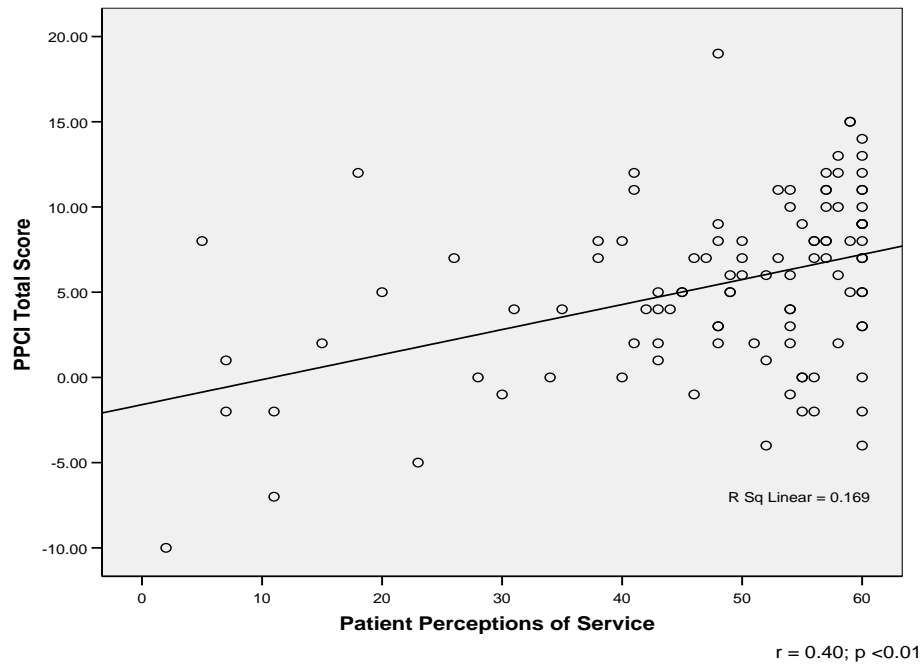


On the next page Figure 4.d shows the association of patient ratings of the service with the PPCI total score ( $r = 0.41$ ), and Figure 4.e with the patient ratings of self ( $r = 0.28$ ). All correlations were significant at  $p < 0.01$ .

**Figure 4.d Correlation between PPCI and perceptions of self**

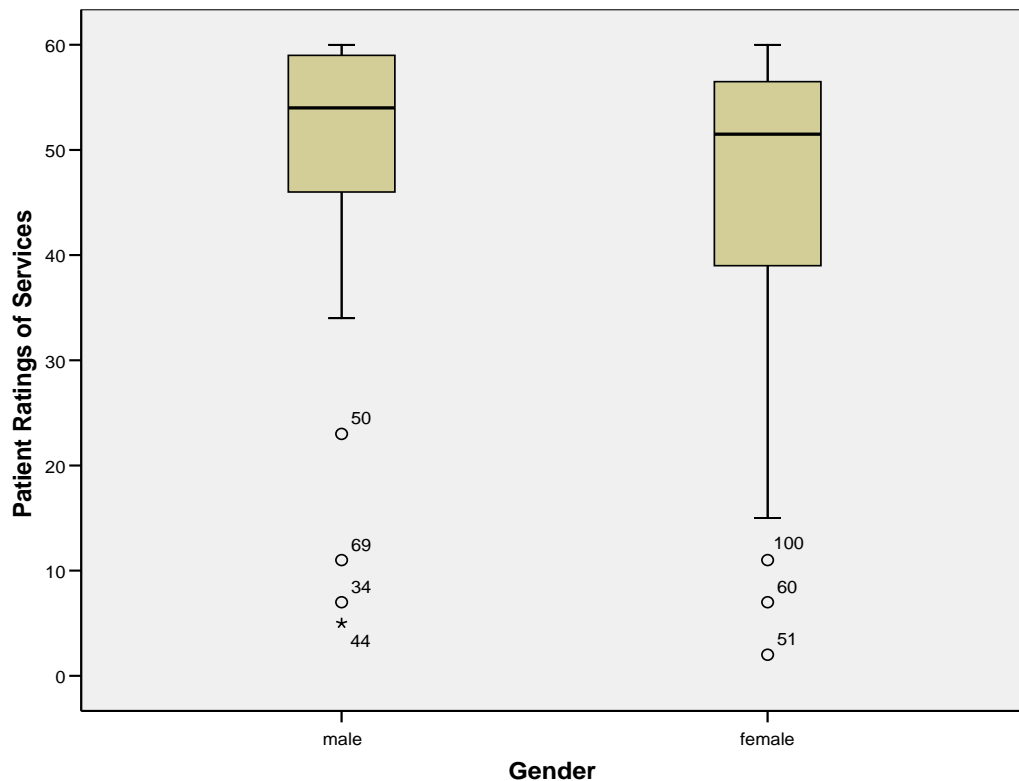


**Figure 4.e Correlation between PPCI and perceptions of service**

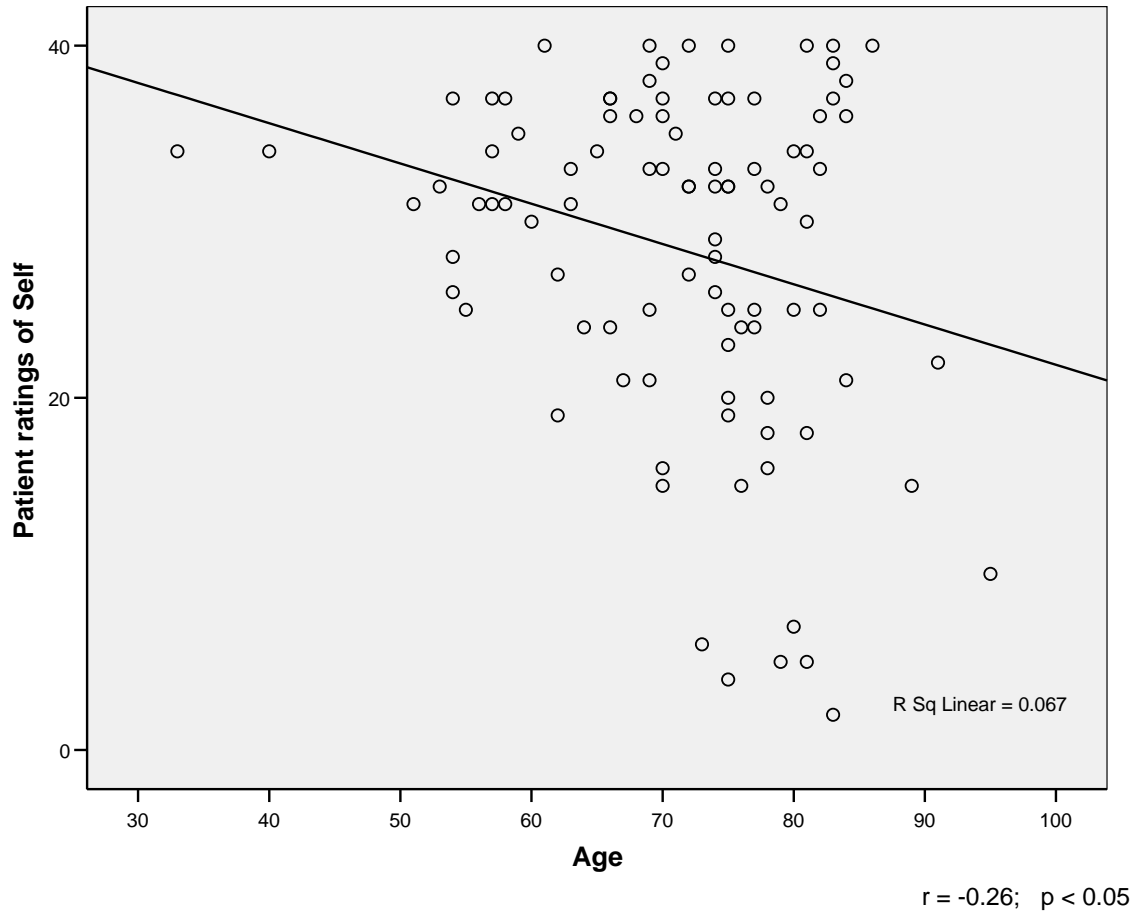


There was no association between age and self-reported ratings of service factors, nor did these differ significantly by gender, although females showed a trend to report lower mean scores for these items, as shown in Figure 4.f below.

**Figure 4.f** Box plot showing perceptions of service by gender



Age was inversely correlated with ratings of self ( $r = -0.26$ ;  $p < 0.05$ ) as Figure 4.g on the following page shows. However the association was not significantly different for older and younger age groups in independent T-tests. There was however a significant association between poorer ratings of self and female gender (Mean difference = 6.65: 95% CI 2.96 to 10.33;  $t = 3.58$ ;  $df = 93$ ;  $p = 0.001$ ). Both findings would be consistent with accepted theories of self image and the way it is perceived in relation to age, gender and chronic illness.

**Figure 4.g Scatterplot of patient ratings of self by age**

## 4.8 Discussion: Measuring patient-perceived care

### 4.8.1 *Interpreting the results of the PPCI*

The issue of recall and the accurate recognition of aspects of care was a recurring theme throughout the PPCI interviews. At the outset it had been hypothesised that certain events or episodes might denote continuity in care processes but patients did not consistently recognise these in their care, and it was sometimes difficult to untangle their descriptions in order to apply ratings. In a few cases where discrepancies arose it was possible to check the meaning of patients' responses by cross-referencing with the SnL checklist. For example: when an event was related that had clearly occurred in hospital or at home but the patient (or carer) could not identify any details of the purpose or personnel involved, clarification of the circumstances could occasionally be obtained from the case-notes. This process meant that more accurate ratings could be applied but this was only appropriate in a few isolated cases. However it does also provide a mechanism to explain the observed lack of correlation between the SnL and the PPCI scores.

Patients frequently exhibited problems recalling MDT and goal setting meetings, as well as home visits and assessments for continuing therapy. In the case of MDT (and some goal setting) meetings the patient may not always have been present when these events occurred. However all these four events in care were poorly recalled, and not always recognised in the way that had been intended, even when the patient clearly had been part of them. Data from the SnL Index checklist, for example, suggested that nearly all eligible patients in the study group (98%) had received an accompanied home visit whereas only 70% of them recalled this event when asked about it during the interview. The latter figure is compatible with a recent National Audit Office survey of stroke patients that reported only 70% as having received a home visit. (NAO, 2005) The difference in the findings from the records and the interviews in this study suggests that patient reported data is not necessarily an accurate indicator of service provision in some circumstances.

By contrast however, several instances were found where patients' accounts provided better information than the case note reviews, for example when rating admission mode. Little could be gleaned about the admission process from the case-notes even if the ambulance crew's assessment form was filed (which was not always the case). The patients' ratings in this section were often a better indicator of how smoothly this

particular transition had been achieved than the hospital records. Differentiation was the main problem for rating this item on the PPCI because experiences varied: there were accounts of bad experiences of getting into hospital followed by excellent care once transferred to the Acute Stroke Unit, and examples of the reverse situation: rapid transfer to hospital followed by a poor experience of care once admitted. Sequencing events (a particular problem for some stroke patients) within an episode of care was yet another issue, as was distinguishing between separate and unrelated episodes. In this respect, adopting an interviewer rated method of scoring was an advantage as it allowed both confused and complex narratives to be unravelled, and the appropriate ratings applied. However, it was by no means a perfect solution for evaluating continuity of care.

#### **4.8.2 Case studies**

This phase of the study generated a wealth of complex data which was difficult to explain in quantitative terms alone. In order to give a better picture of the findings, and relate them to a real world context, a series of short case studies are presented which have been drawn directly from the study group. The case study approach is a descriptive method which is widely used in medicine for teaching purposes or to emphasise or illustrate a particular aspect of care in clinical reports. In the social sciences case studies are used in a different way and are regarded as formal research strategies that are distinct from ethnographic methods. A formal approach was not intended by the use of case studies in this thesis; here they are presented as a means of understanding the data.

Neither the SnL Index, nor the PPCI, nor the patient-rated scores can be regarded as representing a full assessment of the care that patient participants received for their stroke. In this study group it was obvious that there were few if any “typical cases”, and that a number of different care scenarios could result in similar scores on the measures and vice versa. Ostensibly therefore the same type of care could be rated very differently. For example: scores on the SnL were dependent on certain care processes having occurred but lower scores did not mean poor care, if services had not been delivered because they were not appropriate. This illustrates that the relationship between care input and SnL scores is not straightforward. Similarly, the relationship between patient-perceived care measured by the PPCI including the self-rated items and actual care received is complex.

**Case Study #579:** Case Study #579 represents a low but appropriate level of care input which was acceptable to the patient and met both his physical and psychological needs:

<b>Case Study #579:</b>		<b>SnL Score</b>	<b>1</b>	<b>Rating of Services</b>	<b>54</b>
T1 Barthel	20	PPCI Score	10	Rating of Self	28
<p><i>A 54yr-old divorced male smoker suffered a minor stroke, self-referred to A&amp;E and spent 3 days in hospital during which time his symptoms completely resolved. He was discharged home with no care needs and no indications for continuing therapy. He did attend a follow-up appointment with the stroke specialist nurse but his SnL score was reduced by the absence of GP cover. This previously fit mountain biker had not attended at his GP for over 10 years and had consequently been removed from the register. He had to re-register with his GP after discharge from hospital. Nonetheless he was very satisfied with his care overall, presented a positive account in the PPCI and rated it highly.</i></p>					

In contrast Case Study #466, a very similar case with a comparable SnL score illustrates a different response to perceived care:

<b>Case Study #466:</b>		<b>SnL Score</b>	<b>0</b>	<b>Rating of Services</b>	<b>38</b>
T1 Barthel	20	PPCI Score	7	Rating of Self	Missing
<p><i>A 62yr-old divorced female with a strong family history of cardiovascular disease suffered a minor stroke at home. She attended her GP surgery and was immediately referred directly to the stroke specialist at the local Acute Trust. She was admitted next day and spent 2 days in hospital during which time her symptoms resolved. She returned home with no care or therapy needs. This fit non-smoker, who exercised regularly by cycling to the shops, went swimming twice a week, and grew her own organic vegetables was very distressed that her own efforts to minimise her risk of stroke or heart attack by choosing a healthy lifestyle had been futile. She had a supportive GP, who managed her anxiety, and of whom she expressed appreciation in the PPCI. However, she rated her hospital care quite low and refused to rate items in the "perceptions of self" section.</i></p>					

A third case from the study group illustrates how higher scores on the SnL are associated with higher care intensity.

<b>Case Study #594:</b>		<b>SnL Score</b>	<b>11</b>	<b>Rating of Services</b>	<b>46</b>
Baseline BI	17	PPCI Score	7	Rating of Self	25
<p><i>A 55yr-old married man suffered a major stroke on his way to work. He was admitted as an emergency through A&amp;E, spent 14 days on the ASU and a further 22 days on a specialist rehabilitation ward. He was discharged home with input from the Community Stroke Team who provided domiciliary physiotherapy and occupational therapy for 12 weeks. After CST input ceased he received 2-weeks of in-patient therapy at the Community Rehabilitation Unit. He subsequently obtained a place one day per week at a local resource centre. He was assisted with personal care by his wife, who also took care of all the household duties. He was unable to return to work on account of his residual disability.</i></p>					

Current government policy demands that patients should be given choice and opportunities to take responsibility for their own care. Communication and information transfer between clinics and specialties must therefore be considered particularly important if vulnerable groups are not to be disadvantaged by this model of care. Where record-based or independent ratings of care in the study group indicated that appropriate care had not been received, unmet needs were often found to be the result of patients opting out of services. These findings suggest that safeguards are required for those patients who are less aware of the consequences of certain actions or inactions, for whatever reason, if the continuity of their ongoing care is not to be compromised. Two examples of self-discharges arose in the study and illustrate how the patients involved missed out on referrals to ICT and other services. In both cases they were not recalled for follow-up because they had left hospital before assessments had been completed and appropriate referrals made to arrange for ongoing services.

Case Study #553:		SnL Score	1	Rating of Services	11
T1 Barthel	19	PPCI Score	-7	Rating of Self	31
<p><i>A 57yr-old, single, male patient living alone and estranged from his family, took his own discharge after 6 days in hospital, against medical advice because he was angry that his family had been informed of his condition and hospitalisation. He had a Barthel Index score of 19 on admission but needed support at home due to persistent falls. He had refused a kitchen assessment by Occupational Therapists in hospital (although he had been given exercises by the physiotherapy team), and left before any appraisal of his home situation. He therefore received no walking aids to improve his stability and was not recalled for follow-up by the stroke team, or the physiotherapy team as planned. He was managed by his GP, who did not receive any discharge advice or information until 10 months after the stroke event. There was evidence that the GP had attempted to access information as a note in the hospital record dated a few weeks after the patient self-discharged read “GP telephoned – No d/c letter – Chase”.</i></p>					

Key factors in continuity (as distinct from quality care and patient satisfaction) seem to be communication and collaborative working. In the cases studied evidence was found that indicated that the commonest factor causing gaps or delays in service delivery was a failure in the chain of communication or a misinterpretation of requirements. These factors were sometimes exacerbated by patients' behaviours and attitudes, as in Case Study #553 but, in the final case study described on the following page, it was the poor psychological status of the patient that proved to be the barrier to ongoing care.



Case Study #531:		SnL Score	7	Rating of Services	2
T1 Barthel	13	PPCI Score	-10	Rating of Self	7

*An 80yr-old woman with COPD, and other comorbidity, suffered a moderately severe stroke at home. She was admitted to hospital by her GP where she spent 20 days (5 on the Elderly ASU and 15 on an Elderly Rehabilitation Ward). Sadly her husband, resident in long-term care with dementia, died during her admission. She returned home with input from the Intermediate Care Team for 3 weeks whose records note that she was “able to get upstairs, wash and dress unaided”. Her daughter and son-in-law lived next door in the adjacent cottage. Over the next few weeks she became depressed, her mobility decreased and general physical condition deteriorated. She refused to leave the house causing her to miss stroke follow-up and other medical appointments. It was evident from the care records that this state had been recognised by her GP and other agencies, and that referral to community mental health services had been made. However, the family maintained that nothing had been offered in terms of personal care, physical or psychological therapy. At the end of one year follow-up for the cohort study, the situation remained unchanged.*

Case study #531 was a complex case to unravel. It was only as the pieces of information from different sources were put together that the full picture emerged. The interview was conducted with the patient and main carer (her daughter) who described a lack of service provision and failure to respond to requests for help, producing an extremely low PPCI score and very low ratings of services (by the daughter) and self (by the patient). The hospital records revealed little except a record of failure by the patient concerned to attend several clinic appointments. Only one record was found that contained an explanation for this, which was that hospital transport had been sent away by the patient (“unable to get out of house”). The ICT and GP notes were more enlightening as they chronicled the patient’s physical and psychological decline. They showed evidence of home visits by the GP and CPN which had not been reported by the family nor by the patient, which is understandable given that her recall was very poor. Unfortunately it was not possible to determine exactly what had gone wrong in this case from the available data but what it did show was that failure to engage with services can result in unmet needs despite the best efforts of care agencies to address them. Patient compliance with care is an important element of care delivery, as poor compliance, whether resulting from personal choice or psychological (or physical) incapacity, is difficult to address.

In the next section further quantitative analyses and assessments of the new measures are described. The strategy for determining what underlying constructs the SnL Index and the PPCI are capturing is explained before proceeding to an exploration of their associations with patient outcomes using modified measures of care derived using more complex statistical modelling techniques.

## 4.9 Confirmatory factor analysis

### 4.9.1 *Structural equation modelling*

Structural equation modelling (SEM) can be used to extract additional information from questionnaire data, and is considered to be superior to traditional scaling methods by many professional statisticians. SEM is a mainly linear, cross-sectional statistical modelling technique which is generally used as a confirmatory, rather than an exploratory method. It requires the use of specialist software packages in its execution and, as the author had neither access to the software nor the experience or the skills to undertake this type of analysis, the advice and assistance of an expert, professional statistician. This stage of the analysis was therefore undertaken by Dr Robert West using Latent Gold 3 software, (Latent Gold 3, 2006) assisted by KH who prepared the dataset and advised on the selection of candidate variables for modelling.

SEM focuses on the identification of latent constructs or abstract psychological variables that are present in the observed data rather than the explicit variables used to measure them. The modelling technique seeks to derive unbiased estimates for the relationships between latent constructs, and thus allows multiple measures (or candidate variables) to be associated with a single latent construct. In comparison to other methods for determining similar relationships such as regression and factor analysis, SEM is a comparatively new method of analysis that appeared only in the late 1960s and is still developing as method. (Magidson and Vermunt, 2004) However, discussions with Dr West suggested that investigating the complex phenomenon of continuity of care might benefit from a novel and experimental approach like SEM as little is known about the true components of continuity, and how they might be related to the variables being measured. It must be acknowledged that this method could not have been applied in this thesis without the advantage of access to expert statistical support which arose as a result of work on the overall SOS programme.

The first issue to be addressed was that of determining how each of the new measures contributed to the assessment of care processes. The SEM technique offered the opportunity to generate latent constructs with greater construct validity, which could then be converted into variables which in turn could be used in a regression model. Given the number of measures available from the SOS2 cohort data, this would reduce the complexity of the situation to be modelled.

#### **4.9.2 Method**

The measures of care used in Study 4a and 4b had been constructed to target the overall patient care episode recorded in the case-notes (SnL) and the care experienced by patients throughout their care trajectory (PPCI). Single assessments were made for each patient between 6 and 12 months post-index stroke in a cross-sectional design, the rationale for which was explained in Section 4.2.2, page 133. The preliminary results suggested that both function and mood had some impact upon care processes. Repeated assessments of function and mood were available from the parallel, longitudinal cohort study (SOS2) thus stroke severity could be well represented by the initial measures of patient disability (such as the Barthel Index) and mood effects by the GHQ\_28 scores.

The SnL Index and the PPCI Schedule were designed on the basis of the work that had been carried out in earlier phases of the study. The SDO scoping report and the CHSRF workshop findings provided working definitions of continuity that were used as a framework for constructing the measures. The findings from the qualitative work and the case note reviews conducted in Study 2a and 2b provided additional detail relevant to stroke care. Firm indicators of continuity could not be obtained but by combining information from various sources it was hoped to capture the characteristics of care that contributed to the continuing care process in acute stroke and post-stroke recovery. The new measures were applied in a sample of SOS2 cohort study patients in Studies 4a and 4b in order to examine this theory.

The preliminary analyses of the new measures led to the conclusion that uncertainty remained about the phenomenon that the indices were actually measuring. No correlation was found between the total SnL and PPCI scores in a simple correlation matrix although associations did exist between the GP sub-scores ( $r = 0.26$ ;  $p = 0.009$ ) and the community care scores ( $r = 0.32$ ;  $p = 0.005$ ) as measured by the two indices. This association was tested using Spearman's rho and remained despite the non-normal distributions of these cluster sub-scales suggesting that the two indices were measuring different aspects of the care process albeit aspects which could overlap or coincide in certain domains.

The findings from Study 4a had generated the hypothesis that the care measure derived from care records (the SnL Index) was confounded by the physical status of the patient, and that what was being measured was in effect the intensity of care

proportional to the disability of the patient. In the case of the patient-centred measure, the findings of Study 4b suggested that the PPCI was measuring patient-perceived care, but that this was dependent to some degree on the patient's psychological state. A hypothesis was thus generated that the two measures were capturing something different and that two latent constructs were present in the data: '*disability*' and '*perceived care*'. On the basis of the preliminary analyses it was possible to identify a number of theoretical candidate indicator variables as potentially relevant to an evaluation of care. These indicator variables were the measures developed specifically for the study (the SnL Index and the PPCI), plus four items selected from the self-reported ratings of care that had been obtained from study participants:

- *Quality of care*
- *Co-ordination of care*
- *Co-ordination of information*
- *Patient satisfaction*

Ratings of "*trust*" and "*level of care*" were excluded from the model because these two items did not expressly appraise "received" care. Notwithstanding that trust was a recurring theme in earlier phases of this work, and is clearly a key component in interpersonal relationships, ratings of trust could be susceptible to influence from factors external to care delivery like personality and mood. The second rating (level of care) was a subjective view of service input which, depending on the actual rather than perceived needs of the patient, may or may not have been an accurate assessment of the services received.

A range of baseline and repeated measures of function for the patients in Studies 4a and 4b were also available in the pool of shared assessments from the cohort study. These had been measured at up to five time points (including the baseline measure) over a one year period on the longitudinal study of outcomes and included:

- The Barthel Index (Mahoney, 1965)
- Rivermead Mobility Index (RMI) (Collen, 1991)
- Mini Mental State Examination (MMSE) (Folstein, 1975)
- General Health Questionnaire (GHQ) (Goldberg and Hillier, 1979)

It has been established that these measured indicators represent aspects of patients' functional, emotional and cognitive capacity which are often significantly reduced by a stroke event, and will therefore influence the care provided. However, it should be noted that all methods of measurement have an error associated with them and it can be assumed that none of the above measurement instruments measures the underlying construct of "*disability*" perfectly. Each instrument thus has an 'error' term associated with it and the variance of this error is likely to include variation from sources other than the underlying construct.

Initial explorations of the data in Studies 4a and 4b had identified the majority of the linkages between certain of these measured indicators and the hypothetical latent constructs represented by the two new measures. A confirmatory factor analysis was thus indicated rather than an exploratory factor analysis. Undertaking a confirmatory factor analysis would establish the number of constituent measured indicators that were most relevant to the constructs "*perceived care*" and "*disability*" (the latter had already been identified as major confounding factors in the results). It would also determine the loadings of the indicators on the constructs. Using multiple indicators to define the constructs would also mean that the shared co-variances would be less influenced by variation unrelated to the constructs, and as a consequence construct validity would be increased.

For analysis subsequent to this confirmatory analysis, it was intended that the constructs, once derived, would replace a number of strongly correlated, measured indicators. The confirmatory factor analysis benefited from co-linearity between these indicators but if they were to be used in, for example, a generalised regression model, then co-linearity would inflate the problems associated with covariance, and lead to unstable and imprecise estimates. Thus the confirmatory factor analysis step in the analysis strategy was essential.

The Barthel Index, Rivermead, and MMSE were fixed as components for the *disability* construct, although the loadings of Rivermead were permitted to vary in relation to a unit negative weight given to Barthel Index as it is known that lower scores of Barthel are associated with increased disability. For *perceived care*, co-ordination received unit loading and quality, information, and satisfaction were fixed components with free loadings. Other indicators, such as the GHQ, SnL and PPCI were not fixed and were permitted to contribute to either or both of the latent constructs until the optimal model was generated.

The distribution of the GHQ scores was skewed to the lower (positive mood score) end of the scale therefore the square root of the scores was taken to transform this data and improve the normality of the distribution. There was also a ceiling effect in the data for the Barthel Index, which was skewed towards better functional scores. However no transformation could be applied to improve normality in this distribution.

Table 4.m on the next page shows the descriptive statistics for the variables that were used in this stage of the analysis.

**Table 4.m Descriptive statistics for variables in the factor analysis**

Variable	N	Minimum	Maximum	Mean		Std. Deviation
	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic
Barthel Score	111	1	20	16.62	0.475	5.009
Rivermead Mobility Index	111	0	15	10.00	0.451	4.752
T1 GHQ bi-modal scoring total	112	0	27	6.44	0.577	6.107
Mini-Mental State Examination	111	14	30	26.97	0.302	3.181
SnL 12 Items Total	112	-2	11	5.93	0.294	3.107
HCP's knowledge of condition	100	0	10	8.37	0.207	2.073
Coordination of care	97	0	10	8.10	0.265	2.608
Satisfaction with service	103	0	10	8.44	0.257	2.607
Standard of care	103	0	10	8.10	0.237	2.403
PPCI Total Score	113	-10.00	19.00	5.4956	0.47256	5.02338
Sqrt of T1 GHQ bi-modal total	112	0.00	5.20	2.1896	0.12167	1.28759
Disability construct	110	5.91	89.94	28.2824	2.03599	21.35362
Perceived care construct	91	0.60	99.01	71.5830	1.98951	18.97876

### 4.9.3 Results

Figure 4.h shown on the following page gives a diagrammatic representation of the model that was obtained following the fitting of the regression coefficients in the confirmatory factor analysis. It can be seen from the standardised regression weights shown on the diagram that the T1 (Baseline) Barthel Index (-0.93), Rivermead (-0.95), and MMSE (-0.53) all contributed strongly to the latent construct *disability* as had been anticipated given the results of the preliminary analyses. The previously hypothesised association of the SnL measure with disability (standardised regression weight = 0.39) was also confirmed in this model although its effect (and that of the MMSE) were not as strong as the standardised measures of function, the Barthel and the Rivermead. The transformed GHQ score was also found to have some association with disability, although this was considerably less than that of the primary components (0.13).

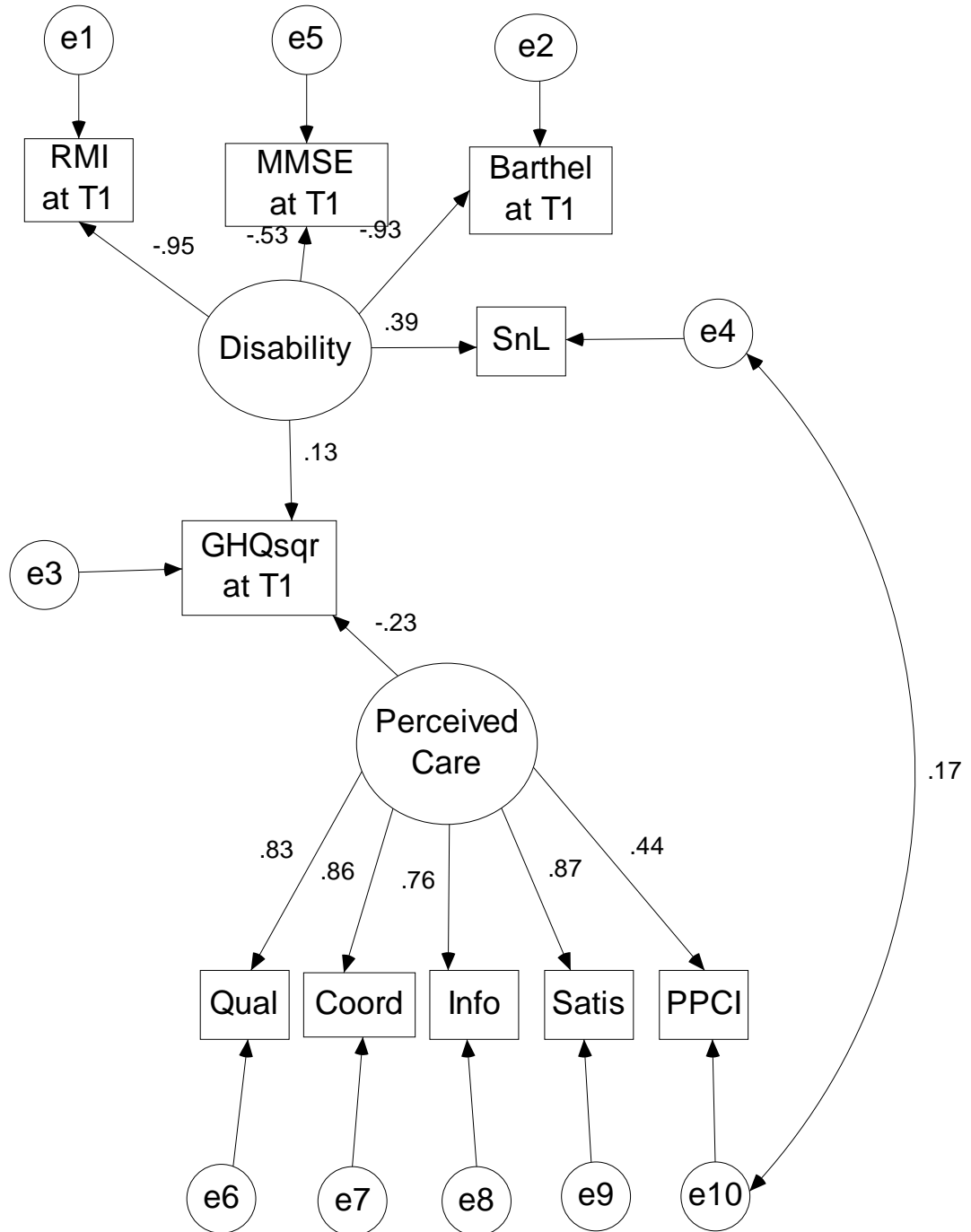
The latent construct *perceived care* proved to be strongly associated with quality, co-ordination and information, with all the standardised regression weights being large (i.e. more than 0.75). A reasonable association (standardised regression weight of 0.44) was also found with PPCI, and a small negative association (-0.23) with the transformed GHQ variable<sup>13</sup>. The SnL measure, although associated with disability, was not significantly associated with perceived care.

