SDO/13/2001(C)

CONTINUITY OF CARE IN STROKE AND ITS RELATION TO OUTCOMES

K. M. Hill
A. O. House
J. Hewison

FINAL REPORT

April 2008

Academic Unit of Psychiatry and Behavioural Science
Leeds Institute of Health Sciences
The University of Leeds
15 Hyde Terrace
Leeds LS2 9LT

ACKNOWLEDGEMENTS

The authors would like to express their sincere gratitude to the following colleagues whose combined knowledge and expertise made a significant contribution to this project:

Professor Justin Keen for the many interesting and lively discussions that helped to shape our thinking about how health care is organised, and for introducing us to a whole new world of networks.

Dr Robert West for his expert statistical advice and for revealing new insights into our data using advanced modelling techniques.

Helen Brooks for her knowledge of stroke care, and her practical assistance in interviewing patients and reviewing case notes. Her cheerful support was a great asset to the project.

Dr Shenaz Ahmed for her advice and support on the qualitative study, and the subsequent analysis.

Karen Smith of York University who helped to develop the search strategy for the literature review.

Dr Patricia Constantino who sourced and shared some of the reading.

We would like to thank them all for their invaluable assistance.

Finally, we would like to thank the patients and relatives who took part in the study, welcomed us to their homes, shared their stories with us and gave so freely of their time.

KMH, AOH, JH.

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List of Abbreviations

BI	Barthel Index
BP	Blood pressure
CHSRF	Canadian Health Services Research Foundation
CoC	Continuity of Care
CST	Community Stroke Team
FAI	Frenchay Activities Index
FIM	Functional Independence Measure
GHQ_28	The General Health Questionnaire (28 Item)
GP	General Practitioner
HRQoL	Health-Related Quality of Life
I_T Analysis	Item Total Correlation Analysis
ICT	Intermediate Care Team
JCMT	Joint Care Management Team
MDT	Multi-disciplinary Team
MLM	Multi-Level Modelling
MMSE	Mini Mental State Examination
NCCSDO	National Coordinating Centre Service Delivery and Organisation
NSF	National Service Framework
OT	Occupational Therapy or Therapist
PEG	Percutaneous Endoscopically-guided Gastrostomy
PPCI	Patient Perceived Continuity Interview
PSE	The Present State Examination
PT	Physiotherapy or Physiotherapist
QSOS	The qualitative phase of the Stroke Outcomes Study
RMI	Rivermead Mobility Index
RMSEA	Root Mean Square Error of Approximation
SALT	Speech and Language Therapy or Therapist
SAP	Single Assessment Process
SEM	Structural Equation Modelling
SF_36	The Medical Outcomes Study short-form instrument (36 Item)
SnL	Snakes and Ladders Index
SOS2	Stroke Outcomes Study 2: The impact of depressive symptoms on outcomes for stroke patients
SOS3	Stroke Outcomes Study 3: Continuity of care in stroke and its relation to outcomes
T1	Cohort Study Time point 1 (Baseline: 2 to 6 weeks post-stroke)
T2	Cohort Study Time point 2 (6 to 10 weeks post-stroke)
T3	Cohort Study Time point 3 (12 to 14 weeks post-stroke)
T4	Cohort Study Time point 4 (6 months post-stroke)
T5	Cohort Study Time point 5 (12 months post-stroke)
TIA	Transient Ischaemic Attack
WHO	World Health Organisation

EXECUTIVE SUMMARY

Introduction and Background

Stroke is a complicated, heterogeneous condition with acute onset but complex and enduring sequelae. 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 high-light the fact that stroke is a major cause of disability. It is also increasing in incidence as a consequence of the growing population of elderly people, which creates particular challenges for continuity of care as patients may present with multiple co-morbidities and social issues arising from isolation in old age and declining cognitive and physical function that can impact on stroke care. Furthermore, stroke is an acute event of sudden onset and is treated in the initial stages as a medical emergency, thereafter the focus and objectives of treatment are aimed at improving function and secondary prevention rather than the suppression of symptoms. Thus it is more often the case that multiple agencies are involved in stroke care than might be so in other conditions with the exception of mental health and some palliative care, therefore stroke is an important condition in which to consider continuity of care.

Objectives

The study had four main aims:

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 both a patient-centred measure and a service record-based measure, that reflected where possible the patient view of continuity of care.

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.

The Setting

This five year programme of NHS SDO work was integrated with a four-year longitudinal, observational cohort study (SOS2) funded by the Stroke Association, which sought to examine the effect of depressive symptoms on outcomes for patients in the year following an acute stroke. The SDO study (SOS3) recruited patient participants from two sources:

1) Longer term stroke survivors identified and recruited from the local stroke database

2) Chronic stroke patients sequentially recruited from the cohort of patients participating in the Stroke Association funded depression study (SOS2).

The Stroke Outcomes Study (SOS3) Programme

The programme comprised a series of inter-linked studies which followed from a review of existing research. (See also Figure 1: SOS3 Study Structure, p. 23).

Study 1: QSOS - An exploratory qualitative study to investigate how stroke patients understand and experience continuity in their care.

Study 2: A review of hospital and community clinical care notes using a count of signatures to provide a measure of continuity of care.

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

Study 4a: A study extracting information recorded in the patients' full complement of clinical case notes using a checklist to measure continuity.

Study 4b: A patient-centred study measuring experienced continuity using a semi-structured interview, the content of which was based on the findings from Study 2 and Study 3.

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

Analysis

Social and demographic characteristics were described for patient participants for each of the separate studies that formed the SOS3 programme. Interviews recorded in the qualitative studies with patients and health care professionals were transcribed and entered into an NVivo 7 database. They were analysed using framework analysis in a theoretical framework derived from existing research by Freeman et al and the Canadian Health Services Research Foundation (CHSRF). Quantitative analyses were conducted on responses to the Chao Questionnaire in Study 3, and to data derived from the Snakes and Ladders checklist (SnL) and the Patient Perceived Continuity Interview (PPCI) in Studies 4a and 4b, using univariate methods to assess the effects on functional and psychosocial outcome variables derived from the Stroke Association funded, longitudinal cohort study (SOS2). We applied multivariate techniques to examine the factor structure of our newly developed PPCI and SnL measures using structural equation modelling (SEM), and assessed the effects of the latent variables derived from the SEM model on outcomes in the SOS2 cohort by undertaking logistic and binary regression analyses.

Main Findings

During both the qualitative and quantitative research processes we found that the currently accepted models of continuity of care did not readily transfer to the type of care or the services received by stroke survivors. In attempting to measure continuity of care we found that 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. However, they could not distinguish the overall process of care, or make an appraisal of it other than to give us their perception of its outcome. From the results of the multi-factorial analysis we found that we could measure “achieved care” by including contributions from components of the physical, psychological and cognitive status of the patient in addition to our own indices, and that the chances of a less successful rehabilitation outcome 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 we also found examples of cases where patient choice or behaviour were the primary factors influencing the care that they received.

Moreover we identified patterns of care in our study that indicated that care networks exist in stroke services, which while not structurally explicit were evident from their activities and functionality. Our findings suggest that it is the *connectedness* of individuals within these networks rather than the longevity or predictability of individual relationships that delivered good care.

Conclusions

Our study of continuity in stroke care led us to conclude that continuity of care is a professional and organisational-centred concept, which focuses on the provision of statutory services, and which is recognised by health care staff but not recognized in the same way by patients. Current ideas of continuity tend 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 were the emphasis is on care planning not consultant led care. It is unclear what aspects of continuity can be generalised from one disorder to another. In relation to measurement from the patient's perspective, continuity is intimately linked to related concepts such as quality of care and patient satisfaction.

Recommendations

Research is needed:

- to determine the nature of the relationship between perceived care, mood and rehabilitation outcomes.
- to identify the characteristics of effective clinical care networks so that as they are implemented (for example in response to the UK National Stroke Strategy) they have most chance of being successful.
- to refine existing measures (such as PPCI) to develop simple-to use measures of perceived care, of which continuity and coordination would be a component, as a means of assessing the patient-centeredness of stroke services.

Service delivery should emphasise:

- the need for both planned care pathway, especially early after stroke, and planned care networks, especially in longer-term care.
- the needs to integrate physical and psychological aspects of stroke rehabilitation and longer term care, given the importance of mood and perceptions of care in influencing rehabilitation outcomes.

1 INTRODUCTION

1.1 Background

The quest for evidence on which to base the modernisation of health care services brought continuity of care to the fore as a research priority for the NHS Service Delivery and Organisation (SDO) R&D, when it was first established in 1999. A listening exercise with patients and health care professionals, followed by a scoping exercise and report [1], produced a working definition of continuity which set the scene for a series of commissioned projects that would seek to explore the concept of continuity in a range of health care settings, and evaluate its association with outcomes for patients. The original briefing document called for studies of continuity of care in chronic conditions. In response to this, and because of our existing expertise, we chose to study a single disorder, stroke, which begins as an acute event but frequently becomes a chronic condition. By selecting one, albeit complex, disorder we aimed to limit some of the heterogeneity in patient populations and service provision that would have been encountered if we had studied a mixture of chronic disorders, thereby reducing some of the variables to be taken into account in a complicated area of study.

Moreover, the nature of stroke means it is an important condition in which to consider continuity of 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 high-light 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, ranging 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 nevertheless 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 ranks only third as a cause of death behind cancer and heart disease, it is a major cause of disability.

From an economic standpoint, 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 [3], which is almost £1 billion more than Coronary Heart Disease. It is, therefore, not only the diverse and complex nature of stroke as a chronic disease of (mainly) older people that makes it an interesting and important condition in which to study continuity of care, but also the economic and financial challenges that providing effective and high quality stroke care presents to health service providers.

1.2 Stroke and Recovery

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."*[4]

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. Thus stroke disease creates particular challenges for continuity of care.

1.2.1 Acute Care

Fewer stroke patients are now treated in the community and most, with the possible exception of some very mild strokes and transient ischaemic attacks (TIA), and some elderly patients with more severe stroke who are resident in long-term care, will be admitted to hospital. Once admitted to an Acute Stroke Unit or a Stroke Specialist Ward they will 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. Thus every patient will 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. Continuity of care is therefore fairly well assured in the acute care phase by adherence to standardised care pathways, which act as a co-ordinating device for the health care professionals delivering care. There are, of course, deviations from the ideal of optimal hospital care for all patients with stroke, and the consequences of these for continuity of patient care will be discussed in ensuing sections of the report. For examples of a stroke care pathway see the NSF for Older People (p. 70). [4]

1.2.2 Rehabilitation

After the initial event has settled and the stroke patient’s condition is stabilised, evidence shows that early assessment of disability and intervention with targeted therapy aids functional recovery.[5] At this stage of care patients are already diverging in terms of the care they require, and the location in which it will be delivered, depending on the type and level of disability that they have experienced, and their pre-stroke health status and social circumstances. Some 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 now begins to have different meanings for patients and standardised pathways are difficult to define because of the varied trajectories of care. Furthermore, continuity may not just be characterised by the type of rehabilitation care required but also by the availability and provision of services at a given place or time-point. These factors present an interesting challenge for describing and measuring continuity of care in stroke.

1.3 Stroke Service Organisation and Recovery

Since the publication of the National Service Framework for Older People in 2001[4], The Department of Health has encouraged improvements in stroke care in order to meet one of the key milestones identified in the framework, which was that by April 2004 all general hospitals would have a specialised stroke service. The National Audit Office Report “Reducing Brain Damage: Faster Access to Better Stroke Care” showed that as late as 2005,[6] this milestone had only been met by around two-thirds of service providers. However, improvements to acute 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 entirely. Although the NSF Standard 5 also included milestones for stroke care in the community, none of these referred 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 is dealt with by the NSF for Older People under the more general heading of Standard 2: Person-Centred Care.

Consequently, while much has been done to modernise acute stroke care and to promote healthier lifestyles, raise public awareness and improve the monitoring of risk factors in general practice in a bid to prevent new and secondary strokes, there has been less emphasis on post-acute and post-discharge care and the services required to provide it. Care pathways that extend to cover longer term care are difficult to design when needs are unpredictable and non-linear in emergence and when care provision, as previously noted, 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, which formed an important part of the final phase of our study, will be discussed in more detail in Section 5 (pp.163-208).

1.3.1 What makes Stroke different?

In addition to the commissioned study of continuity in stroke care, the SDO Continuity of Care research programme included five other major empirical projects. These covered the following conditions or topic areas: Diabetes Mellitus

(Type II), Primary care, Cancer, Intermediate Care (in the context of learning difficulties and stroke),) and severe mental illness (principally schizophrenia). Stroke differs from the other conditions studied in the programme in a number of ways:

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

- Secondly, it is an acute event of sudden onset and is treated in the initial stages as a medical emergency;

- 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, it is more often the case that multiple agencies are involved in stroke care than might be the case in other conditions with the exception of mental health and some palliative care.

1.4 Aims and Objectives of the Study

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. In general practice, continuity of care has been cited as the *"cornerstone of care"* [7] or as an *"essential element"* [8] but how the concept of continuity translates into disease-specific settings or how patients perceive and understand it, is largely unknown. In formulating our approach to this problem we therefore considered three issues:

- What is already known about continuity of care?
- What methods of measuring it have been devised?
- How does stroke care differ from other conditions?

In designing our strategy for the study we had four main aims:

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 both a patient-centred measure and a service record-based measure; that reflected where possible to patient view of continuity of care.

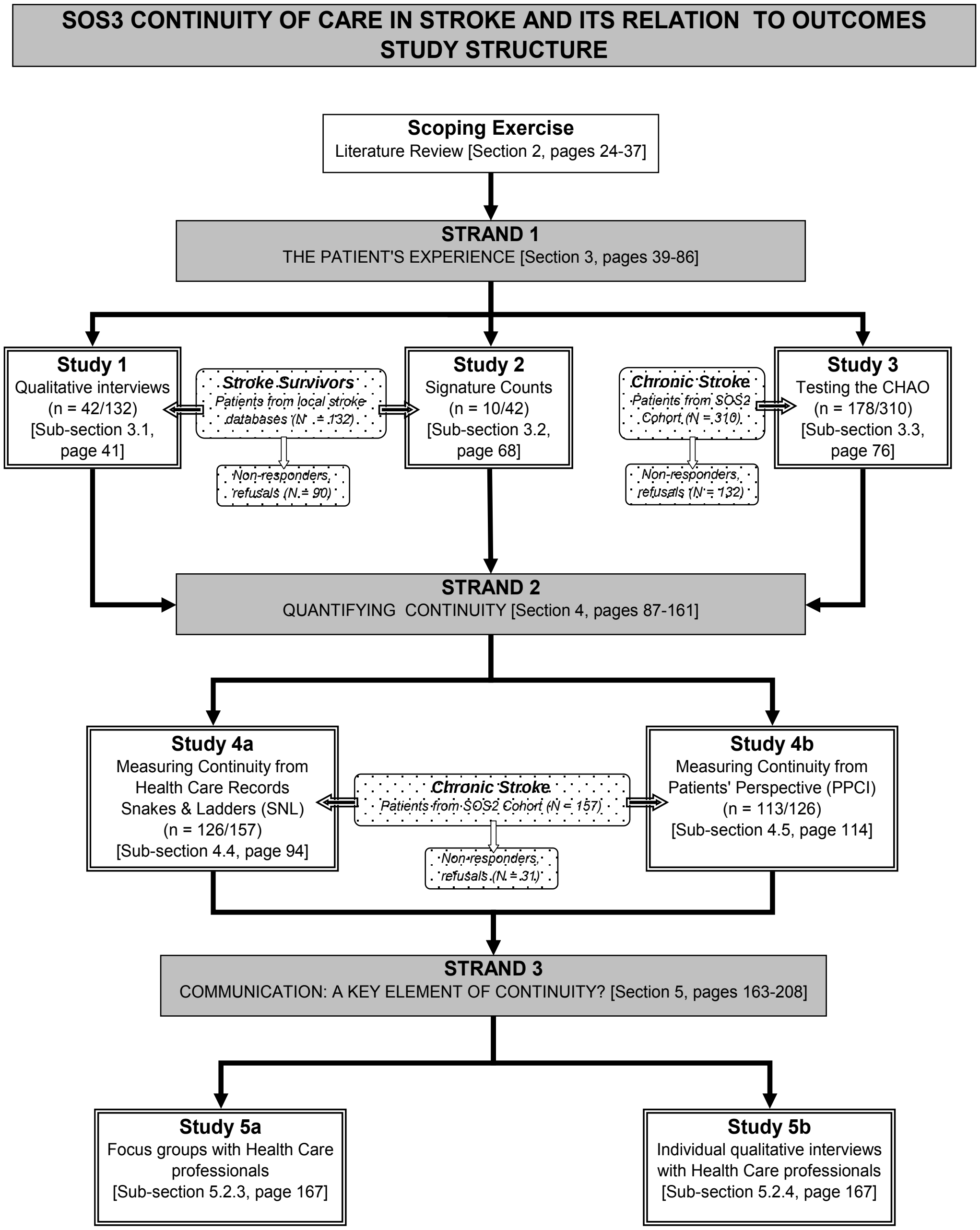
3) To apply quantitative assessments of continuity of care in a cohort of stroke patients in order to examine its impact on functional and psycho-social outcomes for survivors;

4) To seek professional views on the aspects of service organisation that are relevant in determining continuity of care.

1.5 Structure of the Report

In Section 2 (pp. 24-37) we discuss the current concepts of continuity of care and how they relate to stroke care, we review existing research into the measurement of continuity and consider how continuity has been operationalised in previous studies. In Section 3 (pp. 39-86) we describe three studies: the first of these (Study 1: QSOS) reported our empirical work with stroke patients, which sought to identify the patient's perspective of continuity of care and informed the development of two new methods of measuring continuity. Study 3 describes the testing, in a stroke setting, of one of the existing measures of patient perceived continuity identified from the literature review, The Chao Questionnaire [9]. We move on in Section 4 (pp. 87-161) to describe the testing of our newly developed measures of continuity of care in our stroke cohort, and their application in evaluating its effect on outcomes. In Section 5 (pp. 163-208) we describe how our work developed into a study of communication between healthcare professionals and finally, in Section 6 (pp. 210-228) we discuss our findings and how our thinking about continuity of care has evolved. Figure 1: SOS3 Study Structure shows the main strands of our work and an outline of the studies and processes these included.

Figure 1: SOS3 Study Structure



2 CONCEPTS OF CONTINUITY

2.1 A Synoptic Review of the Literature

2.1.1 Aims and objectives

The NCCSDO scoping report provided a comprehensive summary of the existing literature surrounding continuity of care in a variety of care settings[1]. The aim of our review was to extend the scoping report review with particularly reference to stroke care and to supplement it, where required, with recent papers. Our objectives were therefore threefold:

- To review the background to the concept of continuity in healthcare and explore how it has been defined and conceptualised in health care settings;
- To describe the approaches that had been taken to measuring continuity of care;
- To consider the relevance of these to our study in stroke

2.1.2 Methods

The initial search strategy was designed for the MEDLINE database. First level search criteria contained terms for:

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

The second level included terms that related to different descriptions of continuity and experience of continuity in the care process. Finally, the third level of search terms related specifically to stroke and stroke rehabilitation. Details of the full search history are shown in Appendix B. The initial MEDLINE search was adapted for use in the following additional databases:

CINAHL
PsychINFO
British Nursing Index (BNI)
ASSIA
The Social Science Citation Index (MIMAS)
EMBASE
The Cochrane Database (CDSR)
TRIP
The Health Management Information Consortium (HMIC)
DARE
HTA
ECONLIT

The search of bibliographic databases for published papers in peer-reviewed journals was supplemented in the following ways:

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.

2.1.3 Data Extraction

The initial search produced a total of 1047 papers. The abstract of each paper was read by both KH and PC and the full text of the article was obtained if it was agreed that any of the following criteria were met:

- Contained a definition of continuity of care
- Described a method of measuring continuity of care using a new or existing instrument
- Discussed social support or social capital in relation to stroke care

Screening for inclusion criteria reduced the number of full-text articles to be examined to 191, of which 98 were finally included in the review. The starting point for understanding continuity was the Freeman Report, which provided a good framework for comparing new and existing evidence.[1] However, as the focus of this review was on the patient's perspective of continuity, it soon became clear that the existing debate surrounding continuity of care was firmly grounded in the provider domain. Developing understanding thus meant broadening the scope to the search, an exercise which was facilitated by the collaborative nature of the work and the extension of the search into the literature on social networks and social capital. The original search was completed at the beginning of the study and formed the starting point for the work.

2.1.4 Data Synthesis

The method of data synthesis used for this report was essentially qualitative, papers were read and theories, concepts and definitions identified and categorised. Measures of continuity were considered in the same way. Our search strategy found many of the same papers identified in the NCCSDO scoping report[1] but, consistent with the aims of our review, we were specifically seeking evidence relevant to stroke. We also sought to interpret the results in the context of the service user rather than the service provider, a process which required some disaggregation of the current findings in an effort to reconstruct the evidence and ideas from a different perspective.

2.1.5 Concepts of Continuity in Health Care

Continuity of care has been described as a complex, multi-dimensional concept but definitions of continuity of care are vague and a multiplicity of terms have been used to describe it (although wider reading suggests that many refer to the same or essentially similar aspects of continuity). 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 but it was not until the sixties that continuity of care really emerged as a separate and identifiable concept. Three American reports were published in 1966: The Folsom Report; Millis Report and Willard Report. Amongst other things, The Folsom Report recommended that every American should have their own personal physician to provide continuity in their care. The Millis Report (American Medical Association (AMA)) emphasised clinical competence, continuity and prevention. The Willard Report, also sponsored by the AMA, recommended that family medicine should become a specialty in its own right. The American Board of Family Medicine was established three years later, in 1969.

Continuity of care was therefore founded in a primary care setting, and in a health system where eligibility for and access to care are not guaranteed by a National Health Service. As concepts and definitions of continuity of care appeared and the relevance of continuity in different care settings was considered, two distinct conceptual categories emerged:

- a "*continuous, caring relationship*" principally in primary care settings
- a "*seamless service*" more relevant to secondary and tertiary care

Shortell produced one of the first definitions of continuity, 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"* [10]

However, while the first part of this definition describes continuity in the context of a "seamless service", the second part brings in another dimension of care, appropriateness, which is more consistent with the quality of the care delivered.

In contrast to Shortell's definition, Banahan's concept of continuity as an attitudinal contract was firmly founded in the relational model of continuity which relied 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."* [11]

As the divide in thinking emerged, Barbara Starfield recognised the confusion that was growing in the effort to conceptualise and define continuity in health care.[12] Following on from her review in 1980, multi-dimensional models of continuity were developed which attempted to integrate the two strands of continuity. An early paper by Hennen[13] described continuity as having four dimensions: chronological, geographical, interdisciplinary, and interpersonal. These were expanded to seven dimensions by Leona Bachrach in 1981 but her definition of continuity was essentially very similar to that of Shortell:

> *"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"* [14].

The eighties and nineties brought a plethora of definitions amongst which there was considerable overlap of concepts but no real progress towards developing consensus in the understanding of continuity in health care until, at the end of the 20th century, the NCCSDO scoping exercise produced the Freeman model of continuity which was proposed from the review of published work, and presented in the final report. See Figure 2a.

Figure 2a: The Freeman Model of Continuity of Care[1]

'Scoping Definition' of elements of continuity of care

"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 *(experienced continuity)*.

To achieve this central element the service needs:

2 excellent information transfer following the patient *(continuity of information)*
3 effective communication between professionals and services *(cross-boundary and team continuity)*
4 to be flexible and adjust to the needs of the individual over time *(flexible continuity)*
5 care from as few professionals as possible consistent with other needs *(longitudinal continuity)*
6 to provide one or more named individual professionals with whom the patient can establish and maintain a therapeutic relationship *(relational or personal continuity)*."

The Freeman review was quickly followed by the Canadian Health Services Research Foundation (CHSRF) Workshop[2], which provided a forum for discussion and synthesis of ideas, including those that had emerged from the SDO scoping exercise. In this way the CHSRF aimed to contribute to the debate and reduce the confusion that was still apparent in the conceptual framework of continuity in healthcare. The outputs from the workshop proposed two core elements for understanding continuity: That it is ***received and experienced by an individual***, and that ***care is provided over time***. Three types of continuity were described:

Figure 2b: The CHSRF Model of Continuity of Care[2]

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 since been published, some focussing on particular aspects of continuity of care. Krogstad et al based their 2002 definition on the informational dimension of continuity:

> *"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."*

The theme of interpersonal continuity as a core element was adopted by Saulz, who contended the importance of relational versus informational continuity in his 2003 review.[15] He offered a hierarchical definition based on three levels of continuity of care: Informational; longitudinal and interpersonal, which were, essentially, the same as the three types of continuity identified by the CHSRF.

An unpublished review by colleagues at The Nuffield Institute for Health at Leeds University studied continuity of care in relation to stroke care.[16] They identified continuity issues specific to stroke care and sought to identify "hinge points" or transitions in the care process, an approach advocated by Shorr and Nutting (1977) who defined continuity as *"rates of transition between major clinical elements."*[17] They also reviewed working practices and service models designed to expedite stroke care as well as proposing ideas for future service development.

Divergent from the Freeman and Haggerty models of continuity is the novel approach of Molla Donaldson's doctoral thesis[18]. 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".*

Health care agency in this context is described as the interaction between patient and service providers (the agents), and the gathering (and transfer of) information that can then be used for the benefit of the patient (goal alignment). Her work is less often cited by other reviewers in the field perhaps because it uses a different conceptual framework within which to understand continuity or because it is based specifically on a North American health care delivery system which is different from the UK and some European models.

In summary therefore there is some overlap in the elements of continuity referred to in the literature and featuring in various conceptual frameworks, but there is still no universal consensus about what continuity of care actually is, nor what it means to the users of health care services. Moreover there are a number of problems with continuity of care as currently conceptualised, before we can apply it directly to stroke care, particularly in respect of how continuity can be generalised from one disorder to another, and how it may vary by disorder or stage of care.

2.1.6 Methods of Measuring Continuity of Care

In parallel with the development of concepts and definitions of continuity of care there began the search for ways of evaluating it. Initial emphasis was placed on developing methods for the quantitative measurement of continuity but this approach to measurement proved difficult without a conceptual consensus. Measures of continuity using questionnaires or other survey techniques, or collecting data from patient records have been in existence since the mid-seventies.

These were classified in the CHSRF report into four categories:

a. Chronological, focussing on the number, frequency, concentration and sequence of visits by the patient to the healthcare provider[19 20];
b. Measures of communication and information transfer[21];
c. Measures of patient-provider relationships[9].
d. Measures of management-plan continuity

The limitation of many of these methods of measurement is that they focus on a narrow spectrum of available information and, because that may be specific to the service in which the measure has been developed, they are not easily generalised. For example, Bice and Boxerman's continuity index is an adaptation of Rae and Taylor's fragmentation index, and was designed to operationalise Shortell's definition of continuity of care (see p. 28). The formula uses the number of visits to usual, referred or unreferred care providers to derive a quantitative score.[20]

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

Where:

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

Other measures use the number of care providers as a basis for measurement or documentation relating to care such as discharge or referral letters.[10 21] Only one measure was identified at this stage that had been designed to measure the patient's perspective of continuity of care: the Chao Perceived Continuity scale.[9] This survey of patients' views of care was developed to test empirically the concept of continuity as an attitudinal contract between patient and care provider, originally hypothesised by Banahan.[11]

One of our primary objectives for the literature review was to identify an existing measure or measures that would be suitable for application in our cohort study of outcomes for patients after stroke. We were therefore inclined to reject the use of existing quantitative assessments of continuity because the available measures used service provider indicators which were not easily applicable to stroke care: for example continuity of care providers and the number and sequential chronology of clinical consultations. In complex conditions like stroke, care may be provided at different stages of care by providers with different expertise. The concept of a usual provider of care is not appropriate, nor can the number of visits to a care provider be easily applied to inpatient care.

Since our project began in 2002, new instruments have begun to emerge that are disease or condition specific rather than designed for use in a particular field of health care. These include an instrument for mental health settings,[22] for diabetes[23] and for chronic heart disease [24], all of which seek to assess continuity from the patients' perspective. They are designed as self-report questionnaires but, as identified in the published reviews, there is the recurrent problem of overlap with perceptions of quality and satisfaction with care, particularly in the chronic physical disease questionnaires. Only the mental health scale has been subjected to rigorous checking of its construct validity, and refined accordingly, in an attempt to develop a new measure of patient perceived continuity [25].

