

Synthesis and conceptual analysis of the SDO Programme's research on continuity of care

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prepared by

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The Report

1 Introduction, aims and objectives

Despite continued attempts to alter policy and change practice, the ability of health and social care systems to deliver the type and level of continuity of care that service users desire remains in question. Lack of clarity about what continuity of care actually means, as well as imperfections in systems to deliver it, have been identified as part of the cause of this problem. The NIHR Service Delivery and Organisation (SDO) Research and Development Programme funded a series of research projects, both primary and secondary, on continuity of care, specifically to tackle this conceptual confusion. This programme also aimed to add to the knowledge base about what service users want in the way of continuity of care, what influences whether or not they experience it and the outcomes it may produce.

These projects include:

- original scoping work and a literature review (Freeman *et al*, 2001 and 2004) that outlined a conceptual framework for defining continuity of care
- other literature reviews
- a series of empirical projects that explored the meaning and experience of continuity of care for a range of patient groups
- interim synthesis and conceptual analysis of the outputs of the programme (Freeman *et al*, 2007).

The synthesis of the outputs of the programme was carried out before all the empirical projects were complete, and NIHR SDO commissioned further work to build on and complete this work. This report is the outcome of that commission. By formally reviewing all its outputs, we attempted to establish how far the programme had advanced conceptual clarity about continuity of care and increased knowledge about what influences it and to what purpose. Robust information of this sort, translated into service delivery and organisation, is crucial to the delivery of many aspects of current health and social care policy.

The **aims** of the work reported here were:

1. to confirm or further refine the conceptual model of continuity of care elucidated by Freeman *et al* (2001, 2002, 2004 and 2007)
2. to identify what influences the experience and delivery of continuity of care both overall and for different patient groups
3. to identify the outcomes of continuity of care both overall and for different patient groups
4. to identify the links between 1, 2 and 3 above
5. to identify the commonalities and differences in instruments designed to measure continuity of care for different patient groups.

To achieve these aims, the **objectives** of the work proposed were:

1. a qualitative synthesis of the conceptual underpinnings or definitions of continuity of care used in the primary and secondary research projects completed in the SDO Continuity of Care programme
2. a qualitative synthesis of the results of the primary research projects to explore what influences continuity of care, the outcomes it produces, and service users' and carers' preferences in relation to continuity
3. a descriptive, qualitative and, if appropriate, quantitative synthesis of the outcomes of continuity of care
4. a description and analysis of the measures of continuity of care for different patient groups developed in the primary research projects
5. an overview report pulling together findings from objectives 1-4 above.

1.1 Background

Issues around continuity of care, however termed or defined, have run through health and social care policy since the inception of the NHS.

Problems securing continuity of care **across** health and social care boundaries have been evident, particularly in relation to frail older people and those with long-term conditions, since the early 1950s, and there have been almost continuous attempts since to resolve them by changing policy and directing practice (Lewis, 2001).

Similarly, concern about continuity of care **within** service systems has been a consistent feature of evaluative research in both health and social care. This has become more the case as increased specialisation of care, technological advances, and shifts in the place of care have accelerated (Reid *et al*, 2002). Just some of the factors identified as playing a part in the delivery (or not) of continuity of care for service-users and their families or carers are:

- communication between primary and secondary health care and between long-term and short-term care systems
- team working within single sectors
- professional boundaries
- systems for transition between different types of services
- and care pathways for individual service users (Haggerty *et al*, 2003).

Despite these long-standing concerns, and attempts to address them, policy returns repeatedly to the need to deliver 'seamless' care. For example, the recent White Paper, *Our Health, Our Care, Our Say*, (Department of Health, 2007) refers specifically to the need for continuity of care in relation to general practice, people with learning disabilities, people with long-term health conditions, and maternity services. The 'Darzi review' (Department of Health, 2008) promotes a model of integrated care provision that aims 'to enable partners to join together to design and deliver services around the needs of users rather than worrying about the boundaries of their

organisations. These arrangements should help eliminate unnecessary gaps and duplications between services (ibid, pp.13-14 of summary letter).

This long-standing, apparent inability to deliver continuity of care may have as much to do with pervasive confusion about what it actually **is** as with any systemic barriers to integrated or seamless provision, partnership or joint working, or any of the myriad terms used to describe the service delivery and organisational shifts put in place to provide it. If we do not really know what it is then it is difficult to know whether, when and how we have achieved it (Haggerty *et al*, 2003). Indeed, as Freeman *et al* (2001) have argued, systemic or organisational change intended to improve continuity of care when it is widely or inaccurately defined, may have unintended consequences that **reduce** the experience of continuity for patient groups (p.32).

Researchers have been trying since at least the beginning of the 1980s to define continuity of care (Starfield, 1980) and there have been attempts in the recent past to review a growing literature and pin down a definition. For example, around the time that the Freeman *et al* scoping study for the SDO programme was published, researchers in the USA and in Canada published their own reviews of the field. Saultz (2003) reviewed the literature on primary care in order to develop a definition of 'interpersonal continuity' (p.134) and to describe how it had been measured and studied. In Canada, Reid *et al* (2002) carried out an overview of both 'academic' and grey literature to 'explore different concepts of continuity, their common themes and measurement approaches' (p.1), across the medical spectrum but with a particular emphasis on primary care, mental health care, nursing care and care for specific conditions.

Between them, these three pieces of review work, but especially Freeman *et al* (2001) and Reid *et al* (2002), provided an understanding of the basic concepts of continuity of care being described in the literature, a review of the instruments so far developed to measure it, and outlined a research agenda for the future. These two streams of work have also influenced one another. The subsequent summary publication of the Canadian work (Haggarty *et al*, 2003) modified their original model in the light of Freeman *et al* (2001). Further, the Freeman *et al* (2007) review of the SDO programme results as they were at that stage, also included a synthesis of results from a Canadian programme of research on continuity of care. These programmes of research and the two original conceptual models were considered alongside each other in the Freeman *et al* (2007) review and, from them, an 'evolution of the concept of continuity of care' (ibid: 49) was proposed.

However, despite reference by Freeman *et al* 2007 to 'thematic analysis' of the SDO projects, it is not entirely clear, either from the text of the report or the analyses, whether formal methods were used to arrive at the evolved model of continuity of care.

1.2 The conceptual models of continuity of care

In order to understand what comes in subsequent chapters, we outline here the 'original' Freeman *et al* (2001) model of continuity and its subsequent developments.

1.2.1 Original definition (Freeman *et al*, 2001)

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 and with patients¹ (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).

1.2.2 Extended definition (Freeman *et al*, 2002)

A minimum definition of continuity of care should include the following elements:

- the experience of a co-ordinated and smooth progression of care from the service users' point of view (**experienced continuity**).

To achieve this central element the service needs to:

- provide one or more named individual professionals with whom the service user can establish and maintain a consistent therapeutic relationship (**relational, personal and therapeutic continuity**)
- ensure that care is provided by as few professionals as possible, consistent with need and uninterrupted for as long as the service user requires it (**longitudinal continuity**)
- be flexible and adjust to the changes in a person's life over time in their own personal and social context (**flexible continuity**)
- have **effective communication**:
 - based on excellent information transfer following the service user (**information continuity**)
 - between professionals working in statutory and non-statutory agencies, working in primary and secondary care, and with the service user and their informal care networks (**cross-boundary and team continuity**).

¹ Definition is taken from the executive summary. The definition in the main text does not include the words 'and with patients' (see Freeman *et al*, 2001, p.44).