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<sup>13</sup> Lower scores on the GHQ scale indicate better function whereas on the other candidate measures lower scores are associated with worse ratings of care.



Figure 4.h Latent constructs derived from the SnL and PPCI using SEM



#### **4.9.4 Assessing the model fit**

The overall fit to the model produced was satisfactory with a chi-squared value of 44.12 on 33 degrees of freedom. The assessment of goodness of fit was based on three criteria:

- The p-value for the chi-squared statistic, which was not significant ( $p = 0.094$ );
- The ratio of the chi-square value to degrees of freedom which was less than 2;
- The root-mean-square error approximation (RMSEA) which was 0.055 (90%CI: 0.00 to 0.09) representative of a reasonable fit.

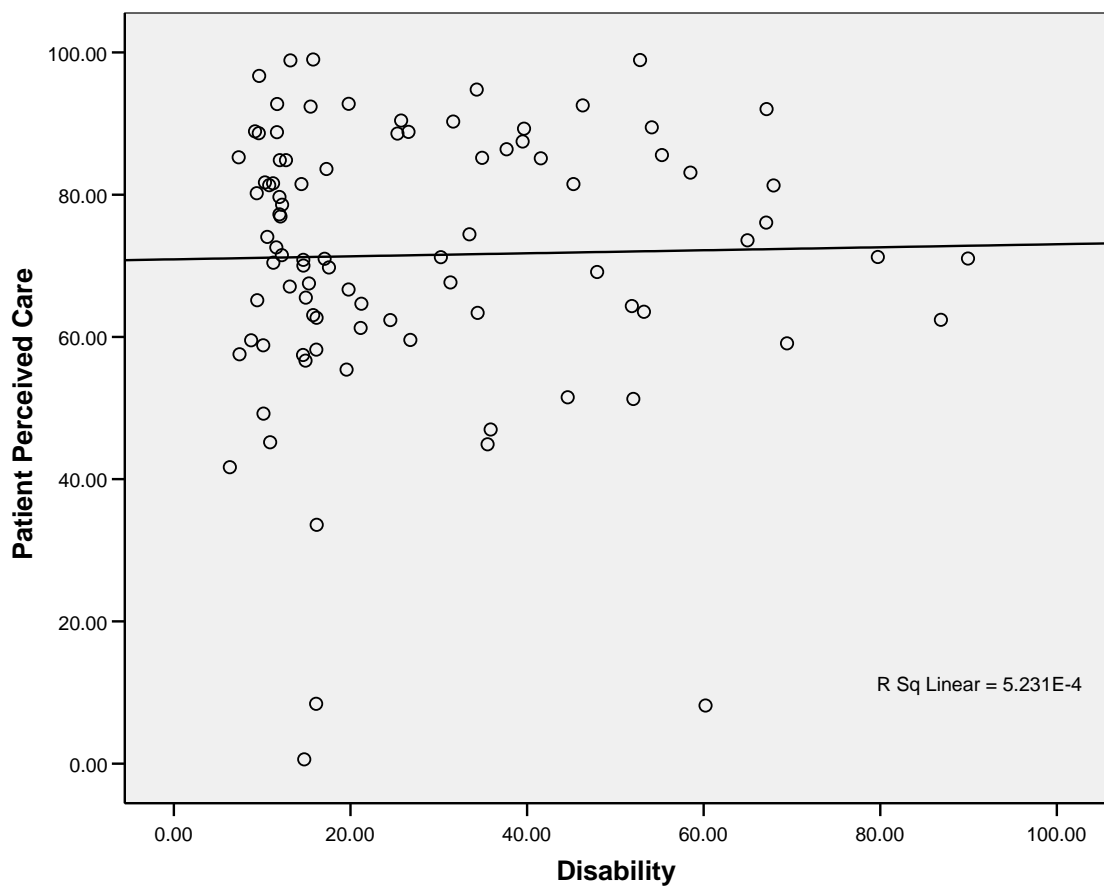
Good models have an RMSEA of 0.05 or less whereas poor models have an RMSEA of more than 0.10. Ideally the lower value of the 90% confidence interval includes or is near to zero (as was the case for this model) and the upper value is not very large (less than 0.08).

In assessing goodness of fit by this method the null hypothesis is that the RMSEA is 0.05, i.e. a close fitting model. The p-value for the chi-squared statistic examines the alternative hypothesis, that the RMSEA is greater than 0.05 and thus not a good fit. In this case, the p-value for the chi-square for the model was 0.094 (i.e. not significant). The alternative hypothesis was therefore rejected and the RMSEA value of 0.055 taken to be a “reasonably close” fit for the model. (Browne and Cudeck, 1993)

The upper confidence interval value for the RMSEA was greater than 0.08 but the likelihood of obtaining any better fit to the model was not anticipated. The majority of the factors were approximately normally distributed except for the key factor, the Barthel Index. Transformations were applied but none were found to improve the normality.

When the association between the two newly identified latent constructs *disability* and *perceived care* was explored it was found that they were not correlated. The scatter plot, Figure 4.i below, depicts the relationship graphically. Only a very slight, non-significant correlation ( $r = 0.17$ ,  $p = 0.09$ ) existed between the residuals of PPCI and SnL once *disability* and *perceived care* had been adjusted for, suggesting that, as had been found in the correlations of the cluster groupings, there could be some overlap in the phenomena that each is measuring possibly through the association with mood.

**Figure 4.i** Correlation between the latent constructs<sup>14</sup>



<sup>14</sup> "Patient-perceived Care" and "Disability" derived from the SnL and the PPCI

## 4.10 The effects of disability and perceived care

### 4.10.1 Method

The secondary aim of this strand of research was to determine whether continuity in care processes, as measured by the new indices, would behave as a predictor of longer term outcomes for patients with stroke. The SOS2 Stroke Outcomes Study cohort was followed up for a year after the index stroke event and thus offered a range of 12 month outcome variables on which to base an assessment of impact.

The preliminary analyses had shown that new measures of care, the SnL and the PPCI, behaved in different ways when applied in this sample of stroke patients: the SnL was associated with measures of physical function and other indicators of disability whereas the PPCI was more closely associated with mood and psychosocial well-being as measured by the GHQ\_28.

The SnL and the PPCI had been designed around a similar framework (the *a priori* model of continuity) but had been applied to two distinct and different data sources: written records of care and the patients in receipt of the care services to which the records referred. Confirmatory factor analysis had shown that the aspects of the health care process that the two new indices were measuring were different, and that their relationship to health status and well-being might not be fully understood.

### 4.10.2 Creating the latent variables

Latent constructs with improved construct validity had been calculated from the confirmatory factor analysis reported in Section 4.9. The latent constructs therefore had to be converted into variables to replace the simple aggregated scores of the new instruments in order to prepare them for a further stage of analysis. The regression weights for the two constructs were taken from the unstandardised confirmatory factor analysis. These data were then simply rescaled and relocated in order to provide scales in the range 0 to 100. The relevant equations for the calculation of the constructs therefore became:

$$\text{Disability} = 100 - 2 * (\text{RMI} + 0.37\text{MMSE} + 1.05\text{Barthel} - 0.27\text{SnL} - 0.04\sqrt{\text{GHQ}})$$

$$\text{Perceived care} = 1 + 2 * (\text{coord} + 0.98\text{satis} + 0.86\text{qual} + 0.71\text{info} + 0.44\text{PPCI} - 0.13\sqrt{\text{GHQ}})$$

Using these calculations two numeric latent variables were derived to be used in the next stages of the analysis including the analysis of outcomes.

It should be noted here that higher scores on the disability construct variable represent poorer function, unlike the Barthel Index (BI) where high scores equal better function. Higher scores for perceived care indicate better perceptions of care.

The hypotheses that had underpinned the examination of the demographic variables against the Chao PC scale (see Section 3.3.2, page 111) and the preliminary analyses of the PPCI (Section 4.6.4, page 162) were again applied to perceived care.

Perceptions of care might differ by age and gender due to generational attitudes to care, and known variations in male and female self-reported health and quality of life. Care processes did not vary by age and gender but disability might. Older people for example could be frailer and less active than their younger counter-parts, and gender could have an effect either through the medium of mood or because of the way loss of function impacts on social and domestic roles. (Atkinson and Caldwell, 1997; Fayers and Sprangers, 2002)

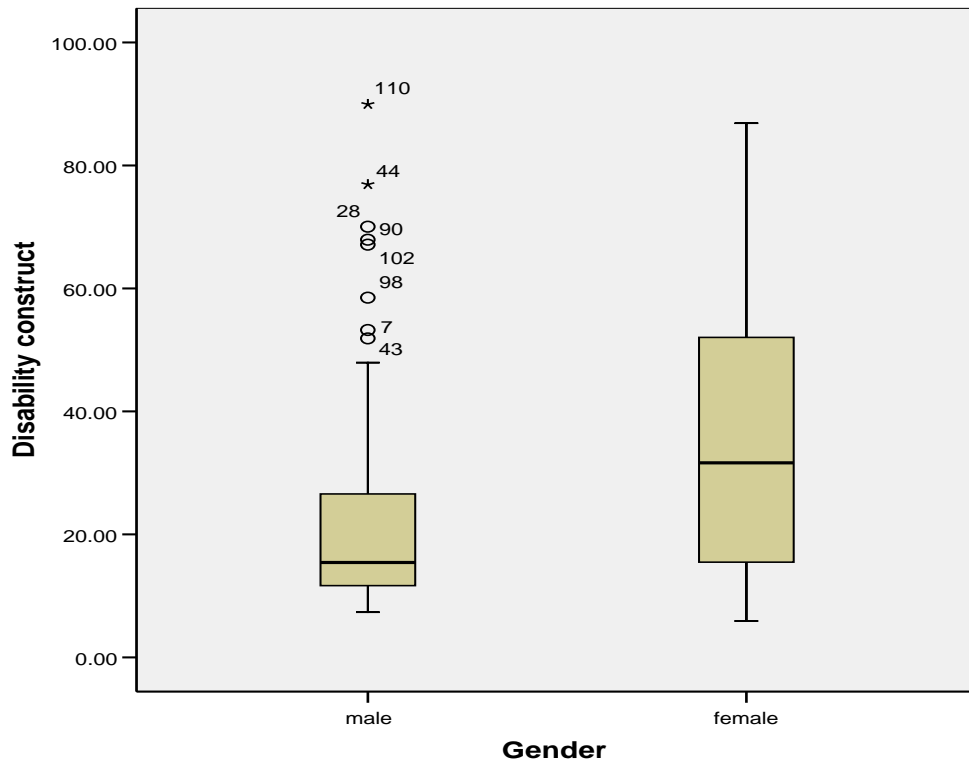
## **4.11 Results**

### ***4.11.1 Disability***

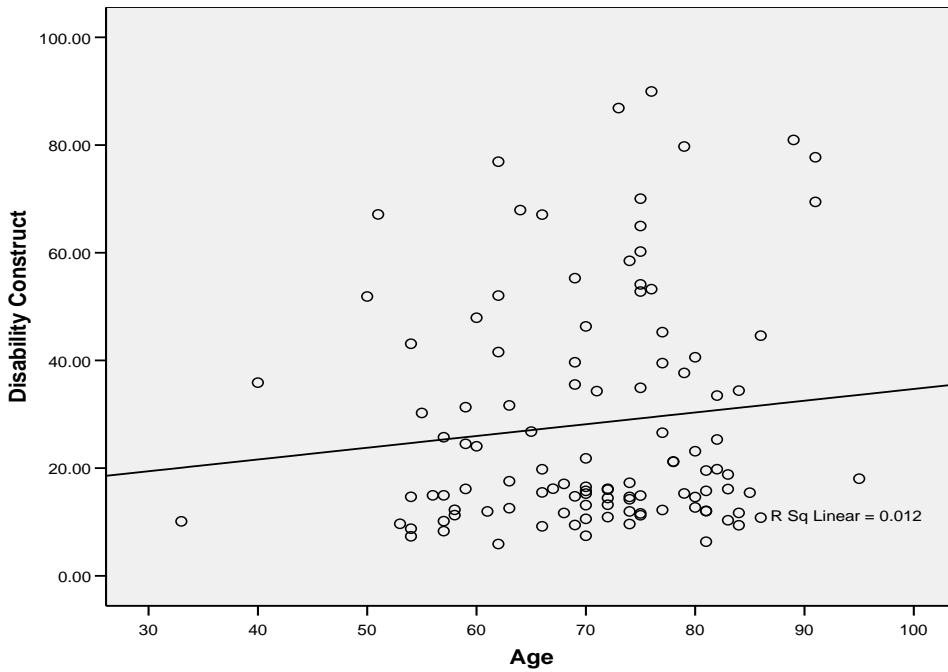
The box plot (Figure 4.j on the following page) shows that median score for the disability construct was higher (worse) for female stroke patients than for males, although the male group had more outliers. Gender had shown no association with the SnL scores, and this was expected as there is no reason why care processes should be different for male and female patients. This finding could be a product of the functional indicators that had contributed to the disability construct, two of which (BI and RMI) were self-reported. The differences in gender associated with self-reported health might then offer one explanation for this result.

When the data for disability were plotted against age on a scatter plot (Figure 4.k also on the next page), the resultant graph showed only a very slight association between worse disability and age, with a tiny r-square value which was heavily influenced by the two younger out-lying patients. Removing these two out-lying cases from the analysis would almost certainly have meant that the association would have been lost.

**Figure 4.j Gender and disability**



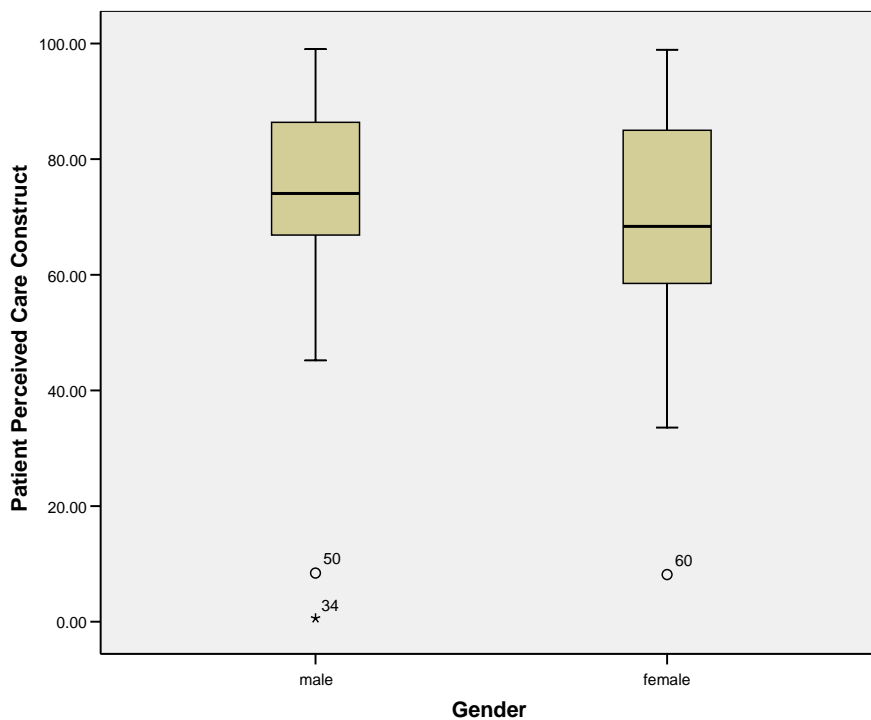
**Figure 4.k Age and disability**



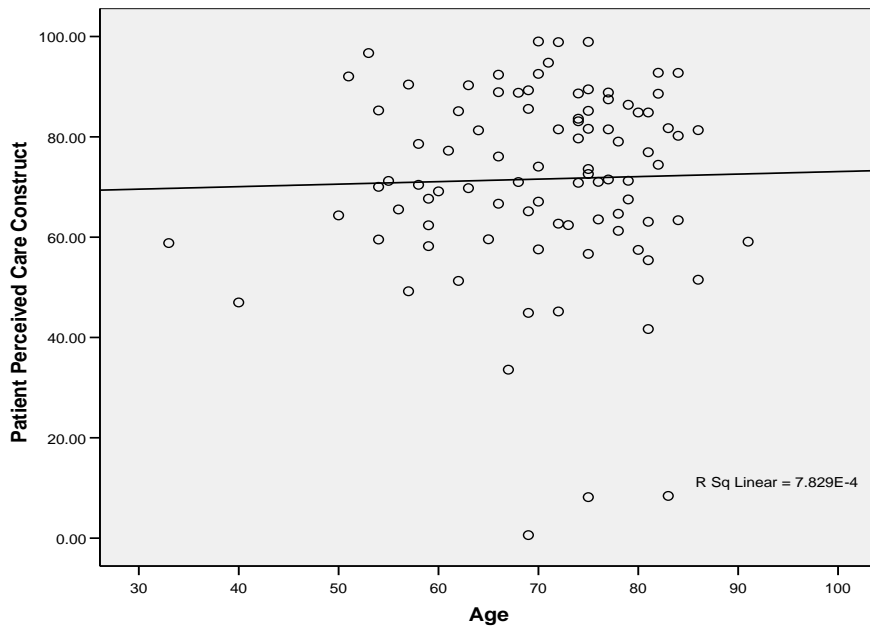
### 4.11.2 Perceived care

A similar pattern was found for the patient-perceived care construct and gender to that which had been seen with the disability construct: lower (worse) median scores for the perceived care construct were associated with female gender as shown below in Figure 4.l.

**Figure 4.l** Gender and perceived care



There was no association between age and the perceived care construct. The scatterplot (Figure 4.m) produced an almost flat fit line for the data. This was not surprising as the findings for the self-reported item scores and the PPCI total scores had not shown any association with age in the preliminary analyses.

**Figure 4.m Age and perceived care**

### 4.11.3 Assessing the impact on outcomes

The next stage of the analysis strategy was to examine the effect of disability and perceived care on key outcome measures. The Barthel Index (BI) is a well established and widely recognised measure of functional outcome. It was used routinely at each follow-up point in the cohort study and it is important to note that the outcome measure for physical rehabilitation proposed for this analysis was the BI measured at 12 months (T5 in the SOS2 cohort study schedule) whereas the covariate latent construct used in the structural equation model was based on BI measured at baseline (T1: 2 to 6 weeks post-index stroke). The two variables thus measured different states of patient well-being at separate points in the care trajectory and there was no confounding between them in this stage of the analysis.

Examination of the longitudinal cohort data had shown that at the time points shortly after stroke, T2 (6 to 8 weeks) to T4 (6 months), the Barthel Index represented a wide range of functional states. However, after 12 months (T5) many patients had recovered and the majority scored 20 on the Barthel scale. The analysis was therefore made more straightforward by dichotomising the Barthel score at 12 months, and recording those patients who scored 20 on the BI as zero (rehabilitated) and those who



scored less than 20 as one (not rehabilitated). This meant that higher scores equated to poorer outcomes as opposed to the original index where higher scores equal better function. This created a new binary outcome variable 'rehabilitated', which was then regressed logistically upon the two constructs: disability and perceived care, to assess their impact on physical rehabilitation. The impact of disability and perceived care on the probability of physical rehabilitation at 12 months being unsuccessful can be seen from the fitted logistic regression:

$$\text{Logit (Not rehabilitated)} = \text{Constant} + 0.09\text{disability} - 0.03\text{perceived care}$$

In this mathematical representation the variable *disability* is three times more important in predicting a poorer outcome for rehabilitation than *perceived care*.

Although the preliminary analyses had suggested that mood was associated with the PPCI but not with the SnL Index, the structural equation model had shown that mood at T1 contributed to both the latent constructs identified in the data. It was interesting therefore to explore how each of the new constructs would behave as predictors if mood at T5 was the outcome.

The outcome measure for mood, the GHQ\_28 score at 12 months (T5) was a continuous variable representing the raw aggregated scores for the 28 items on the GHQ taken from the SOS2 cohort study data. In order to adjust for the skewed distribution of the scores a square-root transformation was performed on the T5 scores, the same transformation that had been applied to the baseline GHQ data used in the SEM. Again it should be noted here that the outcome in this regression analysis was based on T5 GHQ at 12 months whereas one covariate (perceived care) depended upon T1 GHQ measured at baseline.

The transformed outcome variable was then regressed linearly upon the same two covariate latent constructs used in the logistic regression model. The resultant regression equation showed that, in this case, it was perceived care that had the best predictive power for mood outcomes, more than twice that of disability<sup>15</sup>:

$$\sqrt{(\text{Mood})} = \text{constant} - 0.02\text{perceived care} + 0.01\text{disability}$$

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<sup>15</sup> High scores on the GHQ\_28 represent worse mood states.

## 4.12 Discussion: Modelling measures of care

### 4.12.1 Defining the constructs

When the SnL Index was modelled with the PPCI in the structural equation no association was found between the two measures except for a slight linkage via the residual values. See Figure 4.h (page 185) and Figure 4.i, (page 187). This suggested that while the two measures were not correlated they shared some factor in common that influenced both of them. This could be hypothesised to be mood which was the only factor in the SEM analysis that contributed to both constructs.

The SnL Index was shown to contribute to the measurement of the construct disability together with other baseline measures of physical and cognitive function: the Barthel Index, the Rivermead Mobility Index and the MMSE. The preliminary analyses had led to the hypothesis that the SnL was a measure of care intensity – could it therefore be capturing the increased care input for patients with more disabling strokes?

The latent constructs were transformed to create latent variables by rescaling the regression weights taken from the SEM analysis to a 100 scale as described earlier in this section. This rendered comparisons between them easier when they were used as covariates in the subsequent regression analyses. For the outcomes of physical functioning, the disability construct proved to be three times as important as the perceived care construct. For the mood outcome, a clear association was found between mood and perceived care, where perceived care was twice as important as disability in predicting emotional outcomes at one year.

As an illustration of the impact on outcomes from a patient-centred perspective, the best and worse case scenarios can be defined as follows, using the range of available data:

#### ***For unsuccessful rehabilitation as the outcome:***

The model is:

$$\text{Logit}(\text{Barthel}<20) = -0.932 + 0.089 * \text{Disability} - 0.029 * \text{Perceived Care}$$

So that for

Worst case (disability = 90, perceived care = 1)  $\text{prob}(\text{Barthel}<20) = 0.999$

Best case (disability = 6, perceived care = 99)  $\text{prob}(\text{Barthel}<20) = 0.0367$

In other words, in the worst case scenario a poor outcome would occur 99.9% of time and in the best case only 3.7% of the time. Thus a poor physical rehabilitation outcome was much more likely to occur when disability measured in this way was high, and perceptions of care were poor.

***For mood as the outcome:***

- In the worst case where the disability construct score was 90 (poor function) and perceived care was 1 (lower perception of care), the predicted GHQ score was 13 (above the cut-off point (>11) for cases of higher psychological distress).
- In the best case where the disability construct score was 6 (better function) and perceived care was 99 (higher perception of care), the predicted GHQ score was 0 (clearly well below the cut-off for “caseness” on the GHQ\_28).

What cannot be fully explained by this analysis is the nature of the association and the role of the PPCI in this relationship. Accepted theories suggest that mood states can influence not only the way in which life events are perceived and interpreted but also the subjective responses that are given to questionnaires. It may therefore be that mood has a similar effect on patients’ perceptions of health care. This would also explain the association of mood with the Chao scores in Study 3.

#### ***4.12.2 Interpreting the effects of the constructs***

The logistic regression analysis showed that disability predicted functional outcomes at one year. This result is not unexpected given that the severity of the stroke and its consequent disabling effects are usually a good predictors of the level of residual disability that a patient will experience – only in rare cases is a full recovery made from an initially severe and disabling stroke event. If the SnL score is actually measuring care intensity or input as is suspected, then the contribution of this measure to the disability construct can be understood. Patients with severe strokes and higher levels of residual disability would be more likely to be in receipt of higher levels of care than those with lower impact events. The small effect from a component of perceived care is interesting, and was tested further in a one by one binary regression analysis. The association remained with borderline significance.

From associated work on the SOS2 cohort study it has been shown that mood, independent of early disability, predicts functional outcomes measured by the Barthel Index score, for patients one year after stroke. This relationship was not apparent in simple statistical correlations and comparative tests but a longitudinal multi-level analysis (reported elsewhere) identified four distinct trajectories for patients in the SOS2 cohort. (Hill *et al.*, 2008) These trajectories were characterised by the mean GHQ scores at baseline and showed that higher mean scores for mood were consistently associated with poorer functional outcomes. Earlier in this study, it was demonstrated that mood affected ratings of patient-perceived care and, given the association between mood and functional outcomes (independent of early disability) that was identified in the associated SOS2 work, one explanation for this finding could evidently be the influence of mood.

When the GHQ score at one year was used to define mood outcomes, lower perceived care scores were associated with poorer psychological well-being. This association between poor perceptions of care and poor mood scores was not unexpected as it had been apparent throughout each stage of the analysis. Poorer perceptions of care had consistently been found to be associated with poor mood scores using a number of different statistical tests in two separate data sets. However, the measurement of perceived care seems to have an effect beyond that of psychological status alone as a small component of disability was also found in the regression model. This finding would be consistent with the findings from the SOS2 cohort data which showed that a relationship exists between mood and functional status after stroke.

#### **4.12.3 Limitations of the analysis**

The prolonged period of development and testing that was associated with the new methods of measurement of care meant that a reduced number of patients in the SOS2 cohort remained available to participate in the later stages of this study. Unfortunately, the pilot versions of the measures that were used in the early stages of the enquiry did not always provide sufficient data, or data that could be modified for analysis. Data was retrieved for all the items which were unchanged in later versions of the measures but larger numbers of patients would have strengthened the subsequent analyses. Nonetheless there was sufficient data available to render the analyses that were performed valid.

It must be acknowledged that the method chosen to define the outcome indicator for physical functioning was not ideal. Dichotomising the Barthel data into two groups based simply on the final (one year score) facilitated the analysis but may not have accounted for differences in pre-stroke functional status, and thus the potential that actually existed for rehabilitation. The change in pre-stroke Barthel score at 12 months would potentially have provided a better outcome measure but there was a significant amount of missing data for the pre-stroke scores. If this method of discriminating outcome had been used it would have reduced the numbers available for analysis still further. There was also the issue of reliability as this indicator was assessed retrospectively and could not be verified by observation. A pragmatic approach was therefore taken as this was principally an exploratory study, and as much data as possible was retained for the analyses notwithstanding that the representation of functional outcome was adequate but not perfect.

#### **4.13 Summary: Study 4**

##### ***4.13.1 Quantifying continuity***

Two new measures of care were designed and tested. A checklist evaluated the care process as recorded in formal health and social care records. The phases and transitions in stroke care were used to define markers of continuity. This measure was tested in a full case note review of a sample of 126 patients. Using this method it was difficult to separate an evaluation of continuity in the process of care from the input and intensity of care. The scores largely reflected the physical status of the patient, the duration of care and their level of disability. Patient-perceived continuity was measured using structured interviews conducted directly with the same cohort of stroke patients. Care assessed in this way showed a strong association with mood and psycho-social wellbeing.

A confirmatory factor analysis showed that the two new measures were in fact measuring two distinct constructs: “*disability*” and “*perceived care*”, which were separate and uncorrelated. Latent variables were derived as part of this process in order to represent the underlying constructs and used to describe the associations of disability and perceived care with the demographic features of the sample.

The disability construct measured in this study was slightly higher (worse) for female stroke patients than for males. There was however only a very slight association

between worse disability and age. A similar pattern was found for the perceived care construct. Lower (worse) median scores for perceived care were associated with female gender but there was no association between age and the perceived care construct. The association identified between age and disability could have been a consequence of frailty increasing with age, and thus the effects of stroke having a higher impact on older people. However the observed effect was small and likely to have been influenced by outliers in the data thus this explanation cannot be confirmed.

#### **4.13.2 The impact of care on outcomes for patients.**

A range of one year outcome assessments was available from the SOS2 cohort and these were used to test the predictive power of the latent variables *disability* and *perceived care*. The results showed that:

- Worse emotional outcomes were associated with poorer perceptions of care, and to a lesser extent with higher levels of disability;
- Worse physical rehabilitation outcomes were associated with higher levels of disability.

The latter effect is not surprising given that the severity of the stroke and its consequent disabling effects will usually be good predictors of the level of residual disability but poorer perceptions of care were also implicated to a lesser extent.

Determining causality was not straightforward in the relationship between perceived care and emotional outcomes since emerging poor rehabilitation outcomes after stroke may have resulted in perceptions of poor care, in which mood was an important mediating variable. Alternatively it is possible that patients were able to identify aspects of their care that genuinely made a difference to them.

Achieved care, that is care delivered and the recipient's view of it, could thus be measured by including contributions from components of the physical, psychological and cognitive status of the patient in addition to the two new measures of care.

*Perceived care* can be regarded as a separate and measurable construct, and the results showed that the chances of a less successful outcome from rehabilitation went up as disability increased and ratings of perceived care decreased. However, patient mood states and short-comings in services alone did not affect care, and examples

were also found of cases where patient choice or behaviour were the primary factors influencing the care that they received. Disability is clearly a factor in achieved care mainly through its role in determining duration and intensity of care but it is less distinct, and already well represented by existing, standardised measures.