2.1.7 Continuity of Care and Outcomes

If continuity of care is a real concept in health care it is important to understand, and measure, its effect on patient outcomes. A number of reviews have examined the use of early measures of continuity in this context. Saultz discussed methods of measuring continuity in a conceptual review [15], and went on to produce two subsequent papers that examined the links between continuity and patient outcomes. In 2004 (with Albedaiwi) he explored the relation between interpersonal continuity and satisfaction with care and found a positive association between satisfaction and continuity as measured in the reported studies.[26] However, the absence of a standardised measure of continuity and the diverse methods used to assess satisfaction with care made direct comparisons difficult and this limited their findings.

In 2005 (with Lochner), Saultz went on to review the effect of continuity on clinical outcomes.[27] Continuity was measured using various methods in the studies reviewed, and again a positive association between continuity and better clinical outcomes was found in 63% of the outcome assessments. They also found better resource usage to be associated with continuity of care. Once again the findings were limited by the wide range of methods used to assess continuity and an emphasis on service-based, rather than patient-centred, outcomes. The relation between outcomes and continuity in mental health services and in primary care have also been considered in other systematic reviews by Adair et al (2003) and Cabana (2004) respectively[7 28], with similar findings.

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 relevant to health care seem to suggest continuity is a description of a process:

> ***noun*** *(pl.* ***continuities****) 1 the unbroken and consistent existence or operation of something*[29]
>
> ***noun*** *(pl –ties) 1 logical sequence, cohesion, or connection. 2 a continuous or connected whole.*[30]

Secondly, there is the perspective: the predominantly professionally orientated view makes 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 are taken into account there seems to us to be confusion with overlapping concepts of satisfaction with care and subjective ratings of quality of care.

2.2 Formulating an operational definition of Continuity

The preceding review of the published work has been up-dated throughout the course of our study. As a result it contains references to later works, which, although they have informed discussion of the findings reported in later sections of this report, were not available at the outset of our study in 2002. Our initial task therefore was to operationalise our study protocol in the light of existing knowledge in order to measure continuity of care for stroke patients and to evaluate its effect on outcomes in the year after stroke.

2.2.1 Understanding the Patient's Perspective

The concepts and theories of continuity prevailing at the beginning of the 21st Century presented a predominantly professional perspective of continuity of care, and very little was known about how patients understood or experienced it. Our review of continuity of care found many professional definitions of continuity that offered a linear view of continuity grounded in a medical perception of care; a view which did not easily translate to the diverse experiences that characterise longer term care for people with stroke. Our brief from the SDO was not to pursue the concept of continuity further but to use the findings of the scoping exercise to explore the measurement of continuity from the patient's perspective. Thus the first strand of our study was an exploration of continuity with both stroke patients, and lay and professional people involved in their care. This was an empirical study the aims of which were twofold:

1) To establish whether the concept of continuity could be framed for stroke care in the way that existing reviews implied;

2) To derive a patient-centred definition of continuity that could be used as a basis for a measurement, and which as far as possible reflected the stroke patient's perspective.

2.2.2 Measuring Continuity

The second finding from our own scoping review was that the measurement of continuity had been largely operationalised in a pragmatic way, using simple models of care driven by the available data. For example, counts of episodes of care such as attendances in clinics or the number of contacts with specified carers often stood as proxy measures for continuity. There were no disease-specific measures for stroke care and none of the available generic measures were applicable. Measures of relational continuity were rare and only one was identified that incorporated the patient's perspective of continuity: The Chao Questionnaire. For these reasons we undertook three studies in the first strand of our work, aimed at characterising the patient's perspective of continuity of stroke care.

As a starting point, we considered continuity principally as an attribute of the care process and designed our programme of work to investigate the structures that are set up to deliver continuity of care processes from the patients' and the providers' perspectives. In formulating our strategy for measuring continuity of care, the definition to which we might most closely align our evaluation 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"* [10]

Although we regard "appropriateness" of care to be a separate and distinct concept in this definition.

3 STRAND 1: THE PATIENT'S EXPERIENCE

We did not find a definition or theory of continuity in 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), we therefore decided to consider continuity as an attribute of the care process. Our wider reading suggests that processes have certain characteristics. Donabedian's model of structure, process and outcomes describes how quality health care can be assured and measured. Using that model as a framework we decided to investigate the structures that are set up to deliver continuing care processes, and to explore the way they are perceived by patients.

Very little is known about how patients understand and experience continuity in the processes of stroke care, or in a wider context, how health service users understand and experience continuity of process in other healthcare settings. Moreover, relatively few qualitative studies have described patients' experience of physical, psychological and social changes after stroke, as identified by one review of the work in this area by Hafsteinsdottir and Grypdonck in their paper published in 1997.[31]

Stroke rehabilitation and recovery are complex processes and evidence suggests that patients' views of the rehabilitation process and its various stages differ from those of professionals involved in stroke care, particularly in their expectations of functional recovery [32-34]. In view of this we decided to examine continuity not only from the patient's account but also from records of their care. Notwithstanding our interpretation of the literature, we also planned to assess an existing instrument to determine whether it could be used as a measure of continuity of care processes in our parallel study, The Stroke Outcomes Study 2 (SOS2). For this purpose we chose the Chao questionnaire because it was the only standard measure we found, that attempted to measure continuity from a patient perspective. We considered that the emphasis on experience in primary care was relevant in chronic stroke management. This longitudinal cohort study, funded by the Stroke Association, aimed to examine the impact of depressive symptoms on outcomes for patient in the year after stroke. Our aims in this strand of the study were therefore threefold:

- Study 1: to explore the concept of continuity in the process of care with stroke patients;
- Study 2: to examine continuity of the process of care by reviewing the casenotes of our qualitative study participants;
- Study 3: to evaluate an existing measure of patient perceived continuity (The Chao Questionnaire) with patients drawn from our SOS2 cohort.

3.1 Study 1: QSOS A qualitative exploration of the views and experiences of stroke survivors

3.1.1 Background

Many of the current methods of measuring continuity of care have been derived from professional theories of continuity and mapped onto definitions without reference to the patient. This phase of our study aimed to use a patient-centred approach to explore, in a 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. We chose to use individual interviews as our primary method of data collection because it allowed patients to talk openly about care if they wished and because it enabled the inclusion of severely disabled and housebound patients who could be visited at home. We also used focus groups to collect some supplementary data for confirmation and verification of our findings.

3.1.2 Method

Interviewees were drawn from a random sample of 100 patients, selected from the Leeds Stroke Database, who had experienced a stroke between 6 and 12 months earlier. Patients were contacted by the Database manager to obtain consent for their names to be given to researchers. Those that agreed [N = 28] were contacted 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 initial interviews [n = 5] were used to pilot the topic guide and develop the mode of questioning. 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 a total of 114 potential participants we obtained a final total of 24 patient interviews for analysis.

It was not unusual for married patients to request that their spouse remain, and contribute, to the interview as many patients recognised that they had poor recall of initial events. This was also true of patients who lived alone who asked for close relatives or friends to be present during the interview. In both circumstances carers would often be asked to supplement or verify accounts.

> *"…..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: one 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, and one interview was conducted with the spouse of a younger stroke patient at the request of the patient.

In addition to the individual interviews we also conducted four focus groups 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 took place at the regular meetings of the support group in breakaway sessions. The fourth focus group comprised patients drawn from our longitudinal cohort study of 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.

Every participant was given a written information sheet, and the nature and purpose of the study was also explained to them in detail before written consent was obtained. The study received full approval from the appropriate Local Research Ethics Committees.

3.1.3 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 and 2 lived permanently with adult children. Five patients lived alone in their own homes, one lived in sheltered accommodation, one in a nursing home.

It is important to note that our sample only included patients who had a hospital admission related to their stroke event and did not draw patients from the 500 to 600 patients per year who are treated in this area by generic services in the community. We did not consider this to be a serious omission firstly because a hospital admission was a criterion for recruitment to our cohort study and secondly because we surmised that continuity in interactions with community services would be adequately represented, post-discharge, in the sample we had selected.

Our 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 with total aphasia for whom we conducted a proxy interview with the spouse). Major cognitively impaired patients were not able to participate in the interviews and, as no proxy interviewees were forthcoming, these patients were not represented at this stage.

3.1.4 Study Design

At this stage of the study the interviews were intended to be open and flexible but with a structured approach to ensure that the purpose of the enquiry was fulfilled. A topic list (See Appendix C) was derived from the following sources:

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

The topics were organised around dimensions of continuity identified in the literature with questions and prompts that 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 and moved on to explore relationships with health care staff and informal carers, and views about communication, information transfer and co-ordination of care. All the individual interviews were recorded and later transcribed for analysis using QSR NVivo 7. Recordings were made of the focus group discussions but the background interference at the venues used made transcription impracticable. As contemporaneous notes only were available these data did not form part of the formal analysis.

The theoretical framework used was a Straussian modified Grounded Theory approach, which assumes some prior knowledge of the phenomenon being studied but can be used when existing theories lack clarity (as seems to be the case in continuity of care).[35] The analytical method was framework analysis as described by Ritchie and Spencer[36].

3.1.5 Framework Analysis

The individual interviews and focus groups for QSOS study were all conducted and analysed by one researcher (KH), thus the process of immersion in, and familiarisation with, the data developed naturally as the study progressed. All the material was also reviewed during analysis. The objectives of the study were contextual and designed 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 analysis was derived from the dimensions and elements of continuity identified from the NCCSDO and CHSRF reports. (See Figure 3a, p. 46). The transcripts were indexed in QSR NVivo 7 software using the thematic framework below to define the tree nodes[†]. These were supplemented with additional nodes which represented emergent themes and categories as they arose during the process of analysis.

[†] *Node is the term used to describe the headings under which information is collated in the NVivo software package.*

Figure 3a: QSOS Interviews: Thematic Index

1. Patterns of care

- *1.1 Experience of a co-ordinated and smooth progression of care*
- *1.2 Experience of flexibility of care and adjustment to the needs of the individual*
- *1.3 Availability and accessibility of services*
- *1.4 Changes in care over time*

2. Patterns of communication

- *2.1 Experience of information provision*
- *2.2 Knowledge of information transfer*

3. Patterns of relationships

- *3.1 Understanding of the roles of health care professionals*
- *3.2 Nature of relationships*
- 3.3 Changing relationships over time

3.1.6 Results

We conducted several pilot interviews at the outset in order to find the best phrasing for questions and prompts about continuity of care processes, and a glossary of related terms were 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.

3.1.6.1 Narratives of Care

What we did find was that patients could give a very good account of their care. They could also tell us 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 be accepted however that due to the nature of stroke and, in some cases, to age related cognitive factors, several patients had difficulty recounting details of their hospital admissions. This provided more insight into the unique nature of stroke care rather than detracting from the quality or value of the data we collected.

The qualitative interviews therefore provided useful information about the differences between lay and professional views of continuity, and the challenges that these present in the measurement of continuity in care processes. Overall we found 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 special knowledge of the stages of care, and a personally assumed, professional concept of optimal care and an ideal pathway for stroke sufferers whereas the patient perspective was based on personal experiences and attitudes and expectations of care.

We used the Freeman model of Continuity (See Figure 2a, p. 30) to explore the responses that patients gave during the interviews and to introduce themes like flexibility and adaptability of services but for clarity our findings are reported under the headings of the three types of continuity proposed by the CHSRF (See Figure 2b, p. 30).

3.1.6.2 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 that may involve a combination of several specialist and non-specialist care providers. Ideally 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 this view of health care was not readily elicited from the lay respondents in this study and very few in our sample could talk objectively about this aspect of care. 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

Respondents interpreted this line of questioning in many different ways. In contrast to the view of the consultant as the principal agent of care was the response of a younger male patient who felt he had taken primary responsibility for his managing 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 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? (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 for care to be described by patients as a series of separate and unrelated events. This was particularly marked in patients with multiple morbidities who would talk 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, 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 this view of care:

> *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"* and so on 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.

> *"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 nor did they 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 obvious that patients did not normally make these links in 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 ongoing care but this was not explicitly expressed and often hard to elicit.

3.1.6.3 Continuity in Relationships

It was very apparent from talking to patients and from later reviews of the data that although inter-personal relationships with health care staff were important to them they were, nevertheless, very poor at identifying the individuals involved in their care. Moreover they did not easily recognise the different roles of hospital or community staff. 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 but a review of maternity care services also found a mismatch between pregnant women's accounts of the midwives and other practitioners involved in their care compared with clinical records.[37]

The general hustle and bustle of hospital was remarked on by many patients as a barrier to developing relationships with staff, and was a problem not only for the elderly patients as this 65yr old female patient explains 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 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

We found a number of examples of positive bonds with staff both in hospital and after discharge that, in the patients view, had 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

There were also negative examples too, a few that involved of clashes of personality and 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 a number of examples of supportive relationships with fellow patients in the ward but these were not often maintained after discharge. Once home it was families and friends who were most prominent 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 staff in hospital and were regarded as good sources of information, possibly because they were reinforcing information the patient had been given in hospital but had been less able to understand or assimilate. 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 God send 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 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. We found no examples, even when prompted, 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 they undoubtedly valued the therapeutic relationships they developed with health care staff in all care settings, no expectations were expressed of any form of continuity in relationships. On the whole patients seemed to have no expectation of the "Dr Finlay" model of care that relational continuity seems to espouse. Many patients 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 regarded as helping to maintain dignity. One elderly widow said that having the same people come from the Home Care Team who had looked after her husband following his stroke was good because she didn't have to "*get used to different people*". Just a few older patients did make indirect comparisons to care in the past as being more likely to have a relational component as was the case of the carer who felt her husband's care had been disjointed and 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 (See 3.1.6.2). In general the same nebulous view of relational continuity was held by patients as that we had found 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 carers. They too were regarded as separate, providing care for different things, at different times and it is clear, as we discuss later, that these findings have implications for assessing continuity of care from a stroke patient's perspective.

3.1.6.4 Continuity in information

Information was a 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. Patients also frequently referred to discussions with GPs after discharge, in which they had explained *"all about strokes*" or described their GP as "*a good communicator*". Nonetheless, when we tried to explore perception of continuity in respect of information transfer we found the same pattern of responses that we had identified in other aspects of care. 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 did not really think about. Responses to this line of questioning were the most consistent of any of the themes we had discussed with patients and the following 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 happened? / / 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

We found numerous examples of both positive and negatives views of the information that had been given to patients some of which arose from general discussion in the interview. There were instances of conflicting information as in this discussion 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 given to patients was thus highly subjective and no predominant view emerged. Not unexpectedly, patients chose to interpret the topic of information related to their care in many ways, just as we had encountered when talking to them about other aspects of continuity. The sources and types of information described were thus 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 the content especially where it concerned waiting times for service provision or follow-up after discharge:

> *"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 the related themes of 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 do…"*
>
> Carer for Patient #2

Although all the patients interviewed wanted to know about care and service provision, their views about information related to stroke were very varied and individual. Some described a lack of information 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 perceived by some as 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

On the otherhand, seeking information either in written form or from the internet was described by other 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 our patients, it did conform, albeit obliquely, to a notion of a common thread linking care from one provider to another. Although not often identified 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, there did seem to be an underlying theme of some method of communication of information acting as a means of maintaining continuing care.

3.1.6.5 Perceptions of continuity

Where it was deemed appropriate, patients were asked to try and tell us what continuity of care meant to them and whether or not they felt that there had been continuity in their care processes. We used the language and terms relevant to the individual patient to explore these concepts, as described in the method section of this study (S.3.1.2, pp. 41-43). We found that while they would generally affirm that they understood the term "continuity of care" and its associated idioms, it was apparent that participants struggled with the abstract concept of continuity. Their responses were generally subjective, frequently vague, contradictory or confused, and contained no temporal dimension.

When patients were asked to describe what they thought continuity was 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 chosen except that care, as we had found 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 used, 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 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:

> *#128: "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……...."*

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: help with transport, holidays and emotional support. 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 continuing the care process. Finally a few patients also interpreted continuity in terms of their recovery and made reference to *"getting better"* or *"back to how they were before"*.

3.1.6.6 Positive and Negative views of Continuity

When we asked patients 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. We found that eight of the seventeen had positive perceptions of the coordination of their care.

> *“Interviewer: Tell me how joined up do you think your care seemed overall?*
>
> *#20: 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.”*

Only one patient, who had given a very traumatic account of her admission, had a persistent theme of disappointment and dissatisfaction running through her narrative in all the care processes we discussed.

> *#140: “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.”*

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

> *#2: “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.”*

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

3.1.6.7 Supplementary qualitative data

In this early exploratory phase of the study we also interviewed stroke care professionals. This enabled us to develop an understanding of the organisation of local stroke services, which aided the interpretation of the patient's accounts of their care. These interviews were not taped but notes were taken.

The interviews, which were conducted with the following health care practitioners, took place during the same time frame as the QSOS Study:

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

After the patient and professional interviews were complete, and while the qualitative analysis was in progress, we conducted four focus groups with stroke survivors. The format of which has been previously described in the methods (Section 3.1.2, pp. 41-43). The participants (n = 18; 8 male/10 female) ranged in age from 50 to 82. Length of time since acute stroke ranged from 6 months to 12 years. Groups comprised between 4 and 6 patients, and were conducted as a means of checking out the findings from the individual interviews and testing theories. Notes were taken during the meetings but no audio-tapes or transcripts were produced.

It was interesting that the focus group discussions with the support group members, although conducted using the same framework, were different from the individual interviews, and very critical of care. Members were mostly dissatisfied and disappointed with care, and felt "*medically dumped"* after their stroke. The focus group that consisted of patients from our cohort study were more satisfied with their care and closer in their views to the patients in the interview group, and less critical overall. All focus group participants were keen to compare experiences with one another and express their opinions about the health care services they had received. Thus, while many of the general themes were the same, we obtained a more judgemental view of stroke care services overall than we had from individuals.

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. They resented "*bed-blockers*" and delays in discharge waiting for services but did not feel there was any ageism in the care they had received. They felt there were no links between health and social care agencies. The relational aspects of care processes were discussed mainly in the context of intimate personal care, and the preference for the same people to be involved (something which had come out of the individual interviews). 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 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 SA 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 similar, vague interpretations that we had found among our individual interviewees. The most likely explanation for the differences in the findings is that the majority of support group members had a 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 experiences and perceptions of care. The group dynamics were also different since members of the support group met regularly, and the presence of opinion leaders was obvious, whereas our stroke cohort group were strangers.

3.1.7 Discussion and Summary

These findings clearly present problems for the exploration of the continuity of care processes with patients, particularly in the context of the dimensions proposed by both Freeman and the CHSRF. Although the interviews with patients provided a rich and detailed insight into the ways in which people perceived their stroke care, we were unable to derive specific patient-centred indicators of continuity from their accounts. Moreover, with the exception to some extent of information transfer and communication, we could not readily map the accounts onto the elements of continuity that are part of the accepted model of continuity. Instead we obtained 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. We found that care after stroke is delivered in diverse ways, and by a variety of combinations of lay and professional agents, throughout the recovery period. This is not unexpected as the role of informal care in stroke (and other chronic conditions) has long been recognised.[38 39] As Pandora Pound wrote in her 1998 paper *"the effects of stroke are mediated in the context of patients lives"*, and this seems also to be true of the way that their continuing care is organised and maintained.[40]

In parallel with our qualitative interviews with patients we also conducted a review of their hospital and community care records. The case note reviews are reported in the next section of the report.

3.2 Study 2: The Case Note Reviews

3.2.1 Background

Our objectives for this phase of the study were to explore alternative methods of measuring continuity in stroke care processes. Many examples exist in the literature of methods that base their assessments on service provider records of the process of care, including counting the number of referral letters or the number of visits to care providers using entries in care notes. We decided to assess the number of care providers that had been in contact with our patients during the whole period of their acute stroke care, rehabilitation and after care. In order to quantify this, and capture the multi-disciplinary nature of stroke care, we counted the signatures of all care providers in the hospital and community care notes, for a sample of patients in the QSOS study. This method had been used previously to count the midwives involved in pre and post-natal care in a study of continuity in maternity care by Farquhar et al in 1996, and to count GP care providers by Professor Freeman in a study based in primary care.[41 42]

3.2.2 Method

Ten patients (6M/4F) whose stroke had occurred between 6 and 12 months previously and who had completed a qualitative interview as part of the QSOS Study 1 were selected. The median age of the sample was 82 years (Range 48-95). As part of the study a full review of the medical, nursing, therapy and social care notes was also undertaken, including general practitioner and any community care or district nursing notes, to identify the type, and timing, of care delivered. All signatures against entries in the care notes were counted and categorised, and the number and type of care-givers involved in delivering stroke care calculated.

3.2.3 Results

We had intended to complete the signature count review for all 23 patients who had participated in the QSOS interviews. However, we quickly found that the number of health care professionals involved during the acute, post-acute and rehabilitation phases was extremely variable and, in cases of severe stroke, exceedingly high. In most cases a count of the 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 we limited 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 QSOS patients but those with severe cognitive impairment, either pre-existing or post-stroke were not represented because they had not been able to participate in the interview phase of the study.

Table 3a: Variables associated with care process

Variable	Median	Range
No of signatures	59	16 to 111
Length of stay (days)	34	6 to 73
No of Wards in residence	3	1 to 4
No of OP Follow-up visits	1	0 to 3
WHO Performance Status	1	0 to 4

Signature counts were 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, we found that the whole complement of ward or unit clinical staff had made entries in the medical records at some stage. There was a less clear but less strong association between signature numbers and WHO performance status in this small group (r = 0.58) but the patient with the poorest function had the highest count of signatures as Table 3b shows below. (See Appendix D for WHO performance categories).

Table 3b: Cases Studies

Patient #17	**Patient #26**
88 yrs, widow, living alone.	63 yrs male, living with spouse
WHO PFS = 4	WHO PFS = 0
	Full-time employment
Signific*ant cardio-vascular disease with history* of multiple admissions	*No significant medical history or co-morbidity*.
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

Although the count of signatures showed an association with duration of care, which could be regarded as a proxy measure for severity of stroke, there was no obvious relationship with any identifiable dimensions of continuity as nothing can be inferred about the nature or sequence of contacts using this approach. As the two case studies above show, simple comparisons of care in stroke are not straightforward because of the range and diversity of patients and post-stroke effects. What the reviews did show, however, was that it is possible to map patients' stroke care from their medical records, and to gain an overview of care processes the transitions between them. This information was used to identify potential indicators of continuity in processes as Table 3c below shows.

Table 3c: Transitional Stages in Care

Stage	Potential Process Indicators	Source
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

3.2.4 Discussion

3.2.4.1 Methodological Issues

We encountered a number of operational difficulties in applying the signature counting method to enumerate care providers:

- Firstly, the actual number of signatures was hard to determine precisely because the caregivers making entries in the notes often used initials that were difficult to decipher and, in the nursing notes and multi-disciplinary notes of the ICTs in particular, rarely included staff designations or grade. Countersignatures also occurred frequently in nursing notes, due to the requirements for supervision of junior staff and cross-checking the administration of medicines;

- Secondly, the entries in care notes did not always correspond to actual episodes of care nor did they necessarily represent the caregivers actually involved with the patient. Day Hospital attendances, for example, were not recorded in the hospital notes until after discharge when the DH notes were filed but evidence of input was sometimes found as a referral letter if attendance was ongoing.

- Thirdly, although a basic format for patient record keeping exists, there was no way of knowing what was missing from the notes, as different wards and specialties used different documentation and recording practices, and relevant forms were not always filed;

- Finally, many of the stages in the actual process of care were not fully documented in the notes; referrals or handovers may have been made by telephone and transfers and discharges were not always recorded. Advice about discharge and home care given to relatives and carers during visits to the ward was also in this category.

3.2.4.2 Continuity and Caregivers

Green et al (1997) have shown that continuity in the process of maternity care did not necessarily mean continuity of carer to women, and there did seem to be some evidence from our reviews of the case notes that this was also true for stroke patients.[37] There was no association between the number of care givers and the nature of stroke care. The patient with the greatest number of care givers for example had no stroke specific follow-up after discharge. Furthermore, it is commonly hypothesised that having more carers may increase the dependence of patients and act as set-back to rehabilitation effects being maintained or progressed. There is also the possibility that the number of caregivers could mask the onset of symptoms of reversible medical conditions. If community input is increased to compensate as perceived need grows then these types of problems may remain untreated whereas, if successful treatment was given, increased input could be avoided or withdrawn when the condition is treated. Overall, the information collected during this phase of the study suggested 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 provide an indicator of continuity in stroke care processes.

3.2.5 Care records and communication.

The role of care records in maintaining effective care was apparent from our reviews. Hospital case notes were the most problematic and, although we did not quantify them specifically, we found examples of tests and investigations that had been repeated due to unavailability of care records. We also found evidence of the difficulties for medical staff 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 admitted acutely to different specialties. Missing, inaccurate and out of date information was a particular issue related to contact details for patients. We found examples of follow-up clinic appointments, hospital appointments for tests and investigations, and transport pick-ups that had been missed because letters had been sent to the wrong address or telephone numbers were incorrect or missing. In one set of case notes we found 4 different address labels for the same patient; in another address labels for a different patient with the same name, and therefore a different address. Clearly these are simple errors but they contribute to reduced effectiveness and efficiency, and increase the costs of care.

Where written records worked well was in the community care teams such as ICT, CST and Home Care. These agencies keep two patient files during their intervention period: one in the patient’s home and one at the office base. Each practitioner involved made 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 ceased.

Most General Practices in the area we surveyed used electronic records for patients. These obviously have advantages for accessibility and storage of information or data that has been entered but are slow when viewing external correspondence that has been scanned in. This impression was formed during the 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.*"

Complex care requires collaboration between different practitioners, working independently or in separate teams. Communication between the people delivering care is important to maintain uninterrupted care processes and ensure appropriate and timely interventions. However, much of this is not formally recorded and thus written or electronic records do not necessarily provide a full assessment of all the care processes that have occurred.

Our experience of reviewing care records did however prove useful in leading us to a framework for assessing continuity of inpatient care. We used the outline from Table 3c (p. 71) as the starting point for developing our rating of continuity as measured by how transitions in care were handled. (See Section 4.4, pp. 94-113).

3.3 Study 3: Evaluating the Chao Perceived Continuity Measure

3.3.1 Background

One of the objectives of our literature review had been to identify existing instruments designed to measure continuity of patient care, as described previously in Section 2.1 (pp. 24-34) of this report. Before embarking on a full study of our own proposed new measures (the SnL and the PPCI) we decided to test the applicability of an appropriate existing measure in the cohort of patients participating in the cohort study. Measures of provider continuity, such as the COC Index or the UPC, had been identified which use service provider data but do not address the patients' perspective. We therefore searched for measures relational continuity (as categorised in the CHSRF report) and selected the Chao Perceived Continuity measure (PC) [9] which is described by its author as "*measuring patients' attitudes to care to define continuity and provide information which is distinct from provider continuity formulas*". Extensive searching found no references to other studies that had used the Chao questionnaire in any setting but nevertheless, as it was the only measure that addressed patient perceptions, we decided to test it in this patient group. It was originally designed for use in general practice but since the vast majority patients to whom we would be delivering the questionnaire would be out-patients, we did not regard this as an obstacle. (The instrument could be adapted to a hospital setting if required). It had also been previously administered directly to patients for self-completion and as a postal survey, which matched the methods planned for our study. Furthermore it was easily obtained direct from the originator Dr. Jason Chao and without copyright restriction other than acknowledgement of the source.

3.3.2 Objectives

In this study our objectives were twofold:

- To determine the feasibility of using this well established measure of continuity in a new patient group by studying its meaningfulness and usability with stroke survivors;
- To examine associations with scores on the Chao Questionnaire, as a means of exploring the construct related to those scores.