1.2.3 An emerging definition (Freeman *et al*, 2007)

	Person-focussed care	Disease-focussed care
Relationship continuity (longitudinal, personal, continuous caring)	<p>Patient provider relationship that spans various episodes and often different care settings or care given by a core group of providers (e.g. home care)</p> <p>Identified main co-ordinator of health care (e.g. family physician)</p>	<p>Consistent with group of providers with clearly defined role (e.g. mental health care team)</p> <p>Organisational culture responsive to personal needs of patients (e.g. patient care)</p> <p>Identified main care manager for specific disease (e.g. diabetes nurse, mental health key worker)</p>
Management continuity (cross-boundary, team care, flexible, seamless service)	<p>Identified main care manager for specific disease (e.g. diabetes nurse)</p> <p>Co-ordination of care directly affecting patients (e.g. members of individual primary care team or ward based team)</p> <p>Detection of significant changes in functional status (e.g. severe mental health care)</p>	<p>Common care plan between providers (shared goals and agreed-on means)</p> <p>Negotiation of ongoing access to needed services (e.g. long-term community mental health care)</p> <p>Inclusion of patients as partner in the management plan (e.g. diabetes care)</p>
Informational continuity	<p>Accumulated knowledge – often tacit – of values and personal circumstances of the patient (e.g. palliative care or psychosocial problems)</p> <p>Up-to-date record of care and test results available at point of service (primary health care)</p> <p>Patient and family included in information loop (e.g. follow-up cancer care)</p>	<p>Information transfer between different providers (hospital discharge to community care)</p> <p>Up-to-date record of past service and results available at point of service (e.g. maternity care)</p> <p>Consistency of messages communicated to patient (e.g. self-management of diabetes)</p>

2 Methods

2.1 Rationale for our proposed approach: dealing with diversity

The projects in the SDO continuity of care programme were diverse in their design, methods and analysis, and in their focus. This diversity offers many challenges when, as required here, the object is to produce a synthesis of the results.

Designs used across the programme included longitudinal cohort studies, cross-sectional studies, and pre-clinical and phase one evaluations of new interventions. Methods included documentary and policy analysis, systematic and other reviews, diary-keeping, self-completion questionnaires, face-to-face interviews, use of pre-existing psychometric instruments, non-participant observation, in-depth qualitative individual and group interviews, the development of measures of continuity of care and other approaches. Some projects also included an element of service development and testing. Analytical approaches included description, multi-variate and multi-level testing, narrative and other forms of synthesis, and outcome assessment, among others.

The focus of the projects also varied - by patient group (for example, children with long-term conditions or impairments, mental health, stroke, diabetes, cancer, learning disabilities, generic primary care), by the level at which research was conducted (for example, individual patient, professional, care organisation, policy) and by service setting (for example, primary care, acute hospital care, community care).

Therefore, the results from the projects also varied and included a wide range of both quantitative and qualitative material. In addition, as outlined above, some of the projects had already been reviewed and the conceptual model of continuity of care further developed as a result.

All these issues, but particularly that of the diversity of research approaches, made the choice of methods and analysis for this final review challenging. To deal with these challenges, we decided to adopt methods developed for systematic reviews and specifically those for the synthesis of material generated from different research approaches.

Further, rather than trying to build on the developed Freeman model² from the outset, we decided to treat the outputs of the SDO programme in their own right - as if Freeman *et al* (2007) had not been written - and then, after our synthesis was complete, to triangulate our conclusions against those of Freeman *et al* (2007). This allowed the developed Freeman model to stand as it is, and make it clear how, if at all, our synthesis took the conceptual development of continuity of care to a different place.

² For simplicity's sake we refer throughout to the 'Freeman model', with appropriate date, though all the relevant publications were multi-authored. Full authorship and reference details are in the reference section.

2.1.1 Using methods developed for systematic review

As systematic reviews have grown in their influence and spread, approaches towards and methods for reviewing and synthesising results from diverse research projects and approaches have attracted increasing attention. Reviews have moved on from relatively uncomplicated questions about the effectiveness and costs of drugs or 'simple' clinical interventions towards questions about 'complex' interventions (Medical Research Council, 2000) or models of service delivery or organisation. As a result, anxieties have been raised about the usefulness or applicability of conventional review processes for addressing these sorts of questions (Parker *et al*, 2000; Mays *et al*, 2001; 2005). Further, as in the SDO programme, the methods used to study these more complex issues are likely to be more diverse and to include few if any 'gold standard' randomised controlled trials. Debates about **how** reviewers might synthesise material from studies using different approaches, designs and methods (and even whether they **should** at all) have therefore ensued (Mays *et al*, 2005).

While the work that we proposed was not, in the conventional sense of the phrase, a systematic review, we intended that it would be a review carried out systematically, leading to a synthesis of results. We therefore chose an approach influenced by the debates about the synthesis of diverse material in systematic reviews and informed by other researchers who have struggled with questions about elusive concepts in the delivery of health care (Campbell *et al*, 2003; Dixon-Woods *et al*, 2006).

2.1.2 Our chosen approach

We adopted largely qualitative methods of synthesis for the results of the SDO programme of research on continuity of care, varying slightly depending on the question being addressed.

1 What is continuity of care?

We used a broadly meta-ethnographic approach (critical interpretive synthesis – Dixon-Woods *et al*, 2006) to deal with the question of what continuity of care is. This is a new approach, developed specifically as a way of dealing with review of a complex concept in health care (access), and therefore appropriate for further development of the concept of continuity of care. The approach requires a 'lines of argument' synthesis which results in what Dixon-Woods *et al*, (2006) have termed a 'synthesising argument'. Such an argument 'integrates evidence from across the studies in the review into a coherent theoretical framework comprising a network of constructs and the relationships between them' and is 'generated through a detailed analysis of the evidence included in a review, analogous to the analysis undertaken in primary qualitative research' (p.5 of 13 pp., downloaded version). As such, it can perhaps be seen as a form of qualitative secondary analysis.

2 What influences continuity of care and what outcomes does it lead to?

We used narrative synthesis to bring together findings on what influences continuity of care and what outcomes it leads to. This approach is appropriate where studies are not similar enough to allow for statistical meta-analysis (Popay *et al*, 2004). However, it goes beyond a simple narrative review in order not only to organise and describe findings but also to interpret the findings and try to identify 'explanations for (and moderators of) those findings' (cited in Mays *et al*, 2005, p.12). This

allowed us to use both qualitative and quantitative data from the diverse studies and to explore the questions of if, how and why the precursors, experience and outcomes of continuity of care are different for different groups.

3 How has continuity of care been measured?

We addressed this question by using a descriptive synthesis of the measures used in the programme's projects to assess continuity of care. The intention was to describe the methods by which the measures were developed, their psychometric properties, and any commonalities between them.

2.2 Methods of review

2.2.1 Identifying the literature included in the review

At the start of the project, we contacted NCCSDO staff to confirm the list of projects that were funded as part of the original Continuity of Care programme, and to check that all the projects had finished and that final reports had been submitted and were available for review. SDO staff confirmed that 10 core projects had been funded (including some projects that followed on from the early work funded under the programme) and that all had been completed. Final reports were available for all except one project, where problems identified by peer reviewers had not yet been resolved.

The nine successfully completed core projects included six primary studies and three reviews of existing research on a range of patient groups and topics (see *Table 1* for a brief summary of the core projects and *Appendix 1* for a full classification of the projects). All nine projects were included in the present synthesis of the work.³ Copies of the final reports from these projects were obtained from NCCSDO.⁴ We also contacted the lead researcher for each project and asked about any other publications arising from the work to date. Where they did not respond within the timescale of the study, we also searched relevant databases for any such publications and obtained any identified.

Table 1. The SDO Continuity of Care Programme projects included in the review

Lead researcher/s	Patient group/topic	Type of study
Baker	Primary care	Primary study
Burns / Catty	Mental health	Primary study + follow-on
Gulliford	Type 2 diabetes	Primary study
Hardy	Organisational & professional	Primary study

³ When the initial synthesis of findings was carried out (Freeman *et al*, 2007), the results of three of the six empirical studies were available.

⁴ Where follow-on studies had been carried out, these were sometimes written up as part of a single final report and sometimes as separate reports.