Perceived care as identified in this study cannot confidently be claimed to measure patient-perceived continuity of care as it was not possible to separate the components of care with sufficient precision to support this assertion adequately. The nature of continuity suggests that it can manifest itself in different forms at different stages of care. Even within the same condition or episode of care continuity can have different meanings. Indicators of continuity need to reflect this, and consequently they can be difficult to find and hard to define, particularly in terms which are relevant and meaningful to patients. Searching for simple, patient-centred and rateable indicators of continuity in chronic conditions like stroke may therefore be a futile task.

Nevertheless, service providers still require methods of evaluating the effects of care (and its continuity) from the patient's perspective. With further testing to refine and modify it, the perceived care measure described in this thesis might provide a means to that end by bringing service users' ratings of coordination, quality, satisfaction and timeliness together with other, possibly specific condition or care setting, indicators together in one measure. Ultimately, changing the focus of research to try and find new ways of understanding continuity of care might provide an even more rewarding approach to this complicated dilemma.

Communication was a recurring theme in the literature reviewed in Study 1, and arose in both conceptual and operational definitions. In Study 2a it was the only common thread running through the patients' accounts of care that had resonance with any of the currently accepted elements of continuity. Communication had also emerged from an earlier study of continuity in elderly care, and formed the basis of the Care Continuity Instrument (CCI). (Bull *et al.*, 2000) The role of communication as a mediator of continuity can be envisaged, as it is evident that the transfer of accurate and timely information is fundamental to successful coordination of care processes. In the next strand of research the theme of communication is pursued and explored with health care professionals to investigate its mechanism and function in stroke care.

## CHAPTER 5    Communication: A Key Element of Continuity?

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### 5.1    Introduction

The first strand of research undertaken for this thesis included an in depth exploration of how care was perceived by stroke survivors. This was reported in Chapter 2. The interviews with patients conducted in Study 2a revealed that their narratives of care did not make any reference to the managerial or relational elements of continuity that form part of the currently accepted model. A recurring theme of communication and information transfer was found in the patients' accounts but not described in terms that indicated any distinct idea of an organised or structured system that supported the transfer of information.

In the second strand of work, reported in Chapters 3 and 4, an existing measure of continuity of care was tested (Study 3) and two new measures developed (Studies 4a and 4b) in an attempt to quantify continuity of care. The two new measures: the PPCI schedule and the SnL Index were found to assess some aspects of the care process in terms of care delivered and patients' perceptions of care after stroke, but they had limitations for evaluating the role of continuity. Patient-centred assessments using the PPCI were subjective in nature and, as the analyses showed, influenced by mood status. Even so, the latent constructs measured by the two new indices, and derived from the structural equation model, were related to functional outcome. Overall, two important things were learned from the first two strands of research:

- Patients were able to form opinions about the many agencies involved in stroke care, and how they interacted with them individually, but not about how agencies coordinated their activities;
- The vast majority of stroke patients were unable to recognise the professionally defined elements of continuity in their care.

In the light of these findings, the focus of the investigation moved away from the quantitative assessment of process indicators of stroke care and returned to qualitative methods in order to assess the structural and organisational factors that support the care process. This decision was supported not only by the evidence accumulated during the course of this study but also other work that had been conducted in the



Leeds Institute of Health Sciences. This study of the collaborative linkages inside and between organisations provided specific evidence from a study of Intermediate Care that communication played an important role in the organisation of care after stroke. (Hardie and Keen, 2006)

There was also a diverse pool of evidence from both the health and social sciences literature that communication plays a vital role in collaboration and the coordination of organisations and services. (Ovretveit, 1993, Watts, 2003) At this stage of the study Professor Justin Keen provided guidance on the direction in which this research might proceed. Based on this input it was decided to conduct an exploration of the extent to which the people involved in the after-stroke care of the cohort study patients saw themselves as part of a “team” responsible for stroke care provision. The findings and recommendations of the study of intermediate care by Hardie *et al.* supported the “*exploration of concrete events that could provide evidence for continuity in the process of care*”, and more specifically, the exploration of health professionals’ communication networks, and how these function to aid efficient co-working within and between agencies. Communication seemed to represent a key factor that tied together the agencies involved, and was central to the effective co-ordination of care. Therefore, rather than seeking health professionals’ perspectives on continuity of care, it was proposed to find out how health care professionals coordinated their activities to deliver stroke care, and to explore the promoters and barriers to communication between health professionals, which were more likely to provide insights into the successes and failures in service coordination.

## **5.2 Study 5: The communication study**

### **5.2.1 Aims and objectives**

This study aimed to seek professionals’ perspectives on continuity of care. The enquiry focused on the way they worked with patients, and how services were structured to deliver communication and what the processes of information transfer were. By examining care from another viewpoint it was hoped to achieve a clearer understanding of the results of the earlier stages of the study. Therefore it was proposed to:

- Conduct focus groups with stroke professionals to identify the implicit and explicit objectives of communication within and outwith local stroke services;
- Explore how professionals understand service organisation as arranged to meet the above objectives, and how they use communication to coordinate their activities;
- Conduct face-to-face interviews with key personnel (service managers, senior clinicians etc.) to identify key elements of communication in practice that were likely to facilitate or inhibit continuity of care – communication styles, referral policies and the like;
- Review policy documents of relevance to local stroke service delivery.

This phase of the study therefore aimed to explore communication between health professionals' in relation to stroke care specifically by studying:

- patterns of communication – who communicated within and between agencies;
- the modes of communication used by health professionals;
- the content of their communications;
- how communication could impact on patient care.

### **5.2.2 Methods**

In this second round of qualitative research Dr Shenaz Ahmed advised on the conduct of the focus groups. Dr Ahmed up-dated the author's skills in this research technique and advised on the use of Version 7 of the NVivo software to analyse qualitative data. (QSR International Pty Ltd, Version 7, 2006) She also attended some focus groups as an observer and provided useful feedback. All the focus groups were facilitated by KH, assisted by HB, both of whom made notes in addition to the audio-recording. Members of the SOS2 support team provided administrative support and transcription services.

The study was conducted in the United Kingdom in an area covered by two Acute Trusts and (at the time the work was undertaken) eight Primary Care Trusts, although recent service reconfigurations have changed this. Qualitative methods were used and the study was conducted in two phases:

**Study 5a:** an exploration of '*communication*' in four focus groups with mainly hospital based health professionals. The findings from this phase led in part to the development of a stroke care network diagram of communication within and between agencies. (See Figure 5.d, page 230);

**Study 5b:** an exploration of '*communication*' using semi-structured interviews mainly with community based health professionals. At the end of each interview certain participants were asked about their views on the diagram developed from the results of the focus groups.

### **5.2.3 Sampling frame**

The sample selection for Study 5 was made using a purposive sampling strategy (Murphy et al., 1998). Health professionals were invited to participate either because they were identified as potentially knowledgeable informants by virtue of their role in stroke care or because they were professionals who made or received community care referrals. NHS hospital staff were selected on the basis of seniority that is ward sisters or senior staff nurses and senior therapists from the acute stroke rehabilitation units. Staff from the medical admissions units and several elderly care wards were also invited to participate.

Key informants (that is those with specific managerial or commissioning posts) and other specialist health or social care professionals were approached specifically as some of their roles were unique in the area studied. Other participants such as community matrons, district nurses and GPs were identified by contacting primary care centres. The centres were selected by sorting the SOS2 data by the GP practice at which cohort study patients had been registered and ranking according to numbers of patients in the study. Centres were then approached in order until sufficient participants were recruited.

The NSF for older people Standard 5 lists the professional groups that should ideally make up the stroke multi-disciplinary team. (DOH, 2001) Experience gained from the SOS2 cohort study had also identified other practitioner groups and services that were involved in the care of the longer term care of patients after they had left hospital. By inviting participation from members of all the different professional groups recognised as contributing to care it was anticipated that a diversity of experience would be

represented thus enabling a comprehensive picture of communication in stroke care to be constructed across the whole care trajectory.

Participants were recruited by telephone except one who was recruited by letter. Prior to attending the focus groups or being interviewed, participants were sent a letter of invitation and a sheet of written information about the study. The focus group were conducted in meeting rooms on hospital sites. The interviews were conducted at the participant's work place, usually in their office.

### **5.3 Study 5a: The focus groups**

Four focus groups were conducted. Effort was made to include a mix of health professionals with different roles from different agencies within the focus groups in order to facilitate discussion about communication between them. All the focus groups were conducted in hospital settings, included between six and seven participants, and lasted approximately ninety minutes. Prior to attending the focus groups, participants were sent a letter of invitation and a sheet of written information about the study.

All participants were assured of anonymity and confidentiality. All the focus groups were audio-taped and transcribed verbatim, and all the transcripts were subsequently reviewed for accuracy. The focus group discussions were guided by a detailed topic guide that explored aspects of inter-professional communication and communication with service users, including:

- (1) patterns – who people communicate within stroke services;
- (2) modes – how people actually communicate;
- (3) content – what information is communicated;
- (4) impact – how communication impacts on patients.

### **5.4 Study 5b: The individual interviews**

A total of 18 interviews were conducted with participants from agencies providing services for stroke patients. Health professionals who had not been included in the first phase (Study 5a) were specifically recruited. Reasons for non-participation in the focus groups were chiefly practical: consultants for example were unable to attend focus groups during normal day time hours due to clinical commitments. In addition, given that the first phase of the study included mainly hospital based health professionals, it

was endeavoured to interview a number of participants from community based health services. Participants were recruited by telephone except one who was recruited by letter. All interviews were conducted at the participant's place of work.

Using the same method adopted for the focus groups, interviews were guided by a semi-structured interview schedule that explored communication, including patterns, modes, content and impact. In addition, some of the interviews explored participants' views about the diagram developed from the results obtained in Study 5a, with the aim of gaining impressions of professionals' views about it, ascertaining its accuracy and obtaining information about any gaps.

Participants were assured of anonymity and confidentiality, and all the interviews were audio-taped, except one where recording failed due to a technical problem. Most of the interviews were also transcribed verbatim except for five: two with consultants which were not transcribed because the main purpose of their interviews was to obtain views about the diagram; and three interviews that provided no new themes or information.

## **5.5 Results**

### **5.5.1 Participants**

A mix of health professionals with different roles and drawn from different agencies were included in each of the four focus groups in order to stimulate discussions on the topic of communication between different types of services and care providers. A list of 65 potential participants was drawn up and contacted: 27 people eventually attended one of the groups. No medical staff, social workers or service managers were available to attend the focus groups and some ward sisters sent representatives on the day because they were too busy to leave the ward. The groups were therefore made up mainly of hospital-based nurses, physiotherapists and occupational therapists, and community-based intermediate care nurses and therapists. The Community Stroke Team manager, one speech and language therapist, one dietician and two participants from the charitable sector, both employed by the Stroke Association also attended focus groups.

Participants for the individual interviews were selected to address the gaps in informants in the focus groups. They were conducted with a total of 18 people representing the following health care professions:

Two Stroke Specialist Consultants  
Two General Practitioners  
Two GP Practice Nurses (including one lead Practice Nurse for CHD)  
A clinical psychologist  
A Community Matron  
A Hospital Matron  
A Strategic Health Authority Modernisation Manager  
A Community Rehabilitation Unit Clinical Nurse Manager  
A Joint Care Management Team Leader  
A Home Care Management Team Leader  
A Community Disability Team Manager  
A Specialist Stroke Nurse  
A Specialist Liaison Health Visitor  
A Hospital Social Worker Team Manager  
A Stroke Association Dysphasia Support Worker

Recruitment of individual interviewees continued until no new themes emerged from the data.

The focus groups often became lively forums for discussion between participants, and presented an opportunity to air problems and frustrations, and share experiences with colleagues. One group in particular gained useful insights into the work processes of the agencies and services with which they collaborated, and went away with ideas for practice that would improve links between them. Overall the participants in the focus groups, and those that were interviewed as individuals, were skilled and professional people who left a lasting impression of a highly committed and caring work force.

The following sections of this chapter describe the ways and means by which communication is conducted in stroke care, and also its nature. There follows a report of the observations made by professionals about other determinants of continuity. The ensuing sections are organised using the main themes of the interview topic guide as headings.

### **5.5.2 *Patterns of communication***

The main focus for this part of the discussion was the individuals and agencies with which the participants had contact on a regular basis. They were asked to think about

their recent caseload and identify the people they had contacted, or who had contacted them, in the course of organising and delivering patient care. Patterns of communication were identified that were both flexible and reactive. Within local teams there were patterns of regular meetings and briefings but wider communication with other teams and agencies was diverse, and did not consist of a routine series of contacts. There was general consensus between the focus group participants that it was mostly the needs of the patient that determined whom they contacted and when.

*"... we communicate with different people on a day to day basis really, I mean sometimes we need to get hold of the dietician you know because someone comes across the night before and they've got an NG tube but no regime so you know, um or we need to speak to the Speech and Language therapist, so it's you know, it depends what patients we've got on the ward at the time really and what their needs are."*

**Ward Sister, Stroke Rehabilitation Unit**

This finding was echoed by the individual interviewees, even those with managerial roles, to the extent that, beyond the immediate team environment, it was difficult to identify clear channels of communication between all those involved in the care of stroke patients. Some units and agencies had more structured patterns of referral but these were generally a means of introducing patients to services, and usually initiated onward communication to respond to the needs of individual cases or to obtain further information from the referring agency.

*"... the first path of communication will be sort of written communication in a referral but then we would always try and follow that up with one of the senior staff actually telephoning either the person that's done the referrals whether that's Ward (name) or either one of the community teams erm, sort of the GP, the district nurse."*

**Lead Therapist, Community Rehab Unit**

One theme which emerged was the advantage of specialist knowledge and experience, and the way this could enhance patient care. Building links and relationships to facilitate the coordination and delivery of care was well recognised by the participants as a useful skill. Knowing who to contact about what, and giving relevant information was an important time-saver, and produced better results. New services, such as the Community Stroke Team, had adopted models which made best use of this professional network:

*"...there's four key sites that we get people from, so we decided to have like a link therapist sort of model... we were sort of building up a relationship with the*

*link site, as it happened we each had worked on those sites before so that really helped from a relationship point of view."*

#### **Manager, Community Stroke Team**

All the focus groups endorsed the fact that closer proximity between colleagues and team members was an aid to better communication and thus to better coordination of care. This was fairly well assured in the acute setting, and in-patient rehabilitation facilities, where ward-based care was coordinated by regular shift handovers, ward rounds and multi-disciplinary team meetings. These regular meetings were described by the participants as time-points at which patient progress and care planning could be discussed.

*"...more formal meeting with the medical staff which is the, what you might call the general case meeting for the patients, its called a ward round ...and that's when we actually discuss the patient's progress with the medical staff and make some further plans ...that (meeting) would involve the therapists and the nursing staff that are either their (patient's) named therapists because again on the therapy side we have a named therapist for each patient, and again the patients are divided into three nursing teams so there would be the primary nurse or the lead nurse for that particular team discussing their patients in, on a ward round meeting as well while doing that."*

#### **Lead Therapist, Community Rehab Unit**

Arrangements for community teams varied, some shared the same office or suite of offices, and some were based in the same building while others were more distant.

*"...are all based together in the same room... So virtually everyday we are meeting a handover every morning, um discuss the patients, we have on going discussion if there's any problems... we all work together, which is very useful because we problem solve together and we overlap in many ways ...we go out & do joint visits with the Physio and the OT and look at problems together and working together."*

#### **Senior Nurse, Intermediate Care**

It was generally agreed that well planned home visits were the best means of preventing problems that often resulted in failed discharges and the readmission of patients. Home visits were thus regarded as very important meetings in the stroke care process by the participants. Both hospital and community based therapists saw them as valuable facilitators in the transfer of care from hospital to home because they enabled direct communication between all the parties (lay and professional) involved.



*"home visits work really well because you can actually express something that, you know what the problems are and how it's been solved in hospital, and where you are going, what you are trying to sort of, what your main goals are."*

**Senior Physiotherapist**

What emerged from the discussions with stroke care professionals on this topic was that patterns of communication were diverse and needs driven. Hospital staff and community teams described the coordination of activities as "*relatively easy for professionals that all worked in the same place*" through a series of direct, regular, formal and informal contacts. However, the combination of therapy and care needs that may be required to support discharge after a stroke required communication across different health and social care boundaries. It was plain from the discussions between participants that difficulties were compounded when geographical separation also meant that different systems and methods of working were employed, and this point will be returned to later in the discussion of modes of communication.

### **5.5.3 Modes of communication**

Documenting patient information in health care systems has traditionally followed a standardised format of hand written case-notes. Only in recent years has this tradition been broken by the introduction of electronic records to many general practices, and in some areas of hospital care. For this phase of the enquiry participants were asked about the methods they used for communication within their own teams, and outwith their organisations. The effectiveness and reliability of different means of transferring information were the main threads of this part of the enquiry, and what staff found good and bad about them.

The modes of communication found to be most used by the majority of the frontline staff were based on written notes and faxed referral forms. Issues of access to electronic communication facilities and the potential problems surrounding the transfer of confidential patient information were the main reasons cited for not using email as a medium for the communication of health care related material. Most ward-based staff and community based care teams did not, in any case, have access to an individual email address, and were therefore dependent on email messages being passed on by administrative staff (ward clerks and secretaries). This clearly has limitations for the efficient transfer of information by a method which usually relies on direct electronic linkages. Senior and managerial staff, who more frequently had personal work

stations, did make use of email for certain types of inter-professional communication. Face to face and telephone conversations were, however, consistently endorsed by frontline staff as the most efficient and effective means of communication because they enabled the transfer of large amounts of detailed information quickly. Informal meetings, "corridor chats" and regular briefings were also cited as opportunities for this type of communication. The only perceived disadvantage here was that information could sometimes be forgotten or distorted if it was not written down.

*"...there is the danger that someone that you hand over to isn't going to remember it if it is not documented..."*

**Senior Occupational Therapist, Acute Ward**

*"...it ends up like Chinese whispers, you know you can pass the bit of information on to one person who they know, pass it onto somebody else by the time it gets down the line it has completely changed..."*

**Lead Therapist, Community Rehab Unit**

The SAP form (Single Assessment Process form) had caused a number of problems for staff since its inception. The form had been devised as an electronic, web-based form to facilitate sharing between organisations via the Internet. In practice, however, its main application on the wards was as a printed form, and this was evidently the source of some of the problems with it. Lack of space for entering information was a major complaint, and arose because the original electronic format had been designed to expand as required on the computer screen; once the form had been printed off this flexibility was lost. Printing out forms also meant that older versions were in still in circulation, having remained on wards after they had been superseded.

*"The other thing with the SAP and the contact assessment and the twenty four hour nursing assessment is I think I've lost count the amount of times they've changed the documentation in the last twelve months since it was brought in, I cleared out a drawer the other day on the ward it had four separate contact assessment documents in there that were all different."*

**Ward Sister, Stroke Rehabilitation Ward**

Moreover, apart from hospital staff sometimes being unsure when and how to complete the forms, they also felt that the overall burden of form filling had gradually increased over time. This had become an added pressure on busy, and sometimes under-staffed, wards:

*"That's why we don't like the Easy Care documents because by the time it's been filled in on assessment when it's come to us we have to redo it all again anyway because everything's changed, and the space they give you to update things... it's like two inch big."*

**Physiotherapist, Intermediate Care**

*"...we just duplicate an awful lot, and if there was more unification and less duplication then it would be so much easier and be less stressful especially for the nursing staff I think."*

**Senior Physiotherapist, Neuro-rehabilitation Ward**

Documentation clearly has an important role in the coordination of patient care. The recording of information in patient case-notes facilitates co-working between team members, avoids errors and omissions and prevents duplications in care. The hospital based participants for example were unanimously supportive of the Stroke Care Pathway documentation and agreed that stroke care had improved on those wards that had adopted it. Similarly, community teams such as the Intermediate Care Team (ICT), found their dual system of patient-held and office records facilitated their administrative and scheduling processes. By comparison, the Easy Care documentation (SAP) which had been designed to be handed over at discharge from hospital to community care staff had few enthusiasts. Thus documents designed for specific settings seemed to work well, as they had the benefit of recording information that supported the work processes in a particular area. Shared records, on the other hand, are required to report different types of care process, at various time points, in order to provide information that is relevant, and accessible, to the organisations between which they are passed. Thus they are more complicated to design and more difficult to ensure that they are completed to a standardised format.

The telephone and fax machine were the mainstays of communication for hospital and community staff. Often a preliminary phone call would notify a ward of an impending transfer or social services of an imminent discharge. The initial contact would be followed later by a faxed referral form:

*"Most of the official documentation is faxed, and then that's often followed up especially with the complex stroke patients we often find we need phone calls as well to supplement that basic information, or supplementary reports."*

**Senior Occupational Therapist, Rehabilitation Ward**

All the participants expressed frustrations with the technical difficulties that arose in relation to transferring information, and there was a consensus of opinion that technology was not keeping pace with the changes in operational systems. Office systems for example were often configured for business hours and not for 24 hour day, 7 day week working:

*".....we find simple technological stumbling blocks.....Joint Care Managers are working weekends but our fax machines are blocked at the weekend so I have to manually use an operator to fax this documentation through on the weekend to someone that's waiting on the other side and then pages won't have got faxed, another technological problem and I have to go and use a second person again when, so what would have, could have and should have been a five minute job particularly at the weekend, becomes a half hour or a whole shift job."*

**Staff Nurse, Rehabilitation Ward**

Direct contact, either face to face or via a telephone conversation was the mode of communication favoured, and perceived as most efficient and effective, by the participants. Face to face communication was facilitated by proximal work areas and this supported the view that coordination of activities can be more easily achieved when the managerial and geographical areas of teams overlap expressed in the discussions in the focus groups. However, stroke is a complex condition and the delivery of care is frequently fragmented; different organisations and separately managed teams can be involved depending on the nature and extent of a patient's continuing care needs. Clearly, therefore, improving and maintaining communication channels is essential to providing high quality care processes for stroke patients.

#### **5.5.4 Content of communication**

The participants were asked about the nature of the information that they dealt with, and about variations in the quality and accuracy of the information they received. Enquiry was also made about the way in which the type of information they passed on varied in relation to the recipient. The participants detailed an array of information that they had to process in relation to patient care, which ranged in type from difficult and complex clinical details to sensitive information (either formal or informal) about individual patients. The latter was described by the participants as essential to know but sometimes difficult to record, and was another reason why face to face communication was valued by them. For example, in relation to informal information, the participants discussed how important it was to have insight into the social or

personal circumstances of patients. Knowing how much could be expected of the immediate family was considered especially relevant when organising care:

*"With the family dynamics, does the husband and wife get on? Could be very relevant but not because we are being nosey, we want to know what their marital status is like if we are sort of trying to rehabilitate this person and we need their partner to be assisting in their rehabilitation or are they going to be involved in physically getting them up and washed and dressed in the morning or do we need to get home care involved and these things, so getting that sort of bit of a wider picture of you know some of the social issues"*

#### **Community Rehabilitation Unit Senior Therapist**

Relationships or behaviours were also important factors in both ward contacts with patients and families, and during home visits, and many anecdotes were related about patients with complex family lives. However, understanding and communicating the personal dynamics of home situations was not only important for developing continuing care packages for patients but also for staff safety:

*"We've had a gentleman recently as well who apparently had been in prison half his life for beating up every female he has come into contact with and molesting little children and all sorts of things and we didn't find out until somebody had been going into his home for five days and then he ended up turning against staff, threatening to kill himself and all sorts of things and really we felt like that information, we didn't know we went in blind and a lot of time we are going in we are putting us support workers in there, we are putting night sitters in there, we were sitting for people by themselves on a night, and a lot of the time we don't get a lot of information we find it out as time goes on."*

#### **Community Physiotherapist**

Both the giver and receiver of information are important determinants of quality communication; good information is of no more use than poor quality information if it is not understood by the recipient. With regard to formal clinical information, there was unanimous agreement that inter-disciplinary communications were the most effective for this type of specialised content. The benefit of shared knowledge and understanding was an asset in transferring complex details quickly and effectively between professional staff to the extent that staff would specifically seek certain people out:

*"I might want to speak to the physiotherapist, and I might want to speak to the one I know has got more of a neuro bias if it's a stroke patient, I'm going to make that effort, but that possibly can or cannot be acted on within the team, but hopefully I passed on a neuro-type message to a Physio who is going to*

*understand it more so that surely that's going to improve patient care, that's the way I reason it."*

**Senior Physiotherapist, Rehabilitation Ward**

The context in which information was given and interpreted was also important.

Disability, for example, may have different meanings in the supported environment of a hospital from the implications in a home setting:

*" Well one of the key things that we learnt from visiting another team is about how you ask about continence because you could say to somebody 'is so and so continent', and they'll say 'oh yes they are continent', but continent means getting up three times in the night and helped by a nurse whereas that is not realistic in a home setting to do with the relative sustaining that indefinitely so that is one specific area which is really important how specifically you ask the question because it could cause something to fall apart once they go home perhaps you've got the level of detail that you need."*

**Community Occupational Therapist**

The problems arising when trying to convey difficult or complex information to patients and families were also discussed, and it was appreciated that the acute and disorientating nature of stroke sometimes made it difficult for lay people to understand or absorb information.

*"...the patients go through a roller coaster don't they... they come in with a stroke and then they get pneumonia, then they might have a heart attack, and then they get another chest infection, and it's a roller coaster but ... you get quite a lot of those and I always now say to the relative, it's going to be a roller coaster for you, right from the start because they think 'oh they are getting a bit better now and then something else happens and that builds up and then they think, that we're not looking after them, you know, why has this happened now, what, why haven't you done something about it? And I try to pre-empt that by saying.....they are more susceptible they will, you know, it won't all be good, it will be a bit of a roller coaster for you."*

**Ward Sister, Acute Stroke Ward**

Younger patients were, however, generally perceived as having fewer difficulties with information:

*"....with younger strokes you've often got a younger family at home and a more capable spouse, who is able to retain more information and transfer information, and perhaps is more likely to say, 'oh well that isn't how they did it in the hospital', whereas a lot of our relatives, their spouses, you know they wouldn't know really, they perhaps wouldn't remember themselves what to ask for and whether something was being done properly."*

**Ward Sister, Rehabilitation Ward**

The allocation of a primary (or named) nurse and therapist to an in-patient has been common practice in hospitals for some years, more recent initiatives have brought the introduction of key workers and co-key workers (who may not necessarily be qualified staff), but whose role is similar to that of the primary nurse. The purpose of these supportive workers is to facilitate the transfer of information in the care setting, to act as a patient advocate at MDT or care planning meetings, and also to provide a point of reference and continuity for patients and relatives. This practice has been carried over into the community where effort is made (when feasible) for a named therapist on the Intermediate Care Team to follow a stroke patient through home-based rehabilitation during the period of the team's involvement. Community nursing staff change of necessity however, depending on workload and priorities:

*"Therapist wise we always, O.T., Physio we always keep the same, but the nursing staff don't tend to do it the same they tend to, depending on what problems arise whatever nursing staff's on that day, but Physio or O.T. wise they follow the same patient through so, we do the home visit we tend to keep them on once they've come home as well."*

#### **Physiotherapist, Intermediate Care**

The development of therapeutic relationships with patients during the various stages of care was described by both hospital and community staff, nevertheless there was general consensus that sustained relationships were not important in maintaining continuity of the care process provided good handover of care could be achieved during transitions in care. Where concerns did arise was in the transfer of patients to nursing homes. Participants shared the view that information communicated to care staff in nursing homes was not passed on effectively or not acted upon. The consensus of opinion was that this was due to a lack of understanding or skills, which was often the result of high staff turnover in nursing homes. There were several examples of cases where complications had arisen due to failure to maintain the standard of care given in hospital, often leading to re-admission or re-referral to other services. A senior OT described a case of a patient discharged to a nursing home with splints who had subsequently gone home with black heels:

*"There was actually a written report in the notes saying please check the heels, don't allow this lady to wear splints for more than two hours a day please check the heels regularly, discontinue wearing splints... but from what the family had said, they had just kept putting these splints on her, and you know, as a result, when she came home, I then had to order her a different mattress you know, completely look at the care regime for pressure care etc and she'd left the ward without any of those problems."*

Another case which was described was that of a male patient with a PEG feeding tube<sup>16</sup> in situ, who had also been discharged to a nursing home:

*"We had an experience with a gentleman who went to a nursing home for three days and came back in a completely appalling condition. He needed mouth care, his mouth had not been cleaned. It was absolutely awful .... he was in a poorly position for his PEG<sup>+</sup> feeding..... He came back and stayed with us for another three months."*

**Hospital Dietician**

### **5.5.5 Communication and care processes**

As an introduction and in order to set the scene for the focus groups and interviews it was explained that, although the discussion would be focusing on issues around communication, the overarching theme was continuity of care and how services were organised to deliver it. Participants from the professional community, unlike the patients, were comfortable with the term "*continuity*" but, although generally endorsed as an important aspect of care, there was no unanimously espoused opinion of what it actually meant.

*"...we're not in the game of continuity....I don't think continuity is an important issue.....care management is not about continuity, it's about care."*

**Social Worker Team Leader**

It was clear that individual interpretations of continuity were varied and frequently vague, supporting the initial impressions that continuity was primarily a professional concept but that its definition was not consensual. A number of interesting observations were made on how patient care was maintained, and the gaps and barriers that stroke care professionals experienced in providing a coordinated service. Throughout the enquiry parallels were drawn between the data derived from different sources and themes were reiterated for both clarification and reflection. Issues arising such as the interpretation of care needs showed how professionally assessed needs where sometimes at odds with patient-perceived needs. This discrepancy could sometimes lead to disappointment and dissatisfaction for patients. Inter-professional perceptions of services could also lead to a misunderstanding (by both staff and patients) of the nature of services to which referrals were to be made, and consequent breakdowns in the delivery of care. By and large however it was communication

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<sup>16</sup> Percutaneous endoscopically-guided gastrostomy (PEG) tubes are indicated for long term feeding to avoid the discomfort of nasogastric tubes.



problems (being unable or forgetting to contact someone) that were the principal causes of failure to ensure ongoing care arrangements.

### **5.5.6 Continuity and resources**

The rapid advance of technology coupled with an ageing population and rising expectations for care have placed an increasing burden on health care providers to deliver services and meet needs. Diversification of services and providers and market reforms to encourage competition are methods that have been introduced in an attempt to balance needs with limited resources. (Klein and Day, 1996) In complex and chronic conditions like stroke, patients often have long-term care needs that require input from a number of different agencies or providers but nevertheless resources in any service are finite. Where care involves sharing or handing over responsibility for the various stages of the patients' care it is essential that all the parties involved are aware not only of the resources available but also how they are allocated, in order to achieve a smooth transition through the process.