3.3.3 Method

The Chao questionnaire was given to a sample of 310 patients who had consented to participate in the SOS2 cohort study. It was delivered at various time points during the one year follow-up period to those patients who had not completed the study, and also to a sample of patient who had been followed-up for a year. Two modes of delivery were used: those actively participating in the Stroke Outcomes Study cohort (N = 110) were asked to complete the Chao measure as part of their routine assessments; those participants who had completed the cohort study follow-up but had given consent to contact for future research (N = 200) were sent postal questionnaires. In either case, patients were given the opportunity to opt out by not completing the questionnaire if they chose. A copy of the questionnaire is attached as Appendix E. Items on the questionnaire are rated on a Likert Scale; Table 3d (p. 78) shows the distribution of scores:

Table 3d: 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

Participants were encouraged to comment (either verbally or written) on any aspect of the questionnaire. The first round of interview delivered questionnaires showed that absence of a “not applicable” rating was causing some difficulty and postal forms were modified to address this as they would not be completed with an interviewer present to assist with queries. The data collected from the completed questionnaires was entered on 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 subtracted from 6 to convert them to the same order as other items so that a higher score indicated “better” scores. No weighting was applied and an overall mean score was calculated for the 23 items.

3.3.4 Results

3.3.4.1 Comprehension and Utility

Interview data was collected from 108 of the 110 patients approached (98%). Only two interviewees refused to complete the questionnaire, although a number rated items *“not applicable”* and could not score them. Postal data 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 population and these patients form the sample used for analysis of which 104 were male and 73 female (1 Unknown gender); median age of 69 years (Range 33 to 94)].

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 interviewers in response to verbal comments. Interpretation of questions caused most difficulty (24 comments) and 17 comments were made about relevance of the items. The remainder (4 comments) were about difficulties related to specific post-stroke deficits. Only items 1D; 1E; 2E; 2J and 2O were not commented on by patients; comments on the remainder were mostly “Odd question” or “What does that mean?” The most frequently remarked questions 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”*

Items not fully understood were often left blank. This resulted in 29% missing items in Section 1 (Range 1 to 8 items left blank) and 35% in Section 2 (Range 1 to 15).

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

The categorical ratings of Chao assessed continuity are shown below in Table 3e. Five questionnaires had insufficient data for analysis.

Table 3e: Continuity assessed by Chao mean scores

Continuity Category	Patients (n)	Percentage	Mean Score Range
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%	

3.3.4.2 Exploring Associations

The Stroke Outcomes Cohort Study aims to measure outcomes in two main categories:

- **Measures of function:**
  Assessed by the WHO performance index; the Barthel Index (BI); the Frenchay Activities Index (FAI) and the Functional Independence Measure (FIM).

- **Measures of mood and health related quality of life (HRQoL):**
  Assessed by the Present State Examination (PSE); the General Health Questionnaire (GHQ_28) and the Medical Outcomes Study (SF_36) Questionnaire.

Demographic, social and co-morbidity data were also recorded for participants in the outcomes cohort.

As a preliminary analysis selected baseline variables in the cohort study were compared with Chao categorical ratings in a cross-tabulation, and chi-square statistics calculated for the selected variables. The aim was primarily to assess the performance of the Chao measure in our sample (a sequential 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.

We did not detect any relation between physical function and Chao Questionnaire scores. The only significant association in this analysis was for poorer Chao scores to be reported by patients reporting higher levels of anxiety or depressive symptoms at baseline. (i.e. those scoring 12 or more on the GHQ on entry to the cohort study). This was explored further by examining subsequent GHQ 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 score. This could be explained by a 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. The results are shown in Table 3f below.

Table 3f: Comparison of baseline characteristics and the Chao median score

Baseline (T1) Variables	**Distribution**	χ^2	**p-value**	**Sign**[§]
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[†]/non case	Cases (n 38; 22%)	8.33	0.04*	SD

Notes: [§]NSD = No significant difference identified; SD = Significant
[†]Total Score ≥ 12 = a case: Cases report lower (poorer) Chao scores.
**Significant at 5% level*

Responses to individual items were more informative as they gave a better indication of patients' attitudes. Item by item analyses showed that patients trusted their doctor (Question 1F: 90% of respondents agreed with this statement) and 67% agreed they had an ongoing relationship with their own doctor (Question 2A). However, with regard to emergency care, only 38% of respondents preferred to wait to see their own doctor (Question 2H); 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 of patients' views on seeing the same doctor.[43]

3.3.5 Discussion

3.3.5.1 Contextual Issues

The Chao PC questionnaire was originally designed to test the Banahan concept of continuity as an attitudinal contract in an empirical study.[11] It was designed for use in primary care and this was problematic for the patient group assessed in this study, all of whom had had hospital care for stroke in the preceding 6 to 12 months, and were being seen in the context of a stroke-focused cohort study. Notwithstanding the fact that they were always asked to rate the questions in relation to their GP, it was sometimes unclear whether they were rating responses in respect of the hospital medical staff, especially when questions referred to hospital care.

The Chao questionnaire was specifically designed to measure components of relational continuity including attributes of the doctor-patient relationship such as trust, knowledge and satisfaction. There is an implied chronological context to the

Chao measure but it is ill-defined and thus does not correspond with more recent definitions of continuity which include a temporal dimension. It does however allude to certain other aspects of continuity in single items that make reference to informational or 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 questionnaire focuses on the patient's satisfaction with, and trust in, their relationship with their doctor. This is particularly in Section 2 of the questionnaire but is also the case that many of the questions would also be relevant to responder ratings of the quality of their care.

Differing family circumstances also accounted for some discrepancies in the responses. We had a wide age range represented in our sample but our patients were mainly older (median age 69 years) some lived alone and even married couples did not necessarily attend the same GP practice; few had dependent children living with them. As a consequence questions about family medical care such as Questions 2D and 2F (see Section 3.3.4.1, pp. 78-79) were confusing for some.

Specific problems with the format of questions in this study, identified from the patient feedback, mostly arose as a consequence of the different healthcare system (USA) for which the Chao measure was originally developed. For example items such as those about hospital and emergency care (Questions 2K and 2L) were not easily interpreted by patients used to an NHS health care system, and their responses reflected this. By changing the wording of some questions they could be made clearer, and more relevant, to a UK patient population.

3.3.5.2 Scoring the Questionnaire

We found a high proportion of missing values in our data and this, combined with the effect caused by the 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) was unhelpful when summing the data. Our patients frequently used this option when they were not sure what the question meant rather than meaning that they were not sure about their response. In view of this we would recommend that the response categories were amended either by labelling the intermediate value *"neither…nor"* or by creating an additional missing value option for *"not applicable"* or *"not sure".*

3.3.5.3 Sensitivity

Analysis of our data suggested that the Chao measure was not particularly sensitive to factors that might be expected to drive care patterns such as respondent differences in age, gender or level of dependency. Only those outcomes assessed by mental health dimensions of the instruments used in the cohort study showed any differentiation in respect of the Chao scores. Given that this questionnaire is a self-report measure this would 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.[44] Based on our findings from this initial appraisal of the Chao PC measure we decided it was not an appropriate instrument for measuring the processes of care that we hypothesised might contribute to continuity of stroke care.

3.4 Strand 1: Summary of main findings

In Strand 1 of our work we undertook an exploration of stroke patients' experiences of care in order to interpret the concept of continuity of care from their perspective. We also investigated two methods of measuring continuity, one using an existing patient-centred measure and one using service records of care.

In our exploratory qualitative study we interviewed 42 stroke survivors and some of their carers. Thirty-two of these interviews were subject to detailed framework analysis the remainder could not be transcribed or were not adequate for analysis. From our analyses in Study 1 we found that we could not derive sufficient key, patient-centred themes or indicators from which to construct a measure of patient perceived continuity. We could however use the patients' narratives to identify aspects of continuity within them and in this way to assess the process of care from their perspective. This study informed the development of the Patient Perceived Care Interview schedule (PPCI) tested in Strand 2.

In the case note reviews conducted in Study 2 we found that continuity in the process of care could not be determined by quantifying input from care-givers due to the complex nature of stroke and confounding factors which arose from the dependency or physical status (stroke and non-stroke related) of the patients, and the quality of entries in the care records. This led directly to the development of a checklist based on the phases and transitions of stroke care, which was tested in Strand 2.

In our third study in Strand 1 we evaluated an existing measure of continuity of care (the Chao Perceived Continuity Questionnaire) in 310 patients participating in a Stroke Association funded study. This study was conducted in parallel with our SDO work and involved the same research team. As the Chao questionnaire was designed for a primary care setting we recruited patients to this study who had been discharged home following their stroke event in order to determine how continuity of care might be perceived in the post-acute stroke phase. We found that the Chao questionnaire was only responsive to mood and did not discriminate between patients on the basis on any other factors that might influence the care they received. We therefore concluded that it did not provide a method of evaluating continuity which was consistent with our definition of continuity residing in the process of care.

3.4.1 Conclusion

Our conclusions from Strand 1 were that we could neither derive an entirely patient-driven measure of continuity, nor could we readily use a simple available measure. Therefore in the next phase of our study (Strand 2: Quantifying Continuity) we embarked on the development of two new instruments to measure continuity of care process: one using information recorded in the care notes and one, an interview, designed to assess patients' views and perceptions. Each measure used a framework derived to a substantial extent from the professional literature. These measures were subsequently applied in a sequential sample of patients drawn from the Stroke Association funded SOS2 Depression Study cohort. The procedures for Strand 2, and the findings, are reported in Section 4 of the report (pp. 87-161).

4 STRAND 2: QUANTIFYING CONTINUITY

4.1 Developing the Measures

4.1.1 Developing a checklist to evaluate care processes

The organisation of stroke care is complex and patterns of care vary depending on factors such as the age at which the patient suffers a stroke or the configuration of services in the area in which they reside. The information we collected in Study 2 enabled the identification of key stages and transitions in the care processes of stroke patients in our locality. It also enabled indicators to be identified that we hypothesised could be used to evaluate the effectiveness of those processes in delivering optimal care to the patient. These are detailed in Table 3c (p. 71). Using this information and the experience and knowledge we had acquired during Strand 1 of our investigation we developed a checklist to extract relevant data from care notes in order to assess the extent to which aspects of the care process had contributed to care for the stroke patient. The indicators were either scored as present or absent or rated on a three point scale: positive (+1); negative (-1) or stable (0). The derivation of scores will be discussed in more detail in Section 4.1.3 (p.89). Modifying variables were included in the checklist to allow adjustment for factors which moderate care processes. We called the new measure the Snakes and Ladders (SnL) Checklist because of our sense that it described a rather perilous journey through inpatient care with potential for progress and setbacks. A final version can be found in Appendix F.

4.1.2 Developing a patient-perceived measure of care processes

It was not possible to derive clear or consistent indicators from the patients' accounts of their care from which to construct a checklist to assess patient perceived continuity in the process of stroke care. We therefore decided to adopt a different approach and use an interview format based on the themes and stages of care which, based on our qualitative study, we knew patients could recognise. We asked questions about the different stages and processes of care and rated the patients' responses against a set of pre-defined criteria. Developing and using an 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 our SOS2 cohort. The interview method is also a more time consuming process than a checklist style measure, and required more training and standardisation in its administration. It also required a longer period of time to review tapes, rate the interview responses and analyse the data. However, we judged the effort to be worthwhile because of the unfeasibility of using self-report questionnaires in our patients.

Our first attempts to rate items generated during the interview on a Likert scale failed due to the variation in input, and disparity in the type, of care processes to which patients had been exposed. It was not possible to derive generic scales that could be applied in a standardised way across all patient narratives. Once again we used a different approach enabling a more flexible scoring system to be applied, and rated the responses generated from the interview against defined criteria, using a similar method to that used for other standardised interviews. The scoring system followed the same pattern as the SnL Checklist and is discussed further in the next section.

Developing the interview format and the scoring procedures was thus an extended process. It was necessary to pilot several versions before an instrument was available that could be applied in the cohort study, and this reduced the numbers available for inclusion in our final study group. The final version of the instrument, called the Patient Perceived Continuity Interview (PPCI), was used in the next stage of the study and appears in full at Appendix G.

4.1.3 Developing a 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. We began by rating items on a 5 point Likert scale, using descriptors relevant to the variables we were measuring. This type of measurement was piloted in the first version of the PPCI and used in the first 32 interviews. We found that it was not a method of rating that was easily applied to the responses generated by the PPCI, as it was not often possible to differentiate the data in order to attribute a rating on a 5-point scale with precision and reliability. The SnL checklist data presented similar problems with Likert ratings, again mainly with differentiation of scores as a result of too little detail available from the cases notes.

A simpler approach was to regard 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. The same scoring system could be applied to both measures. It was not intended to assign weightings to specific aspects of care. Table 4a (p. 91) shows the criteria for attributing scores to checklist indicators and patient accounts.

Table 4a: Scoring Criteria for the SnL Index and the PPCI Schedule

Positive Score (1)	Negative Score (-1)	Stable (no change) Score (0)
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. *For example*: 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.	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. *For example*: Waiting times of approximately 6 months are standard for out-patient SALT therapy and, none is 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.	Characterised by evidence of appropriate care but transitions which have no positive impact on the progress of stroke specific care. *For example*: Withdrawal of specialist care as a result of a clinical decision to change management.

4.2 Study Aims and Design

Sections 3.1 and 3.2 (pp. 41-74) described the qualitative exploration of patients' perspectives of continuity of care conducted in the first strand of the Continuity of Care in Stroke Study and a full review of entries in health care records to estimate the number and types of carers involved in caring for stroke patients. The results of these early investigations directly informed the development of both the Snakes and Ladders Checklist (SnL) and the Patient Perceived Continuity Interview (PPCI) as described in the previous section. Following completion of the design and development of the measures, and the early piloting stage, they were tested in a sample of patients drawn from the Stroke Outcomes Study (SOS2) cohort. Thus the second phase of the study aimed to apply the measures to a sample of patients participating in this parallel cohort study in order to investigate firstly, the feasibility of quantifying care processes using two different methods and secondly, the association between continuity of care processes (as measured by the PPCI and SnL) and outcomes for patients. The results of the Stroke Outcomes Study 3 (SOS3), which applied the SnL checklist and the PPCI in that sequential sub-sample, are reported here.

4.3 Methods

A cohort of 592 patients was recruited for the Depression Study (SOS2), 189 of these patients were eligible for inclusion in the Continuity of Care Study (SOS3) once the measures were prepared and available for testing. For the purpose of the SOS3 study the patients were interviewed once between 6 and 12 months after their acute stroke admission. Earlier phases of the study had shown that an assessment of care processes was more relevant in the post-acute stage when a strategy for on-going care had been established. The SOS3 study procedures required a full review of hospital and community care notes to extract data using the SnL Checklist, and a structured interview with patients and their carers (if present) using the PPCI schedule.

4.3.1 Characteristics of the patients

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 72yrs (Range 32 to 95). The patients presented with a 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 Depression Study (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:

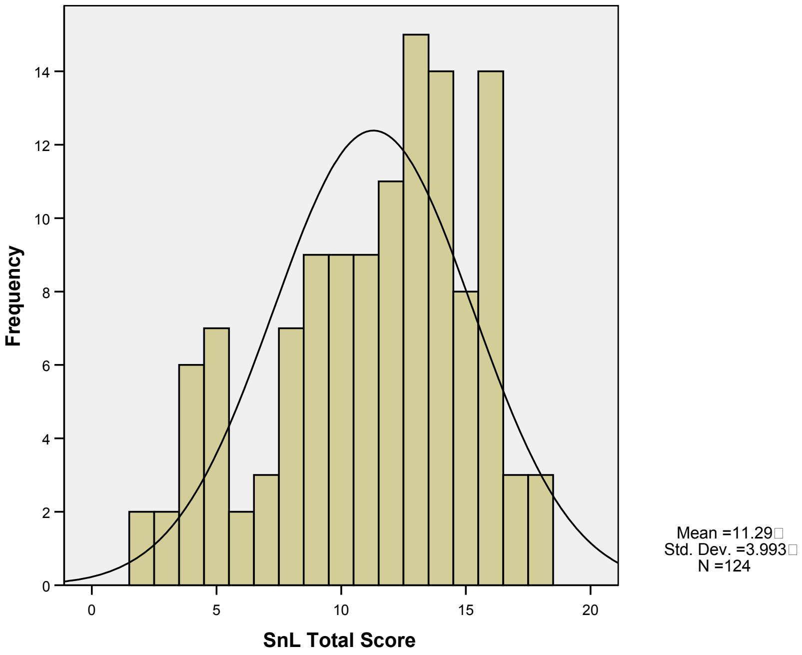
12 patients completed SOS2 but refused to take part in SOS3
19 patients had withdrawn from SOS2 and declined to be contacted again
6 patients died during SOS2 and before consent to SOS3 could be sought
9 patients agreed to case-note reviews but refused the SOS3 interview
2 patients were incapable of interview
1 patient died after consent to SOS3 but before the interview was arranged

This left a sample of 113 completed interviews with patients and 126 sets of case-notes available for review.

4.4 Study 4a: Measuring Continuity from Health Care Records

The Snakes and Ladders Index was developed specifically for the study as we described in an earlier section of this report. It comprised 29 rateable items that used pre-selected indicators to rate care processes from the information that was available in the records. A simple ordinal scale was used to rate items against pre-defined criteria with values of minus 1, zero and plus one to represent discontinuity in the care process (-1); no positive effect (0) and positive continuity of care processes (+1) rather than a scale ascending from 0 or 1. The scaling was designed so that higher scores would represent better care processes as described in Section 4.1.3 (p.89). A simple aggregation of the scores for the 29 items shows a distribution of scores throughout the range of data but biased towards the higher end of the total score range. Figure 4a below shows the total score distribution.

Figure 4a: Histogram of SnL Index Total Score showing normal curve



4.4.1 Results 1: Validating the SnL

There was a high proportion of missing data in the item variables due to the diverse care needs of the participants. This precluded the option to calculate an alpha value for the index to test association between the variables. Two researchers (KH and HB) reviewed 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 senior researcher on the project (KH) throughout the review period.

We had no gold standard measure against which to assess the validity of the SnL Checklist as other record-based measures focus on single indicators such as number of contacts with providers (the CoC Index) or number and content of clinic letters. The investigation of the properties of the SnL checklist therefore began with an Item-Total correlation analysis (I_T Analysis). 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, thus giving an indication of the internal consistency or homogeneity 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 items which graduate in the same direction can be regarded as measuring the same or related themes.

There were 126 hospital case-notes and GP medical records authorised for review by patient consent: 105 sets were completed; 16 sets of hospital medical records could not be retrieved and access to 5 sets of GP notes was denied by the medical practice at which they were held. A first aggregation of results showed that the division into 3 scoring categories produced small numbers of patients in the no positive effect and discontinuous care categories, and none at all in certain categories. This was not unexpected as the chosen indicators were selected as markers of optimal stroke care, and large numbers in the negative categories would be indicative of a service that was failing, something which was clearly not occurring in the locality 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 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 in the following way:

None or specialist transfer	*+1*	*None or appropriate transfers only*	*+1*
Medical Assessment Unit or Rehabilitation Transfer	*0*		
Other ward transfers	*-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 items relating to community therapy were combined into "Any community therapy". This was justified because in the majority of cases the review was only able to determine whether community therapy had been delivered or whether the patient had been assessed for therapy. No judgement could be made about the appropriateness or otherwise of the therapy that was received. This reduced the number of rateable items to 26. There are clearly limitations with this approach and we will return to these in a later section (see S. 4.4.2. pp. 95-99).

The results for the I_T correlation analysis are presented as means (standard deviations) and summarised in Table 4b (p.98). Some items, such as BP monitoring in hospital and medication review by GPs, were positively scored for all patients but were included in the summary because they were reliably recorded. However, items that had been selected as potential indicators of continuity but for which data could not be obtained consistently were excluded. These included a few items such as whether contact telephone numbers had been given to patients or carers at discharge, use of patient-held records and stroke coordinator input.

Table 4b: The Item_Total Correlations for Items in the Snakes and Ladders Index

SnL Items	ITC Totals		Positive Continuity		Sub-Optimal or Discontinuity		Difference Mean X minus Mean Y
Section A: Acute and Rehabilitation Hospital Care	**Mean**	**SEMean**	**N**	**Mean (sd) (X)**	**N**	**Mean (sd) (Y)**	
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*
Section B: Home and Community Care	**Mean**	**SEMean**	**N**	**Mean (sd)**	**N**	**Mean (sd)**	Difference
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 HomeCare	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*

4.4.2 Item Clusters

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

Table 4c: Cluster Groupings for the SnL Checklist

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 HomeCare 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, as can be seen in the histograms, which are shown in Appendix H, were distributed across the range of scores with a similar bias towards higher (positive) scores as we had found in the total scores for the index. (Appendix H: Figures H1 to H7, pp. 249-251). Only admission scores, which had a normal distribution, and community therapy scores which were biased towards lower scores differed from this pattern.

The mean scores for the clusters were compared for different sub-sets of patients in the sample using Student t-tests. We aimed to see if the SnL Checklist would detect differences in the continuity of stroke care processes based on the characteristics of our sample of patients.

4.4.2.1 Demographic factors and scores on the SnL Checklist

The total scores for the SnL Checklist were not significantly different on the basis of <u>any</u> of the following socio-demographic factors: gender, age, marital, residential status or living in an area covered by the Community Stroke Team. Neither did these factors have a very big effect on the cluster sub-scores. No differences were found between the genders for any clusters using parametric methods (see Table 4d footnote, p. 103), nor were any differences seen between scores based on postcode area of residence. Age only showed an effect on follow-up, 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 are more able to attend out-patient appointments then older patients, either because they are fitter or have easier access to personal transport. Attendance for follow-up leads to a greater likelihood of reassessment for targeted therapy at six months. 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 this group. The results of the tests for differences in the mean scores are shown in Table 4d (p. 103). 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 explanation as the potential for bias is high.

4.4.2.2 Post-Stroke Disability

The impact of the index stroke on physical function was assessed for the SOS3 sample by the change in baseline post-stroke Barthel Index (BI) from the pre-stroke score. This 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. The results showed that stroke severity 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, p. 103) This finding was supported by the results for early discharge (length of stay <7days) and continence which revealed an almost identical pattern. Longer admissions and incontinence are both factors which are 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 confounded the assessment of care processes in Study 2 (Strand 1) of the project when episodes of care, and number and types of carer involved in post-stroke care were calculated from case note reviews as reported in Section 3.2 (pp. 68-74). The level of dependence and symptom burden (in terms of disabling effects of the stroke) thus seem to be major determining factors in this method of assessment of care.

4.4.2.3 Mood and Psycho-Social Factors

The patients in the SOS3 study were all participants in the cohort study (SOS2), a study which investigated the impact of stroke on mood and psychological well-being. Consequently all the patients had assessments of mood made at regular intervals throughout the post-stroke period. Two methods of mood assessment were used for the SOS2 study: the 28 item General Health Questionnaire (GHQ_28) and the Present State Examination (PSE), a standardised, in-depth psychiatric assessment. The GHQ_28 is a self-complete measure which uses a standardised scoring method to produce sub-scales for four symptom dimensions: somatic, social dysfunction, anxiety and depression. The PSE by contrast uses interviewer ratings to record the presence, absence and severity of symptoms which can be used to indicate the possible presence of a mood disorder when assessed against the criteria for ICD_10 diagnoses. The measures were completed with patients at five time points:

- 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

The GHQ_28 and the PSE total scores were highly correlated across all time points of the study. The GHQ_28 was selected for use in this analysis because although it can also be used to define cases of potential mood disorder it is more often reported as a numeric variable than the PSE.

The results showed little effect of mood on SnL cluster scores. No significant differences were detected 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. Table 4d below shows only the results for the significant findings of the tests for differences in means scores, reported in the three preceding sections.

Table 4d: Factors differentiated by the SnL Checklist scores

Factor	SnL Variable	Mean difference[1] (95% CI)	t	df	p-value[2]
Age: *<65yrs old v >65yrs old*	Follow-up	0.34 (0.00 to 0.68)	1.99	100	0.050
Residential Status: *Residential Home v Living with someone*	Admission	0.90 (0.10 to 1.70)	2.25	77	0.027
Stroke Severity: *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
Early discharge: *<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
Continence: *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
GHQ Cases (T3): GHQ >11 v GHQ <11	Community Therapy	0.76 (0.11 to 1.41)	2.33	91	0.022

Notes:
1.) Means compared using Student t-tests
2.) Significance set at 95% level. Tests for remaining variables not significantly different.
3.) 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

4.4.3 Using information from different sources

Hospital medical and multi-disciplinary case-notes, GP medical records and other therapy or community care notes can only provide the information that has been entered in them. The format of records according to the care setting: in hospital notes medical staff and (some) therapy staff write in the medical section of the notes, nursing notes are kept separately during the admission period and filed in the patient's case notes after discharge. Specifically designated multi-disciplinary notes were present in some rehabilitation wards but while MDT care notes may be good for tracking (stroke) care within episodes, they may function less well generically across different areas of care. Furthermore, much of the care process is not immediately obvious from the notes because related communications have been verbal or associated written documentation exists that has not been filed. Telephone contacts with other external agencies or internal departments are rarely recorded. Faxed referral letters, forms or investigation results are not always filed. Thus cross referencing may be necessary to rate aspects of care for which records are incomplete but the outcome is apparent from some other sources.

Nursing notes are usually comprehensive but are often swamped by routine details which render information difficult to retrieve, as does the non-sequential filing common in nursing notes once they are merged with other case notes. Case-note files may (and frequently do) contain blank forms, either standard forms on which the patient's name has been entered and no more, or multiple copies of the same form which have been started in different wards or previous admissions. These add bulk but no information and moreover, they can remain in the notes in perpetuity since no one has responsibility for maintaining individual patient files.

4.4.4 Rating the SnL Items

The rationale for selecting indicators and defining the rating criteria was discussed in Section 3.2.4 (p. 72). We found the items 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 care process delivered to all patients admitted with acute stroke.

Records of MDT care 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 specific MDT input. This items was more likely to be contingent on the health and physical status of the patient and therefore early discharges were rated as not applicable for MDT case handling unless their Barthel Index score was less than 19. 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 Table 4c (p. 99).

When the SnL checklist was applied to this sample of patients' case notes, the results obtained highlighted some interesting (but unexpected) anomalies in the rating criteria. We had used the CHSRF model to develop our framework for deriving the items for assessing continuity in the stroke care process. This framework was also applied in considering the rating criteria. We thus had categories of items and ratings for continuity in managerial, informational and relational processes. One interpretation of "relational continuity" is that it resides with the healthcare professional with overall responsibility for management of an individual's care at a particular time, such as the GP in the case of day to day health problems arising in the community setting. In acute care that role would be assumed by the consultant in charge of the condition that had required admission to hospital, and extend after discharge to hospital out-patient care, if applicable. With this in mind one of the indicators that we developed for the acute care phase was the number of consultants under whose care the patient had been during their admission. Change in consultant was rated as a negative continuity event but as the I_T correlation results showed the majority of the patients had at least one change in consultant, and this seemed to confer an advantage in terms of their overall scores. (Table 4a, p. 91). One interpretation of this finding is that most stroke patients are admitted through Accident and Emergency departments to the medical admissions unit (MAU) and transferred from there to Acute Stroke Units or general wards. Thus a change in consultant was associated with a benefit to care, and rated as a positive score, if the transfer of care was to a stroke specialist. This construal is supported by the large number of patients (93) whose transfer of ward was coded as appropriate, that is transfer was effected mainly for specialist acute care or stroke rehabilitation.

This example shows how simple indicators do not capture these more subtle aspects of transitions in care and complicated criteria, requiring some degree of informed judgement in order to rate them. Entries in medical records are routinely signed by the doctor who writes them but senior medical staff do not usually append their grade. While some junior doctors (Senior House Officers and below) and some registrar grades will do so, others may not be identified in any way, thus the reviewer completing a measure like the SnL would need special knowledge to determine an accurate rating against this criterion. This is one of the drawbacks of applying existing indices such as the CoC index, developed for general practice, to care for complex conditions, like stroke, requiring hospital admission.

The item assessing referrals was subject to a similar ambiguity in rating. Referrals to other specialties represent 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 required, and this distinction cannot be made on the basis of the entries in the notes alone. For this reason a negative category was not used and this item was scored zero for no referrals made and +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.

Finally, a number of items proved to be very difficult to rate from the case-notes. These were the items relating to contact numbers given to patients or carers at discharge, patient held records and contact with a stroke care co-ordinator (this role was discontinued with changes in joint care management in Leeds and established in the Bradford area during data collection). These items were not included in the aggregation of the results because of the extremely high proportion of missing data (over 90%) for these variables, and the change in service provision during the data collection period.

The SnL was therefore subject to an ongoing process of development. We learned by trial and error how the well the indicators performed when applied to our sample of patients. We learned too how our early assumptions had been flawed and it was necessary to adjust our ratings to take account of these. The strategy we adopted of combining categories and eliminating variables, although subject to some of the imitations discussed above, enabled us to make the best use of the data that we had collected in this phase of the SOS3 study.