Lead researcher/s	Patient group/topic	Type of study
	boundaries (learning disabilities & stroke)	
Hill	Stroke	Primary study
King	Cancer	Primary study + follow-on
Forbes	Transition from children's to adult care for young people with chronic illness or disability	Review, interviews and survey
Freeman	Severe mental illness	Review, case studies and Delphi exercise
Humphrey	NHS Human Resource management policies (maternity care, primary care, mental health & cancer care)	Review of policy documentation, expert seminars

We also acquired other key reports and publications that were integral or influential in relation to the SDO Continuity of Care programme. These were the original SDO scoping report (Freeman *et al*, 2001) and related reviews carried out for Canadian health services organisations⁵ (Haggerty *et al*, 2003; Reid *et al*, 2002). The report of the initial synthesis of early findings carried out for SDO (Freeman *et al*, 2007) was also obtained.

We read some of the key references in the above reports and publications to other work on continuity of care for background purposes, but did not include these in the main review.

All three members of the research team read all the final reports of the six primary studies in order to familiarise ourselves with the work. We then discussed the design of these studies and the implications for approaching the review work. There were some notable variations in the studies, as well as some common features. For example, the empirical studies varied in terms of:

- the patient groups and topics they examined
- whether the perspectives of patients, carers and/or professionals were included
- the ways in which both qualitative and quantitative methods had been used and integrated
- the ways in which projects had interpreted and applied the concept of 'experienced continuity' as elaborated in the scoping study
- whether studies had ended up confirming, modifying or abandoning the model of continuity of care that formed the backdrop to the studies.

At the same time, it was apparent that these studies did all aim to better define continuity of care from patients' perspectives, and in several cases to measure the outcomes for patients and identify the factors that influenced these. Reading the additional publications emerging from the completed

⁵ The Canadian Health Services Research Foundation, the Canadian Institute for Health Information, and the Advisory Committee on Health Services of the Federal/Provincial/Territorial Deputy Ministers of Health of Canada.

projects suggested that they did not add anything to the detailed material in the final reports; we therefore decided not to review them further.

The final reports thus formed the 'transcripts' for the different forms of qualitative analysis outlined earlier.

2.2.2 Devising an analytical framework

We handled most of the material using the Framework Approach (Ritchie and Spencer, 1994). This method allowed us to maintain the coherence of individual projects ('subjects') while also allowing development of cross-project themes. The Framework Approach involves familiarisation (sifting and sorting 'data'), developing a thematic framework, indexing (where the thematic framework is applied to the 'data') and then charting (which involves abstracting and synthesising the data).

Following these principles, we drafted a series of questions about the conceptual underpinnings, design and findings of the studies, based around the aims and objectives of the synthesis. These questions then formed the basis for constructing a series of charts related to the two review questions of 'What is continuity of care?' and 'What influences continuity of care and what outcomes does it lead to?' This enabled us to extract information from each project into a chart on a particular theme, and for the findings to be used to facilitate and progress thematic and comparative analysis of the work.

So, for example, one chart was based around the theme: 'What were patients' preferences for and experiences of continuity of care?' In this chart, we extracted information from each project on three dimensions: patients' preferences and priorities for continuity of care; positive examples and experiences of continuity of care; and negative examples and experiences. There was also space to add comments and/or to cross-reference material to other charts. The completed chart provided a detailed breakdown of the findings of each of the six empirical projects on this topic.

Working in this way meant that, for each project, there was a chart for each theme. Alongside other charts on related topics, it was thus possible to compare and synthesise results, and to develop higher order categories of analysis or theories, as the work progressed.

We completed the chart described above, on patients' experiences, first, after we had all experimented with it by extracting material relating to one or two of the projects. We then discussed how we each had found this process. There were no major problems identifying which material to extract or how much depth to go into. There were some minor variations in the ways we had used the 'notes' field, and how we had cross-referenced the material, and these were quickly resolved. After this trial, we each worked with our allotted reports and proceeded to extract material for a set of charts on findings from the studies, and one on the design and methods of the studies. The researchers met again after a short interval to discuss progress and any issues arising before completing the task.

The final framework for analysis included the following themes and sub-themes.

The studies

Design and methods - Purpose and aims; design of study; details of qualitative methods used; details of quantitative methods used; notes.

What is continuity of care?*Use of the Freeman model.*

- Existing model used/drawn on.
- New model/concepts/understanding developed through the projects.
- Whether study confirms Freeman's original model.
- Refines or questions/refutes Freeman's original model.

Use of multi-axial model.

- Do authors judge that multi-axial concepts from Freeman review map onto/mirror those of patients' views obtained/observed in SDO studies?
- Do authors judge that multi-axial concepts converge/diverge with carers' views and experiences?
- Do authors judge that multi-axial concepts converge with/diverge from professionals' views and experiences?
- Comparisons with other projects (e.g., what is distinctive about this approach?)

Whose perspectives on experienced care are conceptualised?

- Patients' views?
- Carers' views?
- Professionals' views?
- Comparisons with other projects (e.g., what is distinctive about this approach?)

Nature of experienced care and relationship of experienced care to other concepts.

- Process or outcome?
- Relationship to other constructs/variables (for example, patient satisfaction, quality of care).
- Other.
- Comparisons with other projects (for example, what is distinctive about this approach?).

Conceptual issues encountered/raised by authors.

- Researchers not using the term 'continuity' in the interviews.
- Explicit assumptions made by researchers.
- Other.
- Comparisons with other projects (for example, what is distinctive about this approach?).

Conceptual innovations

- Alternative concepts - as so conceived by authors.
- Discontinuity.
- Other (for example, revisions to multi-axial/experience care concepts; informational continuity as relating to exchange between patients and professionals, not just professionals).
- Comparisons with other projects (for example, what is distinctive about this approach?).

What influences continuity of care and what outcomes does it lead to?*What were patients' preferences and experiences of continuity of care?*

- Patients' preferences and priorities.
- Positive experiences.
- Negative experiences.

What influenced patients' experiences of continuity of care?

- Factors influencing positive experiences.
- Factors influencing negative experiences.
- Other factors.

What were the outcomes of continuity of care for patients?

- Outcomes of continuity.
- Outcomes of discontinuity.
- Other notable outcomes not necessarily attributable to (dis)continuity.

What were carers' preferences and experiences of continuity of care?

- Carers'/close persons' preferences and priorities.
- Positive experiences.
- Negative experiences.

What influenced carers' experiences of continuity of care?

- Factors influencing positive experiences.
- Factors influencing negative experiences.
- Other factors.

What were the outcomes of continuity of care for carers?

- Outcomes of continuity.
- Outcomes of discontinuity.
- Other notable outcomes not necessarily attributable to (dis)continuity.

What were professionals' preferences and experiences of continuity of care?

- Professionals' preferences and priorities.
- Positive experiences.
- Negative experiences.

How was continuity of care delivered and what influenced this?

- How delivered.
- Factors influencing this.

2.2.3 How has continuity of care been measured?

We had originally intended to use charts to extract material on the ways in which the projects had developed new measures of continuity of care, and the results obtained from applying these measures. However, this aspect of the review proved too complex for this approach, mainly because of the widely differing approaches that the projects had used. We therefore analysed these elements of the projects using in-depth description based on close reading of the original reports. This covered what existing measures (if any) were used, any new measures that were developed, how they were

developed, their psychometric properties and any underlying concepts used or revealed during their development and testing.

2.2.4 Assessing quality

We considered using some form of methodological quality assessment of the projects reviewed but, as anticipated, this proved too challenging given the different approaches and methods used.

2.2.5 Analysis

After extracting data to the charts, we then moved to our final stage of analysis using the lines of argument synthesis, narrative synthesis and descriptive synthesis, as appropriate, for each of the research questions.

We then triangulated the output of the synthesis against the scoping study (Freeman *et al*, 2001), the Reid *et al*, (2003) report, and the interim programme review (Freeman *et al*, 2007). In doing this, we hoped to come to a conclusion about the advances that have been made in conceptualising, measuring and understanding the precursors and outcomes of continuity of care, and for different groups.

The last part of the project was to share the draft final report with the original investigators and with our advisor, to gather their views and comments and to make any necessary amendments to the draft report in the light of these.