A theme running through the conversations with health care professionals was that of resource allocation. There was a widely held view that continuity of care for stroke patients was often dependent on the availability and appropriateness of resources: *"...it's no good communicating if there's nobody to communicate with"*. There were concerns too about the capacity and volume of referrals to services. A common problem in hospital was the shortage of appropriately trained nursing staff, and also other specialist professional groups like dieticians and speech therapists (SALT). Strategies adopted to address the shortfalls among dieticians and SALTs included delegating skills to nurses by training them to do some of the routine tasks normally undertaken by these specialist practitioners like swallowing assessments. Outside hospital, disquiet about the low levels of skill among nursing home staff have already been discussed in Section 5.5.4, page 212 but turnover was a problem for continuity too:

*"the through put of staff was amazing you know, you go in and you'd spend a good half a day .... and you'd maybe see ten people... but in two months those ten people weren't there anymore. I think that is one of their problems ...."*

**Senior Occupational Therapist**

Within the hospital setting there were many complaints about the lack of administrative support, particularly secretarial support for hospital doctors, but also clerical staff on wards. Deficiencies in this type of assistance could have a major impact on ensuring timely and accurate communications. For example discharge and clinic letters are delayed (or never sent at all) if secretarial support is not available, and hospital case-notes require routine filing to maintain up to date records. Efficient case note tracking and retrieval was also considered an important feature of administrative support by the health care staff because it reduced the risk to the patient that inappropriate treatments would continue or relevant treatments be withheld when records were not available. It also saved valuable clinical time spent chasing information.

There were examples too given by participants of experience of understaffing in the community, and a perceived lack of therapy resources for onward referrals after discharge from hospital. This was considered to be especially problematic for SALT, but was also referred to in relation to physiotherapy and occupational therapy. In some cases, when home care services were not available to take over care, specialist teams like the ICT would have to continue beyond the usual period of involvement. This plainly had implications for their capacity to accept new referrals.

*"We have people on our books for months...and we are only meant to be a six week service....waiting for someone to do something as simple as empty the commode.... And we can't discharge the person - we've got no choice, because who is going to do it for them? And sometimes we end up getting stuck with patients or we end up going in and we end up being home care which we aren't. Our support work isn't meant to be homecare, we are meant to be doing rehab."*

#### **Intermediate Care Physiotherapist**

In some community situations the role of statutory services was assumed by voluntary organisations like the Stroke Association. They provided support for patients with aphasia in collaboration with the Primary Care Trusts but hospital staff, and other referrers, were not always aware of the service they offered. It was more often the case that patients would self-refer to this type of service after learning about it at one of the charity's support group meetings or through an information leaflets. Raising awareness among professionals of what the voluntary sector could offer was thus considered by charity workers to be one of their main challenges:

*"...we are just not getting the referrals through. ..that's the big thing really, is getting awareness that we are here. The amount of time we'll have the GP coming back... 'well I've never heard of you before', community care teams*

*they're the same. We talk to as many people as possible...constantly go out and talk to various organisations, go to the universities, go to the hospitals, give talks to post-graduates, things like that, just to make them aware that these things are around..."*

**Dysphasia Support Officer**

### **5.5.7 Continuity and organisation**

Linear models are popular for the planning and coordination of care, and work well in settings where care is highly standardised. However, in a complicated and longer-term chronic condition like stroke it is difficult to design a pathway that is applicable throughout all the stages of care. After discharge the care pathway resembles a "cat's cradle" more than a linear process, with varied transitions occurring and numerous potential routes (some circuitous and some iterative) through care. Priorities and demands may also change during the different stages of care depending on the status of the patient (acute versus stable versus chronic).

The acute phase of care, for example, comprises many aspects that are not contingent on the patient's personal status and circumstances. It is amenable to a linear model of care and hence the Stroke Care Pathway is useful at this stage to ensure the delivery of high quality care through standardised procedures. After discharge, care changes and becomes more individualised and contingent on the patient's social circumstances and physical status. In the interviews with patients in the qualitative study (Study 2a), reported in Chapter 2 of this thesis, many examples were given of the ways in which patient care and daily living was maintained after a stroke. For many people, family and friends played a major role in supporting routine activities like shopping, housework and transport. These informal agents of care provided different types of support at different times but the way they are organised is far from homogenous. This type of care cannot be factored into a linear service model.

The organisation of professional services to provide support and maintain care after stroke is also complex. Even these formal services are not easily mapped into a linear model because they may involve the coordination of a number of agencies each of which may be geographically distant, and separately managed. Patients can move back and forth, across and between agencies depending on their needs at any particular time. Moreover, understanding the roles of these services and the systems in which they work is important for effective collaborations. The conversations with participants in the focus groups, and with individual interviewees, revealed that in the

main, experienced staff developed their own network of contacts across the agencies they dealt with regularly in order to facilitate their work.

An awareness of internal politics within agencies, and the different types of approach employed by separate departments, was useful in all settings but particularly in community work where boundaries were not always co-terminous and services had to be commissioned from different divisions of Social Services. A Disability Services Team manager, who worked across the five social services areas in Leeds, explained how different communication styles were required to address issues like adaptations to the home or re-housing with each separate office. He used his accumulated knowledge of their working practices to pre-empt problems by knowing exactly what could be expected from each area team.

*“There’s lots of really close links in this area, and people are all pulling in the same direction whereas in other areas its just the opposite really, people are really having a lot of difficulties around housing because it is still part of the council. I’ll email my orders down to chief surveyor and he’ll have a look at them then pass them on to the adaptations team who then commission the work, that works really well, but in other areas, you know the simplest thing a grab rail has been bounced back and people are arguing about who is going to do it.”*

**Disability Team manager**

Understanding service configuration was fundamental to all aspects of care coordination, especially where changes had occurred. The discussions that arose during the focus groups demonstrated that staff were not always clear about new roles and responsibilities within re-organised teams. There was some tension too between agencies with regard to who should take responsibility for patients with complex needs. This stemmed partly from ambiguity in the definition of “*complex needs*”, and some lack of appreciation about the implications of changing needs in terms of the agencies delivering care and support.:

*“...but if the (ward) staff is not aware enough to think ‘hang on, that isn’t just an increase, that could be a complex issue.’ if he or she does not tick ‘complex’ it still comes to us.”*

**Hospital Social Work Team Manager**

Structural changes in the organisation of hospital social work teams had also caused some concerns about increased workload. These changes had occurred as a consequence of the development of Joint Care Management, which was established to facilitate coordination between health and social services:

*"...when Joint Care Management teams were set up, a lot of the social workers in joint care were taken from hospitals, so social services have always got this thing about all hospital placements, twenty four hour placements should go to joint care because that's where all the social workers went, so and I guess that's still... you hear it even now five years later 'Well you took all our social workers so you should take this case'. So there is a bit of an issue, perhaps more from the hospital social work point of view than ours."*

#### **Joint Care Management Team Leader**

Overall, the wider discussions with participants showed that there was a perception of continuous flux in the way services were organised, and that this was one of the major factors contributing to perceived problems in communication between health professionals and social services professionals. The health professionals believed that they now had a poorer working relationship with the social workers based in the community than they had enjoyed when social workers were assigned to specific wards.

*"We used to have an allocated social worker ... knew patients from day one, was on the ward, was in the building ...in a case conference ... she'd know all about them (patients) ... and they (patients) would know her ...and she would have had all those facts already, what we all thought about it... Whereas you have to explain all that, the joint care manager hasn't a clue. It's just a name isn't it, when they (JCMS) appear here on the ward."*

#### **Senior Physiotherapist**

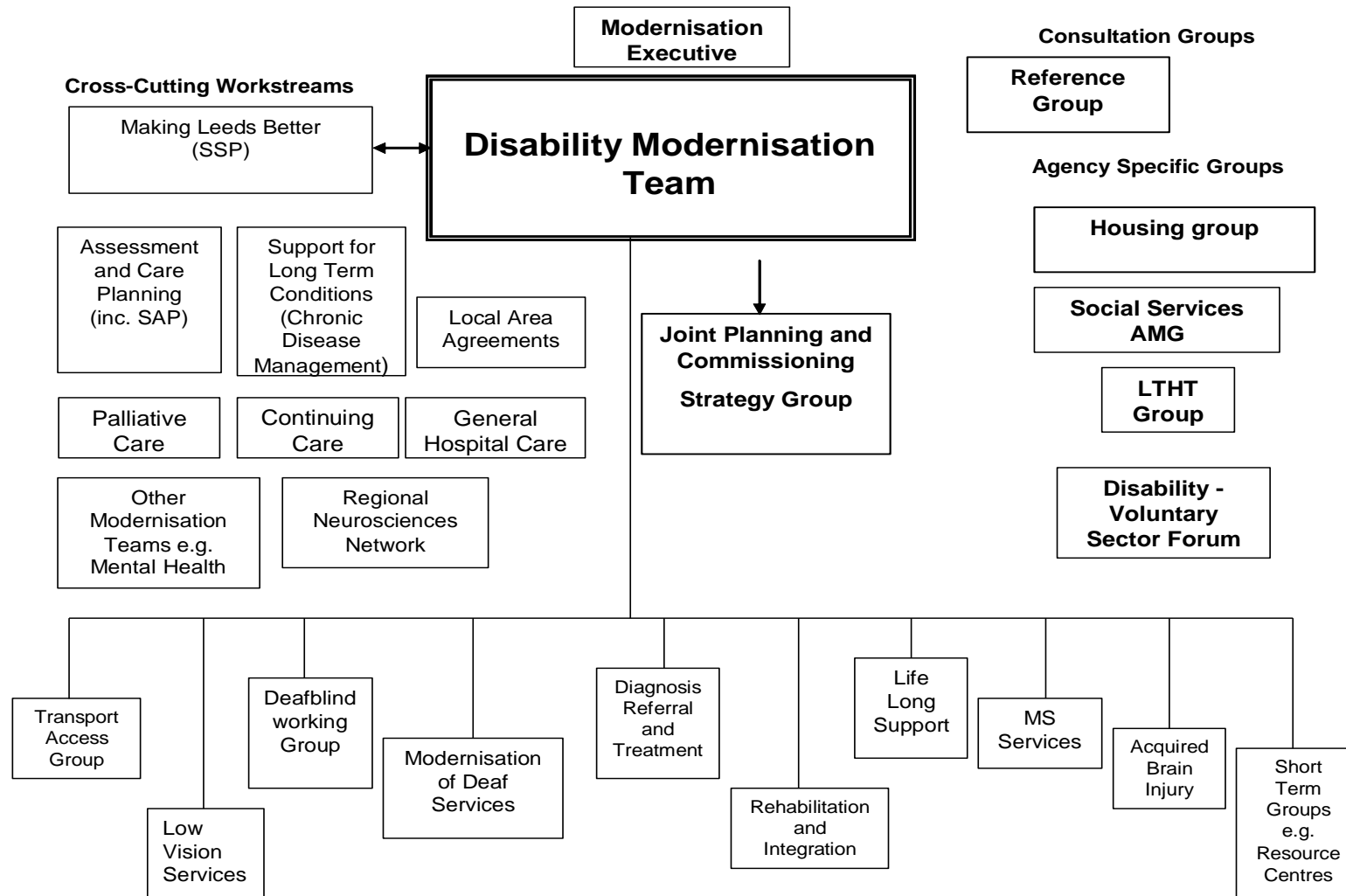
They felt too that removing this link had implications for practice firstly because it meant social workers did not get to know the patients they were dealing with, and secondly because they were less likely to acquire specific knowledge and skills in stroke care. These findings are important because effective communication between the professionals working across service boundaries is key to the successful handover of care of patients from hospital to home.

Eligibility and access to services had issues for continuing care if they were organised in ways that excluded certain groups. Intermediate care for example was an age limited service, which was only available to over 65 year olds in the Leeds area at the time the study was conducted. This meant that younger patients in the study sometimes had to wait longer before discharge if they required ongoing therapy or nursing care at home. Conversely, specialist stroke nurse care (only available to younger strokes in the Leeds area) meant that, in some cases, older patients missed out on follow-up after discharge. Voluntary organisations also provided services which were based on specific criteria like age, faith, ethnicity or private membership. Navigating this complex network of care thus requires either knowledge or dogged

persistence. Vulnerable groups such as the frail elderly or those with low mood or cognitive impairment are frequently unable, or unwilling, to do this without support.

A service model for stroke and transient ischaemic attacks (TIA) was described in Standard 5 of the National Service Framework for Older People. (DOH, 2001) The focus of the NSF however was on defining when particular tasks should be performed but not on which service providers should support different aspects of stroke care. In the intervening years since its publication progress has been made to improve stroke services in acute care settings and in respect of prevention, rehabilitation and longer-term care. More patients are now being treated by specialist services than was previously the case, and evidence has shown that stroke units save lives and reduce disability. (Stroke Unit Trialists' Collaboration, 2004). Post acute care was also under review: in an interview with a hospital matron the way NHS Executives were working with Disability Modernisation Teams from the Strategic Health Authority was described. The remit for these working parties was to build structures that would improve the coordination of service provision for disabled people, and deliver better care after discharge from acute hospital services. Figure 5.a on the following page shows the consultees involved in that process.

Figure 5.a Disability modernisation planning diagram



### 5.5.8 Continuity and autonomy

The complex structures that support health and social care are composed of numerous teams, each organised and managed separately as previously described. In terms of a Donabedian model these teams could be characterised as working at various levels of association within the overall structure of health and social care to deliver the processes of care. (Donabedian, 1966) Each specialist team is autonomous in terms of its activity, whether it is delivering a therapeutic intervention or providing supportive care. This is important for efficiency in practice as the necessity for continual reference back to central management impedes care delivery. Trust in professional competence and integrity is therefore essential for supporting a complex process like health care. It is also important to maintain an organisational structure which promotes the development of autonomous teams and facilitates their functioning in the wider system. In this way flexible and responsive working is enabled in order to deliver and maintain the diverse processes of care.

There were examples throughout the interviews and the focus group data of the value of respect for other teams. Importance was placed on shared decision making to support collaborative working in the delivery of coordinated care. It was evident that tensions in working relationships could arise when this practice was not observed; for example when appropriate consultations did not take place or decisions were not adequately communicated across team boundaries. In such situations patient care could be compromised especially in cases where cross-boundary collaboration was required for discharge planning:

*“...not sure who the multidisciplinary team is because I know more often than not it does not consist of a Social Worker even though we are fundamental, if we have received a Section 2 (Assessment request) we are part of it, we very rarely find out or are asked if a Section 5 (Medically fit for discharge) is relevant to be sent out, we find out by it arriving on our desk. ...I think it is crucial to be consulted if you are going to be issuing a Section 5 rather than have it arrive. ...Well we can challenge it, we do feel in a position to be able to if that's appropriate and to have a discussion about it, but we do get incidences where the consultant will say I am issuing a five, and that's not a discussion, that's being told.”*

**Hospital Social Work Team Manager**

Professional defensiveness can be postulated as a potential barrier to shared care and effective cross-boundary working. It is therefore important to respect and maintain



autonomy in planning services that require multi-disciplinary and multi-agency cooperation, and to develop efficient methods of co-working.

### **5.5.9 Continuity and choice**

Between professionals the factor most frequently cited as leading to breakdowns in the process of care was failure to transfer information adequately, appropriately or within a reasonable timescale. Transitional phases in care proved to be particularly vulnerable to problems and gaps arising from failures of this nature. Communication difficulties also arose with patients either because the information given was misunderstood by them or because inaccurate details were passed on. Lack of understanding could lead to inappropriate arrangements being made in some circumstances. Staff also gave examples of how relatives and carers of patients sometimes failed to appreciate just how demanding it would be to look after someone who is disabled by a stroke. This was considered to be particularly problematic in the case of elderly couples where the main carers themselves were no longer young and fit, and might have their own health problems to contend with.

Participants also gave many instances where patient choice was the direct cause of ongoing care not being maintained as planned. Several examples of patient non-compliance with care were identified by health care professionals and community services during the focus groups and interviews. In Chapter 4, case studies were presented from the patient study group which illustrated how failures in the care process had arisen directly from the influence of psychological morbidity and social isolation on the choices and decisions made about care. Parallel examples were also seen as a result of physical frailty, which was sometimes a barrier to attending for care outside the home, for example at out-patient clinics or therapy sessions.

Patient and family compliance with adaptations to their home or living arrangements was another source of difficulty identified by health and social care professionals for delivering planned care. Focus group participants related examples of patients who were confined to living upstairs because their spouse or carer did not want to turn their downstairs living space into a bedroom with commode in situ:

*"We've had a couple of patients, talking about quality of life after, they've gone home and the relative insisting that they are going to live upstairs ... because they don't want them sleeping downstairs, because they don't want their home turned into a sick room"*  
**Ward Sister, Acute Stroke Ward**

The staff talked too about choices made because alterations were considered to be detrimental to the value or appearance of the property. This supported the findings of Study 4b in which numerous instances were related by patients and carers of refusals to have stair rails fitted or grab handles in the bathroom because they didn't want to spoil their décor. There were also some who did not want to fit grab handles on outside doors, thus labelling the house as occupied by an elderly or disabled person and raising fears about security.

During the focus groups the health professionals described how planned care arrangements were sometimes disrupted when patients or families changed their minds about discharge. For example, arrangements for a patient to stay with a relative could change at the last minute if they decided that they wanted to go home instead. Care plans and requirements for discharge home would then have to be reassessed which could result in a delay, especially if the patient lived alone and required additional services to be put in place. In the reverse situation, when patients decided not to go home as planned but to stay with a relative or friend, it meant that arrangements made for discharge home would have to be postponed or cancelled at the last minute, sometimes resulting in wasted visits by care agencies.

Finally patients' and families' perceptions of need, and the services available to meet them, were sometimes at variance with professionals' views, and this was often the basis for patient and carer dissatisfaction. Changes to the provision of home care services, such as having to pay for cleaning services, were an annoyance to older patients and sometimes caused tensions between them and home care team staff. However, undoubtedly the most difficult issues in this category arose over nursing home placements and the decision to go to long term care, especially in cases where this involved the sale of property or the separation of married couples.

#### **5.5.10 Continuity and informal carers**

The concept of the "Caring Role" emerged in the mid-70s and burgeoned in the eighties driven largely by the feminist movement. That this lobby group should be champions for the cause is understandable considering that informal care, as distinct from organised care provided on a paid basis, has traditionally fallen mainly on the shoulders of female members of society: wives, daughters and mothers. Twigg described informal care as "*One of the lynch pins of the new community care*" in a review which was commissioned by the Department of Health to assist planners and

practitioners to respond to the 1990 NHS and Community Care Act. (Twigg, 1992) The Twigg review was intended not only to disseminate information on the subject of carers more widely but also to stem the tide of empirical work, as it was considered that a great deal was already known about the pattern and incidence of caring, and the experience of carers - the stresses and burdens, and the rewards. An earlier study by Gillian Parker (SPRU York) conducted on behalf of the Family Policy Studies Centre had used caring activities as the basis for producing a typology of carers. (Parker, 1990) She distinguished between carers (those who deliver personal or physical care) and helpers (those who provide practical assistance). Twigg and Atkin (1994) took this work further and described carers in terms of the ways in which they interacted with formal service. Examples of all these types of care and carers were found in the course of this work with stroke patients.

The nature of stroke and the sudden onset of disability can plunge an elderly spouse into a caring role overnight, a task that can be physically demanding. Nearly all the patients interviewed for this research, and their spouses, had received some type of informal support. This had usually been given in the form of practical help with gardening, household tasks and shopping, and less frequently with personal care like bathing and dressing. Help and support of this type was mainly provided by adult children but friends and neighbours also featured in these roles, sometimes stepping in when families experienced a crisis or a change in circumstances. Informal care was thus a major factor in the provision of ongoing support for people living at home after a stroke. In some cases, where informal carers were responsible for collecting or supervising prescribed medication, or arranging and ensuring attendance at clinical appointments, it was also a major factor in maintaining health care processes. This serves to highlight the important role of informal care not just to provide instrumental and emotional support but as an agent of continuity in health care. Indeed the idea of a “nominated” carer is sometimes introduced by wards to aid clinical efficiency. Health care professionals are constantly charged with communicating with relatives, and establishing one point of contact is a means of saving time, the repetition of information and reducing the incidence of conflicted arrangements.

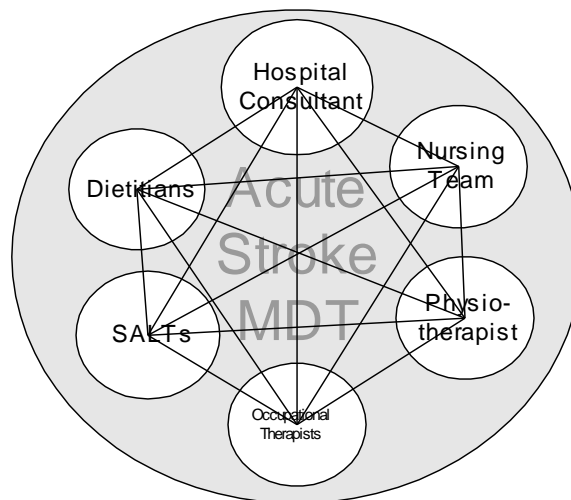
## **5.6 Mapping communication in stroke care**

Participation in research studies is voluntary and it must therefore be acknowledged that in any sample of patients or health care professionals there is always a degree of selection bias. Nevertheless, a vast quantity of data was generated during this phase

of the study from a variety of informants, and an overview of the range and extent of communication links that exist to maintain ongoing care for stroke patients was derived. The extent and complexity of the model would suggest that, even if some specific links were missed, the picture that emerged gave a reasonable representation of the main channels of communication in a typical stroke care setting.

A great deal of informal communication facilitates the movement of patients through care, creating a network of linkages between the individuals, teams and agencies involved in the process. The limitations of this study meant that this implicit network could not be observed in action but could only be inferred from the data that was collected. When the contacts reported between healthcare professionals were mapped onto a network diagram, growing layers of complexity emerged as the patient moved through the stages of care. Figure 5.b below shows the communication channels that were described just in the hospital setting during acute and in-patient rehabilitation care.

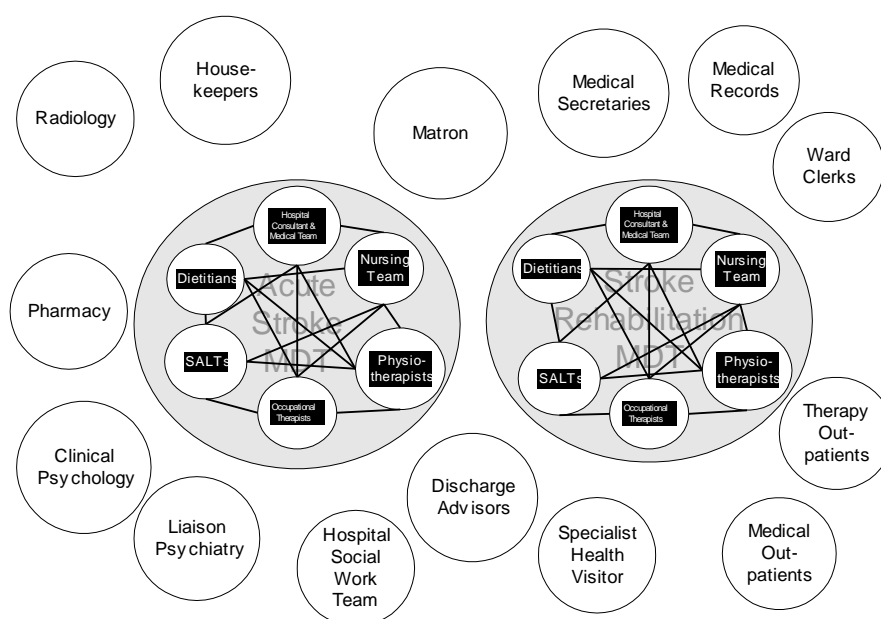
**Figure 5.b** Communication links within the acute stroke care multi-disciplinary team



Within the MDT communication links between professionals were well established and maintained through regular contact and exchange of information, both at scheduled meetings (shift handovers, ward rounds, MDT meetings, goal setting, care planning etc.). There were frequent opportunities too for face to face contact which occurred on a daily basis either on the ward or by personal telephone contact.

Outside the MDT, but still within the Acute Trust setting, communication links were extended and communication modes became technology based rather than inter-personal. More local teams were introduced into the extended network and traffic flowed between individuals within the different teams by a variety of modes, and at a number of different levels. Email transmitted professional and practice-based information but most patient-focused clinical information was transferred by the more traditional methods, for example by telephone, fax and referral forms. Two explanations for this can be substantiated from the data: the limited access to email in clinical settings and the wariness of staff about issues surrounding data protection and patient confidentiality. Figure 5.c below represents the various departments and agencies that were co-located in the Acute Hospital Trust outwith the immediate Acute Stroke Unit but that could be involved at different stages of the care process while the patient was being treated as a hospital in-patient.

**Figure 5.c Extended communication links in hospital and community care<sup>17</sup>**



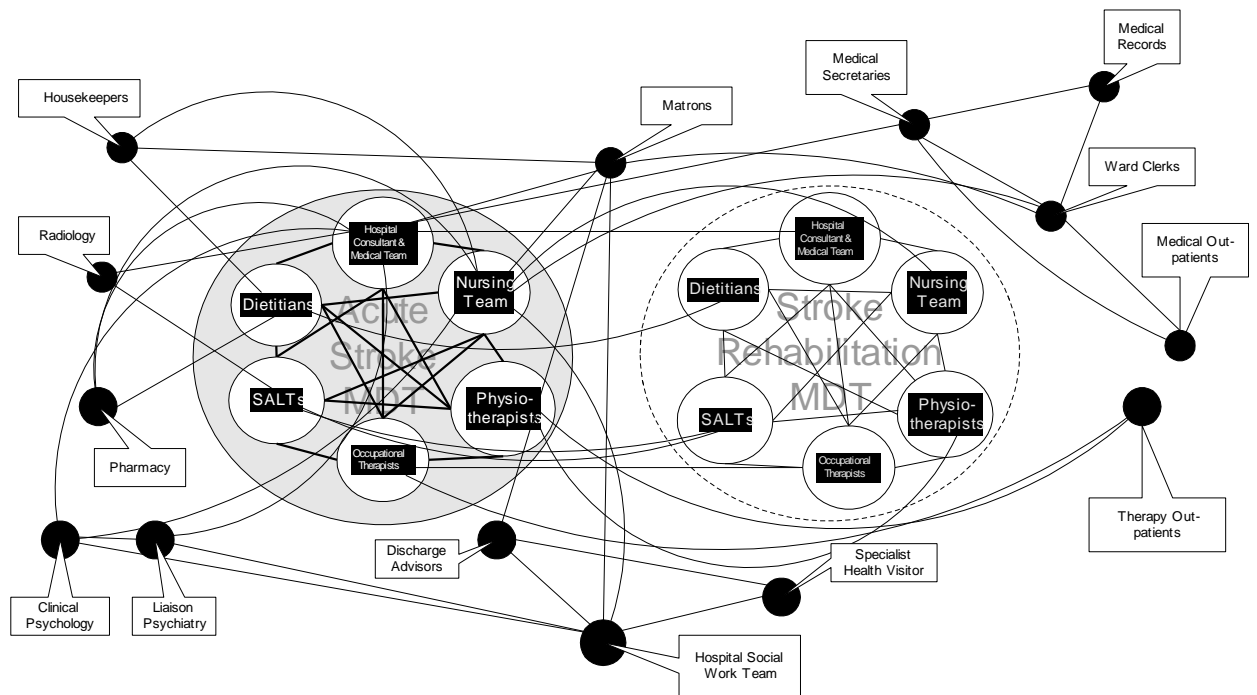
Information transfer is more vulnerable to the influence of external factors like equipment failures (faulty fax machines) or location of individuals. In respect of location, proximal working was cited by the professional participants as enhancing

<sup>17</sup> Figure 5c: While the diagrams show the teams involved in stroke care in different settings and the channels and networks of communication that we identified between them, it only shows the links, and does not represent functionality or density of communication in stroke care.

information transfer between teams. It should be noted however that proximity may have a different meaning in the community setting compared to a hospital, where adjacent wards can be effectively distal in terms of personal contact between staff. The transfer of information is also susceptible to changes to practice, such as the introduction of new documentation or referral systems. Altering practice can impede continuity but generally does not prevent things happening, only slows them down, as it is more likely to result in duplication of effort and repetitive information seeking activities.

Figure 5.d below shows the communication links from departments or agencies in the hospital and community care map to the Acute Stroke Care Multi-Disciplinary Team. All of these links were replicated in the Stroke Rehabilitation MDT (shown in the dotted circle) but are not represented here for clarity.

**Figure 5.d Communication networks in acute stroke care and rehabilitation**



## 5.7 Continuity and networks

The exploration of communication in stroke care undertaken in Study 5 was carried out in order to examine how stroke care is co-ordinated and how key elements of it (handling of knowledge, relations between professional patients and carers) are constituted. The focus groups and interviews generated an account of communication links that, when peopled with health care professionals, lay carers and patients, amounted to a description of care delivered through care networks.

As the patient recovers from stroke and preparations for discharge begin, the communication links are extended beyond the hospital setting, and more diverse agencies become involved. The network of professionals involved in service delivery reaches out into the community so that after the patient leaves hospital it may comprise any combination of public and private sector care agencies including charitable and voluntary groups.

### 5.7.1 *Continuity of care as a function of care networks*

Care processes have sometimes been likened to industrial processes in the quest for models of efficient organisation and management systems. While industrial analogies may be useful for understanding the principles of continuity, they are too simplistic to transfer readily to stroke care. Industrial processes can be complex but, unlike health care, they are not usually characterised by a high degree of individual diversity where sophisticated judgements may be required, at multiple time points, about individual cases.

In stroke care this diversity can be accounted for at one level of planning: for example an Acute Hospital admitting 500 stroke patients per year will need  $x$ -hours of scanner time for routine CT imaging and  $n$ -number of Speech Therapists to do swallowing assessments. However, it becomes more difficult to plan and manage services as care progresses and becomes increasingly hybrid. The brain is a complex organ and the consequences of stroke highly variable, thus each patient can present a unique problem or combination of problems for staff in terms of the type of therapy that is required or the frequency of physiotherapy, occupational therapy and nursing contact time needed. Moreover, when discharge planning begins individual domiciliary and social circumstances add a further dimension and a variety of different situations have to be accommodated by post-discharge services. Added to this are the effects of

change either from personal choice or unforeseen circumstances which mean that planned care often has to be adapted.