4.4.5 Results 2: Pre-Test and Post-Test Items

The I_T correlation analysis correlated each item in the SnL Index with the total score to provide an indication of how far each item contributed to the phenomenon being measured. In the preceding section we discussed how, 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). Refer to Table 4b, p. 98 for full results.

Although these items seemed to have a differential effect, some of the results were counter-intuitive. One of these, the item which rated changes in consultant, we have already discussed and put forward an explanation. We found two additional items that demonstrated this effect: *Documentation transfer* and *Follow-up by Stroke*

Specialist but, since there were only a small number of patients in the sub-optimal groups for these two items (2 and 7 respectively) these results should be treated with a degree of caution. Three broad categories were identified to define these items:

- Those 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.
- Those 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 changes in consultant, which had a strong association with positive (better) overall scores 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 a specialist. However, no significant inter-item association with care on an Acute Stroke Unit was found. A chi-square test of the two categorical variables in a contingency table showed no significant correlations between them: $r = -0.036$ and $X^2 = 0.134$.

Following a review of the first stage results, 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 Item_Total correlation analysis was then repeated for the reduced index. The results are shown in Table 4e (p. 112).

Table 4e (p 112) shows that the items left in the index all contribute strongly to the theme of the overall measure. The negative categories rated by each item are associated with lower and the positive categories with higher overall scores for the SnL Index. The remaining 12 items showed a correlation between higher mean total scores and positive (better) care process category ratings and lower mean totals for sub-optimal or negative ratings, suggesting that these indicators were contributing to overall measurement of the phenomenon. On the basis of this analysis these 12 items were selected as our final measure and used to provide a total score for the next stages of the analytical process.

The next stage of our analysis, using our refined measure, repeated the comparison of the scores for the SnL Checklist across groups of patients on the basis of pre-determined factors such as age, gender and marital status. We used the same criteria to define the groups as for the preliminary analysis and conducted t-tests of the mean scores for the clusters of symptoms detailed in Table 4b (p. 98). T-tests can be justified for this application because we were seeking only to validate our findings rather than testing a hypothesis. However, we were mindful of the fact that some of the variables were not normally distributed, and some of the comparison groups had fewer cases than others. We therefore conducted parallel tests 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 the same results.

Our results showed that with the modified measure older patients were still less likely to be followed up by a stroke specialist after discharge. We also found that living in a nursing home showed a detrimental effect on admission sub-scores. There was an isolated finding for the T3 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. This effect was not seen at any other time-point for the GHQ. It should be noted, however, that reducing the alpha level to 0.01 meant that these three findings were no longer significant.

The factor which had the greatest impact on scores for the SnL Checklist was disability as measured by the Barthel Index and the factors closely associated with it: length of admission and continence. These findings remained significant even if the threshold values were lowered. Given that the items which seemed to contribute most to the overall phenomenon being measured were those which were contingent on the severity of the index stroke and the functional status of the patient, this finding suggests that the SnL index is measuring intensity of care input rather than a characteristic of the process of care. Patients with higher scores on the SnL index would be therefore those in receipt of more therapeutic input or supportive care. We would contend that it cannot be assumed that lower scores indicate a poorer (or less progressive) care process, as good care does not mean necessarily mean more care.

Table 4e: The Item_Total Correlations for Post-Test Items in the Snakes and Ladders Index

SnL Items	ITC Totals		Positive Continuity		Sub-Optimal or Discontinuity		Difference Mean X minus Mean Y
Section A: Acute and Rehabilitation Hospital Care	**Mean**	**SEMean**	**N**	**Mean (sd) (X)**	**N**	**Mean (sd) (Y)**	
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.) Aids & adaptations received	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

4.4.6 Discussion: What is the SnL Checklist measuring?

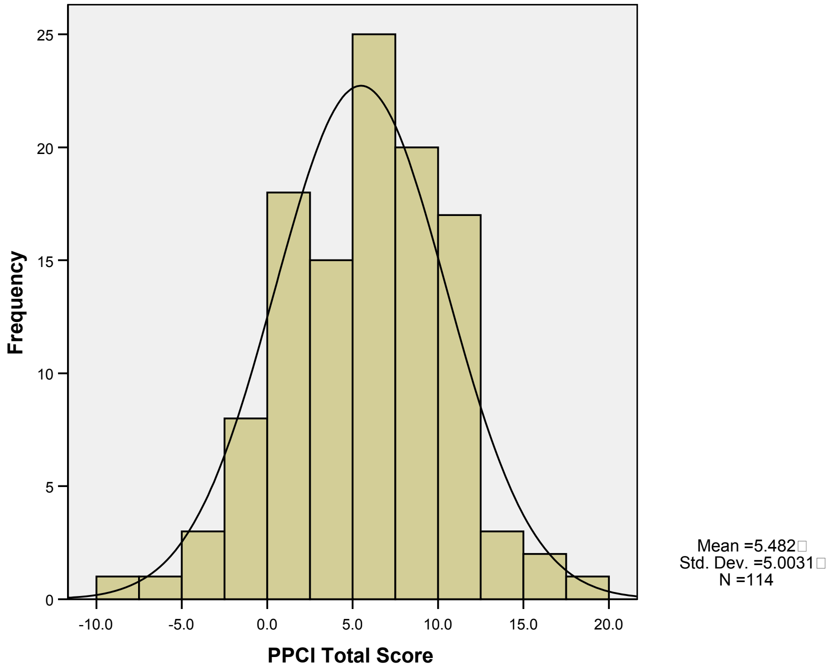
The I_T correlation analysis showed that indicators which measure common aspects of care like medical assessment as an inpatient and blood pressure monitoring are routinely done for all patients regardless of health status or where they are treated. It was items relating to specialist care such as MDT input to care, specialist nursing and rehabilitation assessments and transferring information across care boundaries that had more impact on the overall score. It could be that these factors are 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 is not necessarily a measure of continuity of the process of care, it is equally measuring input and intensity of care. Thus the association with severity of stroke and post-stroke disability are not surprising, and the phenomenon being measured is not continuity in the process but the nature of the care delivered. In Section 4.6 (pp. 139-146) we report a confirmatory factor analysis conducted to study the phenomenon measured by the SnL Checklist using more sophisticated methods.

4.5 Study 4b: Measuring Continuity from the Patient's Perspective

The assessment of continuity of care from the patient's perspective was conducted with the same sample of patients whose case notes we reviewed using the SnL Checklist. They were identified from the SOS2 cohort and comprised a group of 157 stroke survivors (82M/75F) with a median age of 72yrs (Range 32 to 95). Not all the patients who agreed to participate in the SnL case-note review were willing or able to participate in the interview. As previously described interviews were conducted with a total of 113 patients but, although 128 patients had consented to the SnL review, missing notes or difficulty retrieving or accessing notes meant that only 97 patients had both a PPCI interview and a complete case-note review (including hospital and community care notes).

The items on the PPCI schedule were structured within a similar framework to that of the SnL Checklist. They covered themes of contact and relationships with health practitioners, the management of care and information transfer. 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 in the same way as the SnL Index to rate items against the pre-defined criteria with values of minus 1, 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, as previously described. Figure 4b (p. 115) shows a normal distribution of total scores for the PPCI using a simple aggregation of ratings for the 19 items.

Figure 4b: Histogram of PPCI Total Scores



The semi-qualitative nature of the PPCI schedule meant that it continued to develop as the study proceeded. 32 patients in the study were interviewed using the final (Version 6) schedule. As far as possible new data points were retrieved from interviews using earlier versions of the schedule (81 patients) but some missing data did occur as a result of this 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 sections of the schedule are reported separately. We begin with the PPC interview and return to the self-complete items in a later section.

The interview used a standardised semi-structured to collect the data. Responses to the questions were rated by the interviewer and given a quantitative value based on certain defined criteria. This allowed flexibility in ratings to take account of the different patterns of care that we had identified in our preliminary qualitative study. The categories derived from the framework were not combined for analysis in the same way that the SnL index scores were because although some variables and some categories had fewer cases represented, unlike the SnL there were none that did not have any cases at all. There was also a wider distribution of cases through the categories and it was deemed important to preserve this detail in the data. The first approach to analysis was an Item_Total correlation analysis using the same method previously applied to the SnL scores. The results are presented as means (standard deviation) and shown in Table 4f (p. 118). Medians showed exactly the same pattern.

It can be seen that a definite trend was present for negative responder categories to have lower overall mean scores for all the items in the schedule. This effect was more pronounced than that seen in the SnL Index which is not unexpected given the nature of the data and the differing methods of obtaining it: intermediate categories, for example, are harder to define for data extracted from case notes where ratings tend to fall more readily into yes/no; present/absent and done/not done categories. It was also possible (in most cases) to explore the events reported in the interview using probes to clarify the responses and obtain more detailed information before items were rated, something which is not feasible when rating items from clinical or other care notes.

Moreover, most of the items in the PPCI schedule could be applied to all patients in the sample whereas the SnL Checklist contained more items that related to the delivery of services, some of which had not been received by participants in the study. It is interesting to note however that there was some discrepancy between the services which were recorded as being delivered and the services that patients recognised they had received. The most obvious example of this was 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 deemed appropriate because they are indicators of a process of care being applied, (assessment), albeit one that does not necessarily result in an intervention being offered. Patients, however, rarely reported these episodes spontaneously and only rated continuing care in these situations if actual therapy or other care was received. As a result 84 incidents (84% valid cases) of any type of community care were recorded from the case notes 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 we will return to this in a later section. It also reflects the qualitative study where we found a mismatch between patients' recognition and recall of contact with health care practitioners.

Table 4f: 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)	

4.5.1 Item Clusters

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

Table 4g Cluster groupings for the PPCI Items

Cluster Grouping	PPCI Items	Cluster Mean (sd)
Hospital Care Sub-group	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 Sub-group	7.) GP Housecalls 8.) GP Care 12.) Relationship with GP	0.99 (1.26)
Community Care Sub-group	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 Sub-group	10.) Information giving 11.) Information transfer (between agencies)	0.89 (1.14)
Social Function Sub-group	6.) Pt/family rating of 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)

The histograms for two cluster sub-groups scores (Hospital Care and Social Function) showed a normal distribution of scores but the remaining clusters were exceptions to this pattern. GP Care and the Information cluster were skewed towards higher scores, and Community Care was skewed towards the lower end of the scale. (See Appendix J, pp. 252-253). The same factors were used for comparison of clusters sub-scores as those examined in the SnL data but, given the varying patterns of distribution, both parametric and non-parametric statistical methods were applied. 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 test. The results of both statistical approaches were the same (except for a few minor differences, which are indicated in the footnotes of tables of results. Only the parametric test results are reported in full for clarity.

4.5.2 The association of social and demographic factors with patient perceived continuity of care

Socio-demographic characteristics had a different relationship with the PPCI scores derived from the patient interviews than had been noted for the SnL checklist scores. Gender, which had shown no association with the SnL scores, showed a difference in social functioning with females scoring significantly lower than males in this section (p = 0.017). This could be explained by a higher proportion of elderly widows in the sample reporting more isolated existences than their male counterparts. The findings for marital status showed a stronger association with the 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 reported lower ratings for GP care (p = 0.031); Information transfer (p = 0.047) and the overall score for the PPCI (p = 0.005).

In contrast to the SnL tests, age and continence showed no association with the PPCI scores, and 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.

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. This was also the case for the socio-demographic associations that were identified for the SnL index. Table 4h below summarises the significant results.

Table 4h: The Effect of Gender and Marital Status on the PPCI

Factor	PPCI Cluster	Mean difference[1] (95% CI)	t	df	p-value[2]
Gender: *Male v Female*	Social Function	0.95 (0.17 to 1.74)	2.42	108	0.017
Marital Status: *Living alone v Living with partner*[3]	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

Notes:
1.) Means compared using Student t-tests
2.) Significance set at 95% level. Tests for remaining variables not significantly different.
3.) 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.

4.5.3 Post-Stroke Disability

Whereas the severity of stroke and factors associated with stroke severity seemed to be the major influences in the SnL scores they had less association with the patient perceived scores. Early discharge still had a negative association with the overall score for the PPCI. Patients who had had longer admissions reported higher scores than those discharged within a week (p = 0.053) but significance was marginal. Early discharge had more association with the hospital sub-scores with longer stay patients scoring higher (p = 0.000) than those who left hospital within a week of their stroke, and on the community care cluster (p = 0.033). This finding is consistent with a longer admission resulting from more dependency and thus leading to more care input, and more care events to be rated. Some elderly, early discharges felt that they had been sent home too soon and this too could have a negative influence on patient perceived scores. Moreover, two of the early discharges represented in this sample were the result of patients taking their own discharge. This caused 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 $p = 0.037$ respectively), and also with scores for information transfer and social function: $p = 0.014$ and $p = 0.021$ respectively.

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 so strong when severity was measured by change in BI pre and post-stroke (the method we had used to assess post-stroke disability in the SnL analysis). When the impact of stroke was assessed by a change of 3 or more points no significant differences were found between more severe strokes and those whose stroke had had a lesser impact except for the information cluster ($p = 0.006$). This finding seems to suggest that, in this sample, it was overall dependency (and possibly the co-morbidity of patients) that was the factor most strongly associated with the PPCI results rather than the severity of the index stroke. Table 4i (p. 123) summarises the significant findings.

Table 4i: The Effect of Stroke Severity on the PPCI

Factor	PPCI Cluster	Mean difference[1] (95% CI)	t	df	p-value[2]
Stroke Severity: *Barthel Index ≤18 v ≥19 (at baseline)*	*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*
Stroke Severity: *High v Low Impact (Change in BI >3)*[3]	*Information Transfer*	*0.66 (0.19 to 1.12)*	*2.78*	*106*	*0.006*
Early discharge: *<7 days v >7 days*	*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*

Notes:
1.) Means compared using Student t-tests
2.) Significance set at 95% level. Tests for remaining variables not significantly different.
3.) 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).

4.5.4 Mood and Psycho-Social Factors

In contrast to the findings of the SnL, mood measured by the General Health Questionnaire 28 item questionnaire (GHQ_28) demonstrated a consistent association with the PPCI. The total score and the social function component of the PPCI were significantly different for GHQ-derived cases and non-cases at all time points[†]. The GHQ cases reported significantly lower scores on the PPCI than non-cases on all aspects of the PPCI at one or more time points. These findings are not unexpected as the PPCI is a patient-centred measure as distinct from the SnL Index, which uses a clinical audit method of data collection. It has been well established that ratings of health care and responses to self-report measures of HRQoL are affected by respondents' mood states in a variety of settings.[44-46]

[†] *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.*

We identified a strong inverse association between the PPCI total score and the Social Dysfunction sub-scale of the GHQ_28. (at T1; T3 and T5) and for the Social function cluster (with GHQ Social Dysfunction at T3 and T5). The PPCI GP and community care sub-scales also demonstrated a negative association with GHQ social dysfunction at specified time-points. These findings seem to suggest that those feeling less connected to others may require more support in order to facilitate their care and thereby enhance their perceptions of it. This effect has been recognised in other settings such as maternity care.[47]

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

Table 4j: The Effect of Mood State on the PPCI

GHQ Cases	PPCI Cluster	Mean difference[1] (95% CI)	t	df	p-value[2]
T1:Baseline *2 to 4 weeks post-stroke*	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
T2: *6 to 8 weeks post-stroke*	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
T3: *12 to 14 weeks post-stroke*	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
T4: *6 months post-stroke*	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
T5: *12 months post-stroke*	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

Notes:
1.) Means compared using Student t-tests.
2.) Significance set at 95% level. Tests for remaining variables not significantly.
3.) Results using non-parametric methods (Mann-Whitney Test) were the same except for Information Transfer, which was not significantly different for the T2 groups.

Table 4k: Correlation Table for Social Function Sub-Scales

Variable	Patients (N)	Pearson coefficient	p-value
PPCI Total Score & GHQ social dysfunction T1	109	-0.28	0.003
PPCI Total Score & GHQ social dysfunction T3[1]	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[1]	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[1]	80	-0.31	0.005

1. These association were also significant using Spearman's rho

4.5.5 The PPCI patient rated items

At the end of the 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) related to patients' perceptions of self in terms of recovery, dependence on others, control and enjoyment of life. The remaining six items were ratings of their perceptions of services, and here we included items which we theorised might be confounding factors in measuring perceived continuity such as quality of care and patient satisfaction. We also included elements that were present in the existing and accepted models of continuity, and which we knew from our qualitative work stroke patients would recognise, such as coordination of care, level of input, information transfer and trust. Each item was rated on a 10-point linear analogue scale. We decided to include a self-report section in the patient assessment of care processes because our principal measure, the PPCI, was interviewer rated. The patient ratings would enable us to explain and validate the PPCI ratings to some extent. Full details of the items and scale descriptors are shown in Appendix G.

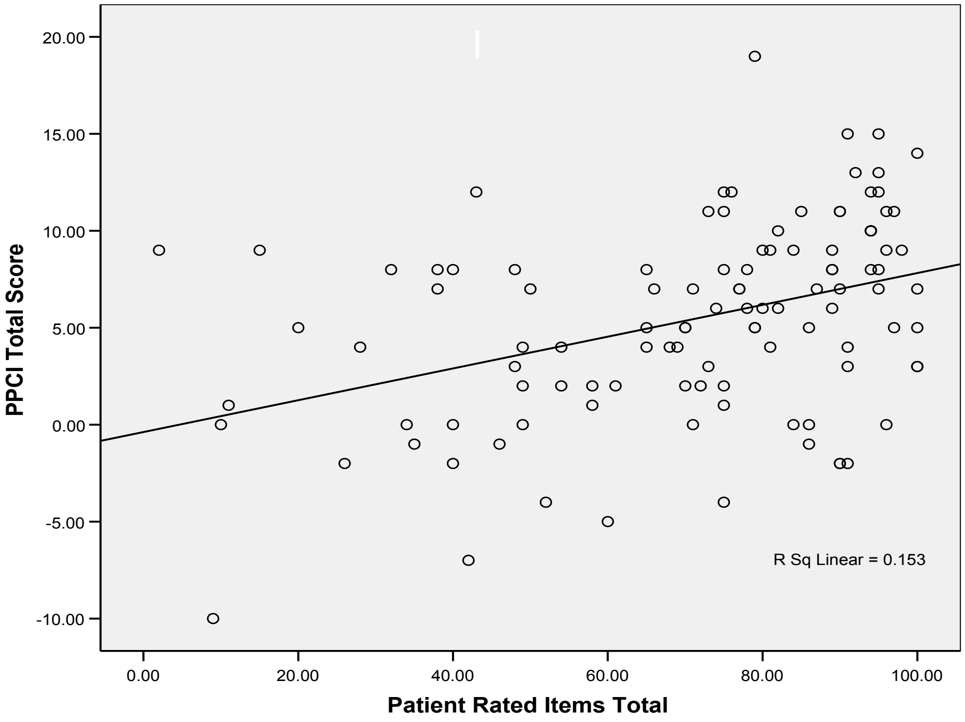
Histograms (not reproduced) showed the distributions of total scores for all items were biased towards the higher end of the scale. Table 4m (p. 127) shows the mean scores, standard deviations and ranges for each item.

Table 4m: 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

Not unexpectedly, scores for the patient rated items showed a moderately good association with the total score for the PPCI. As Figures 4c to 4e show below, we found a significant correlation between the PPCI and the total score for all items (r = 0.40), the ratings of the service (r = 0.41) and the ratings of self (r = 0.28). All were significant at p < 0.01.

Figure 4c: Correlation between PPCI and Patient Rated Items

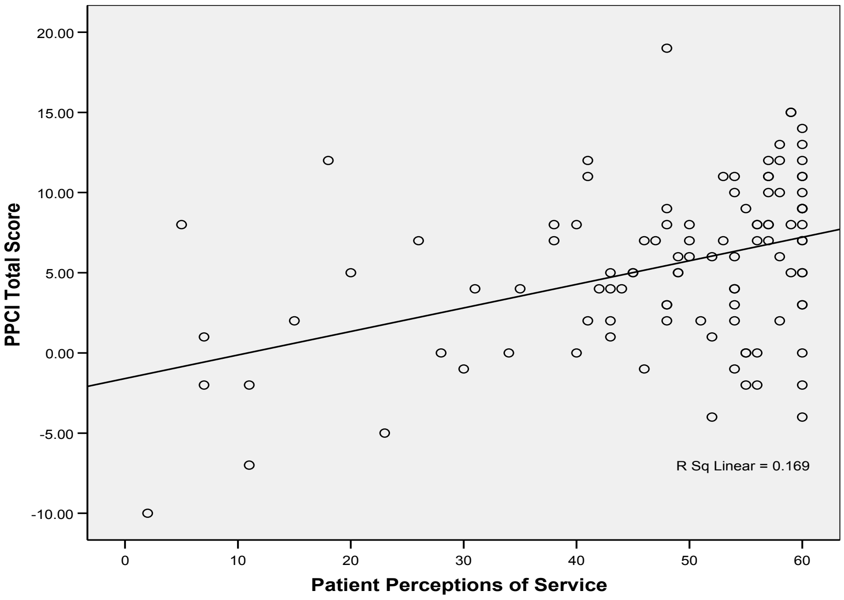


r = 0.40; p <0.01

Figure 4d: Correlation between PPCI and Patient Perceptions of Self

r = 0.28; p <0.01

Figure 4e: Correlation between PPCI and Perceptions of Service



r = 0.40; p <0.01

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

Figure 4f: Box plot showing perceptions of service by gender

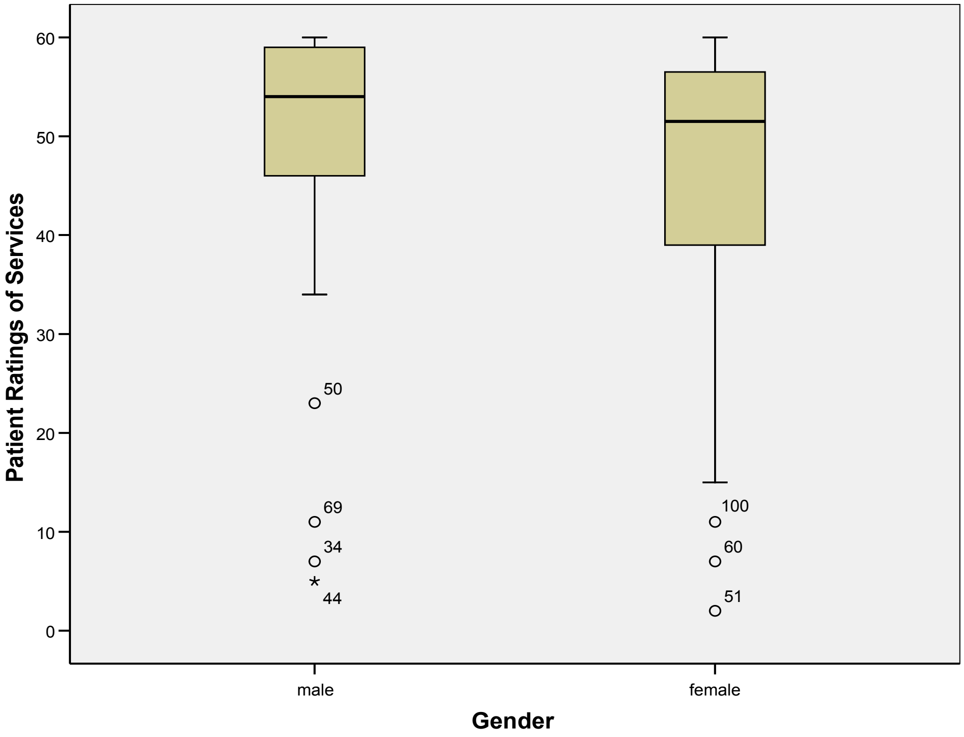
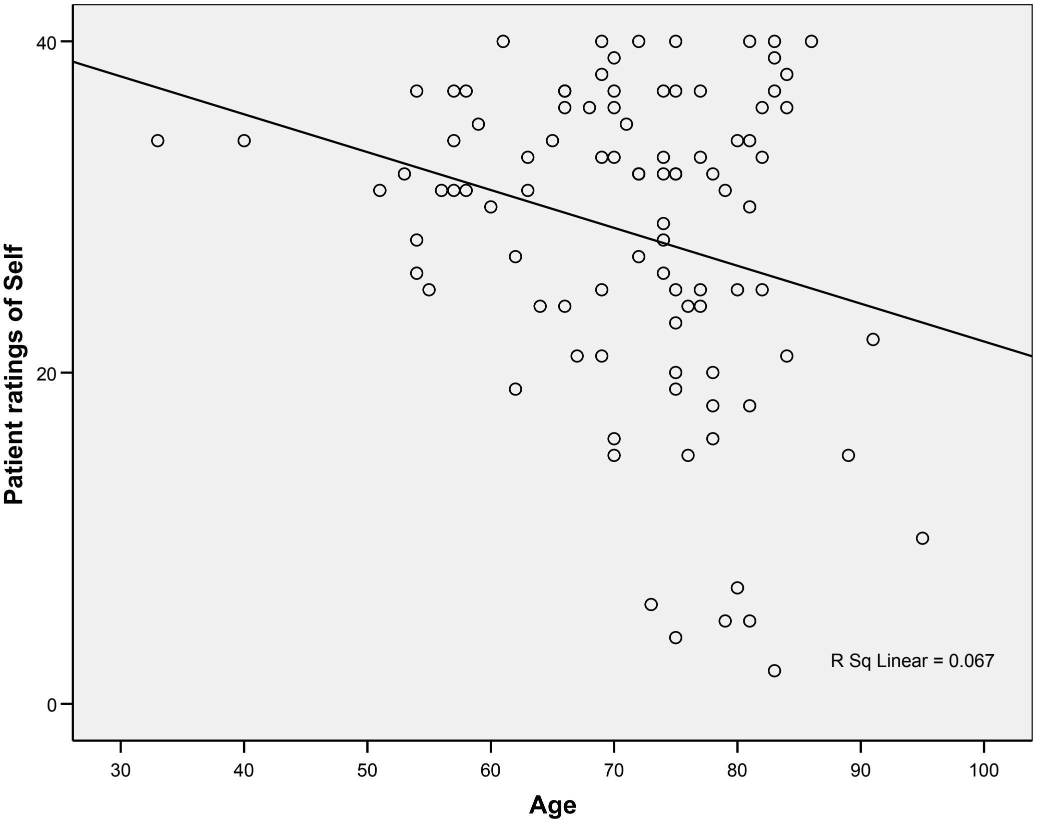


Figure 4g (p. 131) shows that age was inversely correlated with ratings of self ($r = -0.26$; $p < 0.05$) but was not significantly different for older and younger age groups in independent t-tests. There was however a significant association between poorer ratings of self and female gender (Mean difference = 6.65: 95% CI 2.96 to 10.33; $t = 3.58$; $df = 93$; $p = 0.001$). Both findings are consistent with accepted theories of self image and the way it is perceived in relation to age and chronic illness.

Figure 4g: Scatterplot of patient ratings of self by age



r = -0.26; p < 0.05

4.5.6 Interpreting the results of the PPCI

The issue of recall and recognition of aspects of care was a recurring theme throughout the interviews. Patients did not recognise some aspects of care that we had hypothesised would denote continuity in care processes. We were able to detect where discrepancies arose by cross-referencing with the SnL Checklist from which we were usually able to obtain accurate information. We have already discussed this in relation to community therapy and care needs assessments at the beginning of Section 4.5 (p. 114) but we also found that patients had problems recalling MDT and goal setting meetings, as well as home visits. Given that the patient would not necessarily have been present at all or any of these events, it is perhaps not surprising that these items are often poorly recalled. Data from the SnL, for example, suggests that nearly all eligible patients in our study group received a home visit whereas only 70% of them recalled this event when asked about it during the PPC interview. This figure is compatible with that reported in a recent National Audit Office survey, but shows that patient reported data is not necessarily a good indicator of service provision.[6]

We also found instances of patients' accounts providing much better information than the case note reviews, for example when rating admission mode. We were not able to learn much about the admission process from the case notes and the patients' ratings in this section were often a better indicator of how smoothly this transition had been achieved. Differentiation was the main problem for rating this item on the PPCI because experiences varied. We found accounts of bad experiences of getting into hospital followed by excellent care once they get to the

ASU, 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 another issue, as was distinguishing between separate and unrelated episodes in some cases. 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.