2.2.6 Involvement of stakeholders

Stakeholders were involved in all the projects, both primary and secondary, in the SDO programme, and in the work Freeman *et al* (2007) carried out before the programme was completed. Given this and the short timeframe for the current proposed work, we did not set up a formal advisory group for the review. With the agreement of NCCSDO, we asked a member of an existing advisory group for our empirical project on continuity of care for people with long-term neurological conditions to comment on our draft final report.

3 The Studies

Ten studies were reviewed in this project; full authorship and reference details are on page 108. There were three scoping studies covering transition to adult health services (Forbes, 2001), human resources (Humphrey, 2002) and severe mental illness (Freeman, 2002). Seven substantive empirical studies (which we call here the 'main' studies) covered six areas of health care: primary care (Baker, 2006), stroke (Hill, 2008), severe mental illness (Burns, 2007), stroke and learning disabilities (Hardy, 2005), cancer (King, 2006 and 2008) and diabetes (Gulliford, 2006). King, 2008, alone among the studies reviewed, was an intervention study, albeit at the feasibility stage, though the intervention built directly on the earlier study. For ease of interpretation, we refer in this chapter to these studies by their health care focus, rather than by their authors. Thus:

The main studies

- Baker, 2006 – the primary care study
- Hill, 2008 – the stroke study
- Burns, 2007 – the severe mental illness study
- Hardy, 2005 – the stroke and learning disability (LD) study
- King, 2006 – the first cancer study
- King, 2008 – the second cancer study
- Gulliford, 2006 – the diabetes study.

The scoping studies

- Forbes, 2001 – the transition study
- Humphrey, 2002 – the human resources study
- Freeman, 2002 – the severe mental illness scoping study.

3.1 Aims and objectives

Table A.1 (appendix 1) summarises the overall aims and objectives of each study.

3.1.1 The main studies

Six of the main studies had, as some part of their objectives to explore health service users' experiences of continuity of care. Not all, by contrast, referred to exploring service users' understanding, definitions or perceptions of the concept of continuity. The diabetes project, for example, did not refer in its overall objectives to this conceptual approach. The second cancer study built on the findings of the first, which had explored the concept of care from service users' perspectives but did not explore it again in the later study.

The aims/objectives of all but the stroke study mention carers' views or experiences, but they are described and defined in different ways, as *Table A.2* shows, for example as 'close persons' or 'families'.

Exploring professionals' views, experiences, understanding or definitions of continuity was part of four studies. There is no reference to these objectives

in the primary care or stroke studies, although the latter did seek professional views about aspects of service organisation relevant to continuity. An objective of the second cancer study was to test out an intervention targeted at professional behaviour, building on findings of the earlier study.

Beyond these exploratory objectives, the foci of the main studies were different. The primary care study focussed on the different weights that service users might give to different aspects of continuity and to continuity as against other desirable aspects of primary care service delivery. In four studies – of stroke, severe mental illness, the first cancer study, and diabetes – a main objective was to measure continuity of care specific to the health condition in question. These measures were predominantly about continuity for services users but the severe mental illness study also developed one for carers. After developing the measures, these studies also planned to examine relationships between continuity and:

- functional and psychosocial outcomes for service users(stroke study)
- process variables for services users and their health and social outcomes (severe mental illness study)
- satisfaction, and how these relationships were affected by psychological status, expressed needs for care, spiritual belief, quality and life, and coping strategies (first cancer study)
- clinical and patient outcomes (diabetes).

The diabetes study also developed and tested a measure of continuity of care for professionals, and the stroke study a continuity measure to be used to review case notes.

The stroke and LD study was distinct from the others in its exclusive focus on the relationship between continuity and national and local policy-making, inter-organisational arrangements, and inter-professional working. Despite its further objective of exploring the perceptions and experiences of care as viewed by service users and their families/carers, relatively little material related to this is included in the final report. This study was also the only one to have a specific focus on aspects of continuity as they related to social care.

Finally, as outlined earlier, the main objective of the second cancer study was to develop an intervention intended to influence professional behaviour in order to affect service users' experiences of continuity and then to test the feasibility of conducting a full randomised controlled trial of the intervention at some future date.

3.1.2 The scoping studies

All three of the scoping studies were carried out towards the beginning of the NIHR SDO programme on continuity and, given their nature, were more limited in their aims and objectives than were the main studies. However, all three did involve elements of primary enquiry and we have included the material from these elements in the review.

The main objective of the transition study was to identify models of good practice in relation to transition from child to adult health services. The human resources study explored how policy initiatives affecting management and human resources might affect continuity of care and used four exemplar areas of care to look for good practice. Finally, the severe mental illness scoping study aimed to understand what might enhance

continuity of care for people with severe mental illness and to look at contexts where such mechanisms operate, again using service exemplars to do this.

3.2 Settings for the research

All but one of the main studies used specified service settings or localities as their sampling frame for fieldwork (see *Table A.2, appendix 1*). The exception was the stroke study, which sampled service users from a pre-existing stroke database, albeit one based on a defined geographical area. All but one study covered both primary and acute care settings, the exception being the primary care study, as would be expected.

There was a clear bias towards London settings for the main studies – four were exclusively in London, one was in both London and a county setting, one was in the North West and North East of England, and one was in West Yorkshire.

The transition scoping studies used children's services (primary and acute health services, as well as local authorities) in two, unidentified, geographical areas for its fieldwork, while the severe mental illness scoping study explored four sites of presumed good practice, two of which were in London and two outside. The expert seminars in the human resources scoping study were not related to specific service settings or localities.

3.3 Design, methods and research questions

3.3.1 The main studies

Details of the design, methods, and sample size are in *Table A.3* (appendix 1).

The designs of the main studies varied (*Table A.3*). The primary care study was a multi-method descriptive design, while the stroke, severe mental illness and diabetes studies were all multi-method exploratory designs with a component involving development and psychometric testing of instruments to measure continuity of care. The stroke and LD study was the only one that adopted an exclusively qualitative approach in its case study design. The two cancer studies involved, first, the pre-clinical phase of development of a complex intervention and then the development and exploratory RCT of that intervention. Following the MRC guidelines (MRC, 2000) on the evaluation of complex interventions, the studies' authors designate these studies as the pre-clinical and the phase one and two stages of an evaluation.

Most of the main studies were complex in their design, with inter-dependent phases or stages that used different methods and approaches (see *Table A.3*). In all but the stroke and LD study, qualitative methods were used alongside with or to inform subsequent quantitative methods. The research questions for different stages of projects seem largely to have driven the adoption of qualitative methods, as one would expect. However, the 'Freeman framework' (Freeman *et al*, 2001) for defining different elements of continuity of care had already been published before these main studies started (indeed, had informed the commissioning of the main studies). The researchers' wish to re-visit the experience and definition of continuity with their own qualitative research offered the opportunity to 'test out' the

Freeman framework with different patient groups and in different settings. However, as we saw in *Chapter 1*, this was not the case for all main studies, with some (the stroke and LD study) deliberately bypassing the Freeman framework and others (for example, the severe mental illness study) developing their own framework before re-engaging with Freeman's.

Although the methods used in the studies were predominantly cross-sectional, some did include longitudinal elements, which potentially allowed exploration both of change in perceptions or experiences of continuity over time and of relationships between continuity and other change. One stage of the primary care study examined the use of primary care services over time in relation to service users' views of continuity. The main phase of the severe mental illness study explored the relationships between continuity and a range of other variables, both in cross-section and across time. The stroke and LD study interviewed service users and their families and professionals over time, but with varying intervals and frequencies between groups and conditions. The first cancer study included longitudinal quantitative and qualitative approaches to understand both service users' and 'close persons' experiences and perceptions of continuity over time, as service users moved through different stages of the cancer journey. Finally, one stage of the diabetes study was a prospective cohort study (with retrospective elements) that explored changes in service users' experiences of continuity over time and examined whether changes were associated with change in outcomes.

As *Table A.3* shows, methods were largely drawn from mainstream social science – face-to-face or telephone interviews (both quantitative and qualitative, structured and semi-structured), postal surveys, focus groups, expert panels, non-participant observation and documentary and policy analysis. All the studies that developed measures of continuity used standard psychometric approaches to testing these measures, though the development phases varied in their depth and length, from study to study.