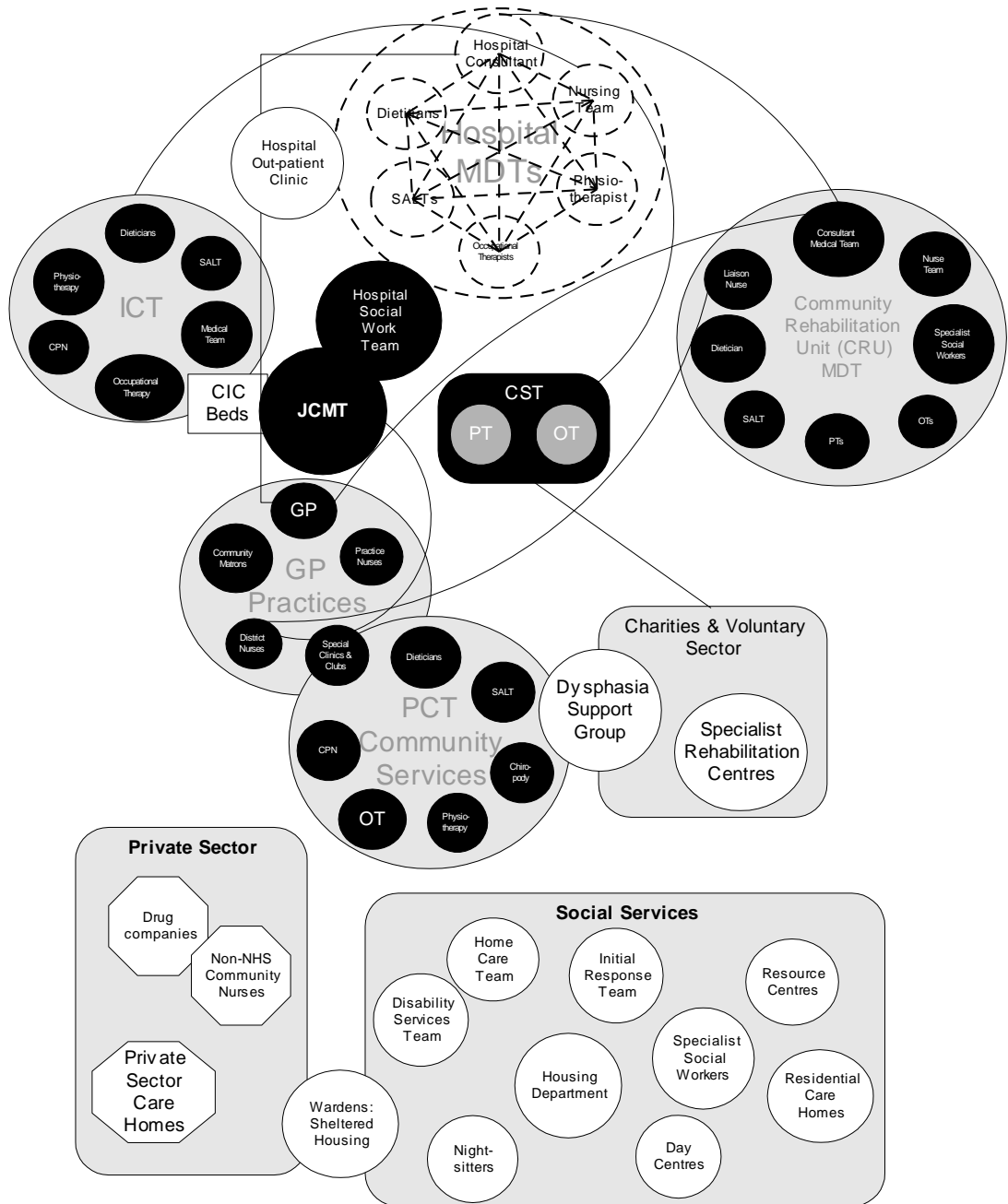
Good networks can provide a platform for delivering high quality care at all stages of chronic illness. A well-connected, non-linear structure enables the flexible and responsive provision of care by supporting skilled individuals or teams within the network to facilitate local decision-making. Quality thus resides in the components that make-up the network and the ways in which they interact and engage with each other. Networks of this type cannot be characterised as managed care networks or integrated pathways because of their nature, which is not only multi-disciplinary but also partly a professional and partly a social network.

It has also been shown in industrial settings that the components of networks require a degree of autonomy to function well. (Watts, 2003) Those that are too closely regulated and subject to central control in a strict hierarchical system are at risk of “command” overload due to the high demands being placed on them by the controlling agencies or individuals: a situation analogous perhaps to the recent emphasis on targets in health services.

On the following page Figure 5.e shows the main agencies involved in providing both short and long-term care and services for stroke patients after discharge, and the communication links between them. The diagram shows a care network made up of a variety of individuals or agencies both professional and lay, with formal or informal linkages between the network nodes. Some of these linkages are based on professional obligation and others on trust or chance. In terms of stroke care therefore, continuity could be interpreted in the context of a network of care where individuals would have access to different parts of the network according to their needs or circumstances.



Figure 5.e Communication networks in health and social care



### 5.7.2 ***Building good care networks***

Networks themselves do not provide good care; it is the skilled individuals and teams within the network whose interactions ensure its functionality and deliver services. The members of a professional network of care for stroke have already been characterised in preceding sections of this chapter. However, in order to understand robust and successful networks it is necessary not only to know their components but also to try and identify their characteristics such as the nature of the engagement between the members, and how they connect to one another. Sharing an overall aim and having an understanding of what is required to meet changing needs is clearly important, and empowers a network to respond quickly, flexibly and independently. To use an industrial example, the Toyota Aisin crisis illustrates how the network structure of a group of commercial companies was fundamental to achieving a successful outcome in a critical manufacturing situation. A serious fire in a supplier's factory meant that the production line in one of the main Toyota factories lost its entire supply of an essential manufacturing component. In common with many large scale manufacturers Toyota operates a "just in time" supply chain and does not hold large stocks of manufacturing components. The network of Toyota subsidiary companies responded quickly to find a solution and, given only information about the part specification, they were able to function effectively without central control to provide the substitute parts. This rapid and well coordinated response enabled production to be restored within 48 hours. (Watts, 2003)

Similarly in stroke care (and it can be hypothesised, in other health care settings), networks cannot be dependent on hierarchies and top-down management: the services they deliver and the functions they perform are too diverse for central control, and neither are they formally connected by technological links. It would be totally impractical, for example, for health care professional to have to consult with the Department of Health for direction at each stage of care.

The disadvantage of a care network is that it is vulnerable to the formation of mini-networks or cliques. These are groups or units within a network that operate in parallel with the main network and are not fully integrated within it, usually as a consequence of becoming isolated from other members. A Canadian study of mental health care in the community, found that clique formation limited access to services and reduced patient satisfaction. (Poirier *et al.*, 2001) This study showed that cliques (and the presence of clique overlap) were detrimental to network function by causing the loss or weakening

of links between the individual or agencies that comprised the network and thereby reduced the opportunities for engagement between them. These isolated cliques become self-contained and do not seek or share resources outside their immediate sphere of influence. Clique overlap is harder to characterise but, at an organisational level, a recent SDO study showed that multiple, overlapping boundaries impeded rather than promoted continuity of care, possibly through a similar mechanism. (Hardie and Keen, 2006)

Finally, and importantly, patients and carers should be regarded as an integral part of the network and not purely as recipients of network functions and out-puts. Stroke care networks develop in response to need for services and support, relying on the integration of formal and informal sources of care. Good networks should therefore provide emotional support as well as technical and practical care to both the professional and lay members within it, thus creating an environment that promotes independence and self-sufficiency.

## **5.8 Summary: Study 5**

In this final strand of research the focus was on health care professionals in the two geographical areas covered by this study. Focus groups and individual interviews were conducted with clinical care staff, community care providers, voluntary sector workers and health care managers working in hospital, primary care and community settings. The aim was to learn about the patterns, modes, content and impact of their interactions and communication.

What emerged from Study 5 was an account of communication links that in essence amounted to a description of care delivered through networks. This led to the theory that, in terms of stroke care, continuity may be more easily understood in the context of a network of care which has patients and carers as an integral part, ideally at its centre. Functionality would be achieved by individuals (both lay and professional) having the ability to access different parts of the network according to their specific circumstances or requirements. The scope of this research did not permit the characteristics of a high quality network to be defined fully but access to knowledge and the sharing of skills and expertise are clearly important factors. The findings support the view that network models offer a mechanism for coordinating care through the sharing of knowledge and collaborative working, which are vital to delivering diversity in care.

## CHAPTER 6 DISCUSSION

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This thesis is about care and the different types of care that people receive after a stroke. The last decade has been a time of reform in the NHS, and much emphasis has been placed on modernising and redesigning services to improve effectiveness and drive up quality. Continuity of care has become a prominent theme in a number of care settings and, particularly where care packages are complex, multi-disciplinary and long-term (as in stroke care) it is considered to be a major factor in the delivery of quality care. Indeed, if optimising care delivery means that patients will be transferred more frequently between care settings, then ensuring continuity of care between different types of provider becomes fundamental to quality care. (Cotter *et al.*, 2002)

Change in large organisations like the NHS needs careful monitoring to ensure that improving practice in one area does not detract from services in another. Studying the effects of change may also require a process of evaluation to ensure that the new systems are an improvement on the old. The measurement of continuity of care has thus become desirable as a means of monitoring quality standards in health care. However, continuity of care has not always been interpreted in a consistent manner and there are differences in the current definitions. Some focus on continuity of health care personnel or the coordination of services while others are based on ongoing access to services either for long-term care or following an acute event, or the exacerbation of a chronic condition.

Embarking on a study of care continuity in stroke therefore meant considering the whole notion of care in the context of both health and social settings with the intention of encompassing the widest possible range of care combinations, and the transitions that patients might experience as a result. This precluded a study of hospital-based care alone and required the study of longer term care extending beyond that offered by acute services to primary and community based care. The population of patients studied for this thesis (see inclusion criteria, Figure 3.a, page 107 and Appendix A, page 272) were those who had suffered the commonest types of stroke: ischaemic strokes or intracerebral haemorrhages, which together represent over 90% of all strokes. (Wolfe *et al.*, 2002) Given the age profile of stroke victims, this was also a study of predominantly older people, an assertion supported by the median age of patients (72 years) in the umbrella study: SOS2 the Stroke Outcomes Study cohort.

The trend for health and social care policymakers over the last two decades has been to meet the growing care needs of an ageing population in the community by enabling older people, with or without chronic and disabling conditions, to remain living in their own homes for as long as possible, or to be cared for in the home of a relative or friend. In stroke care this policy has been shown to match the preferences of patients and families (when circumstances and the patient's level of disability permit), and potentially reduces the demands on institutional care providers. (Chiu *et al.*, 1997) However, achieving good community care requires the mobilisation and coordination of statutory domiciliary services, voluntary organisations and informal carers. The care provided by the latter group, usually made up of family, friends and neighbours, is often ad hoc, sometimes sporadic, and thus difficult to quantify. Nevertheless, it is an important consideration as caring for stroke survivors at home has been shown only to be cost-effective when informal care costs are not taken into account. (Chiu *et al.*, 1997) In the UK, recent studies have shown that informal care represents approximately 35% of the total annual budget for stroke care. (Saka *et al.*, 2005)

## 6.1 Rationale for the study design

In view of the complex, hybrid nature of stroke care, an empirical approach was indicated in order to meet the main objective of the research undertaken for this thesis (understanding continuity of care from the patient's perspective). The preceding chapters have described a series of studies across three strands of research that operationalised the principal aims of the research at each stage:

- Strand 1 explored how care is experienced by patients during the period following a stroke;
- Strand 2 determined the feasibility of measuring care delivery and its continuity, and sought evidence of its impact on outcomes;
- Strand 3 studied the operational aspects of care delivery from the point of view of stroke care professionals.

Using formal records from the primary, secondary and social care sectors, an attempt was made to map the patient's journey through care, and discover how different types of care could be defined in a chronic and disabling condition like stroke. Listening to

the narrative accounts of patients and carers enabled a picture to be built up of the way in which stroke patients viewed their care, and determined what elements of care they could recognise in relation to its continuous or discontinuous nature.

Grounding the work firmly in the patients' (and carers) experiences of stroke care proved to be a major strength of this study. Recent policy developments in health care have emphasised the involvement of patients and carers at all stages in the care process but despite the rhetoric there has been little real research into how this can be achieved, and the impact of patient and public involvement on the way care is organised and delivered. Research into specific therapies has paid attention to patient reported outcomes but few studies have chosen to address the patient's overall perspective of care. This is now beginning to change and more recent researchers have attempted to address this issue; for example the SDO funded study of patients' and carers' views of continuity in primary care. (Baker *et al.*, 2006) This thesis makes a significant contribution to understanding the patient's view of care for a chronic disease, and the differences in the way in which the processes of care are perceived by the recipients and the care providers.

## 6.2 Defining and measuring care

Definitions of continuity of care have emerged over a number of years, developed principally in primary care and mental health settings. These definitions were synthesised in the Freeman scoping report, (Freeman, 2000) to produce a multi-axial definition of continuity, which was distilled down to three types of continuity by its successor the CHSRF report. (Reid, 2002) The CHSRF model of continuity has underpinned much recent research, and provided a framework for both the design and interpretation of this study. However, while Freeman's scoping study and the work conducted by the CHSRF covered a range of healthcare settings they did not focus exclusively on patient-centred continuity, although both emphasised the gaps in research in this area and the need to develop a better understanding of the patient's perspective. Therefore, given that the main aim of this study was to understand continuity of care from the stroke patient's perspective, a re-examination of the topic in the published literature was necessary and supplementary information acquired from other expert sources. The currently accepted model of continuity was thus reviewed in relation to the care received following an acute stroke, and the way that it is perceived by patients. The literature review revealed that studies in stroke had tended to focus on care coordination and planning in which continuity of care is implicit rather than

explicitly defined, and none had sought to measure continuity from the stroke patient's perspective.

The acute onset of stroke means that care inevitably starts as a medical emergency but thereafter quickly diversifies to progress along different pathways dependent on the patient's post-stroke status and needs. Care for stroke thus ranges from the highly technical, medicalised care that is delivered in the acute hospital in the early stages of a stroke, to the type of informal care that can be represented by simple assistance with housework, gardening or shopping for someone living at home with reduced mobility in the post-acute, post-rehabilitation phase. The qualitative survey of experiences of care with stroke survivors, undertaken in Study 2a, provided a patient-orientated view of care which was based upon their firsthand accounts. This proved to be a valuable component of the research, challenging as it did the assumption that professionally derived concepts of continuity could be understood and recognised by patients in the context of their own care. It also revealed that patient and carer involvement can be important at all stages of care from initiating and providing information on admission and supporting rehabilitation to ensuring a successful discharge.

Patients provided a wealth of information about their lives in the year after an acute stroke, with views about the quality of their care easily elicited, and feelings of satisfaction with care readily expressed. Importantly though, it was apparent from listening to their narratives that while they could describe incidents from their experiences of care and identify gaps in the care they had received, patients showed little insight into the mechanisms and systems that underpin care delivery. Even when questioned explicitly about the process of care, it was clear that they did not fully appreciate the relevance of events, and how they impacted on their care overall. This is an important finding because it highlights the differences in the way patients and professionals view care. Lay versions of events sometimes differed from service provider records as a result of patients' or carers' lack of understanding of care processes but not always; in some cases there was a genuine discrepancy between the patient's version of care and that depicted in the formal care records. This was the added value of cross-referencing the two accounts of care afforded by the study design.

Ultimately it must be acknowledged that the qualitative study did not yield the depiction of the continuous or discontinuous aspects of care from the patient's point of view that had been anticipated. As a result no patient-centred definition of continuity of care

could be formulated from the stroke patients' accounts, and no indicators of patient-perceived continuity derived to operationalise it. Nonetheless, the qualitative work made an important contribution to the primary aim of this study because it led to a fuller understanding of how stroke patients actually did make sense of their care.

### **6.2.1 Designing the measures**

In order to pursue the measurement of continuity in the second strand of research the initial literature review had sought to identify an existing measure of patient-perceived continuity. Only two candidate measures were found that met the criteria for this study: the Chao Perception of Continuity Questionnaire (Chao PC) and the Care Continuity Instrument (CCI). (Chao, 1988, Bull *et al.*, 2000) The latter was less suited to this study given its focus on informational processes and the emphasis on patient satisfaction. The Chao PC had been developed in the United States and applied in primary care settings; its provenance therefore suggested that it would be more relevant to stroke patients under the care of their General Practitioner than to those in acute care. Accordingly it was given to a sample of patients drawn from the SOS2 cohort study, all of whom had completed follow-up and were living in a non-institutionalised setting in the community one year or more post-stroke. The Chao PC proved to be associated with mood state but did not discriminate between factors related to the health or physical status of stroke patients, nor was it associated with other factors that might have influenced the care they received like age or living alone. Only one construct, "*Trust*", was found to account for the majority of the variance in the responses when factor analysis was undertaken. Thus the aim of Study 3, to examine the effect of continuity of care on outcomes for patients using an existing measure of continuity, was achieved although the further aim of finding a suitable and appropriate measure for application in successive phases of this work was not. In retrospect it would have been prudent to pilot both the Chao PC and Bull's CCI measure in this sample of patients but this might have reduced the response rate yet more by adding to the burden of form filling.

Since the original literature search was completed, more recent measures have been developed in response to the SDO and CHSRF research programmes. These are based on the multi-axial definitions of continuity of care and now provide a bigger pool of existing measures of care in specific conditions like diabetes, mental health, chronic heart disease and cancer. As these newer measures have only appeared in the last few years it is too soon to comment on their relevance and performance as few reports



have described their application in subsequent research studies. However, from the original published reports, it is clear that the measurement of continuity is not straightforward. Operationalising the multi-axial definition has resulted in long and sometimes complicated multi-item, multi-component measures. Elucidation of the association between outcomes of care and the measures of continuity has also proved difficult, and no impact on physiological outcomes has been found using these measures, although correlations between measures of continuity and satisfaction with care have been consistently noted.

The qualitative research with patients and the quantitative analyses undertaken in the first strand of this work suggested that the currently accepted models (and measures) of continuity of care did not readily transfer to the type of care or the services received by stroke survivors, nor to the ways in which the patients themselves perceive care. This finding is entirely in accord with Freeman's opinion that a "*one size fits all*" view of continuity should not be expected to emerge from future research in this area. (Freeman, 2000) It is possible that the indicators generally used in the assessment of continuity are simply not applicable in stroke care due to the variety of ways in which stroke affects survivors, and the different types of care they receive as a result. However, Freeman's report also stated that it was "*difficult to disentangle continuity issues from other aspects of the care process*" and that in attempting to define continuity it is "*usual for continuity to be part of a complex package of care*". Given these observations could it be also possible that continuity may not be a single construct? Continuity may have different properties in relation to different aspects of care, which if indeed is the case, would explain why people could not recognise it in their care.

Evidence in support of this theory was pursued by breaking stroke care down into its component parts and applying the Donabedian model of structure, process and outcome to pinpoint how and where the continuous and discontinuous aspects of care could be measured. However separating continuity from other components of care, and finding indicators to assess the process of care and the mechanisms by which it is delivered, proved to be complicated because:

- Definitions which are confined to managed care alone, where process is evident, apply only in the early stages of stroke and do not take account of the many informal social structures which serve to maintain, support or enhance the aftercare of stroke survivors;

- It is difficult to derive indicators of care processes that patients understand and can recognise, and to separate them from indicators of quality of care and satisfaction in a meaningful way;

Notwithstanding these obstacles, the objective of measuring continuity was operationalised by developing two new measures (the PPCI and the SnL Index), and applying them in a sample of stroke survivors. The measures were structured around the accepted framework of managerial, informational and relational continuity established by previous research but used a range of indicators that were specifically derived to evaluate the process of stroke care, and which aimed to capture the way its components connected. The patient-centred measure and the record-based measure were intended to be complementary, and to provide data for the evaluation of continuity of care from two independent sources. The rationale for this approach was to strengthen the study design by using mixed methods.

### **6.2.2 *Measuring patient-perceived care***

The qualitative interviews undertaken with stroke patients (and their carers) in Study 2b had shown that they could assess the quality of the individual elements of care, either directly or indirectly, and rate their feelings of satisfaction or dissatisfaction with them. However, they could not distinguish the overall process of care, or indeed make any appraisal of it other than to give their perceptions of its outcome. This is not a surprising finding considering the complexity of measuring multi-factorial concepts like health and health care. Understanding what people mean when they rate their own health has been the subject of considerable study and debate over many years, and there remains no consensus on the best way of measuring it. Self-reported global assessments of health status for example have been shown to be good predictors of outcome that perform better than ratings of performance status or physical function in a range of chronic conditions, yet it is still unclear which components of physical function and psychological well-being people use to frame their responses to questions about their overall health status. (Fayers and Sprangers, 2002) Clearly, therefore, this is also likely to be true of patients' assessments of care, about which much less is known.

It had been planned at the outset of this research to develop a self-reported measure of patient-perceived continuity of care but, recognising in the early stages that a self-rated checklist would be difficult (if not impossible) to design, an approach similar to that used in psychiatry, another area of complex assessment, was adopted. The author

(KH) conducted the first 32 interviews in order to develop the schedule and refine the scoring system. Thereafter two researchers were involved in delivering the interview, (KH) and Helen Brooks (HB), a stroke research nurse on the SOS team under the supervision of KH. This however meant that a process of training and standardisation was also required. The extended period necessary to complete the developmental phase had not been foreseen and this had a subsequent impact on recruitment to Study 4. The SOS2 cohort study continued to accrue participants during this time which left fewer eligible patients for the continuity of care study when the measure was finally ready for use. Data collection and management was thus a more protracted process in the evaluation of patient-perceived care but the effort was considered worthwhile because, as the foundation work had shown, using self-report questionnaires had not proved to be a feasible option in this patient group.

### **6.2.3 *Measuring recorded care***

In contrast to the patient-perceived measure, care recorded in formal sources was assessed using a standard quantitative approach. The SnL Index was a checklist, structured around the phases of care, which applied indicators of the process of care and the transitions between components of the care package to care records in a stroke setting. The core elements of managerial, informational and relational continuity were implicit in the criteria used to rate the indicators at each stage of care and attempted to capture, where possible, something of the transitional aspects of care. These included criteria for evidence of specific care assessments and information transfers such as discharge summaries, and the timeliness with which they were implemented. Further examples of indicators and criteria can be found by referring to the SnL Index checklist which is reproduced in Appendix G, pages 283- 285. The SnL Index proved to be a relatively straightforward method of assessing actual care delivered (or “achieved” care) but could not, in its current format, determine the appropriateness of care or the nature of its continuity or discontinuity.

Records, whether the traditional hospital case-notes or the electronic records used in primary care, only provide a note of episodes of care. Failed care events are rarely recorded except in respect of hospital out-patient or general practice appointments as, for example the DNA (Did Not Attend) notations sometimes found in clinic notes show, but only occasionally is an indication of the circumstances of non-attendance given. Discerning how care episodes linked together was therefore problematic. Moreover, care responds to need, and patients generally receive care in proportion to their need.

For this reason it was difficult to relate the measure of recorded care to outcomes. This was demonstrated not only by the SnL Index but also by another method of measuring recorded care – the number of health care professionals providing care (using the signature count audit). These two independent means of assessing recorded care were both heavily influenced by the degree of disability of the patient but were not related to other factors that might be expected to influence care delivery.

Where gaps were identified in care records it was most often the case that a failure in information transfer had occurred: details were inaccurate, incomplete or out of date, or information had not been sent, not read, not understood or not acted on. As previously discussed in Chapter 4 Section 4.5.1, page 152, problems were most likely to occur during transitions in care, especially when crossing care-provider boundaries where communication links may be weaker or less well established. These findings were confirmed by the information obtained in the qualitative study with professional care-givers (reported in Chapter 5) whose accounts provided descriptions of numerous and varied incidences that supported this assertion.

#### **6.2.4 *Measuring achieved and perceived care***

The ratings of PPCI data were done independently but not blinded from the audit measure of care (the SnL Index), which was also completed for each of the patients interviewed. Occasionally the SnL Index information was used to aid the interpretation of the patient's account of care by providing clarification of events that had occurred. Comparing the patient's account with the records was helpful when patients clearly acknowledged a care event had occurred but were vague about its details. To a greater or lesser extent the records could assist in the interpretation of the patient's account, mainly by placing it in context and enabling a fuller picture of each individual's care to emerge. Information from records was never used to change a rating if a patient had no recollection of an event or denied it had ever occurred.

Different assessment criteria were therefore used for the two measures: the SnL Index rated only evidenced care events whereas the PPCI rated patients' views of care received. Scores for the PPCI were thus based solely on the patients' descriptive narrative and their perceptions of events whereas the SnL Index checklist rated only what had actually been recorded, either as a written entry or a filed document, in the patient's case-notes. When the study was finally completed, the patients' accounts of their stroke care, which had been rated either prospectively during the interview or

retrospectively from the audiotape recording, showed no correlation with the ratings achieved on the SnL Index. This suggested that the two instruments were measuring something completely different despite being framed in the same conceptual model of continuity and structured specifically around stroke care. This finding would also affirm that knowledge of the SnL Index ratings did not bias the interviewer's ratings.

### **6.2.5 What is perceived care measuring?**

Evidence abounds that measures of patients' perceptions of care as well as health status are influenced by characteristics such as mood state and personality, and this effect has been well documented in a range of patient groups and a variety of settings. For example:

- Emotional distress and unmet care needs were associated with satisfaction with care after stroke in a cross-sectional study of quality of care in 23 hospitals in the Netherlands. (Scholte op Reimer *et al.*, 1996)
- In a North American study, Hermann *et al.* showed that older and disabled Medicare beneficiaries with psychiatric disorders were significantly less likely than those without psychiatric morbidity to be satisfied with the overall quality of health care and follow-up care. (Hermann *et al.*, 1998)
- Anxiety has been associated with ratings of satisfaction with care in maternity settings. (Donaghy *et al.*, 2000)

The association of the PPCI with mood identified in Study 4b was consistent with the findings of Study 3 in which a comparable sample of patients had been given the Chao PC Questionnaire, an existing measure of patients' perceptions of care. The Chao PC measure was also found to be associated with mood. Ratings of this type are subjective and cognitive theories of depression suggest that low mood states are associated with negativism in both forward and backwards thinking. There is also evidence that people with low mood have selective recall for events, something which is supported by the case study for Patient #531, reported in Chapter 4 (on page 177). Interpreted in this theoretical framework an association of patient-rated measures of care, both in this and in other comparable studies, could therefore be expected. Psychological well-being or functional and physical status are not the only factors which may have a role to play in connection with measuring continuity of care;

measurement may also be confounded by the fact that aspects of continuity are not necessarily equally important at all stages or in all types of care. Even within single disorders different stages of care may have very different characteristics. Acute stroke care, for example, is more medically driven than the care that stroke survivors experience later in their illness trajectory, when rehabilitation therapy, supportive care or nursing assistance may become the principal components of care. Moreover, framing continuity of care in the currently accepted model could lead to the hypothesis that relational or personal continuity would be important factors during the later periods of stroke care (or more generally in primary care, or a palliative care setting), but would be less relevant in acute stroke care, delivered in a hospital setting, where access to a number of different, highly specialised individuals with expert skills may be more desirable than being seen by the same person. Defining these differences in terms of meaningful criteria for the evaluation of care throughout the whole care trajectory complicates assessment and presents yet more challenges for the measurement of continuity of care in a complex disorder like stroke. As the interpretation of the PPCI ratings in the context of individual case studies suggests, the assessment of patient-perceived care is more complicated than simply re-phrasing the conventional components of continuity of care.

### **6.2.6 *The effect of patient choice***

Disability and dependence are clearly major factors in determining the care required after a stroke, while patients' mood states and short-comings in service provision may also affect the care they actually receive. Patient choice is yet another factor. Several examples were found during the course of this research where patients' choices or decision-making were the primary factors influencing the care that they received. Case study #553 (see Chapter 4, page 176) showed how self-discharge resulted in a series of delays and gaps in care because the usual referral systems had not operated, resulting in a disruption in the sequence of care and loss of contact between care providers. Other less extreme examples taken from the qualitative study of patients' experiences of care showed how, usually after a gap in transfer of care from hospital to out-patient care, some had decided that they no longer needed input from therapists and subsequently refused appointments (most often for speech and language therapy, which had the longest waiting times for community care). The extract from the account of Patient #11 (see pages 71 - 72) illustrates this point well. Patients also chose to turn down other types of input from community care and intermediate care teams for a variety of personal reasons. Adaptations to the home were refused by some patients

too, with stair rails and grab handles being the aids most consistently cited in this respect.

Government policy states that a primary aim of the new NHS is to increase patient choice in relation to their healthcare, a theme which is central to the personalisation agenda. If this policy is to be successfully implemented it will be essential to design care in a way that is compatible with the element of choice. This study has reported instances given by patients and their carers of the ways in which they had negotiated their own roles in their care, and examples of how care was expedited by the intervention of the patient or (more often) a relative or carer, for example by chasing up an appointment or querying a prescription. However, while patients and carers are capable of taking an agency role in their care some may not have sufficient insight into the care process to understand what the implications of their decisions are for their future care. Healthy eating, and a lack of understanding of how poor diet can affect long-term well-being is one analogy for this, not only in stroke but in the general population. Modern medicine has moved away from the paternalistic model of “the doctor knows best” and the role of the doctor has changed to one of supporting patients’ autonomy in their care. Guidance and monitoring of care would therefore be important safeguards in certain circumstances to ensure that patients’ choices did not have a negative impact on the standard of care they received as a result.

### **6.3 Is care associated with outcomes?**

A strong association between the measure of recorded care (SnL Index) and measures of physical and cognitive function was established in the initial analyses. Conversely, the ratings ascribed to patients’ narratives (PPCI) to produce a measure of perceived care were linked to their psychological status, and did not correlate with measures of function or the ratings of care obtained from the SnL Index. On the advice of an expert statistician a more sophisticated statistical approach was required thus several different components from the measurement portfolio were integrated into a multi-variate analysis to explore the possibility of deriving an overall assessment of patient-perceived care from the information that was available. When this process was completed a different picture emerged and it was found that both psychological and rehabilitation outcomes could be predicted over time using the latent variables derived. This analysis required the use of advanced statistical modelling techniques and specialist software. It was performed with the assistance of Dr Robert West, the

statistical advisor on the SOS programme, and the findings reported in Chapter 4, Section 4.11, page 189.

In order to model the data it was necessary to identify a number of candidate variables for inclusion in the analysis. The first step was to distinguish whether items from the SnL Index were 'contingent' or 'non-contingent', with the intention of selecting items that were not dependent on or influenced by the health status of the patient. This process was accomplished using an Item\_Total correlation analysis of the data collected in Study 4a. This approach, which was reported in Chapter 4, Section 4.3.2 pages 139 - 142, selected items from the SnL Index that spanned the types of care stroke patients would receive as part of their specific care package rather than general hospital care. Calculating the total for the ratings of these non-contingent items generated the 12-item SnL Index score that was used in the subsequent analyses.

An Item\_Total correlation analysis was also applied to the measure of perceived care but did not result in any items being removed. The overall assessment of patient-perceived care was thus represented by the total of the scores assigned to the PPCI. Self-reported ratings of services were also available in the variable set, which had been obtained separately from patients at the same visit, after the interview schedule had been completed. These supplemented the pool of predictor variables by the addition of four patient-rated items that specifically appraised the care received:

- Satisfaction with care
- Quality of care
- Coordination of care
- Transfer of information

Two further items that were completed by patients as part of the same assessment were excluded:

- Trust in health care professionals
- Level of service

Trust has emerged as a recurring theme at various stages of this research and it is clearly a key component in inter-personal relationships, and consequently in relational continuity as currently defined. Notwithstanding that trust is important in any study of



continuity of care it was excluded from this stage of the analysis because the focus here was on evaluating the processes of care. A rating of trust would be susceptible to a range of factors outside the remit of service delivery, with the potential to confound the perception of the care process rather than to act as an indicator.