4.5.6.1 Case Studies

Neither the SnL nor the PPCI nor the patient-rated scores can be regarded as representing a full assessment of the care our patients received for their stroke. In our study group it was obvious that there were few “typical cases”, and that different scenarios could result in similar scores on the measures and vice versa. For example, scores on the SnL were dependent on certain care processes having occurred; lower scores do not always mean poor care, if services had not been delivered because they were not appropriate. The relationship between care input and SnL scores is therefore not straightforward. Similarly, the relationship between patient perceived care measured by the PPCI including the self-rated items and care received is complex. In order to understand it in a real world context we present a series of case studies drawn from our study group.

> ***Case Study #579:*** *A 54yr-old divorced male smoker suffered a minor stroke, self-referred to A&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 after discharge from hospital. Nonetheless he was very satisfied with his care overall, presented a positive account in the PPCI and rated it highly.

SnL Score = -1 PPCI Score = 10
Service Rating = 54 Self Rating = 28 T1 Barthel = 20

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. In contrast a very similar case with a comparable SnL score illustrates a different response to perceived care:

Case Study #466: *A 62yr-old divorced female with a strong family history of cardiovascular disease suffered a minor stroke at home. She attended her GP surgery who referred her 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 attempts 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.*

SnL Score = 0 PPCI Score = 7
Service Rating = 38 Self Rating = Missing T1 Barthel = 20

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

> ***Case Study #594:*** *A 55yr-old married man suffered a major stroke on his way to work. He was admitted as an emergency through A&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 by his wife with personal care, who also took care of all the household duties. He was unable to return to work on account of his residual disability.*
>
> SnL Score = 11 PPCI Score = 7
> Service Rating = 46 Self Rating = 25 T1 Barthel = 17

Current government policy demands that patients should be given choice, and the opportunities to take responsibility for their own care. Communication and information transfer between clinics and specialties become particularly important if vulnerable groups are not to be disadvantaged by this model of care. Where record-based or independent ratings of care in our study group indicated that appropriate care had not been received, we found unmet needs were often the result of patients opting out of services. Our findings showed that safeguards are required for patients who are less capable or less aware of the consequences of certain actions or inactions if the continuity of their ongoing care is not to be compromised. We found 2 examples of self-discharges in the study who missed out on referrals to ICT and other services, and were not recalled for follow-up because they had left hospital before assessments had been completed and appropriate referrals made and services arranged.

> ***Case Study #553:*** *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. 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".*
>
> SnL Score = 1 PPCI Score = -7
> Service Rating = 11 Self Rating = 31 T1 Barthel = 19

Key factors in continuity (as distinct from quality care and patient satisfaction) seem to be communication and collaborative working. In the cases we studied we found evidence 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 were sometimes exacerbated by patient behaviours and attitudes, as in Case Study #553 but, in our final case study, it was the poor psychological status of the patient that proved a barrier to ongoing care:

> ***Case Study #531:*** *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.*
>
> SnL Score = 7 PPCI Score = -10
> Service Rating = 2 Self Rating = 7 T1 Barthel = 13

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 PPC interview was conducted with the patient and main carer (her daughter) who described 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 daughter) and self (by the patient). The hospital records revealed little except a record of failure to attend several clinic appointments and one record that stated 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, showed evidence of home visits by the GP and CPN which had not been reported by the family nor by the patient, (but whose recall was very poor). It is not possible to determine from the data available exactly what went wrong in this case but what it does show is 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 as a result of personal choice or psychological (or physical) incapacity, is difficult to address.

In the next section we return to our quantitative assessment of the new measures and describe our strategy for determining the underlying constructs that the SnL and the PPCI are capturing, before proceeding to explore their association with patient outcomes.

4.6 Confirmatory factor analysis

4.6.1 Method

It had been anticipated that in order to assess continuity of care, some variables would be measured repeatedly in the study group at the same assessment time-points as the cohort study. Since these repeated measures would have been clustered within patients, it was proposed in our original submission that a multi-level modelling (MLM) framework would be employed for statistical analysis. For example, patient mood was measured at five time points (T1 to T5) for each patient and could have been modelled as a multi-level time series. In the SOS2 cohort however greater benefit had been found with longitudinal latent class analysis, which had revealed consistent mood trajectories for stroke patients during rehabilitation.

Having assessed the situation, we decided that our two measures of care were best used over the whole period of rehabilitation rather than at time points along it and consequently there were no repeated measures requiring use of MLM. The measures constructed were targeted at the overall patient care episode and the care experienced by patients throughout their care trajectory, as previously explained in Section 4.3 (p. 92). Single measures were therefore taken for each patient between 6 and 12 months post-index stroke rather than repeated measurements. The only repeated measures taken were the assessments of function and mood from the cohort study, both of which we theorised from our preliminary results seemed to have some impact upon care processes. Due to the consistency of trajectories found on the SOS2 cohort (as noted above), stroke severity could be well represented by the initial measures of patient disability, such as the Barthel Index.

The SnL Checklist and the PPCI Schedule were designed on the basis of the work that was done in the initial phase of our study. We had used the proposals of the SDO scoping report and the CHSRF workshop findings as a framework for constructing our measures, and the findings of our qualitative work and case note reviews to provide the detail relevant to stroke care. In this way we hoped to capture the characteristics of care that contributed to a continuing care process. However, after we had completed our preliminary analyses we remained unsure about what phenomena our indices were actually measuring. In a simple correlation matrix we found no correlation between the total SnL and PPCI scores. 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 (an association that was also tested using Spearman’s rho and remained despite the non-normal distributions of these cluster sub-scales). This suggested that the two indices may be measuring different aspects of the care process but which could overlap or coincide in certain domains.

The issue to be addressed by modelling therefore became that of determining how each of the measures contributed to the assessment of care processes and, as a by-product, disability. There was opportunity, given the number of available measures to derive latent constructs with greater construct validity using Structural Equation Modelling (SEM). This reduced the complexity of the situation to be modelled.

Our findings from Strand 1 and Strand 2 led us to hypothesise that our care measure derived from care records was confounded by the physical status of the patient, and that what we were measuring was in effect the intensity of care proportional to the disability of the patient. In the case of the patient-centred measure, our findings suggested to us that we were measuring patient perceived care, which was dependent to some degree on the patient's psychological state. We hypothesised therefore that there were two latent constructs: '*disability'* and '*patient perceived care',* underlying our measures.

On the basis of our preliminary analyses we theoretically identified a number of candidate indicator variables as potentially relevant to our latent construct patient perceived care. These indicator variables were our two new measures (the SnL and the PPCI), plus four items from the self-reported ratings of care that we had obtained from our SOS3 participants:

- Quality of care
- Co-ordination of care
- Co-ordination of information
- Patient satisfaction
- PPCI
- SnL

We excluded the ratings of trust and level of care because these two items do not specifically appraise "received" care. The first is susceptible to factors external to care delivery like personality and mood, and the second is a subjective view of service input which, depending on the actual rather than perceived needs of the patient, may or may not be an accurate assessment of the services received.

As we have already discussed above (and in Section 4.4.3, p. 104), the results we obtained from the SnL had also led us to theorise that measurement of the nature of care process could be confounded in this method of measurement by the latent construct disability, which is usually significantly increased by a stroke event and influences the extent of care received by a patient. From the SOS2 cohort study of depressive symptoms in stroke we had a range of baseline and repeated measures of function for those patients that participated in SOS3:

- The Barthel Index
- Rivermead Mobility Index (RMI)
- Mini Mental State Examination (MMSE)
- General Health Questionnaire (GHQ)

These had been measured at five time points (including the baseline measure) over a one year longitudinal study of outcomes. It has been long established that these measured indicators represent aspects of patients' functional, emotional and cognitive disability, which will influence the care provided. However, it should be noted all methods of measurement have an error associated with them and it can be assumed that none of the above measurement instruments fully 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. Since the majority of the linkages between the measures and the latent constructs we had hypothesised were known from our initial explorations of the data, we decided to proceed with a confirmatory factor analysis rather than an exploratory factory analysis.

We undertook a confirmatory factor analysis to establish the number of constituent measured indicators that were most relevant to the constructs "*patient perceived care"* and "*disability",* and which we had already identified as a major confounding factor in our results. We also wanted to determine the loadings of the indicators on the constructs. With multiple indicators defining the constructs, the shared covariances are less influenced by variation unrelated to the constructs. As a consequence construct validity is increased.

For analysis subsequent to this confirmatory analysis, we intended that the constructs would replace a number of strongly correlated, measured indicators. The confirmatory factor analysis benefits from co-linearity between these indicators but if the indicators were to be used in, for example, a generalised regression model, then this co-linearity would cause variance inflation problems, and unstable and imprecise estimates. Thus the confirmatory factor analysis step in the analysis strategy was essential.

The indicators 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 as it is known that lower scores of Barthel are associated with increased disability. For *patient 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 we took the square root of the scores to transform the data and improve the normality of the distribution. Table 4n (p. 145) shows the descriptive statistics for the variables used in this stage of the analysis:

Table 4n: Descriptive statistics for variables in the factor analysis

	N	Minimum	Maximum	Mean		Std. Deviation
Variable	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

4.6.2 Results

Figure 4h (p. 148) shows a diagrammatic representation of the model we obtained following fitting of the regression coefficients in the confirmatory factor analysis. It can be seen from the standardised regression weights that the T1 (Baseline) Barthel, Rivermead, and MMSE all contributed strongly to disability as we had anticipated from the results of our less sophisticated analyses. The SnL measure showed an association with disability in this model and the GHQ, which had been given a square-root transformation to improve normality, was also associated with disability, although not so strongly as the primary components. The latent construct perceived care was found to be strongly associated with quality, co-ordination, information, and the PPCI, with all the standardised regression weights being large (more than 0.75). A reasonable association (standardised regression weight of 0.44) was found with PPCI, and a small negative association (-0.23) with transformed GHQ. The SnL measure, which we had found to be associated with disability was not significantly associated with perceived care.

When we explored the association between the two newly identified latent constructs disability and perceived care, we found they were not correlated - as the plot, Figure 4j (p. 149), shows. Only a very slight, non-significant correlation (r=0.17, p=0.09) exists between the residuals of PPCI and SnL once disability and perceived care had been adjusted for, suggesting that, as we had 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. The overall fit to the model produced was satisfactory with a chi-squared value of 44.12 on 33 degrees of freedom. This assessment 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 the degrees of freedom which was less than 2
- The root-mean-square error approximation (RMSEA) which was 0.055 (90%CI: 0.00 to 0.094) and thus represented a reasonable fit. Assessed by this method, 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 our model) and the upper value is not very large (less than 0.08).

The null hypothesis is that the RMSEA is 0.05, a close fitting model. The p value examines the alternative hypothesis that the RMSEA is greater than 0.05. If the p value for the model exceeds 0.05 it can thus be concluded that the model fit is reasonably “close”.[48]

Our upper confidence interval value was more than 0.08 but the likelihood of obtaining any better fit to our model was not anticipated since, although the majority of the factors were approximately normally distributed, the key factor, the Barthel Index, was not and we found no obvious transformation that could be applied to improve the normality.

Figure 4h: Latent constructs derived from the SnL and PPCI using structural equation modelling

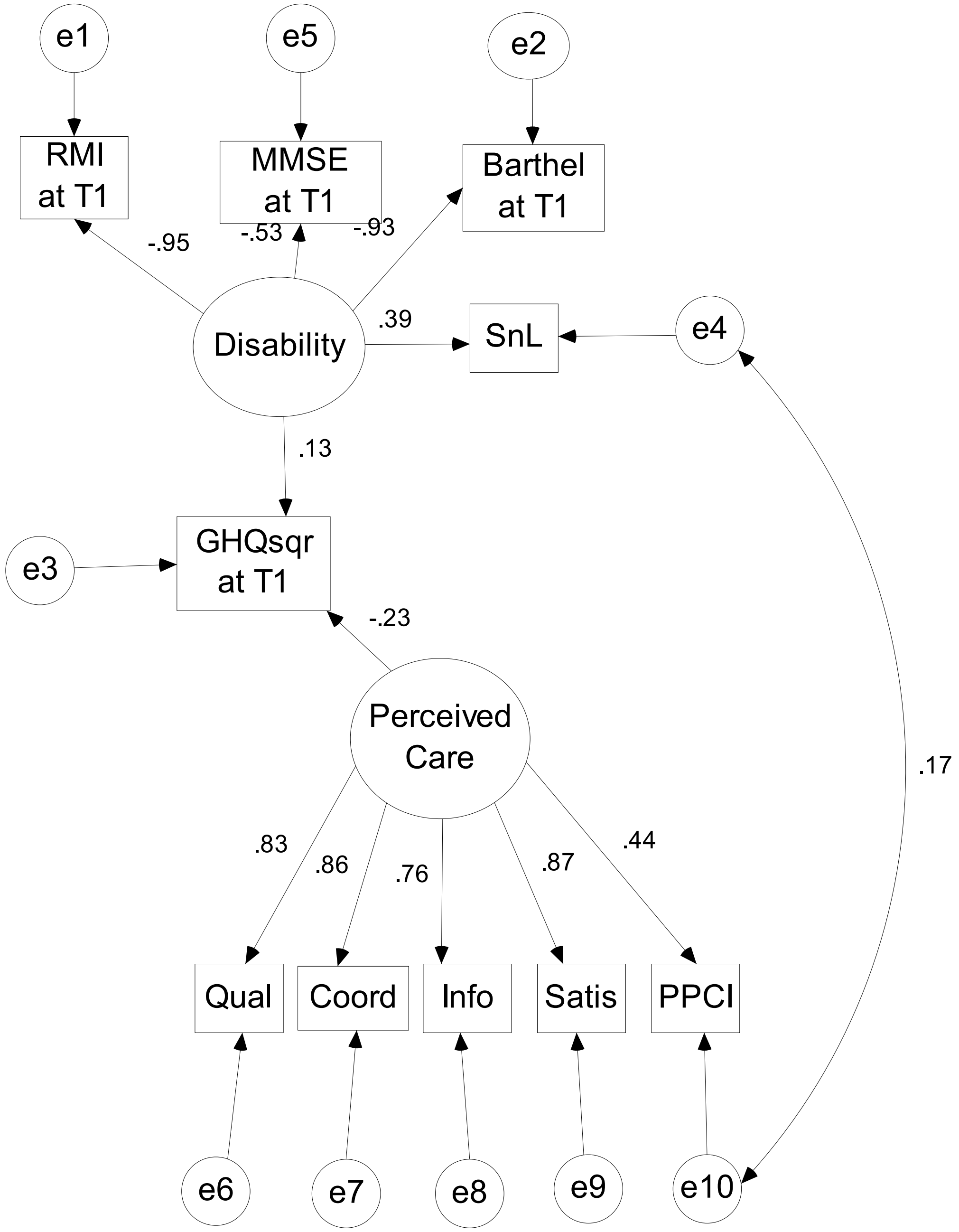
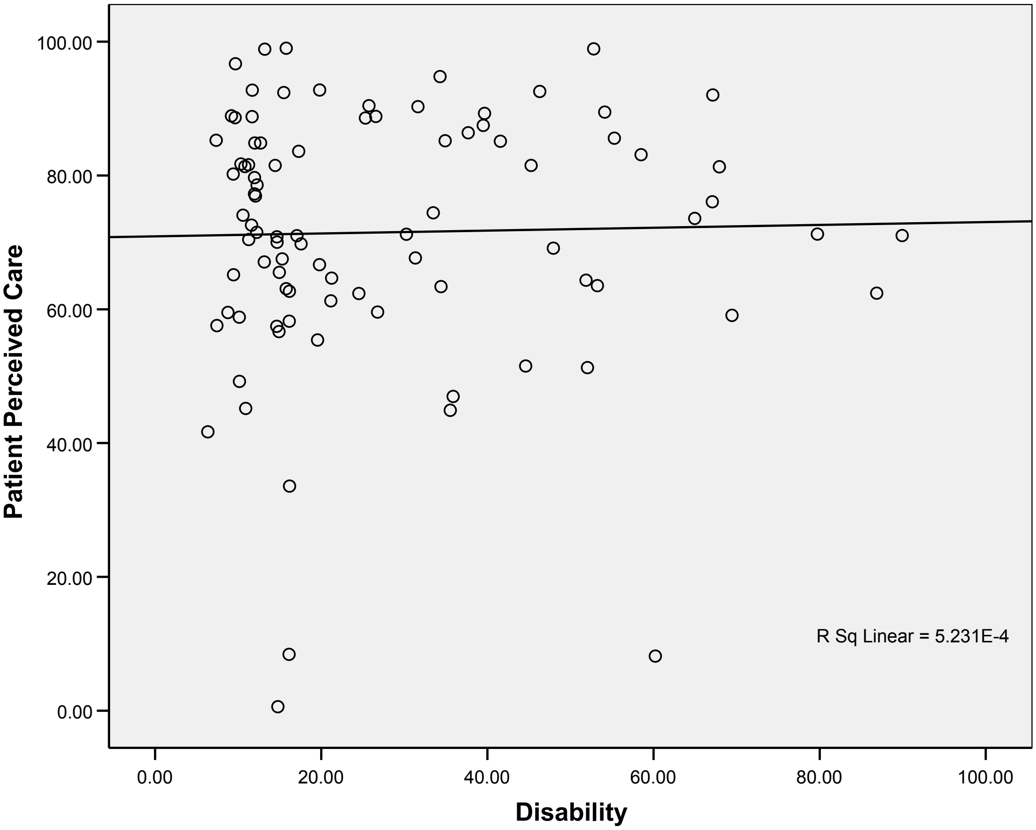


Figure 4j: Correlation between the latent constructs

(“*Patient Perceived Care*” and “*Disability*” derived from the SnL and the PPCI)



4.7 Evaluating the effects of disability and perceived care.

Our preliminary analyses had shown that the SnL and the PPCI behaved in different ways when applied to our sample of stroke patients: the SnL was associated with measures of physical function and indicators of disability whereas the PPCI was more closely associated with mood and psychosocial well-being as measured by the GHQ_28. We had designed both measures around a similar framework but applied them 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. A confirmatory factor analysis showed that the aspects of the health care process that our two new indices were measuring, and their relationship to health status and well-being, might be different and not fully understood.

The original aim of our proposal was to develop new measures of continuity of care and use them to determine whether continuity in care processes 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 thus we had a range of 12 month outcome variables available on which to base an assessment of impact. In order to do this we had to convert the latent constructs into variables to replace the simple aggregated scores of our new instruments. This would enable them to be used in a further stage of analysis.

4.7.1 Creating the latent variables

Latent constructs with improved construct validity had been calculated from the confirmatory factor analysis reported in Section 4.6 (p.139). The regression weights for the two constructs were taken from the unstandardised confirmatory factor analysis. These 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 we derived two new latent variables that could be used in the next stage of analysis including our analysis of outcomes. It should be noted that higher scores on the disability construct variable represent poorer function (unlike the BI where high scores equal better function) whereas higher scores for perceived care indicate better care.

4.7.2 Results

4.7.2.1 Age and Gender

We began by examining the association between our constructs of disability and perceived care with age and gender. The box plot (Figure 4k, p. 152) 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. For age we plotted the data on a scatter plot (Figure 4m, p. 152) and found only a very slight association between worse disability and age, with a tiny r-square value which was influenced by the two younger out-lying patients. Removing these two cases would almost certainly remove the association entirely.

Figure 4k: Gender and Disability

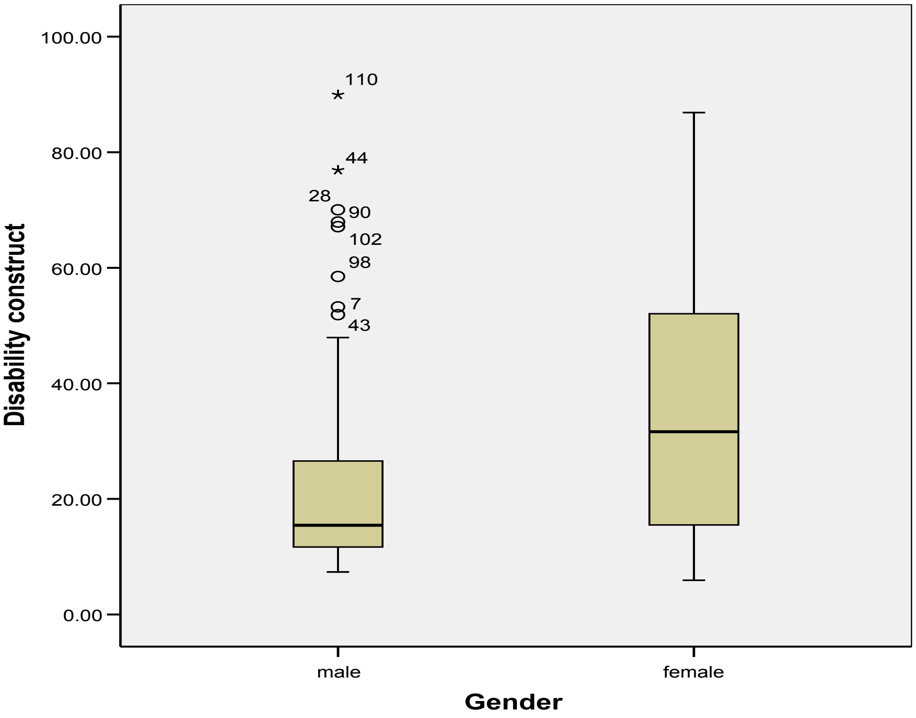
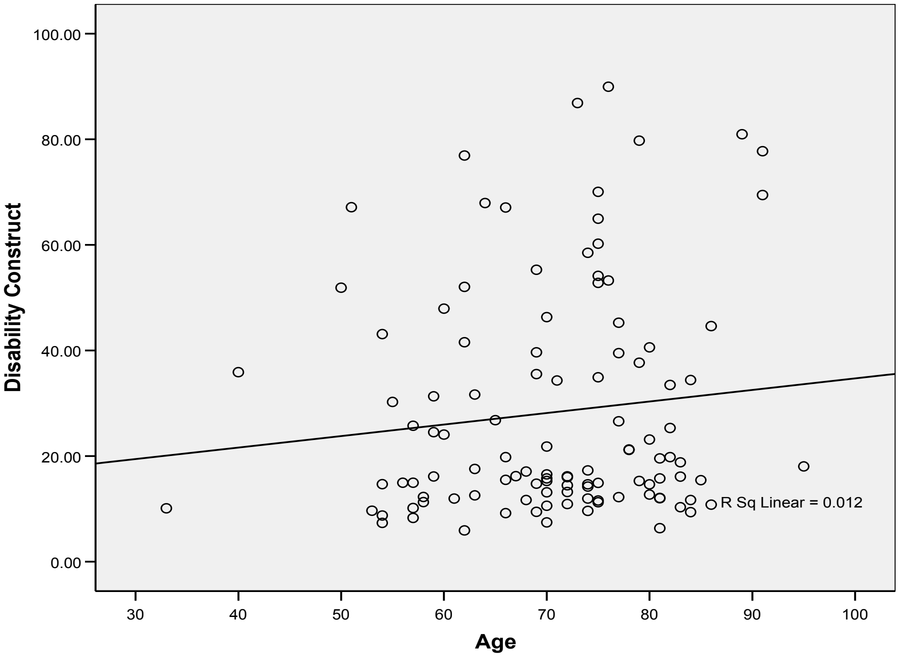
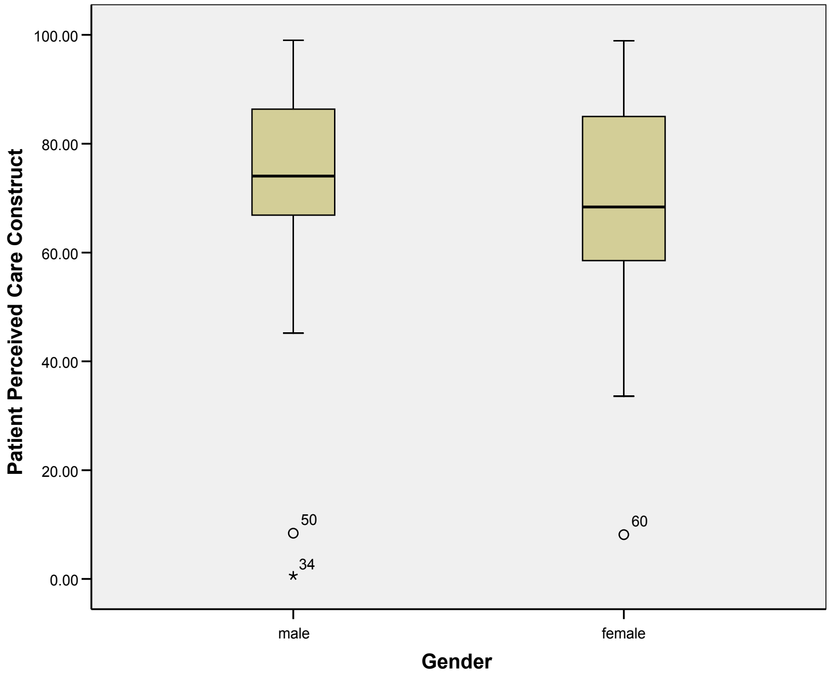


Figure 4m: Age and Disability



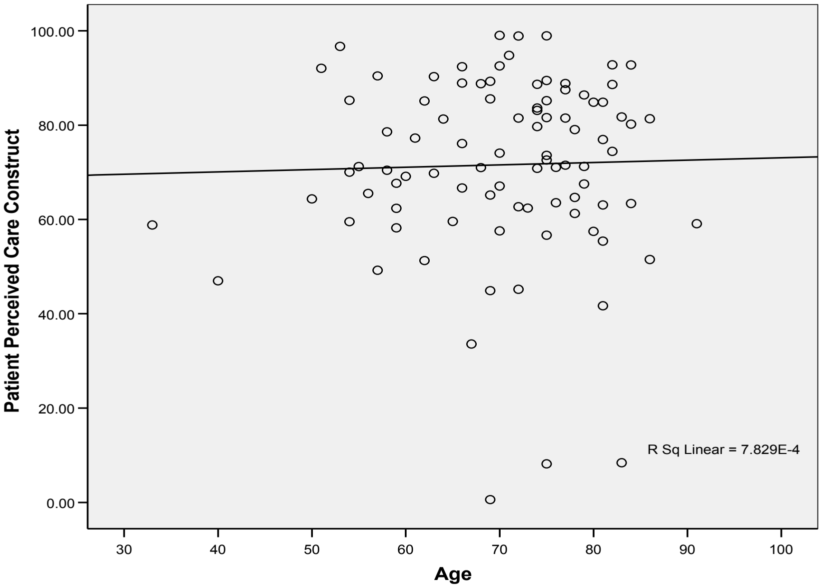
For the patient perceived care construct we found a similar pattern for gender to that we had seen with the disability construct, with lower (worse) median scores for the perceived care construct being associated with female gender as shown below in Figure 4n.

Figure 4n: Gender and Perceived Care



There was no association between age and the perceived care construct. The scatterplot (Figure 4p, p.154) shows an almost flat fit line for the data. This is not surprising as our findings for the self-reported item scores and the PPCI total scores had not shown any association with age in the preliminary analyses.

Figure 4p: Age and Perceived Care



4.7.2.2 Assessing the impact on outcomes

The next stage of our analysis strategy was to examine the effect of disability and perceived care on key outcome measures. For outcomes of physical well being the most common measure might be regarded as the Barthel Index. It should be noted here that the outcome measure physical rehabilitation proposed is the Barthel measured at 12 months (T5) whereas the covariate latent construct was based on Barthel measured at baseline (T1: 2 to 6 weeks post-index stroke), thus the two variables measure different states of patient well-being and there was no confounding between them in this stage of the analysis.

From our longitudinal cohort data we noted that at the time points shortly after stroke, T2 to T4, the Barthel Index represented a wide range of functional states. However, after 12 months (T5) many patients had rehabilitated and the majority of patients 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 score 20 on Barthel as zero (rehabilitated) and those who score less than 20 as one (not rehabilitated). That is higher scores mean poorer outcomes as opposed to the original index where higher scores equal better function. The binary outcome variable outcome 'rehabilitated' was then regressed logistically upon the two constructs to assess their impact on physical rehabilitation.