One study (diabetes) collected clinical measurements and four (stroke, stroke and LD, diabetes, the second cancer study) attempted, with varying degrees of success, to use case notes, and clinical or hospital records to explore aspects of continuity of care.

Only the primary care study used any methods drawn from health economics, using conjoint analysis to explore the trade-offs service users might be prepared to make between continuity and other desired aspects of primary care services.

3.3.2 The scoping studies

All three scoping studies adopted a multi-method approach. The primary research in each differed in methods used, although all were broadly qualitative and mainstream social science approaches (*Table A.3*). All three also involved some element of appraisal of 'expert' views on the topic being scoped. The transition study involved telephone interviews with key informants. The human resources study ran expert seminars in four exemplar areas of care – maternity care, primary care, mental health care, and cancer care. In the severe mental illness scoping study a modified (two-round) Delphi study was run.

3.4 Samples

3.4.1 Qualitative methods

Details of the achieved sample sizes for the different elements of each study are included in *Table A.3*. Samples for qualitative interviews ranged from two carers in the stroke study to 113 professionals in the severe mental illness study. Three studies used focus groups (group discussions); the **total** number of people who participated in the groups ranged from 11 carers in the severe mental illness study to around 28 professionals in the stroke study. Some studies experienced problems generating samples for qualitative work and, for those with longitudinal elements, keeping attrition low. For example, the stroke and LD study interviewed only six professionals involved in stroke care in two sites in its second round, compared to 52 in three sites interviewed in its first round. Similarly, in one element of the first cancer study, of eight service users interviewed at baseline only three were followed-up once or more.

3.4.2 Quantitative methods

Surveys used to test the psychometric properties of newly developed measures of continuity varied in sample size from 32 service users in the second cancer study to 209 patients in the diabetes study. For other surveys, the range of initial sample sizes was from 145 carers in the first cancer study to 1437 service users in the primary care study.

As with the qualitative elements, most studies struggled to build samples for quantitative surveys and to retain them for longitudinal work.

So, for example, the primary care study had response rates of 46 per cent for its conjoint analysis survey and its postal questionnaire. Similarly, the stroke study achieved only a 34 per cent response rate for the postal administration of its first continuity questionnaire, though in face-to-face administration, as part of routine assessment, a much higher completion rate of 98 per cent was achieved, as might be expected.

In the severe mental illness study, 180 out of 498 service users with psychotic conditions identified as eligible were successfully interviewed at time one (36 per cent), although 78 per cent of these were retained until time 3, two years later. By contrast, follow-up in the longitudinal element of first cancer study was lower although follow-up was over only a year; 56 per cent of service users and 48 per cent of 'close persons' were still in the study at the end of the follow-up period. Given the nature of the study, deaths of service users accounted for some, but not all, of the attrition (21 cases, 11 per cent). However, other reasons for refusal were recorded for each interview stage (there were five in total) and it is not entirely clear how many people were successfully interviewed at all five stages.

3.5 Discussion

The main studies reviewed were diverse in their health care focus, and their overall aims, objectives and methods. However, as this chapter has shown, there was some consistency across some projects, particularly in relation to the exploration of service users' experiences and views and, sometimes, understandings of continuity of care. Similarly, a clutch of studies set out to develop measures of continuity of care and then to explore the relationship

between continuity of care and other variables and outcomes. In one case, the measure was developed as part of an intervention intended to affect service users' experience of continuity of care.

Overall, then, despite the diversity of the studies, there is enough overlap of their aims and objectives to attempt to synthesise findings in these broad areas. In the chapters that follow, then, we explore the experiences and views of continuity expressed by service users, carer and professionals. We then synthesise any evidence produced by the study for outcomes related to continuity of care, whether as measured by the instruments developed as part of the studies or more generically derived from other types of data. After this, a chapter describes some of the more detailed aspects of the measures of continuity of care that were used and a final chapter draws our findings together.

4 What is continuity of care?

One of the aims of the present synthesis of the SDO projects was to confirm or further refine the conceptual model of continuity of care developed by Freeman *et al* (2001, 2004 and 2007). As explained in *Chapter 2*, to achieve this aim, we proposed carrying out a qualitative synthesis of the conceptual underpinnings and definitions of continuity of care used in the primary and secondary research projects completed in the SDO programme.

4.1 Use of meta-ethnography

The SDO programme comprised both primary studies and reviews of research on continuity of care spanning a variety of topics, and the empirical studies were complex projects, using mixed methods. Given these factors, meta-ethnography was felt to be the most appropriate and promising approach for synthesising and interpreting the conceptual underpinnings of the SDO projects, and understanding the ways in which the concept of continuity of care evolved over the course of the programme, both within individual studies and across the programme as a whole.

Meta-ethnography stems from the work of Noblit and Hare (1988) and has been developed as a way of synthesising multiple qualitative reports of applied research, using techniques derived from ways of analysing qualitative data (Mays, Pope and Popay, 2005). More recently, a variant of the approach - critical interpretive synthesis (CIS) - has been developed to appraise complex bodies of literature based on mixed methods designs (Dixon-Woods *et al*, 2006). The value of meta-ethnography and related approaches such as CIS is that, unlike narrative review, it is designed to make sense of and provide interpretations of complex bodies of evidence that do not lend themselves to simple summaries or aggregation. Rather, meta-ethnography seeks to provide new knowledge and interpretations that transcend the original work (Mays, Pope and Popay, 2005). In short, meta-ethnography provides an interpretive re-analysis of findings (and not a recapitulation of them).

Briefly, there are three main stages to meta-ethnography as originally described. In the first 'reciprocal translational analysis' stage, the key metaphors, themes or concepts used are identified. The concepts are examined and translated into one another in a bid to find those that best capture and convey the themes identified. Next, a 'refutational synthesis' is carried out to delineate and explain any contradictions in the reports. Finally, a 'lines of argument' synthesis is developed, building on the analysis of the key themes that cut across all the reports reviewed. In the present synthesis, a modified version of this approach was adopted, which we outline below.

4.2 Scope and procedures

The final reports of all the studies were included in this conceptual review, namely the original scoping review, six core empirical studies and their follow-on work, three reviews and the initial synthesis of the early outputs of the programme. The present final synthesis of these reports is itself

recognised as another output of the programme, albeit offering a more over-arching appreciation of it than was possible for the interim review that preceded this synthesis, given that not all the SDO studies were complete at that point.

One of the researchers (JH) carried out this part of the review, although she discussed her ideas with other members of the team at each stage and refined the approach in the light of these discussions. We read the reports and noted key terms and recurring themes relating to the conceptual basis and development of the studies. We used formal data extraction methods systematically to extract and record data from the reports into six charts (see *Chapter 2*). Using the charts helped to compare the concepts used, explore areas of convergence and divergence in the studies, identify crosscutting themes, and identify new findings and directions emerging from the work as a whole.

As the aim of this conceptual synthesis was to examine to what extent the projects confirmed or refined the model of continuity of care outlined in the SDO scoping report (Freeman *et al*, 2001), we adapted the original approach to meta-ethnography outlined above for this purpose.

In the first stage, we identified the main concepts used by the reports and examined the ways in which the projects drew on and developed the concepts originally outlined in the scoping report; or, if they introduced new ones, we examined how they were derived and why these were preferred. While the SDO scoping report was our main reference point, we also considered the influence of the related and contemporaneous Canadian review (Reid *et al*, 2002; Haggerty *et al*, 2003) that some of the projects referred to and were influenced by in the course of their work.

In the second stage, we examined the conceptual positions adopted by the projects and, in particular, how these related to their interpretation of the model of continuity of care outlined in the SDO scoping and Canadian review reports. Where some projects adopted a different stance to the majority, we explored why this was and considered the implications for the overall interpretation of the findings.