Level of service was excluded because of the subjective nature of its rating. There was wide variation in the type and number of services that patients received, and a discrepancy between that and the services they sometimes believed they should have received. The difficulty of assessing the appropriateness of services (received or not) was beyond the scope of this study, and thus this variable could not be regarded as properly validated for inclusion in the analysis.

An association of the record-based measure (SnL Index) with disability and the measure of patient-perceived care with mood had been identified in the preliminary analyses applied in Studies 4a and 4b. This suggested that other candidate variables for the analysis would be measures of physical and cognitive function, and psychological well-being. The Barthel Index and the Rivermead Mobility Index (physical function), the Mini Mental State Examination (cognitive function) and the 28 item General Health Questionnaire (psychological status) were measured in the early weeks following stroke as part of the Stroke Outcomes Study (SOS2) and were thus available for all the patients in the study sample. These were added to the pool of predictor variables to produce the final model.

### **6.3.1 The latent constructs: disability and perceived care**

When the structural equation model (SEM) was completed it revealed two distinct latent constructs, one of which was labelled “*disability*”. As anticipated, in addition to the measure of achieved care (the SnL Index), the variables that contributed most to the disability construct were all measures of function and cognitive status. This was not surprising as both methods of using record-based data to measure continuity had shown that care responds to need thus “achieved” care would likewise be expected to increase in proportion to need. Effectively therefore measures of achieved (continuity) of care were acting as proxy measures for the physical or cognitive status of the patient.

The second latent construct was labelled “*perceived care*” and comprised the patient-perceived measure of care (the PPCI) plus the self-reported variables assessing quality

of care, satisfaction, information giving and coordination of care. To some degree, the inclusion of the self-reported care ratings can be considered to mitigate against any interviewer bias introduced by the indirect assessment of the patient-perceived care measure. More importantly, it also captured aspects of care such as explicit ratings of quality and satisfaction which had been deliberately avoided in the PPCI ratings, which focused on assessing the continuous and discontinuous nature of care.

The model showed that the two latent constructs, disability and perceived care, were distinct and separate. They were only loosely associated through the variances of the two new measures (the SnL Index and the PPCI), and through the measure of mood (the GHQ\_28) as described in Chapter 4, Section 4.9.3, pages 184 - 186. The next stage in the analysis therefore was to convert the two separate constructs identified from the SEM into two new latent variables using the regression weights of the unstandardised confirmatory factor analysis. The new variables were rescaled and relocated as described in Section 4.10.2, page 188 and then examined by testing their predictive power against rehabilitation outcomes in a conventional regression model.

### **6.3.2 *The effect of disability and care on outcomes***

Two regression models were applied to the data. The first of these was a logistic regression analysis which used the dichotomised Barthel Index score at one year as the outcome and showed that poorer physical outcomes were associated with higher levels of disability. Perceptions of care were also represented in this model but to a lesser extent. The role of disability was clearly stronger in this relationship than that of perceived care, which could be anticipated as the likelihood of full rehabilitation is usually less with more severe initial disablement. Nevertheless, perceived care was shown to have some effect on functional outcome and, although it is difficult to explain this fully from these findings alone, mood state is clearly one candidate factor.

In contrast, the second regression model, which used a linear regression on the one year GHQ\_28 score, showed that poorer emotional outcomes were associated with poorer perceptions of care and, to a lesser extent, higher levels of disability. The nature of the relationship with mood and the direction of its causality could not be explored fully in this study and it remains unclear whether patients with low mood are consistently reporting lower ratings of their care or whether, as has been shown in other settings, poor mood status can actually influence the type of care that patients

receive. (Kidder and Smith, 2006) Either way, as these results show, patients can identify aspects of their care that make a difference to their rehabilitation after stroke.

As might be foreseen, the interviews with patients and the ratings obtained from the SnL Index showed that there are variations in the quality of care. Mindful of the association of ratings of perceived care with mood, it can also be surmised that the quality of care may not be as poor as some patients indicate from their accounts. The link between mood and perceptions of care was well illustrated in the case study of patient #531 (see page 177) whose low mood impeded the delivery of care in a community setting. Care could not be provided as planned, mainly as a result of difficulties with patient compliance with care; consequently the level of achieved care was sub-optimal and the patient's physical condition deteriorated much to the distress of the family. These factors influenced both the patient's and the family's perceptions of the care received. This finding is supported by work in other areas where it has been shown that mood affects both memory, recall of events and satisfaction ratings. (Hermann *et al.*, 1998, Sampson *et al.*, 2003, Simis and Nitrini, 2006)

In considering the nature of the relationship between care and outcomes for patients, and the direction of causality, it must be acknowledged that mood, personality and behaviour may all affect the quality of care received. Patients with low mood can be difficult to treat as a consequence of poor motivation, unresponsiveness and non-compliance with care. Furthermore, the mood status of patients may affect the delivery of care: A series of case reviews of nursing home care in the United States for example reported instances in which the attitudes and behaviours of difficult or non-compliant patients (and their relatives) provoked avoidance behaviour in staff, which in turn led to poorer care delivery. (Kidder and Smith, 2006)

Measures of care quality and patient satisfaction have been widely used by researchers as outcome measures, either for assessing the consequences of using services or as predictor variables determining service usage. Although measures of satisfaction are often regarded as audit tools by service providers and designed as simple checklists, they have been subject to scrutiny. Roghmann *et al.* identified several components in the construct "satisfaction" and, in a study conducted in 1979, showed that satisfaction with care was related to service utilisation. This study found a high degree of variance in patients' ratings of satisfaction between providers of care and, when the providers were analysed separately, found that satisfaction explained a high proportion of the variance in increased service usage. The reverse however was

not true: higher service usage was not associated with greater satisfaction with care. (Roghamann *et al.*, 1979)

The causal relationship between patient satisfaction and the use of health services was also examined by the same researchers in a later study (1989). Their findings suggested that satisfaction was dependent on the context in which medical care was given, and confirmed the link to the care provider. The researchers therefore recommended two approaches to progress work in the assessment of satisfaction with care: either a top-down perspective, which would examine structural and systems variables; or the use of "microanalytic" processes, which could detail patient-provider interactions. (Zastowny *et al.*, 1989)

In Study 1 it was observed that throughout the published literature there was a persistent overlap with quality in the conceptual definitions of continuity of care. In studies where measurement of patient-perceived continuity had been attempted, the items and ratings were often formulated in terms of satisfaction with or preferences for care. (Bull, 2000) In this study an effort was made to avoid these confounding factors in the measurement of perceived care by using criteria which focused on the process of care and its delivery. Nevertheless, satisfaction and quality of care were found to be intrinsically bound up in the patient-centred view of care.

#### **6.4 Continuity and care networks**

Delivering the modernisation agenda requires new ways of thinking about health care services. Care pathways, which feature a series of set processes through which patients are directed, may be appropriate for care settings where a high degree of standardisation is desirable such as acute stroke care but, as care diversifies and becomes more complex, pathways become difficult to design. Linear care pathways cannot easily account for the many and different routes that patients may need to travel through care. What is needed is a system that can cope with complexity and which offers the flexibility required for a personalised service. Similarly, care planning needs to be goal directed in order to adapt to a personalised agenda, with the process by which care is achieved assuming less importance than the aim of ending up with the right care package. This model of flexible care moves away from the long-established view of the patient and carer as passive recipients of care, and allows the health care professional to adopt a role as patient advocate, guiding and supporting decision making at the various stages of care. Flexible care is perhaps most easily

conceptualised in a network which can accommodate diversity, provide access to different types of care provider and has the potential to offer more options for patients to choose the care that suits them.

The National Stroke Strategy published in December 2007 emphasised the establishment of care networks as having *“real potential to improve the way that services are planned and delivered for both individuals with stroke and staff”*. Drawing from experiences in cancer care and coronary heart disease, the strategy recommends networks as a means of developing individual services, and improving co-operation and co-ordination in stroke care. (DOH, 2007) Patterns of care were identified in this study that indicated that care networks do already exist in stroke services. Structurally they may not be explicitly defined but their activities and functionality were evident in the accounts given by patients (in Chapter 2) and those of stroke care professionals reported in Chapter 5. What characterises a high quality network is harder to define but access to knowledge and the sharing of skills and expertise are clearly important factors, as identified in this study. These findings support the recommendations of the National Stroke Strategy for the establishment of networks in stroke care in order to facilitate cross-boundary working and improve the efficiency and quality of services by the sharing of information, functions and resources.

Furthermore, the National Stroke Strategy clearly views care networks as key to providing continuity of care enabling *“the individual to experience co-ordinated care from first-contact services, primary, secondary and tertiary NHS care, also extending into social care, housing and the voluntary sector”*. It recognises too that patients and carers need to be involved in the network processes. This is important as there are resonances between what has been learned from the way patients and carers described their experiences of care networks in this study, and what the literature says about continuity of care. However important differences also exist as, for example, in the way concepts of managerial, informational and relational continuity are dealt with in the currently accepted models of continuity, and the way they can be interpreted in a network.

#### **6.4.1 Knowledge in health care**

Knowledge has many forms in health care terms - from the passage of information (sometimes called explicit knowledge) between professionals and patients about their health and care, to the repository of skills and expertise (sometimes called implicit

knowledge) that resides in the workforce. In the Freeman and CHSRF models of continuity, knowledge is encompassed by informational continuity but this conceptualisation, which privileges explicit knowledge (information), for example patient-held records or computerised information, could be counter-productive. The implementation of the Easy Care (Single Assessment Process) documentation was a case in point as shown in the qualitative study with health care professionals (Study 5). This document, designed to improve care handover met with mixed success due to the inadequate training of users, an inappropriate format and version control problems. These are described fully in Chapter 5. Of greater consequence than explicit knowledge is knowing where to find relevant information and having access to it at the right time; too much information means time wasted sorting through a mass of irrelevant or superseded facts to find what is required, too little may compromise patient safety. There are, of course, stages in care when standardised information is needed as, for example, a list of medications on admission to hospital or at discharge will ensure that optimal care is maintained without unnecessary delays, but this form of informational continuity is not a panacea for all care settings.

From the literature it is known that knowledge sharing and the accumulation of implicit knowledge (sometimes termed intellectual capital) are properties of networks. (Polyani, 1966) Poor training or rapid turnover of staff dilutes the knowledge base; a factor cited by participants in Study 5 (Chapter 5 pages 215 - 217) as a reason for failures in care plans particularly when care was transferred from one environment to another. Networks facilitate the transfer of “just in time” information allowing the acquisition of relevant facts at the time they are needed either by the activation of network systems or by pattern recognition (knowing where to give or receive the right information through experience). As networks develop they become repositories of knowledge and support its creation, transfer and storage. (Dyer and Nobeoka, 2000) Examples of all these network functions were implicit in the health care professional participants’ descriptions of routine information transfer in the course of their work with patients.

#### **6.4.2 Relationships in health care**

The role of individual care-givers is central in health care as they are the essential agents of care. It is they who perform the tasks of care from the simplest type of personal care to the delivery of highly technical, specialist procedures. In the continuity literature, the important aspect of this component of care is described as relational continuity and many early measures of continuity were based on the idea that receiving

care from one provider is inherently better than seeing a variety of care providers. Clearly the provision of care by one individual in any complex and chronic long-term condition is not sustainable in modern health care situations. Not only might patients require input from a variety of specialists (routinely or in response to an acute event), but also the organisation of longer-term home care services necessitates team-based working and the sharing of case-loads. More important is the *connectedness* of individuals rather than the longevity or predictability of their individual relationships as teamwork is fundamental for the delivery of good care.

The important principle which would appear to be key to this element of care is *trust* – a recurrent theme in the literature on social networks and social capital, and one which emerged repeatedly (though often implicitly) in the interviews with stroke survivors and their carers, and with health professionals. Trust is important in health care; at its worst extreme, lack of trust can impede care delivery. This was demonstrated by an elderly study participant whose independence and refusal of community services (despite post-stroke visual and cognitive deficits) were clearly based on a sense of mistrust (shared with her spouse) of the NHS and allied professional services, rather than a positive assessment of the best plan for care. While it is not unknown for the elderly to become suspicious and mildly paranoid in their dealings with the authorities, it should be acknowledged that the generation of people largely represented in this study has seen the demise of home help and increased privatisation of public sector services; reason enough, one might consider, to cause them to be wary.

While seeing the same person can be a means of generating trust, there are other ways in which it can be achieved. Confidence in professional competence, an expectation of good standards of care and cleanliness in hospitals, and the timely delivery of care are all important factors in this respect. Analogies can be found here with consumer choice in other areas such as choosing to stay in hotels run by certain chains or to fly with a particular airline because there is the expectation of a known or perceived standard of service even though that service may never be delivered by the same person twice. Care from a single person does not necessarily ensure that these expectations will be met in the modern world of health care, nor does it ensure safety. Renee Amalberti, writing about healthcare systems, describes the need to move away from the idea of a fixed relationship with a known health professional as the *“transition from the mindset of craftsman to that of an equivalent actor”*. (Amalberti *et al.*, 2005) *“Why do we feel the need to know our surgeon personally”,* he asks, *“and not the name of the pilot of the aircraft we are in?”*; particularly so given that flying is considerably

safer than being a recipient of healthcare, thus personalised service is not in itself a marker of safety.

A care network can be conceptualised as a number of skilled individuals and teams each designed to deliver the processes of care as part of the overall network's function. This model emphasises the competency of the skilled practitioners who form the nodes in the network, with the links between them being communication and the transfer of information. Trust, in this conception, is delivered through the connections that exist between the individual members and teams, both professional and lay, and the connectedness that facilitates access to specialised or non-specialised services and resources through the network system. In the study of health care professionals discharge care planning was one example of how trust and relationships are built up in the course of their work with patients. Home visits were cited by participants in Study 5 as particularly useful in ensuring successful discharges. They offered the opportunity for lay and professional carers to meet with the patient in their domiciliary setting to pre-empt problems by identifying important issues and flagging up potential pitfalls beforehand. Collaborative working is a vital part of this process if the aim is to deliver diversity in care whereas over privileging individual relationships could be seen as a barrier to a model that delivers flexibility in services.

### **6.4.3 Coordination in health care**

Coordination of care is a key issue in continuity. An uncoordinated and disjointed service has the potential to cause gaps and discontinuities in care, with effects that can range from minor to serious or even life-threatening. In the CHSRF and Freeman models of continuity coordination is represented by managerial continuity which favours the professional management of care and is interpreted, typically, through the vocabulary of care pathways. In the acute stroke care phase care pathways act as a mechanism for the delivery of safe, coordinated care by adherence to standardised procedures, and have been found to improve short-term mortality. (Fagerberg *et al.*, 2000) In longer-term patient outcomes however their benefit over conventional care is less clear, as are the effects of integrated care pathways for rehabilitation. (Dancer, 1996, Sulch *et al.*, 2000)

Chronic care is complicated and hence pathways are more challenging to design because a linear model does not provide sufficient diversity for chronic illness situations (with or without multiple co-morbidities). It is also difficult to coordinate long-



term care across multiple health and social care boundaries, and care pathways are not usually sufficiently flexible to enable patient choice, or to allow the forwards and backwards movement between services that this type of care sometimes demands.

In health care, as in analogous industrial and commercial processes where quality of service and client satisfaction are paramount, a monitoring system is essential to identify and correct potential failures in the system. This provides a safety net to ensure that needs are met, and that unmet needs are detected in time to prevent serious problems occurring. Network models can offer a mechanism for generating coordination and effective monitoring through the sharing of knowledge, the enhancing of capabilities within the members of the network and the emergence of structure. (Watts, 2003) Examples of successful networks can be found in many industrial and commercial models, such as the Toyota network of companies. In competitive markets, networks can be shown to have desirable effects that can be mainly attributed to the connectedness of the network, which facilitates the rapid transfer of knowledge and information among its members. (Dyer and Nobeoka, 2000) The ability of commercial networks to allow “just-in-time” supplies of manufacturing parts to their constituent companies, for example, negates the necessity to maintain large and expensive stores, and thus confers an economic advantage. In health care this might be compared to a continuous awareness of needs that has a system in place which, when gaps occur (as they inevitably will) is responsive enough to fill them.

Notwithstanding the obvious pitfalls in equating health care delivery directly to commercial and industrial processes (notably the loss of the personalisation agenda), the supply chain model of health care delivery has been drawn upon to inform much of the current approach to designing health care systems. However, as Keen *et al.* proposed in a recent paper, while the linear supply chain model is relevant to the design of services where a high level of standardisation is advantageous (as for example care pathways in acute stroke care services), a non-linear, network-like design could provide an alternative and complementary approach to person-centred or complex and multi-agency care. (Hardie and Keen, 2006)

## **6.5 Limitations of the study**

A great deal has been learned from the experience of conducting this study but reflections on the research process revealed aspects of both the study design and execution that could have been improved upon.

### **6.5.1 Study design:**

The qualitative study (Study 2a) was designed to incorporate the patient's perspective into the research process. Traditionally, patients and carers are seen as passive recipients of care reliant on information given by health care professionals, and trusting in their advice and judgements. The agenda for the qualitative enquiry, which was professionally driven, may have reinforced this viewpoint and thereby lowered the potential for truly representing the patient's perspective of care. Planning the research in a way which incorporated service users' ideas into the overall process of research might have highlighted the active role assumed by some patients and carers in achieving timely and appropriate care, and the role of professionals in supporting their autonomy. The involvement of patients and carers at an earlier stage in the design of the study would, perhaps, have gone some way to addressing the potential for bias in explaining patients' experiences of care, and given new insight that could have added a further dimension to this research.

Pilot work showed that assessing continuity of care too early in stroke care was unproductive but a longer period of follow-up, extending beyond the one year of the SOS2 cohort, would have allowed extra information to be collected on the stages of care. Alternatively, the short, self-rated item list (completed by patients following the PPCI interview) could have been added to the interim follow-up assessments throughout the cohort study. Either of these approaches would have given Study 4b a longitudinal dimension. These modifications could have added value to the study by providing data to enable some commentary on the way continuity is perceived at different stages during the stroke care process.

Potential sources of bias and limitations also remain to be acknowledged, some of which were unavoidable, some beyond the resources of this study and others mitigated for, or minimised, where possible. In the record based measure (the SnL Index) for example it was not always consistently demonstrable that certain types of information recorded in the notes had been acted on, or that information had been used by clinicians. Moreover, the way in which health care events were usually recorded, and the way that patients recalled their care, meant that there was no accurate way of measuring the nature of the care process and the transitions between events: Were they timely? Were they appropriate? Were they connected? This study, however, was an attempt to measure care delivery and not a study of the accuracy of records so, wherever possible, pieces of information from different sources were used and fitted

together to create a whole picture. Similarly, when it was apparent that patients' accounts were muddled or chronologically misplaced, information was drawn from other sources such as carers, or care records, to clarify details and aid interpretation. In some cases this enabled the care events reported by patients to be differentiated and accurate ratings applied. For example, patients often found it difficult to distinguish between different types of care and the teams that had delivered it. It would seem unreasonable not to rate care acknowledged as received simply because the patient could only recall the event and not its details.

### **6.5.2 Geography**

The resources available were not sufficient to support a national, multi-centre study. This thesis therefore reports only the experience and organisation of stroke care in one region in the North of England. As a consequence the full effect of private sector rehabilitation may not be known because the health economy in this region differs from that in the South. It also recruited in the West Yorkshire area alone, albeit from two large acute hospital trusts whose catchments ranged from deprived inner city areas to wealthier outer suburbs, and also included some rural communities from the surrounding district. Ethnic minority groups were under-represented despite the population profile, particularly in one of the areas where the study was conducted. Although every effort was made to ensure equal access to the research process it was still difficult to recruit from the South Asian population. This may be a consequence of the way in which older family members are cared for in Asian households, with fewer being admitted to hospital following a stroke; or it may simply have been that language barriers exist for some older immigrants that limit participation in research studies.

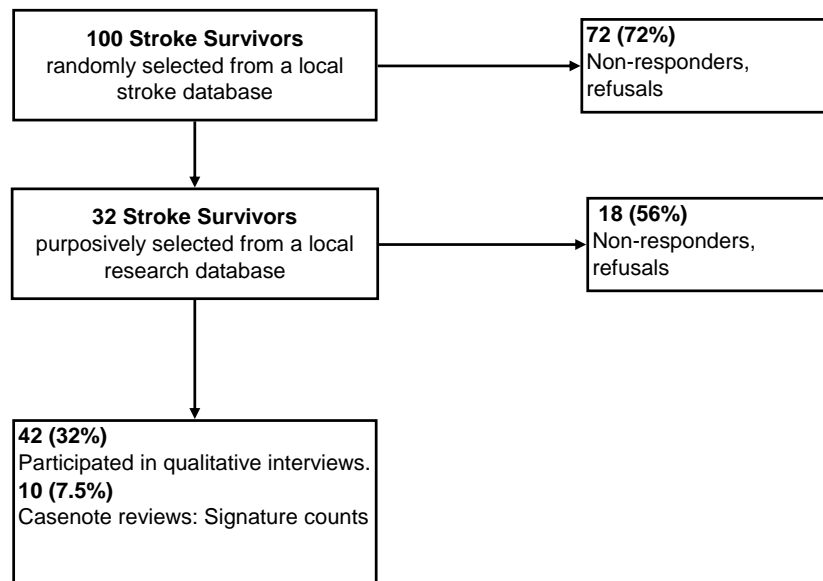
### **6.5.3 Sample size and profile**

The characteristics of the patients making up the samples for the individual studies were described in the methods sections of the relevant chapters. Selection of patients was not based on a lifetime first event thus the patients participating in any phase of the study may have presented with a first-ever stroke or suffered one or more previous stroke events.

In the qualitative study of the experiences of stroke survivors the patients were initially selected as a random sample of longer term stroke survivors but, when this method failed to yield a sufficiently large or representative sample, an additional purposive

selection of patients was added. Figure 6a shown below is a flow diagram which illustrates the recruitment of patients into Study 2. Note that the small number of patients for whom case-note reviews were completed reflects the decision to reject signature counting as a method of assessing continuity of care.

**Figure 6.a** Flow diagram of recruitment to Study 2



Notwithstanding that the patients who participated in the qualitative study were a self-selected sample, their experiences and views of care were diverse. They also had a range of demographic, physical and psychological characteristics (described in Section 2.2.2, page 65), partly achieved by supplementing the original randomly selected sample with a purposive selection of patients to ensure a balanced and representative mix of gender, age and post-stroke residual disabilities.

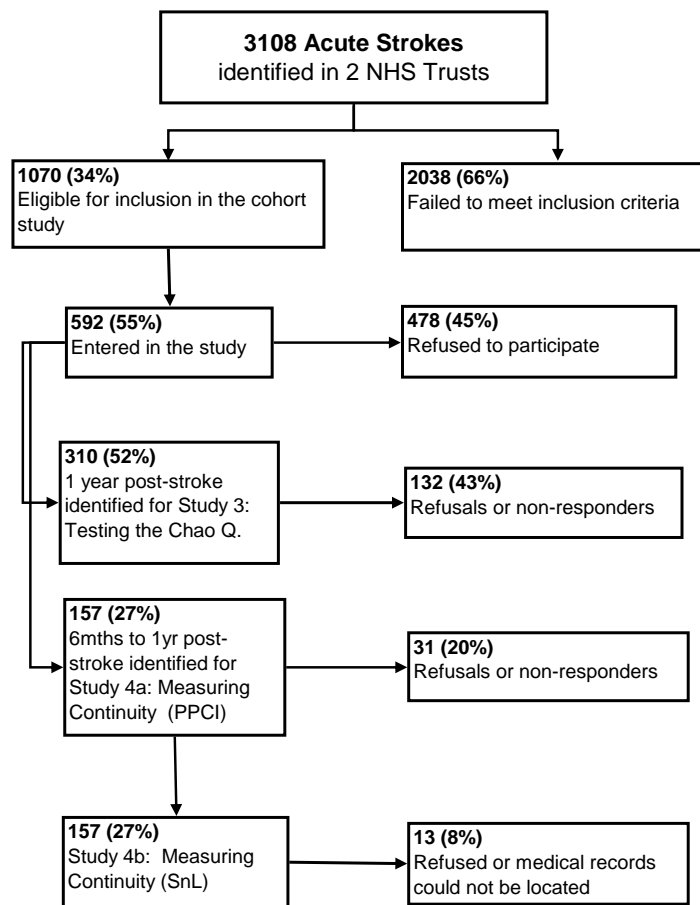
The indirect method of contact which was imposed on this stage of the research by the research governance body may have contributed to the low initial response rate. This supposition is supported by the higher proportion of patients recruited from the purposive sample (44%) who were approached directly compared to patients recruited from the randomly selected sample (28%). People with low mood for example might be characterised as less willing to have their names put forward. Several refusals came from the carers of people with severe disablements who said that the patients did not want to be bothered by researchers but whether this was a genuine reflection of the

patient's view could not be ascertained. Needless to say, both these factors biased recruitment towards patients with better physical and psychological functioning. The purposeful sampling method used to select the second stage sample drawn from the Bradford area went some way to addressing these factors. The final sample of patients included in the qualitative analysis in Study 2 was however slightly older overall than the UK median age for stroke, a consequence perhaps of selection from a population of longer-term survivors.

Irrespective of the method of selection, the people who eventually agreed to participate could be characterised as people who wanted to talk about their care. The large proportion of people who did not respond or refused consent may have had different perspectives of care but their views cannot be represented in the account nor can their reasons for non-participation be more than speculation. It can be postulated that non-responders and refusers are more likely to include patients with poorer physical and psychological status, those who live alone or are socially isolated and those who are disaffected with health care services but this cannot be verified as access to information about this group was not available for analysis.

In Study 3, the evaluation of the Chao Perception of Continuity Scale, and Study 4a: Measuring continuity from health care records and Study 4b: Measuring continuity from the patient's perspective, the samples were drawn from the parallel cohort study (SOS2). The flow diagram (Figure 6b on the following page) shows the process of selection and locates the patients within the overall sample that was recruited to this series of inter-linked studies. The patients in the three quantitative studies were recruited sequentially as the parallel cohort study, which was recruiting from the wider population of stroke patients, progressed. As the different phases of the study of continuity of care were completed successively, patients were not invited to participate in both the evaluation of the existing measure of continuity and the evaluation of newly developed measures.

Selection bias must also be considered a factor in respect of the low response rate (34%) to the postal questionnaires delivered in Study 3. However this was balanced by a very good response (98%) achieved to the interview delivered questionnaires. When the methods of delivery were compared no significant differences were found in the characteristics of the responders which facilitated analysis of the combined data.

**Figure 6.b** Flow diagram of recruitment to Study 3 and Studies 4a and 4b

The sample size for Study 4 was smaller than originally planned as the recruitment period was limited by the protracted development and pilot tests required for the two measures of care. Accruing a larger number of participants in the PPCI and SnL Index evaluations would undoubtedly have been beneficial firstly by increasing the power of the analyses and secondly by enabling modelling of data to be performed. A more sophisticated approach to the comparative analyses would have facilitated further exploration of the effects that were observed in sub-sets of data such as the association of the patient-perceived (PPCI) scores with the social dysfunction subscale of the GHQ\_28.

In order to take advantage of the range of outcomes being measured, the sample was dependent on the parallel cohort study from which participants were drawn. Patients

were recruited in the early weeks following stroke and consequently it was difficult to recruit the most severely disabled, the frailest and the very elderly; a limitation which is not uncommon in studies of other chronic diseases. After stroke approximately one third of patients will die and a further third are left with significant disablement but around half of those who survive the initial event will recover with little or no residual effects. Hence the wider stroke population of stroke survivors capable of participating in research is inevitably biased towards the fitter individuals. Interviews with the carers of the most severely disabled stroke patients in the qualitative study ensured that their experiences were represented as far as possible but cognitive impairment after stroke presented a problem in this respect too. The process of informed consent and the outcome assessments required a certain level of cognitive ability in order to complete them. It was however possible to include in the study patients who failed the cognitive screen because of speech or reading difficulties if an adequate level of communication could be established sufficient to complete the necessary study assessments and measures.

#### **6.5.4 Validity of the measures**

With regard to establishing validity, questionnaires should preferably be judged against criteria for:

- Face validity - coverage, comprehensiveness and format
- Construct validity – how well it separates the concept being measured from related concepts
- Content (or criterion) validity – how reliably the items measure the concept

Face validity checks were possible to the extent that the items on the SnL checklist and the PPCI schedule were critically reviewed by two stroke care professionals (one consultant and one specialist nurse) to ascertain whether the process of care was adequately covered, and the indicators considered appropriate. As far as possible each item represented a single idea but the nature of the interview meant that it was likely that more than one idea could be expressed in response to a question.

Item\_Total correlation analyses were conducted on the two new measures to examine the content validity, and factor analyses were also carried out on the SnL Index and the PPCI (using structural equation modelling), and on the Chao questionnaire (using

principal components analysis). These determined the underlying constructs being measured and the degree to which the questionnaire items contributed to them. Ideally, using an established measure of continuity of care in parallel with the newly developed patient-perceived measure (PPCI) would have enabled the external validity of the PPCI to be assessed. However, no gold standard measure of continuity exists, so this comparison was not possible. Accruing more information on the Chao Questionnaire for example, or introducing another existing measure of continuity of care such as the Continuity Care Index while undertaking Study 4b, (Bull *et al.*, 2000) would have meant that additional data were available to enable some external comparisons of the new measures. The collection of extra data was considered but the idea rejected because it would have represented an additional burden on patients. It must be remembered that participants in this study were already completing a large number of questionnaires and outcome assessments as part of the Stroke Association funded cohort study (SOS2: The effect of early depressive symptoms on rehabilitation outcomes).

The main strength of this thesis is in its empirical approach. The findings are firmly grounded in the views and experiences of those at the frontline of stroke care: the patients, their informal carers and the professional staff who work with them. Although there are caveats on the research, namely the sample size and profile, and the geographical limits of the area studied, it has nevertheless been conducted systematically and with attention to methodological rigour. Throughout the research process the author benefited from experienced supervision given by a highly skilled team with specific expertise in health services research, stroke, psychiatry and biostatistics.

## **6.6 Clinical and research implications**

### **6.6.1 Clinical and service implications**

The case studies described in Chapter 4 highlighted that some people may be at risk of not getting the care they need. The findings suggested that people with certain characteristics (both social and psychological) can become disengaged from services if sufficient safeguards are not in place to prevent it. In terms of service provision for stroke, therefore, it is essential to consider the integration of the physical and psychological aspects of rehabilitation and longer term care. This is particularly



important given that the findings of this study show that mood and perceptions of care are important factors in influencing rehabilitation outcomes over time.

An effective care network that enables lay and professional carers to communicate and collaborate effectively can provide the connectedness of services needed to ensure that at risk patients are identified and monitored. Discontinuities in care may have long-term health consequences for patients leading to poor functional outcomes and reduced quality of life. The implications for patients of not getting the care they require were clearly illustrated in the dialogues with stroke care professionals, and the areas of greatest risk (cross boundary transitions) were acknowledged.