We had noted from our previous analyses that mood was associated with the PPCI but not with the SnL. The impact of disability and perceived care on the probability of physical rehabilitation at 12 months being <u>unsuccessful</u> can be seen from the fitted logistic regression:

$$\textit{Logit (Not rehabilitated)} = \textit{Constant}+0.09\textit{disability}-0.03\textit{perceived care}$$

Where the variable disability is three times more important in predicting a poorer outcome for rehabilitation than perceived *care.*

From the structural equation model we had found that mood at T1 contributed to both the latent constructs we had identified. We were thus interested to explore how each of the new constructs would behave as predictors if mood at T5 was the outcome. In order to adjust for the skewed distribution of the scores we performed a square-root transformation of the T5 GHQ measured at 12 months. This variable was then regressed linearly upon the same two covariate latent constructs. Again it should be noted that the outcome is based on T5 GHQ at 12 months whereas one covariate depends upon T1 GHQ measured at baseline.

We took the outcome measure for mood, the GHQ score at 12 months (T5) from the SOS2 cohort study data and found from the linear regression equation that in this case it was the perceived *care* that had the best predictive power, more than twice that of disability: Note: High scores on the GHQ_28 represent worse mood states

$$\sqrt{(Mood)} = constant - 0.02 perceived\ care + 0.01 disability$$

4.8 Interpreting the impact on patient outcomes

4.8.1 Defining the constructs

When we modelled the SnL with the PPCI in our structural equation we had found that there was no association between the two measures except for a slight association via the residuals. (See Figures 4h and 4j, pp. 148 and 149). This suggests that although the two measures are not correlated they may have some factor in common that influences both of them. We could hypothesise that this might be mood which was the only factor that contributed to both constructs.

We found that the SnL contributed to the measurement of the construct disability with other measures of physical and cognitive function. Our previous analyses had led us to hypothesise that the SnL was actually a measure of care intensity –

could it therefore be capturing the increased care input for patients with more disabling strokes?

We transformed the construct variables to a 100 scale as described earlier in this section in order to make comparisons between them easier when they were covariates in the regression analysis. For the disability outcomes, the disability construct was three times as important as the perceived care construct. For the mood outcome we found a clear association between mood and perceived care where perceived care was twice as important as disability in predicting mood at one year.

The impact on outcomes can therefore be described using our data range to define best and worse case scenarios:

For unsuccessful rehabilitation as the outcome:

The model is:

$$\mathit{Logit}(\mathit{Barthel}<20)= -0.932+0.089*\mathit{Disablity}-0.029*\mathit{Perceived\ Care}$$

So that for

Worst case (disability = 90, perceived care = 1) prob(Barthel<20)=0.999

Best case (disability = 6, perceived care = 99) prob(Barthel<20)=0.0367

In other words, for the worst case scenario poor outcome occurs 99.9% of time and for best case 3.7% of the time.

For mood as the outcome:

- In the worst case where the disability construct score is 90 (poor function) and perceived care is 1 (lower perception of care), the predicted GHQ score would be 13 (above the cut-off point for cases of higher psychological distress).
- In the best case where disability construct score is 6 (better function) and perceived care is 99 (higher perception of care), the predicted GHQ score would be 0 (well below the cut-off for “caseness” on the GHQ_28).

What we do not fully understand is the nature of the association and the role of the PPCI in this relationship but as we have previously mentioned, accepted theories of evidence suggest that mood states influence not only the way in which life events are perceived and interpreted but also subjective responses to questionnaires.

4.8.2 Interpreting the impact on outcomes

From our associated work on the SOS2 cohort study we learned that mood, independent of early disability, predicted functional outcomes, measured by the Barthel Index score, for patients one year after stroke. In a longitudinal multi-level analysis (reported elsewhere) we identified four distinct trajectories for patients in the SOS2 cohort characterised by their mean GHQ scores at baseline.

When we applied the SnL and PPCI measures of care processes to the SOS3 study group we identified two underlying constructs: “*disability*” and “*perceived care*”. These constructs were derived from the two new measures in combination with associated variables. We represented the constructs as numeric variables using the regression weightings from our factor analysis, to examine their effect on functional and mood outcomes for patients.

Our results showed that disability predicted functional outcomes at one year. This result is not unsurprising given that the severity of the stroke and its disabling effect will usually be good predictors of the level of residual disability that the patient will experience. If the SnL score is measuring care intensity or input as we suspect, then the contribution of this measure to the disability construct would be understood as patients with more severe strokes and higher levels of residual disability would be likely to be in receipt of higher levels of care. The small effect from a component of perceived care is interesting. This was tested in a one by one binary regression analysis to see if the association remained, which it did, with borderline significance. We have demonstrated that mood affects ratings of patient perceived care earlier in this study and, given the association between mood and functional outcomes (independent of early disability) that we have shown in associated work, on one explanation for this finding could be the influence of mood. Poorer perceptions of care were consistently found to be associated with poor mood scores using different statistical methods.

We used the GHQ score at one year to define mood outcomes and found that lower perceived care scores were associated with poorer psychological well-being. This was not unexpected as we have shown the association between poor perceptions of care and poor mood scores through each stage of our analysis. However, the measurement of perceived care has an effect beyond that of psychological status alone: we also found a small component of disability in the regression model which is consistent with the findings from our SOS2 cohort data that a relationship exists between mood and functional status after stroke.

4.8.3 Limitations of the analysis

The prolonged period of development and testing that is associated with a new method of measurement reduced the number of patients in the SOS2 cohort that were available to participate in the later stages of the SOS3 continuity of care study. The early versions of the measures that we piloted initially did not always provide sufficient data, or data that could be modified for analysis.

4.8.4 Conclusions from strand 2

Our analysis has shown that it is possible to derive two care-related measures in stroke that predict rehabilitation outcomes. One measure (SnL) was derived from case note data. Although attempting to record aspects of longitudinal and managerial continuity particularly, it was confounded with intensity and duration of treatment – both associations with stroke-related disability. The other measure (PPCI) was derived from patient-reported perceptions of care. Although the interview in which these perceptions were identified was structured according to existing notions of continuity of care, the measure was confounded with perceptions of quality of and satisfaction with care and was associated with the patient’s emotional state.

Both measures were associated with rehabilitation outcomes, the PPCI association being less easy to interpret than that with SnL. There may be reverse causality (emerging poor outcomes lead to perceptions of poor care); mood may be an important mediating variable between care and outcomes, or patients may be able to identify aspects of their care that genuinely make a difference.

In the third strand of our work we have undertaken further qualitative work aimed at contextualising our findings in the professional literature on continuity of care, and in the accounts of stroke service provision offered by health care staff.

4.9 Strand 2: Summary of main findings

In Strand 2 of our work we designed two new measures of care. One of these, the Snakes and Ladders (SnL) checklist used the phases and transitions in stroke care as markers of continuity. This was tested in Study 4a in a sample of 126 patients drawn from the Stroke Association funded, longitudinal cohort study (SOS2). We found that it was difficult to separate an evaluation of continuity in the process of care from the input and intensity of care delivered thus the SnL checklist evaluation was driven largely by the physical status of the patient and their level of disability.

The second measure of perceived continuity (PPCI) used a structured interview format constructed around the conceptual framework derived from the CHSRF study. Responses were rated by the interviewer. This was tested in Study 4b using the same cohort of stroke patients in which the SnL was evaluated. The PPCI measure was found to be strongly associated with mood and psychosocial wellbeing. We acknowledged however that causality was not straightforward in this evaluation since emerging poor outcomes may lead to perceptions of poor care, in which mood is an important mediating variable; or patients may be able to identify aspects of their care that genuinely make a difference.

As part of our evaluation in Strand 2 we undertook statistical modelling of our SnL and PPCI data. This showed that our two care-related measures in stroke could predict rehabilitation outcomes, and using the latent variables we derived from them we showed that worse psychological status and higher levels of disability were associated with poorer rehabilitation outcomes.

5 STRAND 3: COMMUNICATION: A KEY ELEMENT OF CONTINUITY?

5.1 Introduction

The first strand of our work included an in depth exploration of how care was perceived by stroke survivors. From our interviews with patients we found that their narratives of care did not contain or make reference to the managerial or relational elements of continuity that are part of the currently accepted model. We did find a recurring theme of communication and information transfer 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.

From the second strand of our study, in which we tried to quantify continuity of care, we found that the PPCI schedule and the SnL Index could measure some aspects of the care process in terms of care delivered and patients' perceptions of achieved 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 our model showed, influenced by mood status. Even so, the latent constructs we derived from our analyses of the responses were related to functional outcome. Overall, from our work with patients we learned two important things:

- Patients are able to form opinions about the many agencies involved in stroke care, and how they interact with them individually, but not about how agencies coordinate their activities;

- The vast majority of patients are unable to recognise the professionally - defined elements of continuity in their care.

In the light of these findings, we decided it was necessary to change the focus of our investigation away from the quantitative assessment of process indicators of stroke care and return to a qualitative assessment of the structural and organisational factors that support the care process.

In our original proposal we stated that we would seek input from the research team working on Topic 1, “Collaborative linkages inside and between organisations”, and draw on the short-term project “What are the current and future barriers to continuity of care in organisational and work force issues”. There was specific evidence from this work, a study of Intermediate Care, that communication played an important role in the organisation of care after stroke.[49] 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.[50 51] Based on this input, we proposed to examine the extent to which the people involved in the after-stroke care of our cohort members saw themselves as part of a “team” responsible for stroke care provision. The findings from the work on Topic 1 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 various agencies and was central to the effective co-ordination of care. Therefore, rather than seeking health professionals perspectives on continuity of care as our original proposal had stated, we decided to find out how health care professional 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 Studies 5a and 5b

5.2.1 Aims and Objectives

This third and final phase of our work aimed to explore communication between health care professionals in relation to stroke care by:

- Conducting focus groups with professionals to identify the implicit and explicit objectives of communication within and outwith local stroke services (Study 5a);
- Exploring how professionals understand service organisation as arranged to meet the above objectives, and how they use communication to coordinate their activities;
- Conducting face-to-face interviews with key personnel (service managers, senior clinicians) 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 (Study 5b);
- Reviewing policy documents of relevance to local stroke service delivery.

5.2.2 Method

The studies were conducted in the United Kingdom in an area covered by two Acute Trusts and (at that time) eight Primary Care Trusts. We used qualitative methods for both the studies we conducted:

Study 5a which involved an exploration of ‘communication’ in four focus groups with mainly hospital based health professionals. Part of the findings from this study, on who communicated within and between agencies, led to the development of a stroke care network diagram (See Figure 5d, p. 202)

Study 5b which also involved the exploration of ‘communication’, but using semi-structured interviews, conducted with some NHS staff but mainly with community based health professionals. At the end of each interview, participants whose role required an overview of services were asked for their impressions of the diagram developed from the results in Study 5a.

Participants for the two studies were recruited through NHS stroke services (primary, tertiary and social care), including services for both under and over 65 year olds, and voluntary organisations for stroke. The inclusion criteria for this study were that community and voluntary sector participants worked with stroke patients as part of their routine work, and that NHS staff were frontline health professionals with some seniority, hence knowledge of the various agencies within stroke services.

5.2.3 Study 5a: The Focus Groups

Four focus groups were conducted with participants from stroke services. Effort was made to include 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 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 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.

5.2.4 Study 5b: The Individual Interviews

A total of 17 interviews were conducted with participants from various agencies providing services for stroke patients. Effort was made to include health professionals that were not included in Study 5a for practical reasons, such as consultants who were unable to attend focus groups during normal day time hours

due to clinical commitments. In addition, given that Study 5a included mainly hospital based health professionals, we also endeavoured to interview a number of participants from community based health services.
One health professional was recruited by letter, while all the other participants were recruited by telephone. All interviews were conducted at the participants' workplace.

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 in Study 5a, with the aim of gaining impressions of professionals' views about it, ascertaining its accuracy and obtaining information about any gaps.

All participants were assured of anonymity and confidentiality, and all the interviews were audio-taped, except one which failed due to technical difficulties. 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 on the diagram and three interviews that provided no new themes or information.

5.3 Results

5.3.1 Participants

We achieved a good spread of professional groups represented in Studies 5a and 5b. The focus groups included hospital-based nurses and therapists, community-based intermediate care nurses and therapists, the CST manager and two participants from the charitable sector, both employed by the Stroke Association. The individual interviews were conducted with the following health care professionals:

Two Stroke Specialist Consultants
Two General Practitioners
Two GP Practice Nurses(including one lead Practice Nurse for CHD)
A Community Matron
A Hospital Matron
A Strategic Health Authority Modernisation Manager
A Community Rehabilitation Unit Clinical Nurse Manager
A Joint Care Management- t 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

The focus groups 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 found they gained a useful insight 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 our participants in the focus groups, and those we interviewed as individuals, were skilled and professional people who left a lasting impression of a highly committed and caring work force.

Sections 5.3.2 to 5.3.5 (pp. 170-184) describe the ways and means by which ***communication*** is conducted in stroke care, and also its nature. We then go on to report in Sections 5.3.6 to 5.3.10 (pp. 185-198) the observations made by professionals about other ***determinants of continuity***.

5.3.2 Patterns of communication

The main focus for this part of the discussion was the individuals and agencies with which our participants had contact on a regular basis. We asked them 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. We found that their patterns of communication were flexible and reactive, and that although communication within the local team involved a pattern of regular meetings and briefings, wider communication with other teams and agencies did not consist of a routine series of contacts. There was general consensus between the focus group participants that it was the needs of the patient that determined whom they contacted and when.

> ***Ward Sister, Stroke Rehabilitation Unit:*** *"… 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."*

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 identity clear chains of communication for everyone involved in the care of stroke patients. Some units and agencies had more structured patterns of referral but these simply introduced the patients to their service and usually initiated onward communication to respond to the needs of individual cases or to obtain further information from the referring agency.

> ***Lead Therapist, Community Rehab Unit:*** *"… 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."*

One theme which emerged was the advantage of specialist knowledge and experience, and how this could enhance patient care. Building links and relationships to facilitate the coordination and delivery of care was well recognised by our participants as a useful skill. Knowing whom to contact about what, and giving the 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:

> ***Manager, Community Stroke Team:*** *"…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."*

All the focus groups endorsed the fact that closer proximity 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 our participants as time-points at which patient progress and care planning could be discussed.

> ***Lead Therapist, Community Rehab Unit:*** *"…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."*

Arrangements for community teams varied, some shared the same office or suite of offices, some were based in the same building while others were more distant.

> ***Senior Nurse, Intermediate Care:*** *"...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."*

It was generally agreed that well planned home visits were the best means of preventing failed discharges and the readmission of patients due to problems managing at home. These were regarded as very important meetings in the stroke care process by our 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 in care.

> ***Senior Physiotherapist:*** *"home visits work really well because you can actually express something that, you know what the problems are and how its been solved in hospital, and where you are going, what you are trying to sort of, what your main goals are."*

What emerged from our 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 through regular formal and informal direct contact as relatively easy for professionals that all worked in the same place. 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 we will return to this point later in our discussion of modes of communication.

5.3.3 Modes of communication

Documenting patient information in health care systems has long 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 GP practices and in some areas of hospital care. For this part of our enquiry we asked participants about the methods they used to communicate within their own teams, and outwith their organisation. We talked about the effectiveness and reliability of different means of transferring information, and what they found good and bad about them.

We found that the modes of communication most used by the majority of our frontline staff were based on written notes and faxed referral forms. Issues of access to electronic communication facilities and the potential issues surrounding the transfer of confidential patient information were the main reasons cited for not using email as a medium of communication for health care. Most ward-based staff and community based care teams did not have access to an individual email address, they were therefore dependent on email messages being passed on by administrative staff (ward clerks and secretaries). This obviously has limitations for the efficient transfer of information using this method. Senior and managerial staff, who more frequently had personal work stations, used 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 it 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 of this method was that some information could be forgotten or distorted if it was not written down.

> ***Senior Occupational Therapist, Acute Ward:*** *“…there is the danger that someone that you hand over to isn’t going to remember it if it is not documented..."*
>
> ***Lead Therapist, Community Rehab Unit:*** *"…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…"*

The SAP form (Single Assessment Process form) had caused a number of problems 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 was as a printed form, and this evidently had been the source of some of the difficulties. Lack of space arose because the original electronic format had been designed to expand as required on the computer screen; once 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.

> ***Ward Sister, Stroke Rehabilitation Ward:*** *" 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."*

Moreover, apart from hospital staff sometimes being unsure when and how to complete the forms, they also found the overall burden of form filling had become an added pressure:

> ***Physiotherapist, Intermediate Care:*** *"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."*
>
> ***Senior Physiotherapist, Neuro-rehabilitation Ward:*** *"…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."*

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. Our 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 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 seem to work well, as they have the benefit of recording information that supports the work processes in that particular area. Shared records, on the other hand, have 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. This makes them both complicated to design and difficult to ensure that they are completed to a standardised format in practice.

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, to be followed later by a faxed referral form:

> ***Senior Occupational Therapist, Rehabilitation Ward:*** *"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."*

All our 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:

> ***Staff Nurse, Rehabilitation Ward:*** *".....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."*

Direct contact, either by face to face conversation or via a telephone conversation was the mode of communication favoured, and perceived as most efficient and effective, by our 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 as we discerned throughout our discussions with the groups. However, stroke is a complex condition and the delivery of care fragmented with different organisations and separately managed teams involved depending on the 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.

5.3.4 Content of communication

We asked about the nature of the information that our participants dealt with, and about variations in quality and accuracy of the information they received. We also enquired how the type of information they passed on varied in relation to the recipient. We found that our participants had to process an array of information 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 our 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 (and sometimes sensitive) information, our participants discussed how important it was to know about social or personal circumstances. They felt it was especially necessary to know how much could be expected of a patient's immediate family when organising care:

> ***Community Rehabilitation Unit Senior Therapist:*** *"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 martial 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"*

Relationships or behaviours were also important factors in both ward contacts with patients and families, and during home visits, and we heard many anecdotes 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:

> ***Community Physiotherapist:*** *"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."*

Both the information giver and the information recipient 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 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:

> ***Senior Physiotherapist, Rehabilitation Ward:*** *"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."*

The context in which information is given and interpreted is also important, for example disability may have a different meaning in hospital from a home setting:

> ***Community Occupational Therapist:*** *" 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."*

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.

> ***Ward Sister, Acute Stroke Ward:*** *"...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."*

Younger patients were, however, perceived as potentially having fewer difficulties with information:

> ***Ward Sister, Rehabilitation Ward:*** *"....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."*

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 been the introduction of key workers and co-key workers (who may not necessarily be qualified staff), who have similar roles. The aim was to facilitate the transfer of information not only in the care setting, for example at MDT or care planning meetings but also to provide a patient advocate, a point of reference and some continuity for patients and relatives. This practice has been carried over into the community where effort is made when possible for a named therapist on the Intermediate Care Team to follow a stroke patient through rehabilitation at home during the period of the team's involvement. Community nursing staff would change however, depending on workload and priorities:

> ***Physiotherapist, Intermediate Care:*** *"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."*

Although the development of therapeutic relationships with patients during the various stages of care was described by both hospital and community staff, there was general consensus that sustained relationships were not important in maintaining continuity of the care process provided good handover of care was achieved during transitions. Where concerns did arise was in the transfer of patients to nursing homes. There was a general perception among our participants 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 is turn was often caused by the high turnover of staff in the nursing homes. There were examples of cases where complications had arisen due to failure to maintain the standard of care given in hospital, and had resulted in re-admission or re-referral to other services. A senior OT described a case of a lady 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 in situ, who had also been discharged to a nursing home:

> ***Hospital Dietitian:*** *"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† feeding...... He came back and stayed with us for another three months."*

†Percutaneous endoscopically-guided gastrostomy (PEG) tubes are indicated for long term feeding to avoid the discomfort of nasogastric tubes.

5.3.5 Communication and Care Processes

As an introduction in order to set the scene for the focus groups and interviews we had explained that, although we were focusing on issues around communication, our overarching theme was continuity of care and how services were organised to deliver it. Our participants from the professional community, unlike the patients, were comfortable with the term "*continuity*" and, although generally endorsed as an important aspect of care, this was not a unanimously espoused opinion.

> ***Social Worker Team Leader:*** *"…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."*

It was clear that individual interpretations of continuity were varied and vague, supporting our initial impressions that continuity was primarily a professional concept but that its definition was not consensual. We also made a number of interesting observations on how patient care was maintained, and the gaps and barriers that stroke care professionals experienced in providing a coordinated service. Throughout our enquiry we drew parallels between our data from different sources and reiterated themes to clarify our thinking. One issue that had arisen was that of the interpretation of care needs, and how professionally assessed needs where sometimes at odds with patient perceived needs, which sometime led to disappointment and dissatisfaction for patients. With regard to inter-professional perceptions of services, we found that not understanding the nature of services to which referrals were made or communication problems (being unable or forgetting to contact them) were the principal causes of breakdowns in the delivery of care and poor arrangements for patients.

Apart from these comments on the main topic of ***communication*** our respondents made other observations about ***determinants of continuity of care.***

5.3.6 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.[52] However, 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, and resources in any service are finite. Where care involves sharing or handing over of responsibility for the various stages of the patients' care it is essential that the all the parties involved in care are aware not only of the resources available but how they are allocated in order to achieve a smooth transition through the process.

A common theme running through our 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. A commonly held view was *"…it's no good communicating if there's nobody to communicate with"*. Communication was not therefore perceived as the only problem but the capacity and volume of referrals to services.

A common problem in hospital was shortage of appropriately trained staff, not only nursing staff but also specialist professional groups like dietitians and speech therapists (SALT). Strategies to address deficits among dietitians and SALT included delegating skills to nurses and training them to do some of the routine tasks like swallowing assessments. Outside hospital, concerns about low levels of skill among nursing home staff have already been described in Section 5.3.4 (p. 178), but turnover was a problem for continuity too:

> ***Senior Occupational Therapist:*** *"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 ...."*

Within the hospital setting there was also a problem with administrative support, particularly administrative support for hospital doctors, but also clerical staff on wards. This had a major impact on ensuring timely and accurate communications. For example discharge and clinic letters would be delayed or never sent if secretarial support was not available and hospital case notes require routine filing to maintain up to date records. Good and efficient case note tracking and retrieval was also important in administrative support because it reduced the risk to the patient that inappropriate treatments would continue or relevant treatments be withheld. It also saved clinical time chasing information.

There were descriptions too of understaffing in the community, and a perceived lack of therapy resources for onward referrals in the community, particularly for SALT, but also for physiotherapy and occupational therapy. In some cases, when home care services were not available to take over care, specialist teams like ICT would have to continue to provide services beyond the usual period of involvement. This plainly has implications for their capacity to accept new referrals.

> ***Intermediate Care Physiotherapist:*** *"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."*

Voluntary organisations like the Stroke Association provided support for patients with aphasia in collaboration with the Primary Care Trusts, but their service was not always widely known. Raising awareness was thus one of their roles:

> ***Dysphasia Support Officer:*** *"...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..."*

5.3.7 Continuity and Organisation

Linear models are popular for the planning and coordination of care but in a complicated and chronic condition like stroke they are not applicable to all stages of care. After discharge the care pathway resembles a “cat’s cradle” more than a linear pathway, with varied transitions and numerous routes (some circuitous and some iterative) through care. Priorities and demands change throughout the stages of care depending on the status of patient (acute vs. stable vs. chronic). The acute phase of care has many aspects that are not contingent on the patient’s personal status and circumstances, as we described in Section 4.4 (pp 94-113), and are more amenable to a linear model of care. Hence the Stroke Care Pathway is useful at this stage to ensure the delivery of high quality care through standardised procedures. Post discharge, care changes and becomes more individualised and contingent on patient’s social circumstances and physical status. Our interviews with patients in the QSOS study, reported in Strand 1 of our study, gave us many examples of the ways in which patient care and daily living is maintained after a stroke. For many people, family and friends play a major role in supporting routine activities like shopping, housework and transport. These agents of care and the way they are organised are impossible to factor into a linear care model.

The organisation of professional services to provide support and maintain care after stroke is complex. It involves the coordination of a number of agencies each of may be geographically distant and separately managed. As a result these services are also difficult to map into a linear model as patients may move back and forth, across and between agencies depending on the needs at any particular time. Moreover, understanding the roles of these services and the systems in which they work is important for effective collaborations. Our conversations with the focus groups participants and individual interviewees revealed that in the main experienced staff developed their own network of contacts across the agencies they dealt with in order to facilitate their work. An awareness of internal politics and the different approaches employed by 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 Team manager (one of five managers based in the five local social services' area teams) explained how he used different communication styles to address these issues and pre-empted problems by knowing exactly what could be expected from each area team.

> ***Disability Team manager:*** *"There's lots of really close links in the 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 and 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."*

Understanding service configuration was important in all aspects of care coordination, especially where changes had occurred. We found that staff were not always clear about new roles and responsibilities within re-organised teams. There was some tension too between agencies about who should take responsibility for patients with complex needs. This stemmed partly from the ambiguity in the definition of *"complex needs"*:

> ***Hospital Social Work Team Manager:*** *"…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."*

Structural changes in the organisation of hospital social work teams during the development of Joint Care Management, which was established to facilitate coordination between health and social services, had also caused some concerns about increased workload.

> ***Joint Care Management Team Leader:*** *"...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."*

Overall, our wider discussions with participants showed that the organisation of services 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 had a poorer working relationship with social workers based in the community than they had enjoyed when social workers were assigned to specific wards.

> ***Senior Physiotherapist:*** *"We used to have an allocated social worker … knew patients from day one, was on the ward, was in the building …in a*

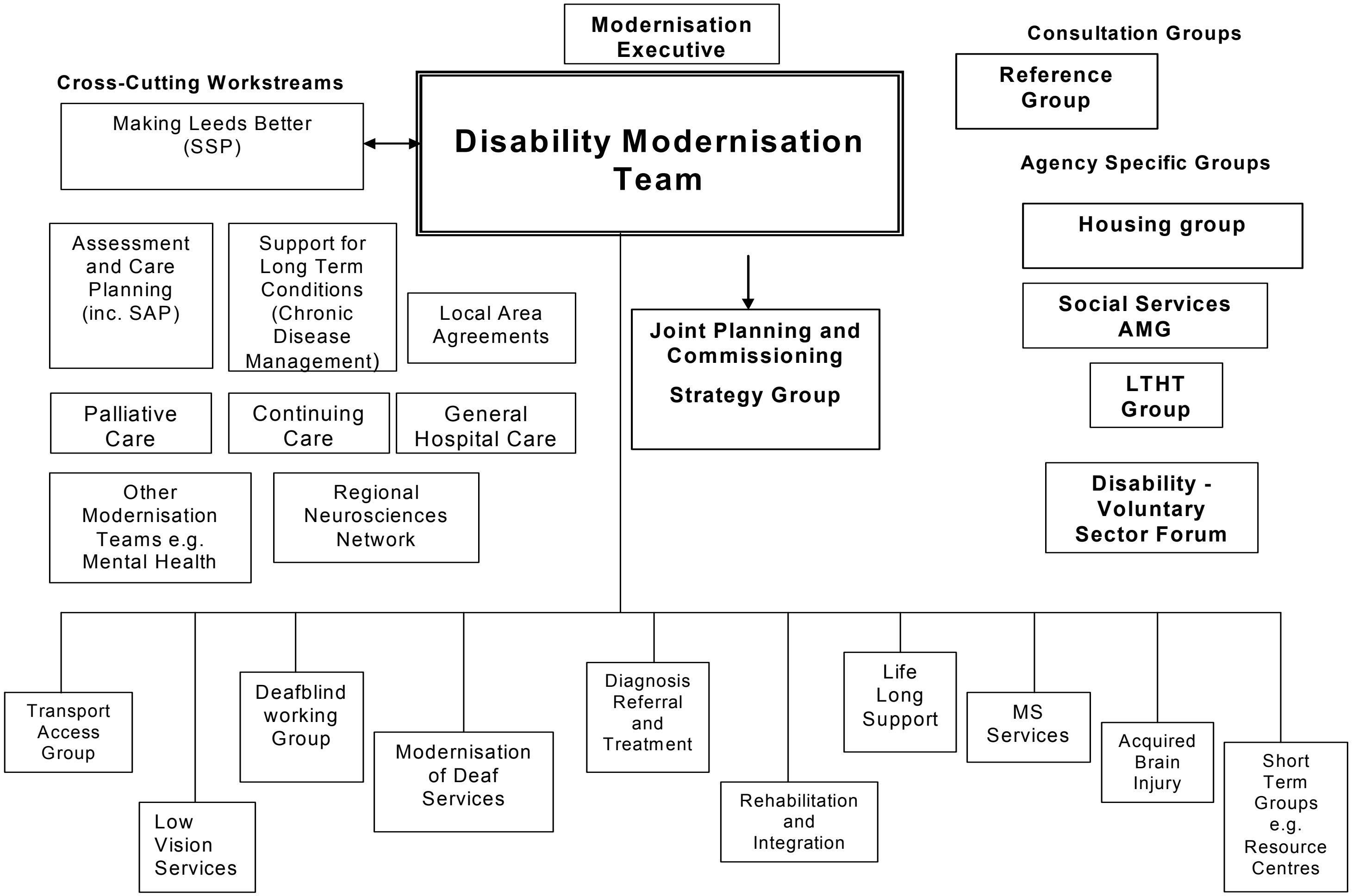
> *case conference … she'd know all about them (patients) … and they (patients) would know her …and she would have had all those facts already, what we all thought about it… Whereas you have to explain all that, the joint care manager hasn't a clue. It's just a name isn't it, when they (JCMs) appear here on the ward."*

They felt too that removing this link had implications for practice because it meant social workers did not get to know the patients they were dealing with, and were less likely to acquire specialist knowledge and skills in stroke care. These findings are important because effective communication between these professionals 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. Age limited services, as for example ICT, which is only available to over 65 year olds, meant that younger patients sometimes had to wait longer before discharge if they required ongoing therapy or nursing care at home, and Specialist Nurse care (only available to younger strokes) meant that in some 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 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 when it was published in 2001.[4] The focus of the NSF was on when particular tasks should be performed and not on who should be supporting the different aspects of care. In the intervening six years progress has been made to improve stroke services in areas 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.[53 54] A hospital matron described how NHS Executives were working with Disability Modernisation Teams from the Strategic Health Authority to build structures that would improve the coordination of services and deliver better care after discharge from acute care services. Figure 5a (p. 193) shows the consultees in the process.