In the final stage of analysis, we stepped back from the reports and developed a more overarching interpretation of the themes and findings that emerged from our appreciation of the reports as a whole. The main results of this process of analysis were also triangulated with the findings from the earlier interim review by Freeman *et al* (2007) – although the scope for this was limited as the interim review focussed mainly on the issues relating to the measurement of continuity (Freeman *et al*, 2007: 6).

4.3 Findings

The findings of our analysis are discussed in two main sections. In the first, we stay relatively close to the surface of the projects, and compare and contrast the different approaches to and positions taken on certain key conceptual issues (this section mainly combines findings from the first and second stages of the analysis). In the second section, we take the analysis to another level. Here we step back and survey from a more independent and interpretivist perspective (Dixon-Woods *et al*, 2006) how the SDO programme as a whole has advanced understanding of the concept of continuity of care and the new emphasis and direction it has signalled for future research (this section corresponds to the higher order, third stage of the analysis). We conclude by summarising the main features of the model

that emerge from the present synthesis of the SDO programme and how this model differs from those that preceded it. Where appropriate, we have incorporated throughout the report the findings arising from the triangulation of the present final synthesis with those of the interim review by Freeman *et al* (2007), highlighting major points of similarity and difference, and any new findings, where applicable.

4.3.1 Interpretation and use of the conceptual model outlined by the SDO scoping report

Core concepts

The model of continuity of care outlined in the SDO scoping report (and related Canadian review) is founded on the idea that continuity of care is something that is **experienced** by patients and carers. Hence, their views need to be examined to establish how they define and value it, whether services satisfy these requirements, and what impact continuity (or lack of it) has on patients and their families. This model aims to supersede previous conceptualisations of continuity of care, which, it is claimed, are based on professionals' perspectives where continuity of care is regarded as a process that, with proper organisation and co-ordination of services and systems, can be delivered 'to' patients.

Another core claim of the SDO scoping report is that continuity of care is a complex, **multi-dimensional**, concept. The achievement of good continuity from the patients' perspective largely depends on services doing well on these dimensions (depending on which are important to individual patients and carers). Freeman *et al* (2001) initially identified and defined six dimensions, later amended in the SDO-funded review of continuity of care in the area of severe mental health (Freeman *et al*, 2002). The Canadian review (Reid *et al*, 2002; Haggerty *et al*, 2003) proposed a simpler tripartite framework which some of the SDO projects preferred (and which Freeman *et al* (2007) subsequently adopted as a general framework, while retaining the more detailed categorical descriptions of dimensions of continuity to distinguish different sub-types of continuity).

A third, intrinsic but far less explicit and developed theme underpinning the model of continuity of care advanced in the SDO scoping report was that patients' and carers' perspectives on both the **process and/or outcomes** of continuity of care were important to consider. Here the emphasis is on the need to consider patients' and carers' views on these topics, rather than staff views on the processes that facilitate or obstruct the achievement of continuity of care. Crucially, this model stresses the importance of examining patients' and carers' views on the consequences of continuity (or lack of it) on their health outcomes, as well as their satisfaction with the process of care – both of which were not given such prominence in previous, professionally-defined, conceptualisations of continuity of care. However, in our view, the scoping report did not provide a clear agenda for how the SDO projects might best investigate patients' and carers' views on and experiences of the processes and/or outcomes of continuity of care. In his later review on mental health, Freeman *et al* (2002) refers to the concept of 'process outcomes' for the first time, although none of the other projects used this term, and there was no planned or coordinated approach to the exploration of this matter.

In the following sections of this chapter, we consider how the projects interpreted and developed understanding of these core concepts. From here on, in this chapter and those that follow, we largely refer to studies not by

their formal references but by their 'patient group'. We do this to aid understanding of the ways in which different patients, carers and professionals might have understood and experienced continuity of care. Where we do reference included studies we use the convention of first author and date only. Full references to the studies included in the review are given in *Appendix 1*.

Mapping perspectives on continuity of care

All the primary and review projects adopted what we shall refer to as a 'perspectivist' model of continuity of care outlined in the scoping report. By 'perspectivist' we mean that they each attempted to ascertain the views and experiences of patients and/or carers (or close persons) and/or professionals, although the degree to which each party's views were explored varied from study to study. Overall, studies tended to prioritise understanding the patients' perspective, then carers/close persons and finally professionals. In the 'perspectivist' model, the views of patients, carers and professionals are recognised to be distinct (see *Table 2* at the end of this chapter for an outline of this emergent model and the two models that preceded it).

The studies used a range of qualitative methods to explore the respective perspectives of patients, carers and professionals on continuity of care. These methods were used to ascertain how each group defined and valued continuity of care in the individual study topic areas. In some projects, the results of this work were then used to inform the development of measures of 'experienced continuity' which were subsequently tested. Some also attempted to develop measures of carers' and professionals' experiences of continuity of care. In their doing this, we observed a tension between the extent to which the studies began exploratory work mindful of the concepts already advanced in the scoping report(s), as opposed to starting with a 'blank sheet' and doing more fundamental qualitative work to establish from scratch patients' and carers' views.

In practice, many of the studies seemed to start with the conceptual framework in the scoping report in exploring different perspectives (even where they claimed to be adopting, for example, a 'grass roots' approach to eliciting the patients' perspective, for example, cancer studies 1 and 2). Some were able to work with this framework, whereas others found it more problematic. For example, as we discuss later, most of the studies tried to 'map' the correspondence between their analysis of patients' and carers' views with the multiple dimensions outlined in the scoping report(s), and many avoided the jargon of 'continuity of care', for example by describing its characteristics as they saw them, to facilitate the interviews with patients and carers.

A few of the primary studies examined carers' perspectives on continuity of care (for example, primary care, severe mental illness, diabetes). One also aimed to but had to abandon this plan because of difficulties in getting ethical approval for different stages of the research (cancer 1 and 2). However, where carers were included, the ways in which they were conceptualised varied in two important respects. First, there was no common definition of a carer used across the studies. Thus the 'carers' interviewed included some who were actively engaged in various care work and others who were less so or not currently 'caring' as such. One study acknowledged this by choosing to refer to this group as 'close persons' because of their varying caring relationship with the patients over time, although they retained the term 'carers' in the title of the report (cancer 1).

Another study acknowledged that less than two-thirds of the people interviewed as 'carers' regarded themselves as such (severe mental illness).

Secondly, the capacity in which 'carers' were interviewed varied. In some studies, they were interviewed as people who had experiences of continuity of care themselves, and whose views might differ from those of patients and professionals. One study even went on to develop a measure of carers' experiences of continuity of care (severe mental illness). However, in another study, carers were interviewed in part about their views on the patients' experience of continuity of care, as well as how the patient's illness had affected them. Their proxy views were compared with those of patients themselves to see if the assessments matched and provided a valid rating of the patients' experience (cancer 1).

Where professionals' perspectives were examined as well as those of patients and/or carers, the aim seemed to be to explore to what extent views converged and diverged with those of patients and, to a lesser extent, carers. One study went further and developed a measure of professionals' views of continuity of care (diabetes). By prioritising the professional view in this way, alongside that of patients (this study looked at carers' perspectives but did not develop a measure of their views), this study (along with the transition review) breaks somewhat with the framework developed by Freeman *et al* (2001) in the scoping report. It also clashes with the strong view of the authors of one report who claimed that only patients' and carers' views 'count' (stroke and learning disability, pp.208, 209, 222, 223).

Mapping the dimensions of continuity of care

Nearly all the studies attempted at some level to investigate to what extent the various dimensions of continuity of care elaborated in the scoping reports 'mapped onto' or corresponded with the views and experiences of those interviewed in the empirical projects, and reviewed in the other projects. Several found that, largely, there was a degree of correspondence and that the model was a useful framework, which they were able to add to and refine, using their own results (for example, the severe mental illness, diabetes, stroke, and cancer main studies and the maternity care and mental illness reviews). However, others started with the dimensions in mind but ended up adopting another framework for organising their work and presenting the results (for example, the transition review). Hardy *et al* (2005) - in the study on organisational and professional boundaries - make no reference to the SDO scoping report in one of their case conditions (stroke) but draw on a version of the framework from the Canadian review (Reid *et al*, 2002; Haggerty *et al*, 2003) in the analysis of the other case (learning disabilities).