Economic consequences for care providers ensue when readmissions to acute care services or extended admissions to hospital or institutional care occur in response to complications arising from breakdowns in service provision after discharge. There are organisational risks too, as an over linear view of care and reliance on care pathways may result in services that fail to reach the vulnerable patients identified above. Previous studies have shown that planned care pathways are beneficial in early stroke care, (Fagerberg *et al.*, 2000) but a recent organisational study of intermediate care suggested there is a need for planned care networks to support longer term care. (Hardie and Keen, 2006) Professor Justin Keen provided advice during the latter stages of this research, which guided the design and implementation of Study 5. From the information collected it was possible to identify the presence of implicit networks in stroke care.

Questions remain for service organisation about what constitutes a high quality care network, and how networks can be made to work effectively in a resource limited, publicly-funded health care system. While an ideal scenario can easily be conceived and described, it is important to recognise what can realistically be achieved within the budget available. Finally there is the issue of evaluation. How can the operational aspects of a network be assessed in a health care system? There are processes and activities of a care network which are not yet fully understood, and nor is it known how they might be measured. It can be hypothesised however that measuring process in a care network would be more complex than measuring process in a care pathway.

### **6.6.2 Research opportunities**

This study began with the aim of understanding and measuring continuity of care in stroke from the patient perspective, and moved on to evaluate its impact on rehabilitation outcomes. As it progressed new questions emerged which merit further investigation. Firstly there is the complex and multi-directional nature of the relationship between perceived care, mood and outcomes that was observed in Study 4b (Chapter 4): Does poor care always result in less successful outcomes for patients, or are those with worse outcomes more likely to perceive their care as poor? Secondly, there is the need to describe the nature of this relationship more precisely, and determine whether it is confined to rehabilitation in stroke or whether it applies to other types of care too.

Further research is needed to pursue the measurement of perceived care. Ultimately, the two measures developed for this study (the PPCI and SnL Index) did not function exactly as intended but nonetheless the PPCI may still have a role to play in the assessment of care from the patient's perspective. Refinement of the PPCI measure, and the Chao Perception of Continuity measure, for example, could form a part of future studies in this area. There is the potential to select items from both based on the factor analyses undertaken in this study, and to combine them to develop a modified measure of patient-perceived quality of care. This would include items related to the components of care: coordination, satisfaction, information transfer and quality, and encompass other relevant constructs like trust and respect. It is not known whether the continuous and discontinuous aspects of care can be generalised but it is reasonable to assume that there could be commonality in the way care for any chronic condition is perceived by patients. Extending studies beyond stroke care to new and different populations would offer the potential to test this hypothesis.

This study of continuity in stroke care gives an indication of the direction work in this area should travel. While care pathways act as useful coordination mechanisms in acute care settings more work is needed to characterise effective care networks in chronic illness and community care. The measure of patient-perceived care developed during the course of this work might form one component of future research as proposed above, but there is also the need to include comparative models drawn from commercial and industrial processes. Industrial processes can provide useful analogies for understanding the principles of continuity even if the mechanisms they use cannot be translated directly into health care processes. In order to determine

what makes a network effective would require the development of measures of professional expertise, and methods of assessing ties and the ways in which networks provide connectedness through information transfer and the coordination of processes. It is out of work like this that a new conceptualisation of co-ordinated, continuing care could emerge.

## 6.7 Conclusions

This doctoral study had two main objectives:

1. To investigate the understanding and experience of continuity in stroke care from the patient's perspective
2. To explore the feasibility of measuring continuity of care in stroke

A detailed, qualitative exploration of stroke care with patients and carers, and a reappraisal of the published literature met the first objective of the study: *to understand what continuity means in stroke*. Chapters 1 and 2 described the journey through a research process that revealed the differing perspectives and meaning that continuity has for patients and professionals, and the difficulties of applying existing theories.

In respect of the second objective: *the measurement of continuity*, success criteria are harder to apply. Chapter 3 described an existing measure of patient perceived continuity, the Chao Perception of Continuity Scale, tested in a community dwelling population of longer term stroke survivors. The questionnaire proved to be responsive to mood but not to factors specifically related to care delivery (like physical disability for example), and the constructs measured turned out to be those of trust, inter-personal knowledge and consistency of care. The Chao PC scale was thus rejected as a measure of the process of care and Chapter 4 reported the development of two new measures of continuity, one patient centred and one record based. These were tested in a further sample of stroke patients but statistical modelling showed that the record based measure was essentially a measure of disability (as counting care providers in Study 2b had proved to be) and the patient-centred measure, like the Chao, was associated with mood status.

Throughout the design, analysis and interpretative phases of this study the existing, multi-axial definition of continuity formed the theoretical framework. The qualitative data showed that this definition was of limited use when applied to patients' views of

care because their accounts of care were difficult to separate from their representations of illness, and their understanding of care processed was limited. Moreover, while the managerial and informational elements of the definition could be operationalised in a record based measure of continuity like the SnL checklist (Study 4a) and the relational and longitudinal elements in the counting of care providers (Study 2b), the construct being measured was found to be the level of disability of the patient and not the continuity of their care. These findings argue strongly that continuity may not be a discrete concept but a property of care, relevant to many aspects of care and important in the delivery of good quality care but changing dependent on the context of care and the time of its delivery. If this is true, a generic definition of continuity would not be feasible, and separating its measurement from other components of care complicated. This study has therefore contributed substantially to the debate regarding the measurement of continuity in chronic conditions, and to the overall understanding of the ways in which patients and carers perceive their care. In this respect, the main aims of this study have been fully achieved.

### **6.7.1 *Can continuity of care be measured?***

Continuity of care, as currently defined, is a professional and organisational-centred concept, which focuses on the provision of statutory services, and which is understood by health care staff but not necessarily interpreted by them in the same way. It remains unclear what aspects of continuity can be generalised from one disorder to another and across care settings. If continuity is a characteristic of care as this thesis proposes, and patients in this study were describing their involvement in the care network described by the health care professionals who participated in Study 5, it would explain why patients could not separate the quality of their care (or the care provider's expertise) from their satisfaction with care (a major part of which is trust) or from the coordination of care. It would also explain why patients, and their carers, could not describe the coordination of their care as top-down managed within a traditional, hierarchical organisational structure.

When measurement of patients' perceptions of care was attempted, this issue became central to understanding chronic care. Current ideas of continuity have tended to privilege certain factors as invariably important such as relational continuity (seeing the same person) in primary care; managerial continuity in acute care and informational continuity in areas like mental health where there is more emphasis on care planning than on consultant-led care. This study found, for example, that while stroke patients

could recognise the individuals involved in their care, they did not seem to associate these relationships with continuity of care. This is significant as it is something which may have misled researchers in the past. The literature abounds with measures based on continuity of care provider either operationalised as counts of frequency and density or as a preference for seeing the same person. These assessments cannot be meaningfully applied in stroke where care is complex and can be delivered by different providers at different times depending on the stage of illness and needs of the patient. When care was measured from the patient's perspective the underlying construct "perceived care" included components of mood, satisfaction with care and quality in addition to the new patient-centred measure of continuity. In relation to the measurement of care from the patient's perspective therefore, continuity was intimately linked to related concepts such as quality of care and patient satisfaction. This is significant because it adds weight to the emerging argument of this thesis that continuity is an intrinsic characteristic of quality care and not a single, measurable construct.

The evaluation of health care services, as Donabedian illustrated, is important not only for maintaining the quality and efficiency of existing services, but also for ascertaining the effects of reconfiguration or the introduction and development of new services. (Donabedian, 1992) The Sentinel Audit offers an established method of evaluating stroke services that is acceptable to NHS staff and policymakers alike, and has been tested and validated. (Rudd *et al.*, 1999; Gompertz *et al.*, 2001) Further development of the Sentinel Audit tool to encompass the quality of longer term care in the community would increase its scope and relevance as a measure of the care delivered for stroke and its continuity. The findings of this study suggest that the SnL checklist could add little to this existing validated and reliable tool.

Measuring the patient's view of care means measuring care from a different perspective, one which includes an emotional component. Moreover, research is needed to understand better how patients represent care in the context of chronic illness. This thesis has shown how patients' accounts of care received can differ (sometimes substantially) from the formal records and accounts of care provided, and that patients perceive care differently from health professionals. Howell *et al.*, 2007 reported that although patients' ratings of experienced care were associated with clinicians' assessments of the organisational quality of stroke care, they were largely unrelated to clinical process standards. They also found other discrepancies between clinicians' and patients' reports on the subject of communication and information giving.

It is important to know what these differences mean if patients' preferences and attitudes to care are to be understood and measured in a meaningful way.

### **6.7.2 *Designing care in the future***

The recent trend for policymakers to establish care networks as a key element of care planning is a welcome development. Nevertheless, it is important to recognise that informal networks of care may already be present within, and outwith, stroke services. These networks may be at risk if it is not known how to identify or evaluate them. The fragility of emergent implicit networks is unknown and thus there is an inherent danger that the introduction of managed care pathways or networks could have a detrimental effect on existing and effective networks. Change, for example through the setting up of new systems, could damage the links and ties residing in informal networks as currently configured. A better understanding of the generative rules of care networks and the way in which components of formal and informal services are integrated within them is needed to safeguard against this eventuality.

Major restructuring of services without more insight into how care is achieved in the present system could also have fundamental implications for service delivery. A sustained period of reform in health care services in the UK has led to changes that have left many practitioners with uncertainties about the future. In Chapter 5, the interviews and focus groups with health care professionals revealed how a number of tensions between agencies involved in stroke care had arisen as a result of reorganisation or restructuring. Their accounts illustrated how disruption to established working relationships, and lack of clarity about new roles and responsibilities, could lead to low morale and staff turnover. The introduction of joint care management and the way consequent changes to hospital social work roles were perceived by staff was one example of this in practice. Another recent example is the announcement of polyclinics in primary care, a development which has been opposed by many General Practitioners and the BMA, who fear the decline of successful practices in the locality of the new clinics, and a subsequent loss of continuity of care for patients. (The Guardian, Friday, June 13 2008) These factors have the potential for negative impact on care delivery, leading to poorer patient perceptions of care quality and less satisfaction with care received.

From the patient's point of view services need to be approachable, responsive and appropriate. Flexibility is a key factor in developing care of this nature. Clinicians, on

the other hand, need to have confidence in ongoing care, and to know that their patients can move seamlessly and safely between different arms of the service. Quality care networks can provide the means of delivering all these requirements effectively. Finally, outcomes need to be viewed in a wider context, both in relation to community services and to the service users' informal social networks. Pound *et al.* (1998) wrote that "*the effects of stroke are mediated by the ongoing context of people's lives*"; (Pound *et al.*, 1998), and this is almost certainly true for their continuing care. It is also an important consideration for developing a personalised agenda for care.

## APPENDIX A: The Stroke Outcomes Study Programme

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### The SOS2 Study

Funded by the Stroke Association, SOS2 comprised a four year observational cohort study of the effect of early depressive symptoms on outcomes after stroke. The first 32 months of this prospective study were used for active recruitment. The original protocol included patient follow-up at 6 to 8 weeks and six months after the index stroke but additional funding from the NHS Service Delivery and Organisation (SDO) programme enabled two additional follow-up time point at 3 and 12 months. By sharing outcomes assessments between the two studies the combined funding enabled best value to be achieved from the work.

The programme commenced in March 2002 with applications to the research ethics committees of the local major acute trusts. Once ethical approval was granted, recruitment commenced on 1 July 2002.

In order to capture a truly representative sample, admissions for stroke, collapse query cause, seizures, falls and any other possible cases were followed up in two acute Trusts to identify those patients with a final diagnosis of infarct or haemorrhagic stroke (sub-arachnoid haemorrhages excluded).

Table A1 (page 273) shows the inclusion criteria for the study. These were broad and designed to enable as full a range of patients as possible to participate:



**Table A.1 Criteria for entry into the Stroke Outcomes Study**

INCLUSION CRITERIA	EXCLUSION CRITERIA
<p>Patient has survived a first or recurrent stroke and is fit to be seen at 2 – 4 weeks.</p> <p>Patient is aged 18 years old.</p> <p>Patient is able to give informed consent.</p> <p>MMSE (Mini Mental State Examination) score of 23 or above (Borderline scores between 20 and 23 to be accepted if physical or speech deficits impair scores.)</p>	<p>Severe cognitive impairment</p> <p>Sub-arachnoid haemorrhage</p> <p>Transient ischemic attack</p> <p>Non-English speaking</p> <p>No concurrent major illness the management of which is likely to predominately determine care.</p>

### The SOS2 Study Schedule

Consenting patients were interviewed within the 2 to 6 weeks after their index stroke episode (T1) depending on their cognitive and physical state, and a four follow-up points thereafter: 6 to 8 weeks (T2); 12 to 14 weeks (T3); 6 months (T4) and 1 year (T5). Patients were asked to complete a range of outcomes measures at each visit providing information on functional status and psychological well-being. Table A.2 (p. 232) shows the full complement of outcome assessments and the timetable for their completion. Recruitment took place between July 2002 and March 2005 during which period 585 patients were entered into the study. This represented approximately 10% of the total population of stroke victims who were assessed for eligibility. Of these patients 493 (84%) completed all five follow-up visits without protocol violation or drop-out and were subsequently included in the analyses. The final follow-up visits were completed by 31 March 2006.

**Table A.2: Timetable of outcomes assessments in the SOS programme**

<b>SOS2: THE EFFECT OF EARLY DEPRESSIVE SYMPTOMS ON OUTCOMES AFTER STROKE</b>		
<b>BASELINE ASSESSMENT (T1)</b>	<b>6 WEEKS (T2)</b>	<b>3, 6 AND 12 MONTHS (T3, T4 AND T5)</b>
Demographic data: age, sex, residential status, occupation etc is collected, Current medication. Smoking history.	Current medication Place of residence	Current medication Place of residence
<b>Impairment</b> Glasgow coma scale on admission Urinary continence in the first 2 weeks Presence of hemianopia WHO Performance Status ratings (See Appendix D)	<b>Impairment</b> WHO Performance Status rating	<b>Impairment</b> WHO Performance Status rating
<b>Cognition</b> Mini Mental State Examination (MMSE) – a brief screening for cognitive impairment Frenchay Aphasia Screening Test	<i>If cognitive state changed or in doubt</i> repeat Mini Mental State Examination (MMSE)	<i>If cognitive state changed or in doubt</i> repeat Mini Mental State Examination (MMSE)
<b>Functioning</b> The Barthel Index - pre- and post-stroke Rivermead Mobility Index	<b>Functioning;</b> Barthel Index Frenchay Activities Index (FAI) – if the patient is at home Functional Independence Measure (FIM) Therapist-rated measure of participation in rehabilitation (If applicable)	<b>Functioning;</b> Barthel Index Frenchay Activities Index (FAI) – if the patient is at home Functional Independence Measure (FIM) Therapist-rated measure of participation in rehabilitation (If applicable)
<b>Mood</b> GHQ-28 – a self report mood rating scale; Modified short form Present State Examination (PSE) – a standardised psychiatric interview to derive ICD-10 diagnoses (with additional questions on alcohol consumption and emotionalism).	<b>Mood</b> GHQ-28; Modified short-form PSE	<b>Mood</b> GHQ-28 Modified short-form PSE
		<b>Quality of Life</b> SF-36: a self-reported measure of health-related quality of life
<b>Co-morbidity</b> Dukes Severity of Illness Scale		
<b>SOS3: THE IMPACT OF CONTINUITY OF CARE ON OUTCOMES AFTER STROKE</b>		
<b>BASELINE ASSESSMENT (T1)</b>	<b>6 WEEKS (T2)</b>	<b>3, 6 AND 12 MONTHS (T3, T4 AND T5)</b>
All outcome assessments as SOS2	All outcome assessments as SOS2	All outcome assessments as SOS2 <b>Between T4 –T5</b> Patient-centred Continuity of Care measure (PCCI) Casenote review using SnL checklist

## APPENDIX B: MEDLINE Database Search Strategy

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- 1 exp Patient Discharge/ (9129)
- 2 exp Long-Term Care/ (14085)
- 3 exp Delivery of Health Care, Integrated/ (3285)
- 4 exp Intermediate Care Facilities/ (434)
- 5 exp Caregivers/ (6042)
- 6 exp Continuity of Patient Care/ (6150)
- 7 exp Patient Care Team/ or exp Nursing, Team/ (31099)
- 8 exp Case Management/ (3329)
- 9 exp Interinstitutional Relations/ (4598)
- 10 exp Patient Care Team/ (31099)
- 11 exp Patient Satisfaction/ (18242)
- 12 exp Personal Satisfaction/ (3931)
- 13 exp Patient Care Planning/ (27937)
- 14 exp Interprofessional Relations/ (25691)
- 15 exp Primary Health Care/ or exp Community Health Services/ (354531)
- 16 exp CONSUMER ADVOCACY/ or exp PATIENT ADVOCACY/ (18762)
- 17 [from 17 keep 1-10] (0)
- 18 continuity of care.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (1522)
- 19 supported discharge.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (22)
- 20 long-term care.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (17233)
- 21 ((integrated or co-ordinated) and care).mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (5189)
- 22 intermediate care.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (481)
- 23 carer support.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (20)
- 24 transitional care.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (93)
- 25 long term follow-up.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (15875)
- 26 long term outcome\$.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (7173)
- 27 ((seamless or joined up) and care).mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (437)
- 28 team care.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (226)
- 29 multi agency working.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (4)
- 30 interpersonal continuity.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (1)
- 31 care process.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (524)
- 32 periodic health checks.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (2)
- 33 gap\$.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (34058)
- 34 interface\$.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (30223)
- 35 case management.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (5514)
- 36 seamless care.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (32)
- 37 inter agency working.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (8)

- 38 key worker\$.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (68)
- 39 expectation\$.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (18928)
- 40 discontinuity.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (1917)
- 41 transition\$.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (78702)
- 42 satisfaction.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (23059)
- 43 care plan\$.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (3985)
- 44 multi professional working.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (2)
- 45 inter professional working.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (2)
- 46 care experience.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (454)
- 47 check up\$.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (1018)
- 48 information.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (260694)
- 49 longitudinal.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (49750)
- 50 advoca\$.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (18171)
- 51 exp Cerebrovascular Accident/ (20789)
- 52 stroke\$.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (63214)
- 53 cerebrovascular accident\$.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (9644)
- 54 cva.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (839)
- 55 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 (948316)
- 56 51 or 52 or 53 or 54 (77033)
- 57 55 and 56 (7260)
- 58 limit 57 to (human and (english or german or italian or spanish) and adult <19 to 44 years>) (2167)
- 59 exp REHABILITATION/ (129090)
- 60 exp "Physical Therapy (Specialty)"/ (147)
- 61 exp Activities of Daily Living/ (22633)
- 62 exp Exercise Therapy/ (11588)
- 63 physiotherapy.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (4200)
- 64 educat\$.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (264556)
- 65 59 or 60 or 61 or 62 or 63 or 64 (387209)
- 66 57 and 65 (1118)
- 67 limit 66 to (english or german or italian or spanish) (1047)

**APPENDIX C: The Chao Perception of Continuity Scale**

**THE CHAO PERCEPTION OF CONTINUITY QUESTIONNAIRE**

© Dr. Jason Chao M.D., M.S. Associate Professor of Family Medicine,

Case Western Reserve University, Cleveland, Ohio.

Please follow the instructions to answer the following questions. Your replies are confidential and will not be identified in any way. If you have any queries about the questionnaire or need help to complete it please ring us on 0113 343 1964.

1. PLEASE USE A SCALE OF 1 TO 5 TO INDICATE HOW TRUE OR FALSE YOU FEEL EACH OF THE FOLLOWING STATEMENTS IS:				
DEFINITELY TRUE 1	MOSTLY TRUE 2	UNCERTAIN 3	MOSTLY FALSE 4	DEFINITELY FALSE 5
Please write your score in the box next to the question or mark X if a question is not applicable to you:				X
A. If more than one family member needs medical care, we go to different doctors.				
B. My doctor often mentions or refers to my past medical problems and treatments.				
C. I receive my medical care at more than one location.				
D. The doctor has a list of all the medicines which I am taking now.				
E. I rarely see the same doctor when I go for medical care.				
F. My medical care improves when the doctor has seen me before.				
G. I have medical problems that the doctor doesn't know about.				
H. My doctor provides care for any type of problem which I may have.				

**Now please complete the questions on the next page:**

<b>2. PLEASE INDICATE YOUR OPINION OF THE FOLLOWING STATEMENTS, USING THE SCALE 1 TO 5:</b>				
AGREE STRONGLY 1	AGREE 2	UNCERTAIN 3	DISAGREE 4	DISAGREE STRONGLY 5
Please write your score in the box next to the question or mark X if a question is not applicable to you:				X
A. I feel that I have an on-going relationship with a doctor.				
B. It is difficult to bring up unrelated medical problems with the doctor.				
C. I am uncomfortable in discussing a personal problem with the doctor.				
D. The doctor knows a lot about the rest of my family.				
E. I feel comfortable asking questions of the doctor.				
F. The doctor doesn't know about my family problems.				
G. The doctor does not explain things to me.				
H. In an emergency, I want my regular doctor to see me.				
I. I would rather see another doctor right away, instead of waiting a day or two to see my regular doctor.				
J. My doctor provides appropriate referrals to other specialists.				
K. My doctor would take care of me if I had to go to the hospital.				
L. My doctor would take care of me if I require emergency care.				
M. I trust a specialist recommended by my doctor.				
N. My doctor would know me by name if we met on the street.				
O. I trust my doctor.				

**Please return your completed questionnaire in the envelope provided. If no envelope is enclosed or it is lost or damaged, please send the form by freepost (no stamp required) to:**

**The Stroke Research Office,  
FREEPOST NEA 15583,  
The University of Leeds,  
Leeds LS2 3YY.**

## APPENDIX D: The Qualitative Interview Topic List

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Opening questions to orientate patient on stroke episode and establish level of disability and needs. “*Tell me a little bit about your stroke and how you’ve been getting on since you came home (or to your relative/nursing home etc).*” “*What care needs do/did you have?*” Then explore the following themes:

### Is there an outside thread of continuity?

Who are the intermediaries for the patient?  
 What are the pathways of care?  
 Are they structured?  
 Are there key contacts? Do they have a contingency plan when their key contact is away?  
 Are there people that they avoid?  
 What happens when the structure breaks down?  
 How much do they do for themselves and how much do they rely on others?

### Relationships

Do you have any help from other people? Who are they?  
 What types of things do they do?

#### *More probes:*

Who helps you with practical things like shopping, cleaning the house, doing the garden, washing, ironing etc?  
 Is there a particular person?  
 Who helps if you go to the hospital or have to sort out an appointment with the doctor?  
 Is there a different person?  
 What about prescription medicines – does anyone help you by fetching them or sorting them out for you?  
 Ask about the person/people you would go to if you had a particular problem with one of these things?  
 (For a particular problem) Did they deal with it or did they pass it on?

### Portals of entry/accessibility

Did you need any special services or care to help you manage when you came out of hospital after your stroke?  
 Did you know what was available?  
 Tell me how you found out about the services/care that you might be able to get?  
 Did you have any problems getting what you needed?  
 Did everything happen when you expected it to or did you have to wait for things?

#### *More probes:*

What did/would you do if things went wrong?  
 Did anyone help you? Tell me how/who?  
 Who would you talk to about medical care, aids and appliances, benefits or help at home?

### Communication

Did it seem to you that information about your stroke care had been passed on to the people who are/were looking after you since/when you left hospital?  
 Did the people who are/were looking after you seem to share information or did you have to fill in the gaps sometimes?  
 Was there a two-way process – did the information you wanted to pass on get to the right people?  
 Did there seem to be any links that were useful for getting information/passing it on?  
 Did you have any unanswered questions about your stroke or your care?  
 How did you get the information you needed?  
 Where or who did it come from?

Did you find things out for yourself or did someone else do it for you?

Did you want to find out about everything at the beginning or did you just find out about things as the needs arose?

Tell me how you found out about the things you wanted to know.

*More probes:*

Was there a particular person who helped you to find out about things?

Was there anyone at the hospital/from your doctors who especially helped you find out about things or told you what was happening?

Was there anyone who was particularly good (or particularly bad) at explaining things to you or telling you about things?

### **Longitudinality, comprehensiveness and consistency**

Were there people that you saw regularly?

How often did you see ... (certain types of professionals)..?

Did/Does it seem to you that there is one particular person who oversaw/oversees you care for your stroke?

Has that person changed?

Did you ever get any conflicting advice or information about your care?

Were there times when you felt that there were breaks or interruptions in your care?

When you had to go to (different places) for care, did things go smoothly or did it seem to be a bit disjointed as though things hadn't been handed over very well?

Did you have to ask for the things you needed or did you just get them?

*More probes:*

Tell me what it was like when you went to (Chapel Allerton/came home etc.)

Tell me about the gaps in your care, or if there were times when you felt that things were not happening when you had expected them to.

### **Individuality and flexibility**

Tell me a little about your rehabilitation.

Did the things you were doing or being asked to do seem relevant to you?

Did anyone talk to you about what you would be able to achieve?

Did you get the chance to say what you expected or wanted to achieve from the rehabilitation?

Did you feel that you were listened to?

Was there any conflict between your personal aims and those of the therapists?

Tell me how you sorted that out.

Did people seem to understand your particular circumstances/preferences?

Did you feel involved in planning things like your rehab or discharge?

Tell me about the things that were especially difficult for you.

Did things change either before you left hospital or since?

Was the help/care that you were getting able to respond to those changes?

*More probes:*

Tell me how you felt overall about the care you got after your stroke.

Tell me how you feel about the way it all fitted together.

Did it seem like one joined up process or like lots of people doing their own bit to help you?

Did it feel as though your care was designed for you or as though you had to fit in with what was on offer?

Did it feel as though you needed to find or speak to the right person in order to get things done?

Was there one particular person who seemed to hold everything together for you?

What happens when that person isn't there?



## APPENDIX E: The WHO Performance Status Scale

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### WORLD HEALTH ORGANISATION (WHO) GRADES OF PERFORMANCE STATUS

Grade	Summary	Criteria
0	Normal	Able to carry out all normal activity without restriction
1	With Effort	Restricted in physically strenuous activity; ambulatory, can do light work
2	Restricted	Ambulatory and capable of all self care but unable to carry out any work; up and about more than 50% of waking hours
3	Dependent	Capable of only limited self care; confined to bed or a chair for more than 50% of waking hours
4	Immobile	Completely disabled; cannot carry out any self care; totally confined to bed or a chair

## APPENDIX F: Pearson Correlation Matrix of Chao PC Questionnaire Items

	1A	1B	1C	1D	1E	1F	1G	1H	2A	2B	2C	2D	2E	2F	2G	2H	2I	2J	2K	2L	2M	2N	2O
1A: Different Doctors	—																						
1B: Past Medical Problems	-.197(*)																						
1C: Location	0.115	-.181(*)																					
1D: Medication	-0.134	0.151	-0.062																				
1E: Same Doctor	.192(*)	0.156	0.023	.171(*)																			
1F: Prior Knowledge	-0.075	.318(**)	-0.119	.187(*)	0.092																		
1G: Unknown Problems	.237(**)	-0.116	0.106	0.090	.216(**)	0.053																	
1H: Care For All Problems	0.124	0.149	0.038	.259(**)	.199(*)	.186(*)	.179(*)																
2A: On-going Relationship	0.009	.370(**)	-0.078	.189(*)	.334(**)	0.116	0.154	.367(**)															
2B: Unrelated Medical Problems	0.046	0.089	0.132	0.095	.168(*)	0.055	.231(**)	.330(**)	.266(**)														
2C: Personal Problems	-0.015	-0.063	0.131	0.035	0.114	0.045	0.100	0.104	0.115	.414(**)													
2D: Knowledge of Family Members	0.101	.243(**)	-0.040	.222(**)	.173(*)	.280(**)	0.073	.261(**)	.444(**)	0.122	0.119												
2E: Ease of Communication	0.132	0.031	0.112	0.065	.234(**)	0.085	.180(*)	.369(**)	.346(**)	.341(**)	0.150	.215(**)											
2F: Knowledge of Family Problems	.241(**)	.216(*)	0.150	0.096	.267(**)	0.159	0.159	.278(**)	.374(**)	.247(**)	0.048	.588(**)	.225(**)										
2G: Poor Explanations	.226(**)	0.117	.220(**)	0.026	.246(**)	0.106	.181(*)	.382(**)	.247(**)	.269(**)	.272(**)	.333(**)	.215(**)	.461(**)									
2H: Emergency Care Preference	-0.111	0.122	-0.055	0.114	0.023	0.107	-0.057	.294(**)	.192(*)	0.121	0.019	0.080	0.077	.175(*)	0.073								
2I: Waiting For Own Doctor	.208(*)	0.058	-0.068	-0.082	.240(**)	0.075	0.107	-0.012	.237(**)	0.053	0.046	0.142	-0.043	0.124	0.138	.190(*)							
2J: Referrals	0.073	.227(**)	-0.133	.251(**)	.208(**)	0.111	.189(*)	.408(**)	.388(**)	.213(**)	.180(*)	.246(**)	.208(**)	0.141	.290(**)	0.140	0.080						
2K: Provides Pre-admission Care	0.060	.194(*)	-0.061	.194(*)	0.108	.164(*)	0.005	.345(**)	.279(**)	-0.055	0.000	.221(**)	.257(**)	0.008	.164(*)	0.150	0.118	0.150					
2L: Provides ER Care	-0.005	0.139	-0.128	.177(*)	0.132	.192(*)	0.079	.554(**)	.259(**)	0.099	0.092	.216(**)	.277(**)	.186(*)	.232(**)	.302(**)	0.121	.353(**)	.519(**)				
2M: Trust Recommendations	0.019	0.111	0.006	.176(*)	0.129	0.051	.176(*)	.388(**)	.309(**)	.308(**)	.199(*)	.257(**)	.199(*)	.230(**)	.287(**)	.242(**)	0.052	.514(**)	0.128	.443(**)			
2N: Recognition	0.093	.321(**)	-0.026	0.122	.441(**)	.177(*)	0.068	.273(**)	.607(**)	.185(*)	0.025	.449(**)	.171(*)	.361(**)	.280(**)	0.125	.309(**)	.334(**)	0.155	.244(**)	.260(**)		
2O: Trust Personal	0.019	.233(**)	0.047	0.109	.220(**)	0.120	.240(**)	.456(**)	.533(**)	.374(**)	.193(*)	.407(**)	.359(**)	.350(**)	.379(**)	.339(**)	0.153	.506(**)	.178(*)	.293(**)	.540(**)	.513(**)	—

Note: \* Correlation is significant at the 0.05 level (2-tailed).  
 \*\* Correlation is significant at the 0.01 level (2-tailed).