Figure 5a: Disability Modernisation Planning Diagram



5.3.8 Continuity and Autonomy

The complex structures that support health and social care are composed of numerous teams, each organised and managed separately as we have described. In a Donabedian model these teams can be characterised as working at various levels of association within the overall structure of health and social care to deliver the processes of care.[55] Each specialist team is autonomous in terms of its activity, whether it is a delivering a therapeutic intervention or supportive care, and this is important for efficiency in practice. 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, and a structure which supports the development of autonomous teams to enable flexible and responsive working to deliver and maintain the diverse processes of care.

There were examples throughout our data of the value of respect for other teams and the importance of shared decision making for collaborative working and the coordination of care. Tensions in working relationships could arise which could compromise patient care when this practice was not observed to communicate decisions adequately across team boundaries. For example during discharge planning:

> ***Hospital Social Work Team Manager:*** *"…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."*

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.

5.3.9 Continuity and Choice

Between professionals the main factor that led 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 such failures. Communication difficulties also arose with patients either through their misunderstanding of information or from the passing on of inaccurate details. We heard examples too of a lack of appreciation by relatives of how demanding it can be to look after someone who is disabled by a stroke particularly for elderly couples where the main carer is no longer young and fit and may have their own health problems.

There were many more instances however where patient choice was the direct cause of ongoing care not being maintained as planned. Examples of patient non-compliance with care were identified by health care professionals and community services during focus groups and interviews. In our own study we also found examples failures in the care process resulting from psychological morbidity and social isolation as we have described in the case studies in Strand 2. Parallel examples were also seen in our study group as a consequence of physical frailty.

Patient and family compliance with adaptations to their home or living arrangements was identified by health and social care professionals as one source of difficulty in delivering planned care. Our participants related examples of patients who were confined to living upstairs because their spouse did not want to turn the living space into a bedroom with a commode in situ.

> ***Ward Sister, Acute Stroke Ward:*** *"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"*

In completing the PPCI with patients we too had found numerous examples of patients who had refused stair rails or grab handles for the bathroom because they didn't want to spoil their décor, and refusals to fit grab handles on outside doors thus labelling the house as occupied by an elderly or disabled person and raising fears about security.

Health professionals also described abrupt changes to planned care arrangements that resulted from patients or families changing their minds about discharge. Arrangements would be in place for a patient to stay with a relative when they would decide at the last minute that they wanted to go home. Care plans and requirements for discharge home would then have to be reassessed which could result in a delay while additional services were put in place. In the reverse situation, when patients decided not to go home as planned but stay with a relative or friend, meant arrangements in place for discharge home would have to be postponed or cancelled at the last minute, sometimes resulting in wasted visits by care agencies.

Finally patient and family perceptions of needs, and the services available to meet them, were sometimes at variance with professional 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, perhaps 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.

5.3.10 Continuity and Informal Carers

The concept of the "Caring Role" emerged in the mid-70's and burgeoned in the eighties driven largely by the feminist movement. Informal care as distinct from care provided on an organised and paid basis fell 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 commissioned by the DoH to assist planners and practitioners to develop new responses to the 1990 NHS and Community Care Act.[56] The intention of the review was to not only to disseminate information on the subject of carers more widely but also to stem the tide of empirical work as a great deal was already known about the pattern and incidence of caring and the experience of caring both the stresses and burdens, and the rewards.

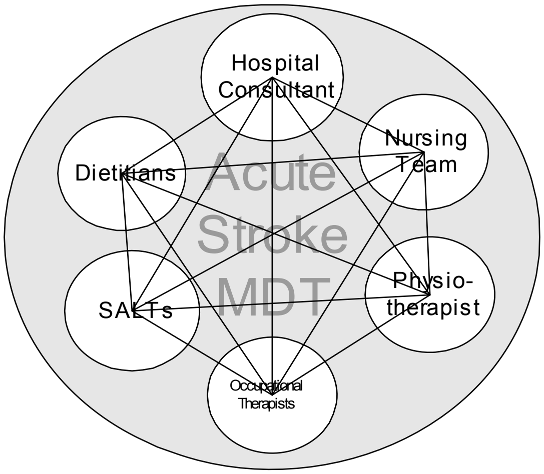
Gillian Parker (SPRU York) had previously used caring activities as a basis for producing a typology of carers.[39] She distinguished between carers (those who deliver personal or physical care) and helpers (those who provide practical assistance), and we found examples of both in our work. In health care terms, 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 having one point of contact is a means of saving time and repetition of information.

Stroke is a sudden onset disability which can plunge an elderly spouse into a caring role overnight, a task that can be physically demanding. Nearly all the patients we interviewed, and their spouses, had received some form of informal support, usually practical help with gardening, household tasks and shopping and less frequently with personal care like bathing. This 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 care 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.

5.4 Mapping communication in stroke care

From the vast quantity of data that was generated during this phase of the study we were able to derive an overview of the range and extent of communication links required to maintain ongoing care for stroke patients. A lot of informal communication facilitates the movement of patients within the network of care. The limitations of our study meant that were not able to observe this in action, only to make inferences from the data we collected. We mapped the reported contacts onto a network diagram and found growing layers of complexity as the patient moved through the stages of care. Figure 5b below shows the communication channels that were described in the hospital setting alone during acute and in-patient rehabilitation care.

Figure 5b: Communication Links within the Acute Stroke Care Multi-Disciplinary Team

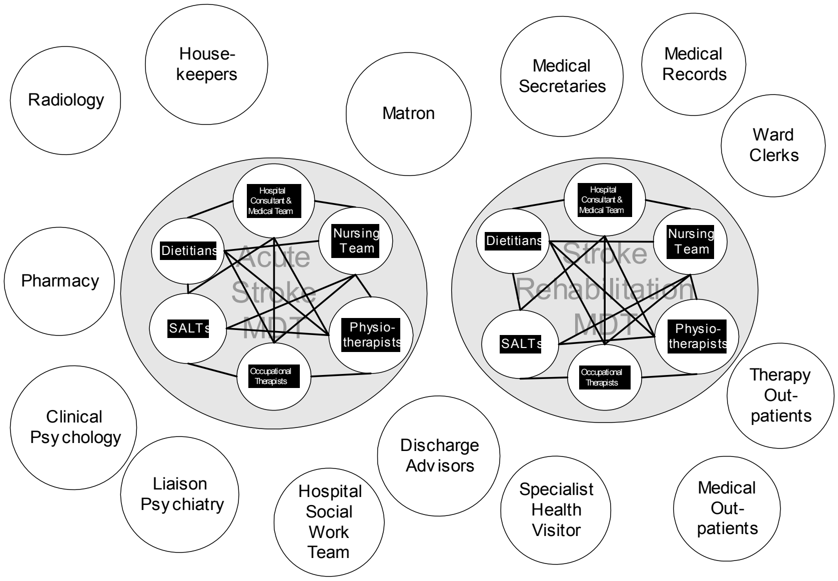


Within the MDT communication links between professionals were well established and maintained through regular contact and exchange of information, both at scheduled meetings (shift handovers, ward rounds, MDT meetings, goal setting, care planning etc. There were opportunities too for face to face contact which occurred on a daily basis on the ward and 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-focussed clinical information was transferred by traditional methods such as phone, fax and referral forms. We found two explanations for this: access to email was limited in clinical settings and staff were wary of issues surrounding data protection and patient confidentiality.

Figure 5c (p. 201) represents the various departments and agencies that were co-located in the Acute Hospital Trust outwith the immediate Acute Stroke Unit but that may be involved at different stages of the care process while the patient is treated as a hospital in-patient.

Figure 5c: Extended Communication Networks in Hospital and Community Care

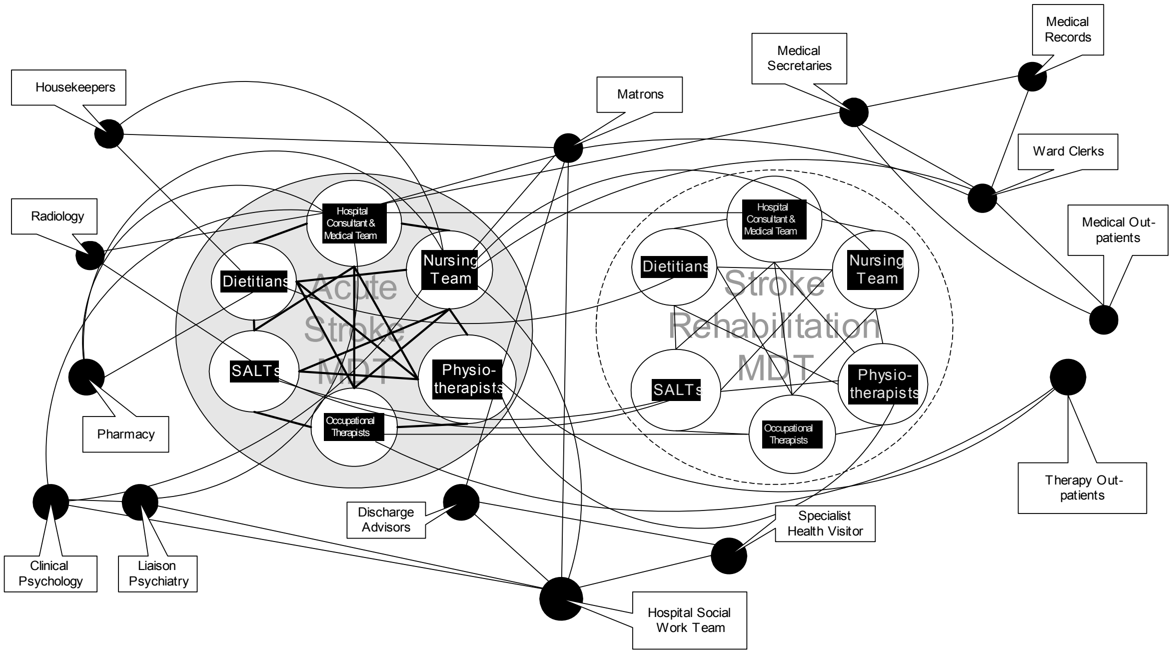


Note: While the diagrams show the teams involved in stroke care in different settings and the channels and networks of communication that we identified between them, it only shows the links, and does not represent functionality or density of communication in stroke care.

Information transfer is more vulnerable to influence by external factors like equipment failures (faulty fax machines) or location of individuals. In respect of location we found that proximal working enhances information transfer between teams although proximity may have a different meaning in the community setting compared to hospitals, where adjacent wards can be effectively distal in terms of personal contact between staff. Changes to practice, such as documentation or referral systems, impede continuity but generally do not prevent it as they tend to result in duplication of effort and repetitive information seeking activities rather than stopping information flow.

Figure 5d below shows 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 are replicated by the Stroke Rehabilitation MDT but are not represented here for clarity.

Figure 5d: Communication Networks in Acute Stroke Care and Rehabilitation



5.4.1 Continuity of care as a function of care networks

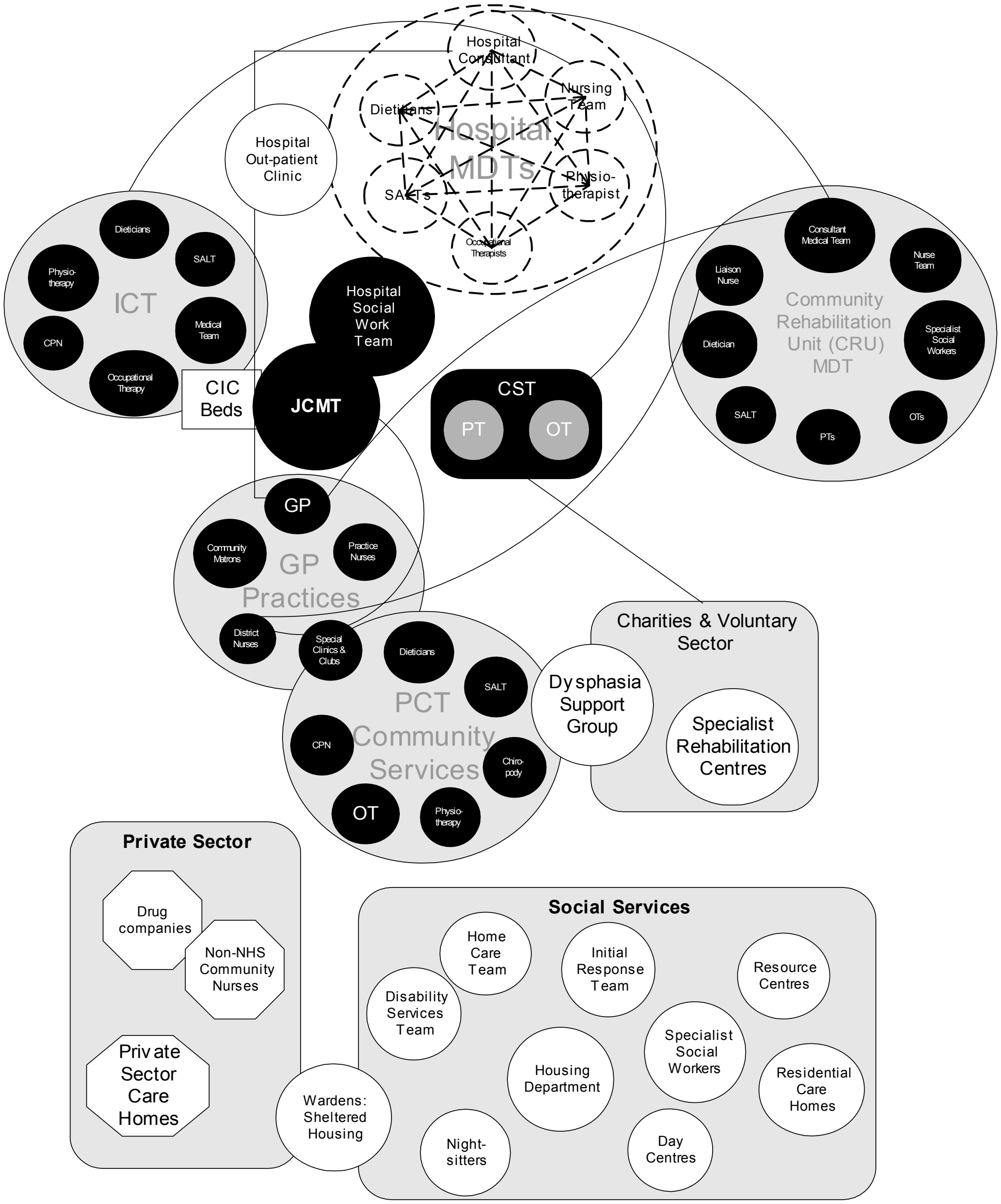
Our original aim in strand 3 of our work had been this: We knew from Strand 1 that service users could not provide us with a user-derived (patient perspective) measure of continuity. We knew from strand 2 that by using measures derived from the literature we could obtain a view of patient-perceived care that was related to outcomes (and not mediated by disease characteristics). But we also knew that this patient-perceived care was more complex than simply a rephrased version of the by-now-conventional components of continuity of care. So we hoped by an exploration of communication in stroke care to gain an understanding of how that care is co-ordinated and how key elements of it (handling of knowledge, relations between professional patients and carers) are constituted. What we found was an account of communication networks that, when peopled with people 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 extend even further and more diverse agencies become involved. The network of professionals involved in service delivery reaches out into the community and, once the patient leaves hospital, may comprise any combination of public and private sector care including charitable and voluntary groups. Figure 5e (p. 205) 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.

Industrial processes may be used to provide useful analogies for understanding the principles of continuity but are too simplistic to transfer readily to stroke care because, while industrial processes may be complex, 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 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 more hybrid, each patient presenting a unique problem for staff in terms of the type of therapy they require or the frequency of physiotherapy, occupational therapy and nursing contact time will they need, especially if changes occur and planned care has to be adapted. When discharge planning starts the diversity increases yet more as individual home and social circumstances add a further dimension.

Figure 5e: Communication Networks in Health and Social Care



In terms of stroke care therefore, we find that continuity may be more easily understood in the context of a network of care with individuals accessing different parts of the network according to their needs or circumstances. Care networks of this type may be made up of a variety of individuals or agencies both professional and lay, with formal or informal linkages between the network nodes based on professional obligation, trust or chance.

Good networks provide a platform for delivering good 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-disciplined but also partly a professional and partly a social network.

The components of networks also require a degree of autonomy to function well. Those that are too closely regulated and subject to central control in a hierarchical system are at risk of “command” overload due to the high demands being placed on the controlling agencies or individuals: a situation analogous perhaps to the recent emphasis on targets in health services.

5.4.2 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 to deliver services. We have already characterised the members of our professional network of care in the preceding sections of Strand 3 of our study. In order to understand robust and successful networks it is necessary not only to know its components but also to try and identify the characteristics of a good network, and to understand the nature of the engagement between the members of the network and how they connect to one another. Sharing an overall aim and an understanding of what is required to meet changing needs is clearly important, and empowers a network to respond quickly, flexibly and independently. This was illustrated in a commercial setting by the Toyota Aisin crisis in which the network model was fundamental to the successful outcome. In this case, following loss of supply of an essential manufacturing component, the Toyota network of subsidiary companies was able to function effectively without central control and provide substitute parts that enabled production to be restored within 48 hours. [51]

Similarly in stroke care (and we hypothesise, 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, neither are they formally connected by technological links. It would be totally impractical, for example, 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 – groups or units within the network, usually arising as a consequence of some form of isolation, that operate in parallel with the main network and are not fully integrated. In a Canadian study of mental health patients in the community, clique formation was found to limit access to services and reduce patient satisfaction. [57] As this study showed, 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 comprise the network and an ensuing reduction in the opportunities for engagement between them. 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.[58]

Finally, and importantly, patients and carers should be seen as an integral part of the network rather than regarded 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 in order to develop independence and self-sufficiency.

5.5 Strand 3: Summary of main findings

In Strand 3 we focussed on health care professionals in the two areas covered by our study, and the patterns, modes, content and impact of their interactions and communication. We conducted focus groups and individual interviews with clinical care staff, community care providers, voluntary sector workers and health care managers in hospital, primary care and community settings.

What we found was an account of communication networks that, when peopled with people and patients, amounted to a description of care delivered through care networks. This led us to propose that, in terms of stroke care, continuity may be more easily understood in the context of a network of care of which patients and carers are an integral part, with individuals accessing different parts of the network according to their needs or circumstances. In this study we were not able to define the characteristics of a high quality network but access to knowledge and the sharing of skills and expertise are clearly important factors. Network models offer a mechanism for coordinating care through the sharing of knowledge and collaborative working which are vital to deliver diversity in care

6 DISCUSSION

In this discussion we will do three things. First we will outline our main findings in relation to defining and measuring perceived care and its association with outcomes after stroke. Second, we will discuss how these findings can be understood from two perspectives: from that of stroke care as residing in a care network rather than in a series of managed care pathways, and from that of the professional literature on continuity of care. And third, we will discuss the implications of our findings for future research and practice.

6.1 Defining and measuring care

Our work began by taking existing definitions of continuity of care and examining them empirically in the context of care following an acute stroke. We drew on information from published literature on the topic and from a number of expert sources. As a first approach we conducted a qualitative survey of experiences of care with stroke survivors, then moved on to use an existing measure of patient perceived continuity (The Chao PPC Questionnaire) before developing and piloting two new measures of care: the PPCI and the SnL Index. During both the qualitative and quantitative research processes we found that the currently accepted models of continuity of care did not readily transfer to the type of care or the services received by stroke survivors.

In our conceptualisation continuity resides in the process of care and the mechanisms by which it is delivered, and this complicates its measurement because:

- Definitions which are confined to managed care alone only apply 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 care outcome in a meaningful way.

6.2 The patient's perspective

The main focus of our work centred on developing a method of evaluating the process of care and the transitions between components of the care package in a stroke setting. When we tried to measure these aspects of continuity of care from the patient's perspective we found that patients could, either directly or indirectly, assess the quality of the individual elements of care they had received, and rate their feelings of satisfaction or dissatisfaction with them. However, they could not distinguish the overall process of care, or indeed make an appraisal of it other than to give us their perception of its outcome. This is not a surprising finding if we consider 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 debate and study, 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 performing 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.[59] Clearly, therefore, this is likely to be true of patients' assessments of care, about which much less is known. Instruments for measuring health related quality of life such as the widely used Medical Outcomes Study Short Form 36 Item (SF_36) questionnaire have been meticulously and repeatedly tested and validated over a period of many years, and response patterns have been shown to be detrimentally affected by negative personality traits, independent of age and chronicity of illness.[44] On the otherhand measures of care and patient satisfaction are generally regarded as audit tools and have been subject to far less rigorous scrutiny.

6.3 Can researchers measure continuity of care?

Recognising at the outset that it was difficult to design a self-rated checklist for measuring continuity of care we adopted an approach similar to that used in other areas of complex assessment such as psychiatry. We listened to patients narratives and used pre-defined criteria against which to rate their experiences of care. This we did independently of our audit measure of care (the SnL Index) in an attempt to gain the patient's perspective of care. We found that patients could relate incidences from their experiences of care and identify gaps in the care they had received but, even when questioned explicitly about the process of care, they showed little insight into the mechanisms and systems of care, and did not understand the relevance of how these events impacted on their care overall. When we completed our study we found that although we could attribute ratings to the patients' accounts of their stroke care there was no correlation between these and the ratings achieved on the SnL Index, suggesting that the two instruments were measuring something different, despite being framed in the same conceptual model of continuity and structured specifically around stroke care.

Hence we found that we could measure events in the care process in two separate ways: From the documented evidence of care that was available either as a written or electronic record, and from the account of care given by the patient. We could, to a greater of lesser extent, determine when, where and how the events had occurred. However, there were limitations in both our measurement methods:

- We could not always demonstrate consistently that certain types of information recorded in the notes had been acted on or that information had been used by clinicians;

- Patients accounts were often muddled and chronologically misplaced;

- The way in which health care events are recorded, and the way that patients recalled their care, meant that we had no way of measuring the nature of the care process and the transitions between events: Were they timely? Were they appropriate? Were they connected?

In the light of these findings we decided that we would integrate several different components from our measurement portfolio into a multi-factorial analysis in an attempt to arrive at an overall assessment of "care". In order to do this we distinguished items that were either contingent or non-contingent on the health status of the patient from our item total correlation analysis of the SnL Index. By using this approach, which we reported in Section 4.4 (pp. 94-113), we aimed to derive a measure that spanned the types of care stroke patients would receive as part of their specific care package rather than general hospital care.

In addition to our audit measure of care we took an overall assessment of patient perceived care. This we represented by the scores assigned to the PPCI to which we added the four items that specifically appraised the care received from the self-reported ratings of services that patients had completed as part of the PPCI:

- *Satisfaction with care*
- *Quality of care*
- *Coordination of care*
- *Transfer of information*

We excluded the remaining two items from this section: *“Trust in health care professionals”* (because this rating would be susceptible to a range of factors outside the remit of service delivery), and *“Level of service”* (because of the wide variation in the type and number of services that patients received and the difficulty of assessing how appropriate those services were. This bias in measurement was discussed fully in Section 4.4.6, p. 113).

6.3.1 Measuring recorded care

From the results of the multi-factorial analysis we found that we could measure "achieved care" from recorded health care by including contributions from components of the physical, psychological and cognitive status of the patient in addition to our own SnL Index. Moreover we found that the measure of care that we derived did discriminate between patients. However, care responds to need, and because patients generally receive care in proportion to their need, we found it difficult to relate our measure of "achieved care" to outcomes. This was demonstrated by two independent methods of measuring achieved care – the number of health care professionals involved in the delivery of care (using the signature count audit) and the SnL Index, both of which were heavily influenced by the degree of disability of the patient.

Where problems were identified with recorded care 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 we have previously indicated, these problems were most likely to occur during transitions in care.

6.3.2 Measuring perceived care

The structural equation model that we derived from our multi-factorial analysis produced two distinct latent constructs. These were only loosely associated through the variances of the two new measures (the SnL and the PPCI) as we described in Section 4.6 (139-149). The SnL contributed to the latent construct we called *disability* but not to the construct that the PPCI measured, which we found to be related more to case mix and mood. We called this construct *perceived care*. It was not related to other disabilities nor to our audit measure as we showed in Figure 4j (p. 149).

The association of the PPCI with mood was consistent with the findings of Study 3 in which we gave a comparable sample of patients the Chao Questionnaire, another measure of patients' perceptions of care. This too we found to be mood responsive, which is by no means unexpected when we consider the subjective nature of ratings of this type, which offer the potential for them to be influenced by patient characteristics such as mood state and personality. This effect has been well documented in a range of patient groups and a variety of settings:

- Emotional distress and unmet care needs were identified as the major factors affecting satisfaction with care after stroke in a cross-sectional study of quality of care in 23 hospitals in the Netherlands.[60]

- 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,[46] and anxiety has been associated ratings of satisfaction with care in maternity settings.[47]

Patient characteristics such as age, functional status and physical and psychological well-being are not the only factors which affect perceptions 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. 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 functional rehabilitation and supportive or nursing assistance may become the principal components of care. Framing continuity of care in the currently accepted model could lead to the hypothesis that relational or personal continuity would be important factors during periods of care of this type (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 evaluation of care throughout the whole care trajectory presents even more challenges for the measurement of continuity of care.

6.4 Is perceived care associated with outcomes?

The use of multivariate analysis and the structural equation modelling techniques enabled us to derive latent variables in an attempt to more accurately represent the concept that our instruments were measuring. The strong association of the SnL Index with functional and cognitive measures was confirmed in the factor analysis. Moreover, the PPCI ratings that we had ascribed to patients' narratives were linked to their psychological status and did not correlate with measures of function or the ratings of care obtained from the SnL. We added in four items from the self-reported ratings of care to mediate against the effect of interviewer bias in the interpretation of the patients' accounts of care, and to capture aspects of patient perceived care that might have been missed in the PPCI such as explicit ratings of quality and satisfaction. We found that these two items together with the ratings of coordination of care and information transfer made an important contribution to the latent construct of perceived care.

The latent variables were calculated from the regression weights of the unstandardised confirmatory factor analysis and rescaled as described in Section 4.7 (pp. 150-155). These new variables "*disability*" and "*perceived care*" were used in a regression analysis to explore their potential as predictors of patient outcomes. When this analysis was performed we found that if we took rehabilitation at one year as our outcome, the chances of a less successful rehabilitation outcome went up as disability increased and ratings of perceived care decreased. The role of disability was stronger in this relationship than that of perceived care, and this is not unexpected as the likelihood of full rehabilitation is usually less with more severe initial disablement but perceived care does have an effect on functional outcome. We cannot explain this fully but mood state is clearly one candidate factor or, as we have previously conjectured, it may be that patients can identify certain aspects of their care that make a difference to their rehabilitation after stroke.