Why did some researchers interpret and use the multi-dimensional framework differently from others? There are several possible reasons. One is that the projects explored different conditions and that the framework was more applicable to some than to others. Another is that often large, multi-disciplinary teams carried out the projects and some authors drew on a wider literature to inform their work, as well as the scoping and review reports. Both of these reasons were probably influential. However, another factor we identified through the synthesis of the reports and which we think was crucial in shaping the results of the studies was the researchers' approaches to the qualitative work in which the patients' and carers' views on and experiences of continuity of care were investigated. Freeman *et al* (2007) make a related point in the interim review of the programme.

In the interim review, Freeman *et al* (2007) noted that there was perhaps some 'misunderstanding' of the original model, resulting in a preoccupation with the dimensions rather than a focus on patients' and carers' own definitions and experiences in line with **their** concepts of continuity. For example, some studies started with the various dimensions and explored whether patients' and carers' preferences and priorities corresponded with this multi-dimensional model, adding or refining the number and definition of the dimensions where appropriate and exploring their views and experiences on each of these topics. As noted in the interim review, this approach led to an expansion and further fragmentation of the multi-dimensional concept rather than improved knowledge of patients' and carers' understanding of the meaning and importance of continuity of care to them. This point is further illustrated and amplified in the next section, where we discuss the ways in which the researchers choose to ask patients and carers for their views on continuity of care largely without using the phrase.

Whose concept is it anyway? Avoiding the use of 'continuity of care' jargon in the interviews

In the original scoping report, Freeman *et al* (2001) briefly acknowledge the language gap between professionals, who are accustomed to the phrase 'continuity of care', and patients and carers, for whom the phrase may not be familiar. This was indeed an issue for the researchers.

In only one primary study (severe mental illness) did the researchers elect to use the term directly in the qualitative phase of the project. Here service users and carers had not heard the term before, but after it was explained to them, the researchers claimed that participants were able to generate ideas successfully (pp.19, 44, 267). This study was unique in arguing that the concept of continuity of care is meaningful to patients and carers and that they can discuss this concept (after explanation) with researchers (pp.19, 22-3, 44, 186, 267). (This study was also unique in using 'participatory methods' and a researcher who had personal experience of supporting someone with mental health problems.)

In the remaining studies the authors elected to avoid using 'jargon' and to ask questions about continuity of care that focussed on particular aspects of it that were believed to be more meaningful to patients and carers. This raises an obvious paradox. How could the researchers be confident that they were exploring patients' and carers' own conceptualisations of continuity of care if they were translating this concept and making assumptions about what were meaningful and relevant aspects of continuity of care for patients and carers when designing topic guides for the interviews? Few reports problematised and discussed this crucial issue (an exception being the stroke study where researchers found that patients struggled with the abstract concept of continuity of care, pp.61, 210, 211). This was particularly surprising given that subsequent phases of many of the studies were founded on the results of the qualitative work and that the scoping report had identified the issue of the language of continuity of care. This, in turn, represents an important limitation of the programme as a whole, given that the original scoping report pointed to the lack of consideration of patients' and carers' perspectives in the existing literature and hence called for this to be the focus of the SDO projects.

How the individual SDO projects developed the conceptual model of continuity of care outlined by the SDO scoping report

To conclude this section, the findings of the first and second stages of the analysis suggest that the individual projects contributed in a number of important ways to the 'perspectivist' model of continuity of care originally outlined by Freeman *et al* in the scoping report (2001). However, we also suggest that, collectively, the projects failed to progress understanding very far on some aspects of this model. These strengths and limitations of the 'surface' level findings are described below, before we move on to the next, more interpretive, synthesis of the SDO programme of work.

The main contribution of the individual SDO projects to the 'perspectivist' model of continuity of care was to the understanding of patients' perspectives on continuity of care. By using qualitative methods, researchers were able to refine the framework outlined by Freeman *et al* (2001) by clarifying the definition of some dimensions from the patient's perspective, and by identifying new ones that were important to them. Thus, in the severe mental illness study, patients highlighted the importance of continuity of information exchange between patients and professionals, whereas before 'informational continuity' had been conceived as concerning the transfer of information and records between services and professionals only⁶. In the same study, two new dimensions of continuity of care were identified, namely 'avoidance of services' and 'peer support' (pp.267, 269). In the cancer 1 and 2 projects (p.91), the dimensions of 'coping' and 'connections with family' were added. In the review of continuity of care in young peoples' transition to adult services (pp.69-72, 83) the dimension of 'developmental continuity' was added.

In addition, by talking to patients and carers, researchers were also able to show that often patients' journeys through the health system were very complex and did not correspond to idealised and linear 'care pathways' (for example, the stroke and LD study). This highlighted the need for more sophisticated methods of mapping patients' and carers' 'care networks' and their experiences of continuity over time (for example, the stroke study). This qualitative work also showed how some groups of patients may be more 'expert' than others at maintaining or obtaining continuity (for example, getting appointments) than others (for example, the primary care study).

Related to this, some researchers found that, as Freeman *et al* (2001) had suggested in the scoping report, patients did not always necessarily value continuity *per se*. That is, for some patients, on some occasions, discontinuity was in some ways regarded as desirable by patients, for example, because a break from service provision represented a return to 'normality' for a period (for example, primary care study, p.46; cancer 2 study, p.61).

While only a few studies included professionals' perspectives, researchers argued that it was important still to include them. Where the views of two or more parties were included, researchers were potentially able to compare them though did not do so in any detail (see *Chapter 7*).

The main limitation of the SDO projects was that they did not add much to existing understanding of carers' perspectives on continuity of care. They

⁶ Although in Freeman *et al* 2002, this line of information transfer was included in the refined model.

also took different views about a definition of carers, in what capacity they should be interviewed, and whether a measure of their experiences of continuity should be developed as a priority alongside measures for patients. That said, interviews with carers and close persons did provide information on the roles of family members and their relationships with patients and professionals which, we suggest, further points to the potential value of a new emergent model of continuity of care for future research to pursue, which we outline below.

In addition, as mentioned above, and by Freeman *et al* (2007) in the interim review, the ways in which the researchers interpreted and used the multi-dimensional model in their research may have resulted in an expansion and fragmentation of the concept rather than a fuller appreciation of patients' and carers' perspectives on continuity of care. Indeed, Freeman reflects in the interim review that he no longer thinks (if he ever did) that the outcomes of the various dimensions of continuity of care can be 'packaged' together into an overall measure or concept of 'experienced' continuity of care (Freeman *et al*, 2007: 47).

Finally, there was a lack of consensus and clear debate within and between the projects on the subject of whether continuity of care is a process and/or an outcome of care from different perspectives. Some projects also highlighted the related issue of whether and, if so, how the processes and outcomes of continuity of care can be distinguished from other related constructs such as patient satisfaction (for example, the stroke study).

4.3.2 Interpretive synthesis: from a 'perspectivist' to a 'partnership' model of continuity of care

Core concepts

The model of continuity of care outlined in the SDO scoping report recognised that patients and carers have different perspectives on and experiences of continuity of care relative to professionals, and that their views on both the processes and/or outcomes of continuity of care were important to assess. In the course of exploring patients', carers' and professionals' perspectives, several studies reported findings that, we suggest, signal a new emerging model that focuses less on individual perspectives (though these are still important) and more on the partnerships between patients, carers and professionals through which continuity of care is achieved as desired (or not). (c.f. primary care, severe mental illness, cancer 1 and 2, stroke). This underlines the interim review findings, which also found strong support for the concept of patients as partners in their care (Freeman *et al*. 2007: 9).

We summarise the ways in which this 'partnership' model of continuity of care is distinct from that of the 'perspectivist' and 'professional' models of continuity of care that preceded it in *Table A.2* and discuss this below.