## APPENDIX G: The Snakes and Ladders Index Checklist

Patient ID:  
Date of Admission:

Date of Index Stroke:  
Date of Discharge:

Stage	Continuity Indicator	Continuity Score	Actual Score
<b>Admission</b>	Direct referral by GP	+1	
	Admission through A&E	0	
	Initial A&E episode followed by later admission	-1	
	Number of ward transfers: None	+1	
	Specialty Transfer	+1	
	MAU/Rehabilitation ward	0	
	Other transfers in acute/rehabilitation hospital	Each = -1	
	Referral to other specialty (+1 for each referral)	Yes/No	
	Transfer for rehabilitation	Yes/No	
	Early discharge	Yes/No	
<b>In-Patient Stay Acute Phase</b>	Standardised assessment and plan within 3 days	+1	
	Non-standardised assessment	0	
	No assessment	-1	
	Problem based medical management plan	+1	
	None specific management plan	0	
	Nothing	-1	
	Regular blood pressure monitoring: Yes	+1	
	No	-1	
	Any other risk factors	Yes/No	
	If Yes: Other risk factors identified and monitored	+1	
Other risk factors identified	0		
No other risk factors identified	-1		
<b>Rehabilitation Phase</b>	Stroke specific nursing assessment within 3days	+1	
	Non-stroke nursing assessment	0	
	No assessment	-1	
	Full rehabilitation assessment and plan in 7 days	+1	
	Assessment by rehabilitation services >7 days	0	
	No referral or assessment by rehabilitation services	-1	
	MDT case conference review: Yes	+1	
	No	-1	
	Received care on designated stroke unit	+1	
	Received input from specialised stroke team	0	
	No care/input from specialised stroke service	-1	
	Transfer with notes & existing problem list	+1	
	Transfer with summary report	0	
	Transfer with nothing – full reassessment	-1	
	Therapy goals negotiated and actioned	+1	
	Therapy goals noted but not actioned	0	
	No therapy goals negotiated	-1	

<b>Discharge</b>	Record of MDT planned approach to discharge	+1	
	Appropriate agencies involved in discharge	0	
	No record of planned approach to discharge	-1	
	Home visit required	Yes/No	
	Home visit completed, verbal handover and report	+1	
	Home visit – verbal handover only - no report	0	
	No home visit	-1	
	Named contact given to patient/carer	+1	
	No named contact	-1	
	<b>Community Care and Rehabilitation</b>	Discharge summary/advice received by GP	+1
Telephone advice to GP		0	
No discharge advice to GP		-1	
Record of regular BP monitoring by GP / Practice Nurse		+1	
Occasional BP check		0	
No record of BP checking or monitoring		-1	
Record of review or change to medication		Yes/No	
Risk factors communicated to or identified by GP and monitored		+1	
Risk factors communicated to or identified by GP but not monitored		0	
No risk factors communicated or identified		-1	
Patient aged >65 (Score services below as appropriate)		Yes/No	
Community Physio/OT input		+1	
Community Physio/OT not required		0	
Community Physio/OT planned but not delivered		-1	
Outreach team input		+1	
Outreach team not required		0	
Outreach input planned but not delivered		-1	
ICT input		+1	
ICT not required		0	
ICT input planned but not delivered		-1	
DSS/home care team input		+1	
DSS/ home care team not required		0	
DSS/ HCT input planned but not delivered		-1	
Aids/adaptations requested and received		+1	
No aids/adaptations required		0	
Necessary aids/adaptations not received		-1	
OP therapy planned and given		+1	
OP therapy not required		0	
OP therapy planned but not given/not timely		-1	
Day hospital planned		+1	
Day hospital not planned		0	
Day hospital planned but not attended		-1	
Follow-up by Stroke specialist/Stroke Nurse	+1		
No follow-up required	0		
Follow-up planned but not given	-1		
Patient held record	Yes/No		

<b>Long-Term Support</b>	Patient has on-going care needs	Yes/No	
	Contact initiated by stroke care co-ordinator	+1	
	Information/contact number available	0	
	No record of information or contact	-1	
	Patients has significant residual disability	Yes/No	
	Suitable for targeted therapy at 6 months?	Yes/No	
	Record of reassessment and targeted therapy	+1	
	Record of reassessment but no therapy offered	0	
	No record of reassessment	-1	
	Voluntary care organisations involved	Yes/No	
	Clinical Psychologist involved (community or hospital)	Yes/No	
	Total number of care agencies involved		

**APPENDIX H: The Patient-Perceived Continuity Interview****Schedule**


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**The PPCI (Stroke)  
Patient-Perceived Continuity Interview in Stroke Care**

<b>Study ID: SOS3/</b>	<b>Patient ID:</b>
<b>Casenote No.:</b>	<b>Hospital:</b>

<b>Visit code</b>	<b>Date</b>	<b>Interviewer</b>	<b>Location</b>	<b>Barthel Score</b>	<b>WHO PS grade</b>

**Instructions to Interviewers**

This questionnaire is delivered as a structured interview and should be recorded. The questions are organised in sections. If a section is not relevant to a patient, please note this by ticking not applicable (N/A) in the box provided.

The questionnaire consists of a core section, social network map, patient ratings and a follow-up section. At the end of the interview please ask the patient to rate the items on page 6.

Begin by asking the patient: *“Tell me a little about what happened when you had your stroke”*. If the patient refers to issues or incidents that are relevant to the questionnaire items use them to frame follow-on questions, otherwise use the standard wording and prompts. Remember to record or list information as requested at the relevant stages of the questionnaire. The responses can either be rated by the interviewer during the interview or later, from the tape-recording, by the interviewer or by an independent assessor.

**SECTION 1: MANAGERIAL CONTINUITY**

1a.) Tell me a little about what happened when you had your stroke. How did you get into hospital? What happened when you got there?		
<b>Core item:</b> Rate perception of admission		
Positive	No problems in admission. Rapid ambulance or private pick-up. Smooth transition through A&E/ MAU to Stroke Unit. Rapid access to stroke specific services.	+1
Neutral	Some delays in admission. Waiting for transport. Longer period in A&E or MAU or waiting for stroke specific services.	0
Negative	Long delays waiting for bed or sent home without admission. Transport unavailable or long delay or repeat requests required. Extended period in A&E or MAU. No access to stroke specific services.	-1
1b.) Tell me what happened when the time came for you to come home. How was your discharge arranged? Did things go smoothly? Did you have a meeting in hospital with the people involved in your care or a home visit before you came home?		
MDT meeting ( ) Home Visit ( )		
<b>Core item:</b> Rate perception of discharge home		
Positive	Discharge well planned by MDT; issues discussed and identified beforehand; home visit (if applicable); family support/HC services in place.	+1
Neutral	Some discharge planning and discussion but may have short delays waiting for HC Services or minimal d/c planning or discussion required as mild stroke with few / no needs.	0
Negative	Discharge delayed or too soon; needs not identified or addressed beforehand; No home visit or inadequate assessment; family support/HC services inadequate or prolonged delays or not delivered.	-1
1c.) Do you need any aids or adaptations to help you manage at home? Who organised them for you? Did you have to wait for anything? (If yes: Note any gaps/delays)		
<b>If applicable:</b> Rate timely provision of aids and adaptations to home		
Positive	Everything in place before or on discharge, or very soon after (within 3 days).	+1
Neutral	Necessities in place, some gaps filled with 7 days.	0
Negative	Missing things that impact on daily living, waiting longer than 7 days.	-1
1d.) Have you seen your GP or has he/she been to see you since you came home? Did you request a visit or did you just expect him/her to come?		
GP visit without request ( )		
GP visit expected without request ( )		
GP appointment/visit requested ( )		
<b>Core item:</b> Rate continuing GP care for stroke		
Positive	Reports regular monitoring/follow-up in place if appropriate OR GP will see as required.	+1
Neutral	GP care adequate but on-demand service only. Intermittent monitoring or only when attending for other appointment.	0
Negative	Expectation of monitoring/follow-up of related factors but reports no monitoring OR GP difficult to see when required.	-1

**SECTION 1 (Continued)**

1e) What about appointments at the hospital for follow-up or outpatient therapy for your stroke? (If yes: Who organised it? Note gaps/delays)

**Core item:** Rate experience of follow-up

Positive	Aware of/or has already attended planned follow-up by Stroke specialist care team.	+1
Neutral	Aware follow-up with Stroke specialists not planned.	0
Negative	Aware follow-up required/or had expectation of follow-up but not arranged OR failed to attend follow-up.	-1

1f.) How have you been managing since you came home after your stroke? What has changed since you had your stroke? Are you receiving any Home Care? (If Yes: What sort of service do you get?)

**If applicable:** Rate consistency of statutory home care services

Positive	Reports good consistent service.	+1
Neutral	Reports service adequate but some gaps.	0
Negative	Reports visits often missed. Poor, inconsistent service.	-1

**SECTION 2: INFORMATIONAL CONTINUITY**

2a.) Tell me what sort of information you've had about stroke and what it means for you? Has someone talked to you about your condition or told you what's going on? Did you receive a Stroke Pack? (If yes: Who? Note agents of communication.)

**Core item:** Rate perception of information giving

Positive	Kept informed at all stages.	+1
Neutral	Informed but some gaps.	0
Negative	Important information missing or reports not given any / enough information.	-1

2b.) Had your GP/Home Carers received information from the hospital. Did s/he know about your stroke or that you had been in hospital?

**Core item:** Rate perception of information transfer

Positive	Reports professionals seem to have all relevant information available by time of first contact.	+1
Neutral	Reports professionals have information but with some gaps when seen. Not sure if GP knew about stroke.	0
Negative	Reports professionals lack relevant information or not available at time of contact with GP.	-1



**SECTION 3:****RELATIONAL CONTINUITY (Personal and Social)**

3a.) Tell me about your GP. How do you get on with him/her? Can you talk about things with him/her? What about the other staff at the Practice?		
<b>Core item:</b> Rate relationship with GP		
Positive	Reports GP and Practice staff approachable and interested. Good relationships. No barriers to discussion.	+1
Neutral	Reports adequate relationship with GP but may find it less easy to raise matters or discuss them.	0
Negative	Reports difficult relationship with GP and/or Practice. GP not easy to approach or appears disinterested. Unable to raise matters or discuss things.	-1
3b.) <u>ONLY</u> for patients with Home Care or ICT services: Tell me about the people who come. Do you see the same people regularly? How do you get on with them?		
<b>If applicable:</b> Rate relationship with statutory home care personnel		
Positive	Knows all the team. Good relationships with all members of HCT.	+1
Neutral	Some consistency of carers. Knows about half the regular team. Adequate relationships with most.	0
Negative	A lot of different carers. Difficult to get to know them OR relationships strained	-1
3c.) <u>ONLY</u> for patients with Home Care or ICT services: Do you have contact details for your ICT or HCT carers?		
<b>If applicable:</b> Rate responsiveness of statutory home care services		
Positive	Contact number/named person(s). Service friendly and approachable.	+1
Neutral	Contact numbers but no named person. Service patchy but adequate in the main.	0
Negative	No contact number. No named person. Service distant and inaccessible.	-1
3d.) Do you any family or friends nearby? Do you see them regularly? How long have you lived round here? Do you know many of your neighbours? How often do you see them?		
<b>Core item:</b> Rate extent of social support		
Positive	Describes wide network of family, friends or contacts. Frequent and regular contact.	+1
Neutral	Describes limited network of close family or friends. Regular contact but may distant or less frequent.	0
Negative	Describes isolated existence. No family or no contact, few friends. Infrequent contact with anyone.	-1

<p>3e.) Do you have any problems or needs not met by home care (if applicable)? Do you get any help with them? What would you do if things changed or if your usual help wasn't available or (use discretion when asking) if things had been worse? (Prompt by referring back to any changes identified in Managerial Continuity Section. Note back-up system and any agents of change.)</p>		
<p><b>Core item:</b> Rate function of social support</p>		
Positive	Wide network provides practical and/or emotional support as appropriate.	+1
Neutral	Limited or distant network provides some practical and emotional support but may have difficulties/gaps.	0
Negative	No network or relationships broken down. Little or no support (except from statutory services if applicable).	-1
<p>3f.) Are you (or any member of your family, or friends) involved or a member of any clubs or organisations (including church or religious)? Do you get any help or support from any of these?</p>		
<p><b>Core item:</b> Rate extent of social capital</p>		
Positive	Describes wider connectedness. Involved in local or special interest group/s or may be member of church.	+1
Neutral	Describes some connections or has indirect access to them OR has cut back on involvement in social groups/activities.	0
Negative	No connections outside immediate family or statutory service carers OR has lost wider connections.	-1
<p>3g.) Do you have family or friends, or contacts to people or organisations with experience of healthcare services? Have you ever asked them for or been given advice by them? Has anyone helped you in that way or done something on your behalf?</p>		
<p><b>Core item:</b> Rate value of social capital</p>		
Positive	Describes open access to or contact with people/organisations with relevant knowledge, aptitude or skills	+1
Neutral	Describes limited contact or indirect access to people/organisations with relevant knowledge, aptitude or skills	0
Negative	Describes no access to or contact with people/organisations with relevant knowledge, aptitude or skills	-1

<b>Visit:</b>	<b>Date:</b>	<b>ID:</b>	<b>Name:</b>
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Circle or tick the number that best describes how you feel about each of the statements.

**FEELINGS OF WELL-BEING: Adapted from the McGill Existential Well-Being Scale)**

Since my stroke I have felt that:

I have made no progress with my recovery	0	1	2	3	4	5	6	7	8	9	10	I have made complete progress with my recovery
I have no control over my life	0	1	2	3	4	5	6	7	8	9	10	I have complete control over my life
I do not enjoy life like I used to	0	1	2	3	4	5	6	7	8	9	10	I enjoy life to the full
I am very dependent on others	0	1	2	3	4	5	6	7	8	9	10	I am completely independent

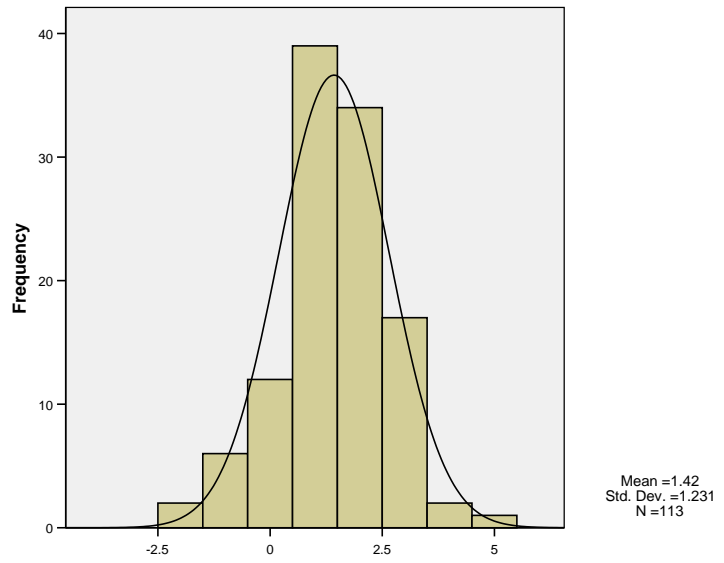
**PERCEPTIONS OF CARE**

Since my stroke I have felt that:

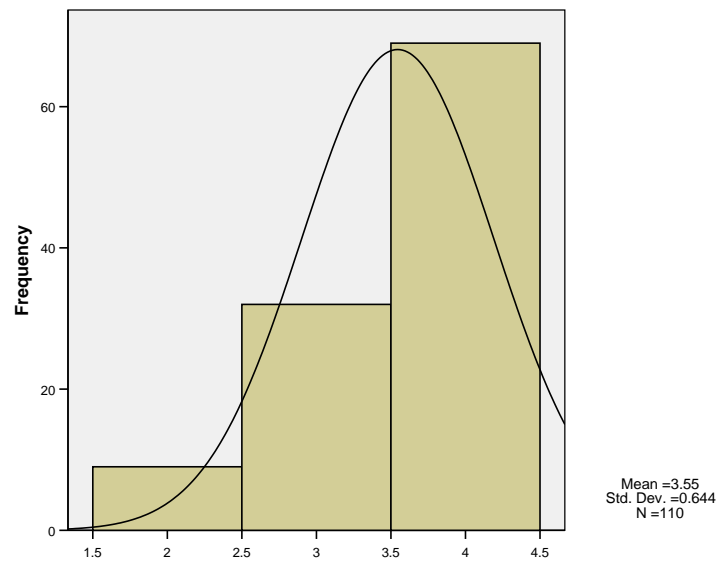
The standard of my care is poor	0	1	2	3	4	5	6	7	8	9	10	My care was excellent
I have no confidence in the people who look after me	0	1	2	3	4	5	6	7	8	9	10	I have total confidence in the people who look after me
No-one seems to know anything about me or my condition	0	1	2	3	4	5	6	7	8	9	10	People seem to have relevant information about me
The care I get is patchy and uncoordinated	0	1	2	3	4	5	6	7	8	9	10	My care is well organised and coordinated
I am not getting the services or help that I need	0	1	2	3	4	5	6	7	8	9	10	I get <i>a/l</i> the care and services that I need
I am not at all satisfied with my care	0	1	2	3	4	5	6	7	8	9	10	I am completely satisfied with my care

## APPENDIX J: Figures J1 to J7 SnL Cluster Histograms

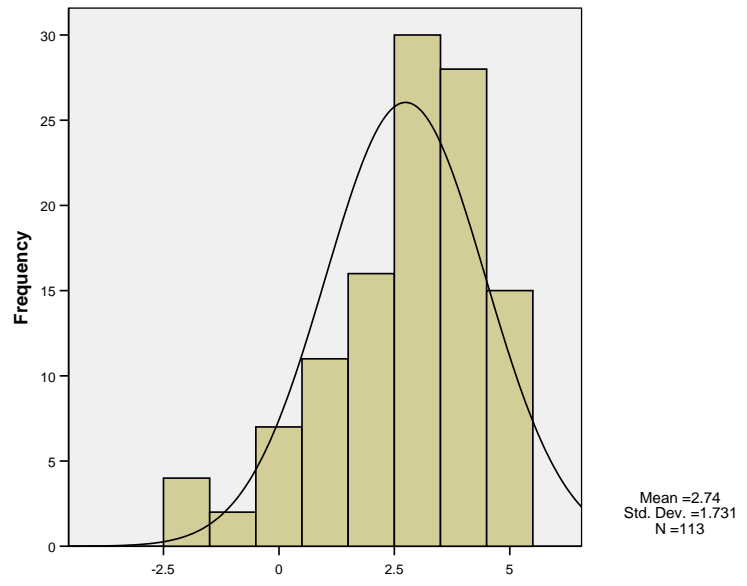
**Figure J1:  
Admission**



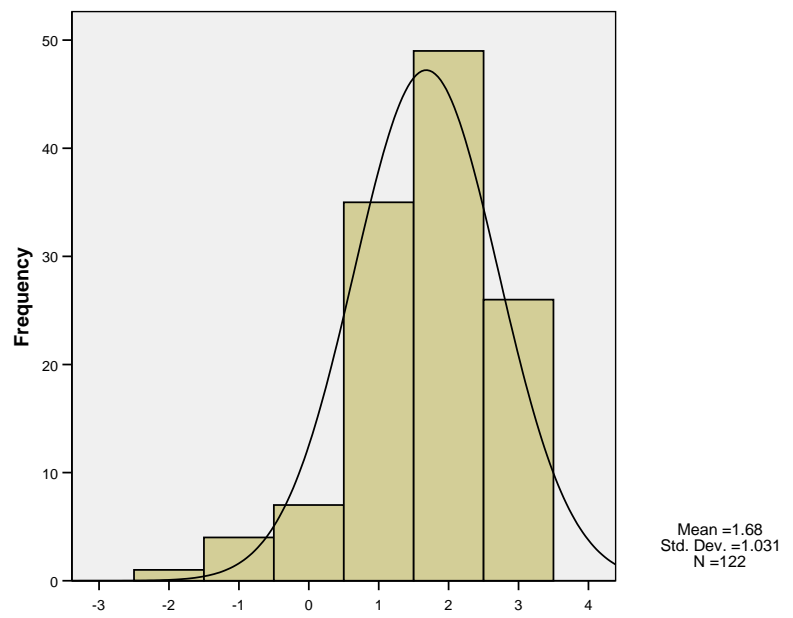
**Figure J2:  
Clinical Care**



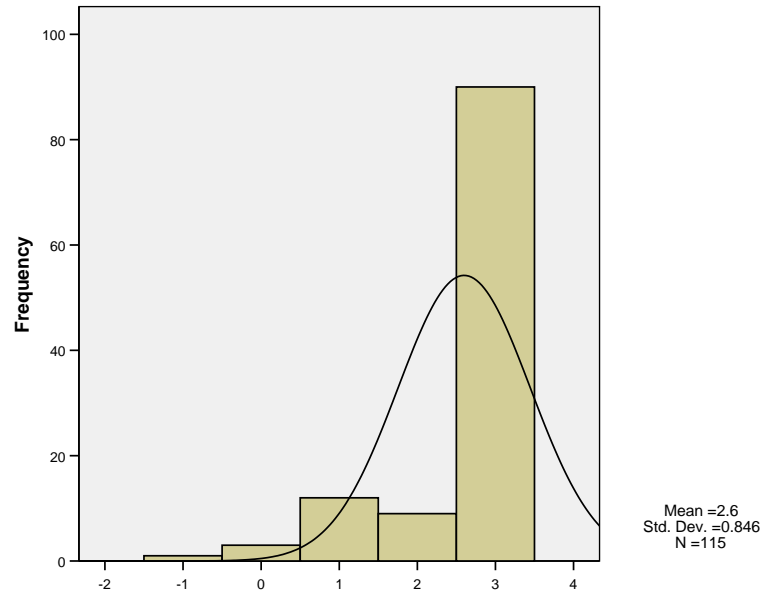
**Figure J3:  
MDT Care**



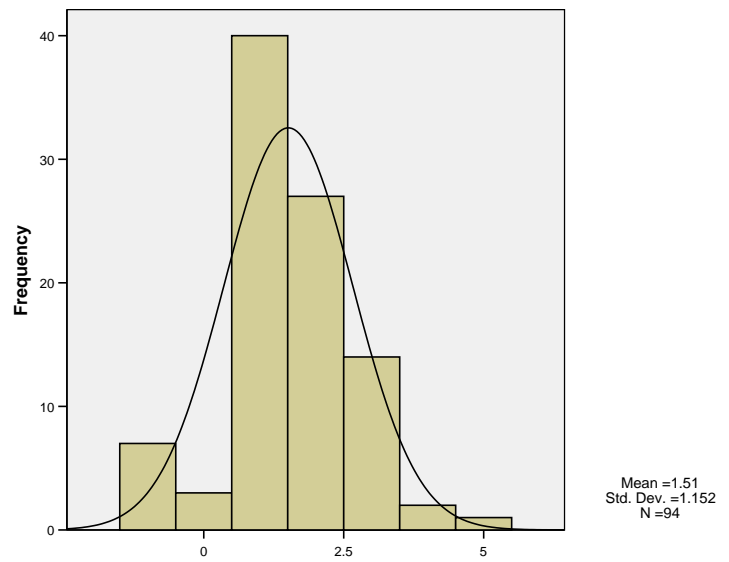
**Figure J4:  
Discharge**



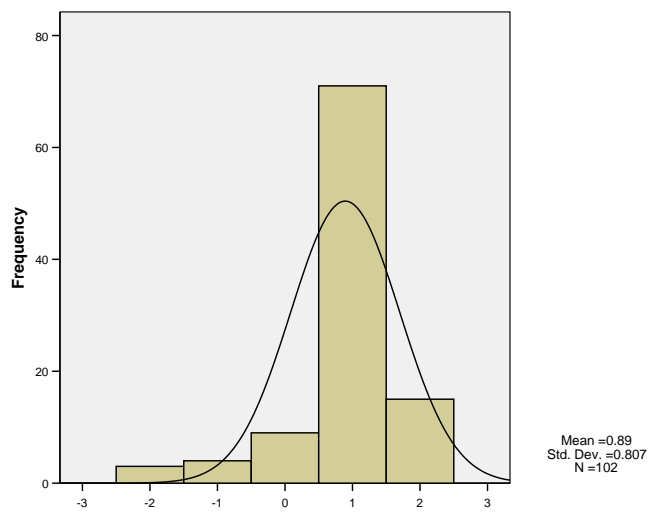
**Figure J5:  
GP Care**



**Figure J6:  
Community Care**

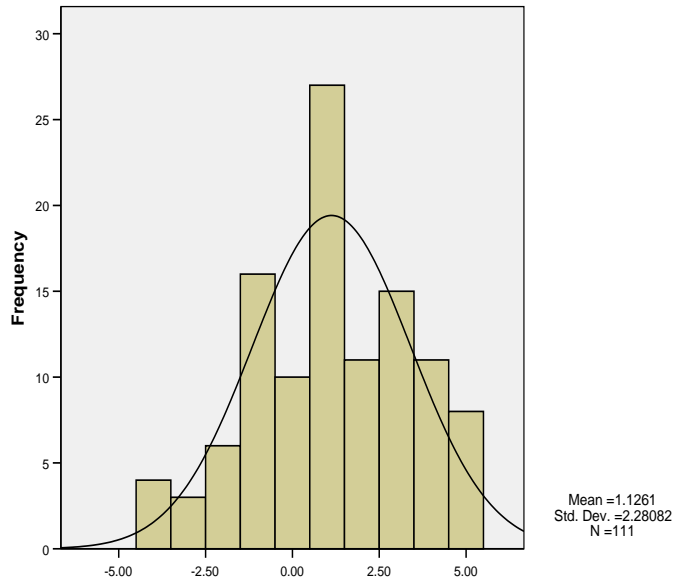


**Figure J7:  
Follow-up**

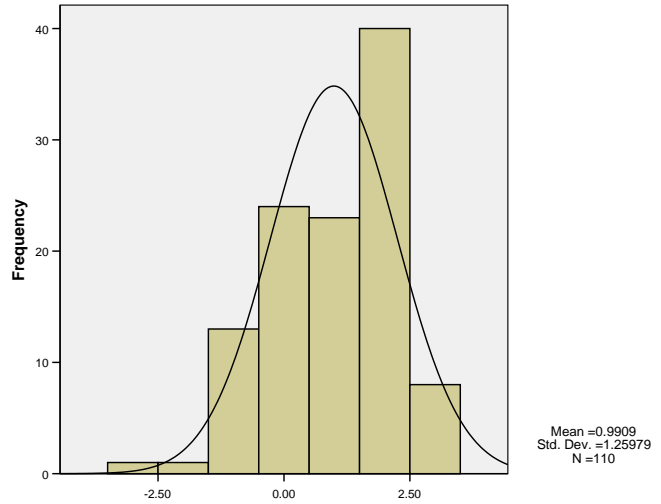


**APPENDIX K: Figures K1 to K5 PPCI Cluster Histograms**

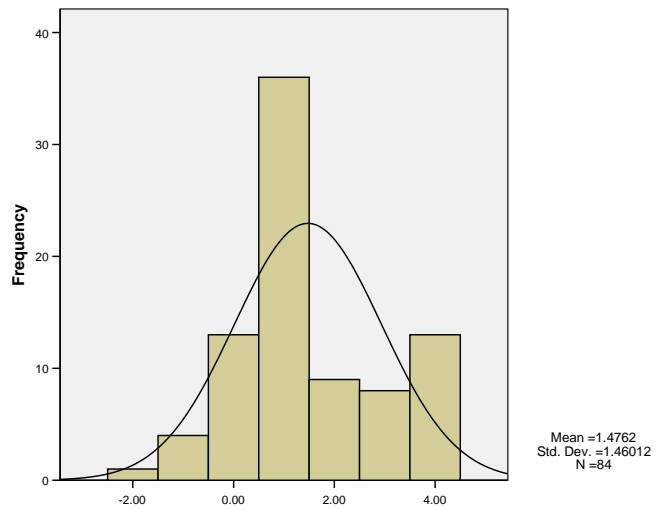
**Figure K1:  
Hospital Care**



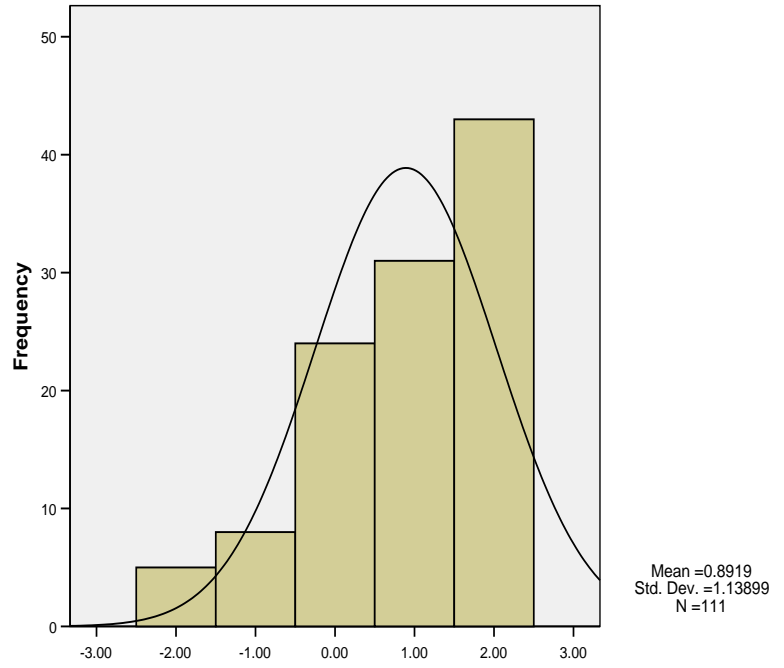
**Figure K2:  
GP Care**



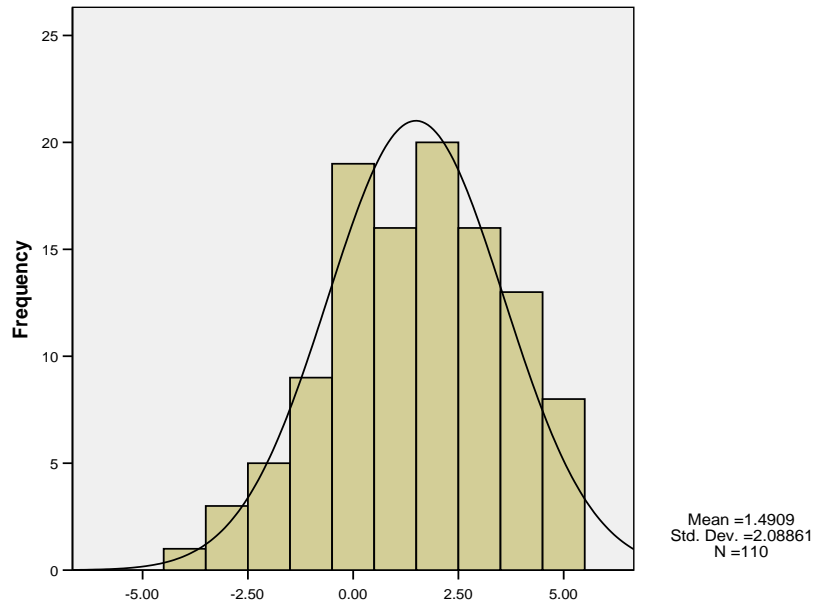
**Figure K3:  
Information**



**Figure K4:  
Community Care**



**Figure K5:  
Social Care**





## APPENDIX L: BIBLIOGRAPHY

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