The interviews with patients and the ratings obtained from the SnL have shown that, broadly speaking, there are some variations in the quality of care. Notwithstanding this finding, we can surmise that the quality of care may not be as poor as some patients indicate from their accounts because of the association of ratings with mood. The was well illustrated in our case study of patient #531 where low mood impeded the delivery of care in a community setting and consequently influenced both the patient's and the family's perceptions of the care received. We can explain this in the context of other work that has shown that mood affects both memory, recall of events and satisfaction ratings.[46 61 62]

However it should also be kept in mind 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, a series of case reviews of nursing home care in the United States has suggested that difficult or non-compliant patients (and their relatives) may provoke avoidance behaviour in staff, leading to poorer care delivery.[63]

6.4.1 The effect of patient choice

It is clearly not just patient mood states and short-comings in services that can affect care. We have given examples of cases where patients behaviour was the primary factor influencing the care that they received. Case study #553 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. We also found examples in our study of patients who had decided, usually after a gap in transfer of care from hospital to out-patient care, that they no longer needed input from therapists (most often speech and language therapy, which had the longest waiting times for community care), and subsequently refused appointments. Patient #11 in our qualitative study illustrated this point. Adaptations to the home such as rails and grab handles were the aids most consistently refused but some patients also chose to turn down input from community care and intermediate care teams for a variety of personal reasons.

Government policy states that the aim of the new NHS is to increase patient choice in relation to their healthcare, a theme which is central to the personalisation agenda. It will be essential therefore to design care in a way that is compatible with this element of choice. We were given many instances by patients and their carers of ways in which they had negotiated their own roles in their care, and many more examples of how care had been 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 many may not have sufficient insight into the care process to understand how the decisions they make might impact on their care. Some form of guidance or monitoring of care would be required to ensure that the choices that were made were right in order to prevent the delivery of care to patients becoming sub-optimal as a result.

6.5 Continuity and Care Networks

Delivering the modernisation agenda requires new ways of thinking about health services. An emphasis on care pathways featuring a series of set processes through which the patient is directed limits the opportunities for diversity and reduces the flexibility needed to deliver a personalised service to the patient. Care planning which can be adapt to a personalised agenda needs to be goal directed, with the aim of ending up with the right care package assuming more importance than the process by which it is achieved. This model of care, most easily conceptualised in a network, accommodates diversity and has the potential to offer more options for patients to choose the care that suits them.

We identified patterns of care in our study that indicated that care networks already exist in stroke services. It is interesting in this respect that the recently-published National Stroke Strategy (Dott 2007) recommends the establishment of stroke care networks. Implementation in most places would not therefore require the establishment of major new structures and relationships, but support for more effective functioning of existing ones. Structurally they may not be explicitly defined but their activities and functionality are evident. 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.

There are resonances between what we have learned from the way patients and carers described their experiences of care networks and what the literature says about continuity of care. There are however also important differences between the existing treatment of managerial, informational and relational continuity, and the similar concepts encountered in considering care networks.

6.5.1 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 current model of continuity, knowledge is encompassed by informational continuity but we believe that this approach – which privileges explicit knowledge (information) could be counter-productive. The implementation of the Easy Care documentation was a case in point in our study with health care professionals. This document, designed to improve care handover met with mixed success for reasons we have already described. What is required is relevant information given at the right time; too much information means time wasted sorting through a mass of irrelevant or superseded facts to find what is required. There are, of course, stages in care when standardised information is needed as, for example, a list of medications on admission to or at discharge from hospital will ensure optimal care is maintained without unnecessary delays, but this form of informational continuity is not a panacea for all care settings.

From the literature we know that knowledge sharing and accumulating implicit knowledge (sometimes termed intellectual capital) are properties of networks.[64] Poor training or rapid turnover of staff dilutes the knowledge base: in Strand 3 of our study participants cited this 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.[65] We found examples of all these network functions implicit in our health care professional participants' descriptions of routine information transfer.

6.5.2 Relationships in health care

The role of people is central in health care as they are the care-givers, from the simplest task in personal care to the delivery of highly technical, specialist procedures. In the continuity literature, the important aspect of this component of care is described a relational continuity and many early measures of continuity were based on the idea that receiving care from one provider was inherently better than seeing a variety of care providers, but we would argue that it is the *connectedness* of individuals rather than the longevity or predictability of their individual relationships that delivers good care. The important principle that we would propose as key to this element of care is *trust* – a recurring theme in the literature on social networks and social capital and (often implicitly) in our interviews with stroke survivors and their carers and with health professionals. Trust is important in health care as we found in our interviews with patients. One elderly study participant's independence and refusal of community services (despite post-stroke visual and cognitive deficits) was clearly based on a sense of mistrust of the NHS and allied professional services rather than a positive assessment of the best plan for care.

While seeing the same person can be a means of generating trust, there are other ways in which it can be achieved such as confidence in professional competence, an expectation of good standards of care and cleanliness in hospitals, and the timely delivery of care. This is analogous to consumer choice in other areas such as choosing to stay in hotels run by certain chains or to fly with a particular airline because of 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 however fit well in the modern world of health for other reasons. For example Renee Amalberti, writing about safety in 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".*[66] 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 given that, since flying is considerably safer than being a recipient of healthcare, personalised service is not a marker of safety.

A care network can be conceptualised as a number of specialised individuals and teams each designed to deliver a care process as part of the overall network's function. Trust, in our conception, is delivered through the connections that exist between the individual members and teams both professional and lay, and connectedness that facilitates access to services, specialised or non-specialised, through the network system. Discharge care planning, for example, is one example of how trust and relationships are built. Home visits were cited by participants in Strand 3 of our work as particularly useful in this respect because they gave insight to patients and to lay and professional carers of the issues of importance in their domiciliary setting. Collaborative working is a vital part of this process if the aim of 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.

6.5.3 Coordination of 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, we found care pathways were a useful method of delivering safe, coordinated care through standardised procedures, and this could be anticipated to be the case in other areas of specialist care. Chronic care, however, is complicated and challenging to design because a linear model does not provide sufficient diversity for chronic illness (with or without multiple co-morbidity). It is also difficult to coordinate across multiple health and social care boundaries, and care pathways are not sufficiently flexible to enable patient choice, or for patient or carers to assume an agency role in their care.

Network models offer a mechanism for generating coordination through the sharing of knowledge, the enhancing of capabilities within the members of the network and the emergence of structure.[51] In commercial models, like the Toyota network of companies, this has been shown to have advantages in a competitive market mainly due to the connectedness of the network which facilitates the rapid transfer of knowledge and information among its members. [65]

6.6 Conclusions

Our study of continuity in stroke care has led us to the following conclusions:

- continuity of care is a professional and organisational-centred concept, which focuses on the provision of statutory services, and which is recognised by health care staff but not recognized in the same way by patients;

- it is unclear what aspects of continuity can be generalised from one disorder to another;

- 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 were the emphasis is on care planning not consultant led care;

- particularly in relation to measurement from the patient's perspective, continuity is intimately linked to related concepts such as quality of care and patient satisfaction.

If, as we believe, the patients in our study were describing their involvement in a care network, it would explain why they could not separate the quality of their care (or expertise) from their satisfaction with care (a major part of which is trust) 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.

When we attempted to measure perceptions of care we found this issue was central to understanding chronic care. It was entirely missed if only questions about the managerial, informational and relational aspects of care were used and components of mood, satisfaction with care and quality were not included in the evaluation of perceived care.

The networks of care that were emergent in strokes services as currently configured may be at risk if we do not understand them. This is an inherent danger, as the imposition of care pathways could have a detrimental effect on existing and effective networks by damaging the links and ties between them, and disrupting their logical connection to the generative rules that created them. Major restructuring of services without more insight into how care is achieved in the present system could lead to an over-modularised, “cliquey” version of care with all the associated disadvantages that were seen in the Canadian study of continuity in community mental health services.[57] In Strand 3 of our work we found that where tensions were identified between agencies involved in stroke care these were often the results of reorganisation or restructuring which had caused disruption in established working relationships and a lack of clarity about new roles and responsibilities. The introduction of joint care management and the way consequent changes to hospital social work roles were perceived by staff was a good example of this.

6.7 Implications for future work

There are two areas we would highlight in which we do not fully understand what is going on - although we do have some ideas. Firstly there is the complex and multi-directional nature of the relationship between perceived care, mood and outcomes that we observed in Strand 2 of our work. Secondly we do not know what constitutes a high quality care network nor how to make it work. Finally we do not yet know how the processes and activities of a care network might be measured although we can hypothesise that it would be more complex than measuring process in a care pathway.

Our study of continuity in stroke care offers an indication of the direction in which work in this area should travel. We propose that while pathways act as useful coordination mechanisms in acute care settings much more work is needed to characterise effective care networks in chronic illness and community care. We would propose our measure of patient perceived care as one component of this work but it would also need to include comparative models drawn from commercial and industrial processes like those run by Toyota, and referred to previously. In order to determine what makes a network effective we need to develop 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 this work a new conceptualisation of continuous or co-ordinated care can emerge.

Finally we need to view outcomes in a wider context, both in relation to community services and to patients' informal social networks. Pound et al (1998) wrote that *"the effects of stroke are mediated by the ongoing context of people's lives"*; this is almost certainly true for their continuing care, and is an important consideration in a personalised agenda for care.[40]

APPENDIX A: The Stroke Outcomes Study Programme

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 (p. 231) 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 A1: Criteria for Entry into the Stroke Outcomes Study

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.

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 A2 (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 A2: Timetable of Outcomes Assessments in the SOS Programme

SOS2: THE EFFECT OF EARLY DEPRESSIVE SYMPTOMS ON OUTCOMES AFTER STROKE		
BASELINE ASSESSMENT (T1)	**6 WEEKS (T2)**	**3, 6 AND 12 MONTHS (T3, T4 AND T5)**
Demographic data: age, sex, residential status, occupation etc is collected, Current mediation. Smoking history.	Current mediation Place of residence	Current mediation Place of residence
Impairment Glasgow coma scale on admission Urinary continence in the first 2 weeks Presence of hemianopia WHO Performance Status ratings (See Appendix D)	***Impairment*** WHO Performance Status rating	***Impairment*** WHO Performance Status rating
Cognition Mini Mental State Examination (MMSE) – a brief screening for cognitive impairment Frenchay Aphasia Screening Test	*If cognitive state changed or in doubt* repeat Mini Mental State Examination (MMSE)	*If cognitive state changed or in doubt* repeat Mini Mental State Examination (MMSE)
Functioning The Barthel Index - pre- and post-stroke Rivermead Mobility Index	***Functioning;*** 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)	***Functioning;*** 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)
Mood 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).	***Mood*** GHQ-28; Modified short-form PSE	***Mood*** GHQ-28 Modified short-form PSE
		Quality of Life SF-36: a self-reported measure of health-related quality of life
Co-morbidity Dukes Severity of Illness Scale		
SOS3: THE IMPACT OF CONTINUITY OF CARE ON OUTCOMES AFTER STROKE		
BASELINE ASSESSMENT (T1)	**6 WEEKS (T2)**	**3, 6 AND 12 MONTHS (T3, T4 AND T5)**
All outcome assessments as SOS2	All outcome assessments as SOS2	All outcome assessments as SOS2 **Between T4 –T5** Patient-centred Continuity of Care measure (PPCI) 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: Qualitative Interview Topic List

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 you 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 D: WHO Performance Status Scale

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 E: The Chao Questionnaire

THE CHAO 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:

2. PLEASE INDICATE YOUR OPINION OF THE FOLLOWING STATEMENTS, USING THE SCALE 1 TO 5:	
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 (<u>no</u> stamp required) to:

The Stroke Research Office,
FREEPOST NEA 15583,
The University of Leeds,
15 Hyde Terrace, Leeds LS2 3YY.

APPENDIX F: The Snakes and Ladders Checklist

SnL Casenote Review Checklist: Hospital and Community Care

Patient ID:	Date of Index Stroke:
Date of Admission:	Date of Discharge:

Stage	Continuity Indicator	Continuity Score	Actual Score
Admission	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	
	Number of changes in consultant: None	+1	
	Yes	Each = -1	
In-Patient Stay Acute Phase	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	
	Stroke specific nursing assessment within 3days	+1	
	Non-stroke nursing assessment	0	
	No assessment	-1	
Rehabilitation Phase	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	

Discharge	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	
Community Care and Rehabilitation	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	

Long-Term Support	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 G: The Patient Perceived Continuity Interview

The PPC (Stroke)

Patient Perceived Continuity in Stroke Care

Interview Questionnaire

Study ID: SOS3/	**Patient ID:**
Casenote No.:	**Hospital:**

Visit code	**Date**	**Interviewer**	**Location**	**Barthel Score**	**WHO PS grade**

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?

***Core item**:* 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 ( )

***Core item**:* 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)

If applicable: 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 ( )

Core item: 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? ***Core item:*** 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? ***If applicable:*** 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? ***If applicable:*** 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? ***Core item:*** 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

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.)

Core item: Rate function of social support

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

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?

Core item: Rate extent of social capital

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

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?

Core item: Rate value of social capital

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

Visit:	**Date:**	**ID:**	**Name:**

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 all 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 car

APPENDIX H: Figures H1 to H7 SnL Cluster Histograms

Figure H1:
Admission

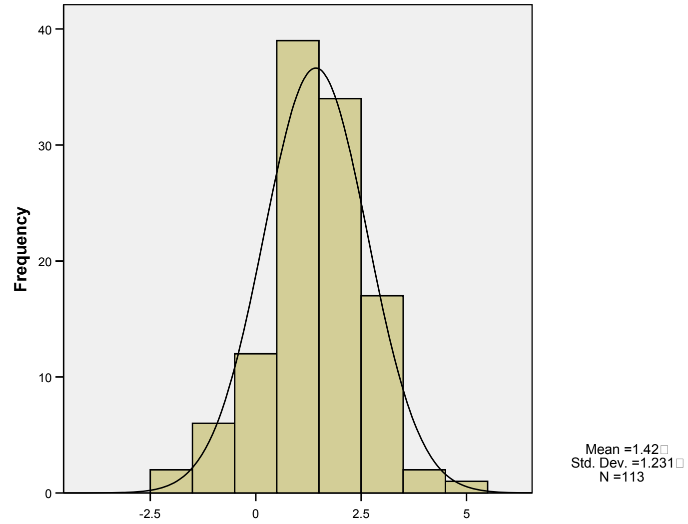


Figure H2:
Clinical Care

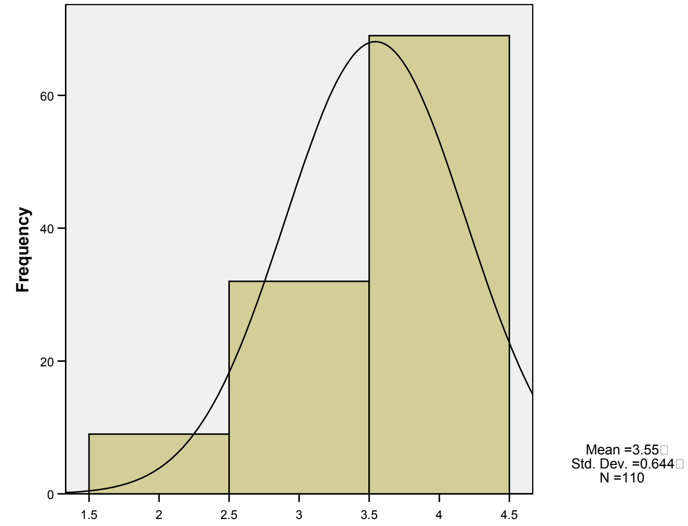


Figure H3:
MDT Care

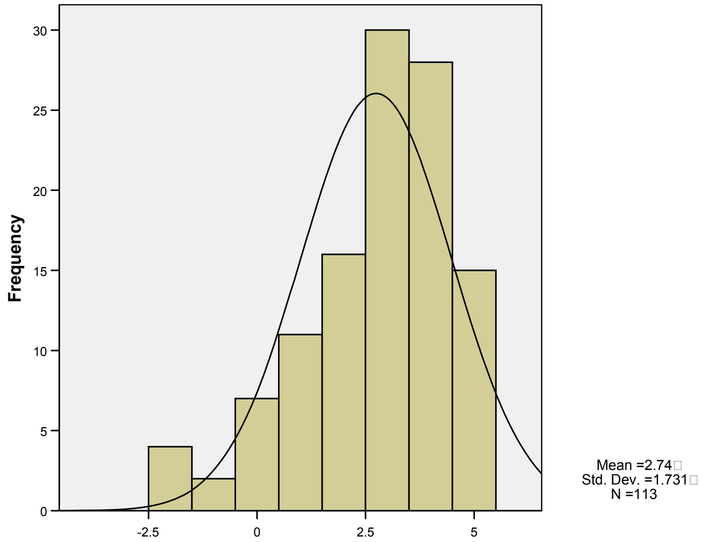


Figure H4: Discharge

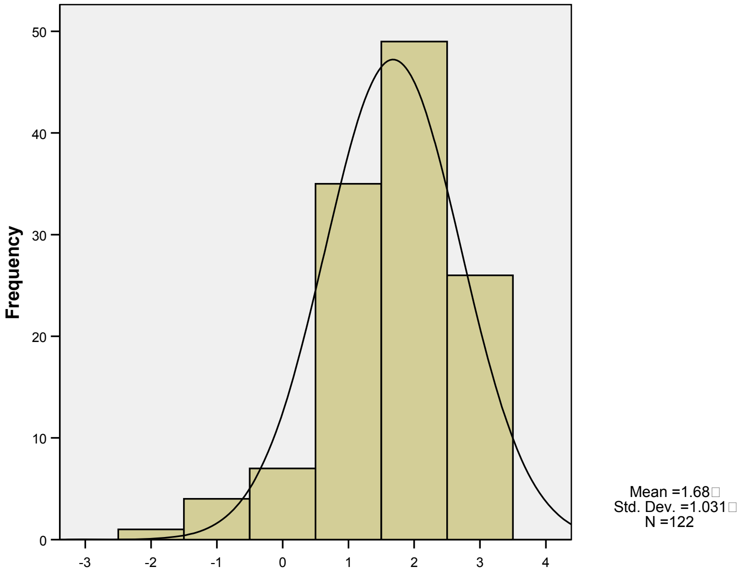


Figure H5: GP Care

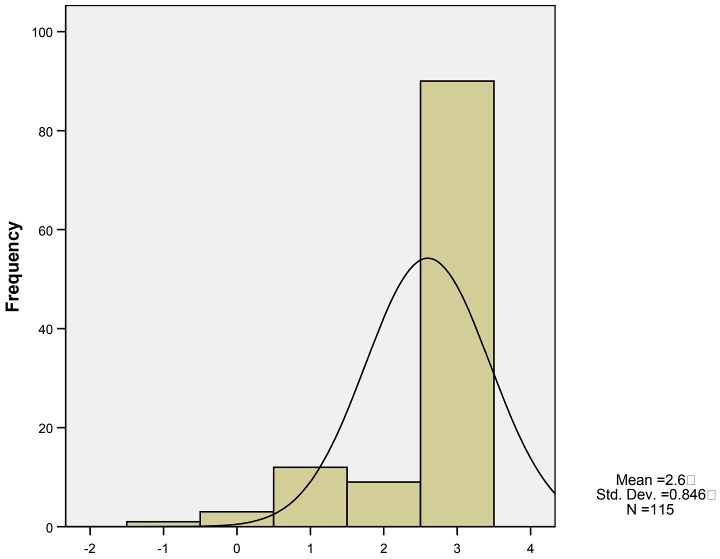


Figure H6: Community Care

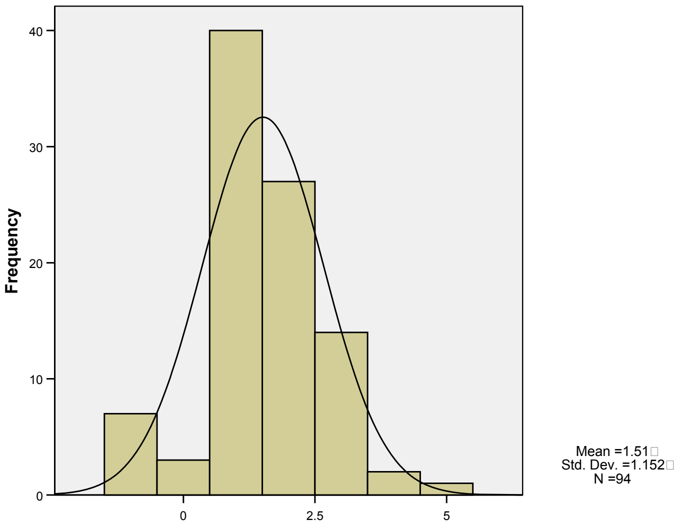
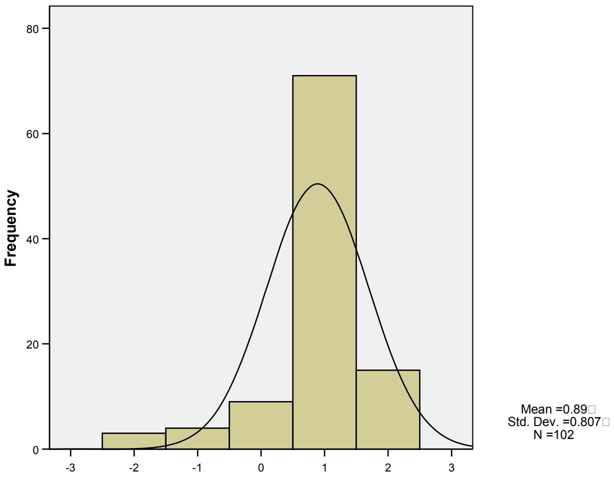


Figure H7:
Follow-up



APPENDIX J: Figures J1 to J5 PPCI Cluster Histograms

Figure J1:
Hospital Care

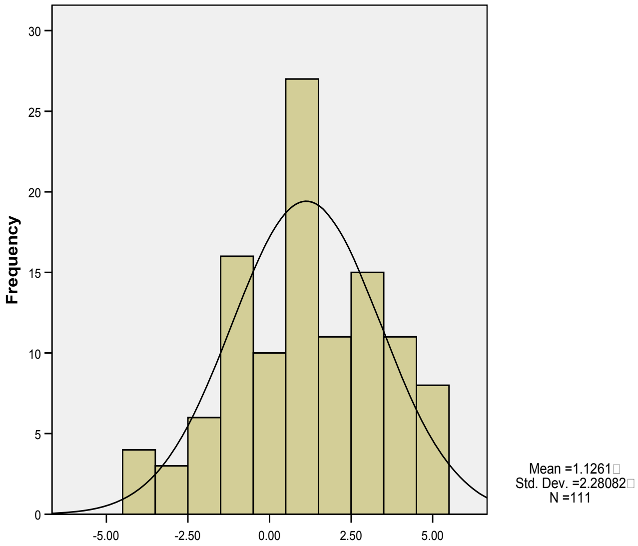


Figure J2:
GP Care

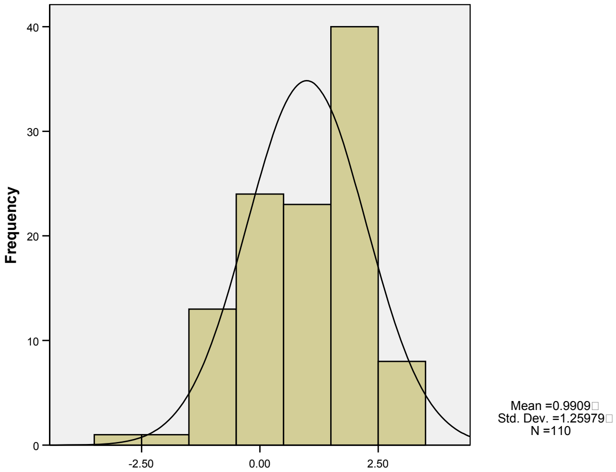


Figure J3:
Information

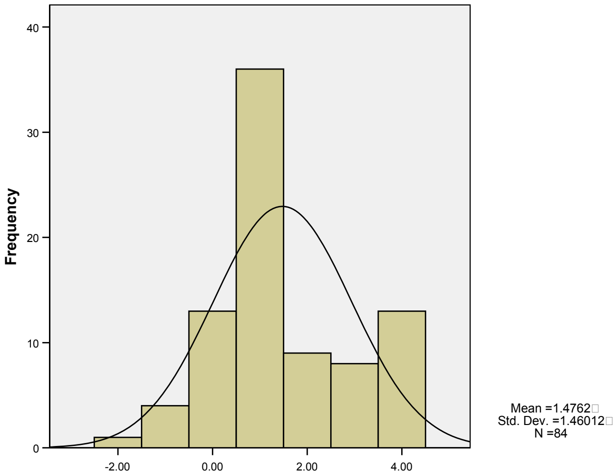


Figure J4:
Community Care

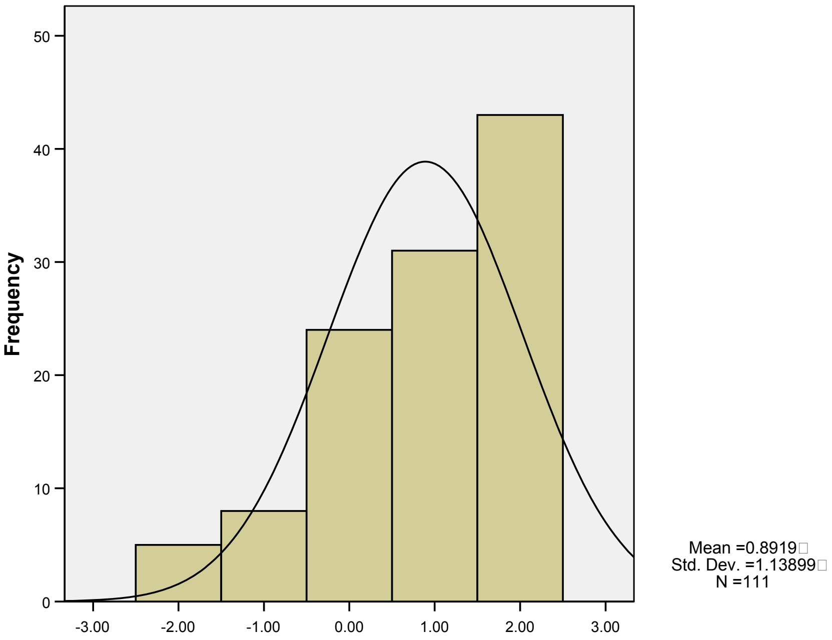
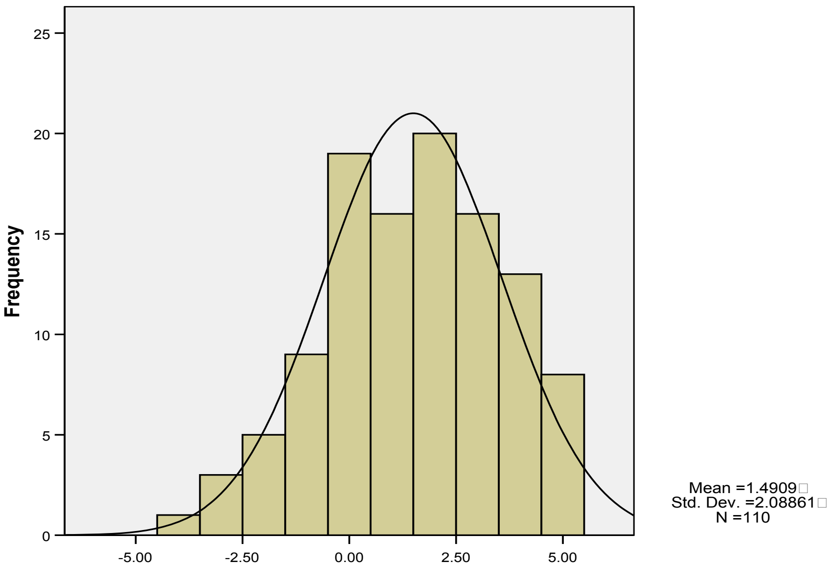


Figure J5:
Social Care



APPENDIX K: REFERENCES

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Addendum

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

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