The co-construction of continuity of care by patients, carers/family and professionals

The core issue that distinguishes the 'partnership' model is the shift in focus from individual perspectives to the connections and relationships between patients, carers/family and professionals, and the extent to which patients and carers are engaged as active partners in care with professionals. Here continuity of care is **co-constructed** through the interaction between patients, carers/family and professionals. The achievement of good

continuity depends on the strength of these connections and relationships. Within this model, it is recognised that, for example, patients may value access to and contact with a responsive service rather than with a single named individual professional over time. In addition, carers may have multiple involvement in and perspectives on continuity of care, depending on whether they are acting as service users themselves, as advocates for patients, and/or as proxies for patients.

The ways in which patients and carers are conceptualised likewise shifts from their being relatively passive recipients of care in the 'professional' model, and individually resourceful (or not) in the 'perspectivist' model, through to having agency, choice and control over defining and achieving continuity of care in the 'partnership' model, working in partnership with family and professionals. Here professionals do not so much deliver continuity of care 'to' patients as work 'with' them and their family to assess needs and preferences and facilitate contact and continuity (and possibly change) of provision as appropriate. For some groups, professionals may have to be more proactive in identifying and working with people who are poorly connected and less engaged, and hence at risk of having trouble accessing services and sustaining contact and continuity, with potentially negative consequences for their care and health outcomes.

A related point to note is that in the 'partnership' model the views and experiences of professionals are valued alongside those of patients and carers, as they are an important part of the partnership (for example, the transition review, pp.8, 82; the maternity care review, pp.15-16, 74). However, not all studies included the professionals' perspective. Further, the authors of one study strongly asserted that only patients' and carers' views on continuity of care are meaningful, not professionals' – although this study does actually imply that continuity is a co-product of the relationship between patients, carers and the care system (stroke and LD study, p.223).

Understanding complexity, discontinuity and change

Just as the individual SDO studies pointed to a more active view of patients and carers roles in co-constructing continuity of care, so some findings captured the complex nature and context of the journeys that patients, carers and family members experienced and how these differed from, say, idealised 'care pathways'. At the same time, the focus on the patients' preferences and priorities revealed that, as Freeman *et al* (2001) speculated in the scoping report, for some patients on some occasions, discontinuity may not be a bad thing from their perspective (for example, Baker, 2006: 17, 46; Freeman, 2002). The review study that explored continuity of care in young peoples' transition from child to adult services, also stressed that change *per se* may not necessarily be a bad thing. Indeed, it should be encouraged and facilitated in certain circumstances, for example, to help promote young peoples' development and transition to adulthood.

In these various ways, some of the studies signal a more **dynamic** conceptualisation of complexity, discontinuity and change which more closely reflects the reality of the lived experience of patients and their families over time. One report (stroke study, pp.31-2) did refer to a more 'dynamic' model of continuity of care, based on work by Donaldson (2001), as a possible alternative to the conceptual model outlined in the scoping report (Freeman *et al*, 2001) but did not elaborate on this in their subsequent analysis.

Continuity as both a process and an outcome of care

As previously noted, the 'perspectivist' model has provided a better understanding of patients' and carers' views on the processes and/or outcomes of continuity of care. Many of the SDO studies appeared to have interpreted the scoping report as suggesting that continuity of care **was** a process and that the experience of this **was** an outcome (for example, primary care). Several also investigated to what extent the experience of continuity of care related to and influenced (or was influenced by) other outcomes, especially patient satisfaction and clinical health outcomes (for example, primary care, diabetes, stroke, cancer 1). Overall, it was difficult to discern the underlying arguments on this topic, particularly on the issues of how the concept of continuity of care related to other constructs such as patient satisfaction. It was also difficult to detect the nature, extent and direction of the association between particular processes and outcomes, such as frequency of contact with services, patient satisfaction, experienced continuity, and various measures of health outcomes.

4.4 Conclusion

The scoping reports carried out by Freeman *et al* (2001) as a precursor to the SDO programme, and by Reid *et al* (2002) and Haggerty *et al* (2003) for three Canadian health policy and research bodies, were important because they provided the conceptual framework for the SDO programme and the commissioning of the various empirical and review studies. In this synthesis, we found that the majority of the studies referred to one or both reports, although the extent to which this work shaped and informed the design and conduct and analysis of the studies varied.

In stages one and two of this analysis, we have shown how the individual SDO studies have variously contributed to a 'perspectivist' model of continuity of care, and identified where the gaps remain to be filled. In stage three, we have developed a more interpretivist synthesis of the work. This reveals what we believe are signs of an emergent 'partnership' model of continuity of care that offers the potential both for informing future research on this topic and for understanding better practice in health and social care.

Table 2. Three models of continuity of care

Models	Pre-SDO model	SDO scoping review model	SDO synthesis model
Central theme	CoC is a professional and organisational construct.	CoC is experienced by individual patients and carers/close persons.	CoC is co-constructed through patient, family, and professional interactions and partnerships.
Characteristics	<p>CoC is an inherent property of the NHS system; discontinuity is a mark of failure in the system.</p> <p>Assumption that patients want to see the same individual professional over time.</p>	<p>CoC is an individual, relational, concept.</p> <p>The (non-)achievement of continuity depends on the preferences and priorities of individual patients and carers and how they view and experience their care over time.</p>	<p>CoC is co-constructed through patients', close persons' and professionals' interactions.</p> <p>The (non-)achievement of CoC depends on the strength of the partnerships. Focus is on the quality and strength of relationships (not the individuals concerned – hence more emphasis on access to an informed and responsive service may be important to patients, rather than a single named individual).</p>
Main dimensions	Assumption that patients want to see the same individual professional over time.	Originally six dimensions identified by Freeman <i>et al</i> (2001), later reduced by Haggerty <i>et al</i> (2003) to three. Dimensions were identified through literature reviews of research based on pre-SDO model (i.e. professionally-defined). Recognition that patients and close persons may have other priorities and preferences on dimensions still to be identified through the SDO projects.	<p>Some new perspectives identified on existing dimensions (e.g. information) and various findings as to which dimensions were shared by different parties and to what extent. Also some new patient-defined dimensions identified.</p> <p>Overall, a tendency to greater complexity and fragmentation and re-packaging of the concept of experienced continuity, which Freeman <i>et al</i> (2007) later reflect on and consider an unhelpful development, based on a misinterpretation of the scoping report proposed model and call for research topics.</p>

Models	Pre-SDO model	SDO scoping review model	SDO synthesis model
Process or outcome?	CoC is a process; a function of service delivery and organisation.	CoC is a process and the experience an outcome, although this outcome is regarded as distinct from other outcomes e.g. patient satisfaction and clinical outcomes that the achievement of 'good' CoC is thought (but not yet proven) to improve. Several SDO studies seek to measure CoC and the outcomes of this.	CoC is complex and, for some researchers, not easily separated from the experience of e.g. patient satisfaction. CoC is to be valued in itself, not for what difference it might make to clinical effectiveness [mainly taken from Gulliford <i>et al</i> , 2006: 142-3].
Patients and close persons as passive or active?	Patients tend to be regarded as passive recipients of service provision and organisation, with little insight or influence on this.	Patients, close persons and professionals tend to be seen as each having own separate perspectives on CoC, with patients the most privileged. However, conceptualisations of carers vary – sometimes they are seen as proxies for patients, other times they are seen as people who themselves experience CoC and its effects.	CoC is something patients can achieve through their own agency and quality of relationships and connections with others, and not just the result of e.g. an intervention done 'to' them. The more engaged patients and close persons are, the better for CoC. However, more vulnerable patients may need more support to enable them to engage with services and foster better relationships.
Assumptions re discontinuity and change	Discontinuity is a mark of failure in the system, to be ironed out by e.g. more 'joined up' and 'integrated' working. Change in health status and transitions in care (e.g. along care pathways) may represent weak spots to be smoothed out.	Discontinuity may not necessarily always be a bad thing from patients' perspectives e.g. a break in contact may symbolise a period of normality for patients.	Change may not necessarily be a 'bad' thing and could be promoted to facilitate e.g. development and transition for young people to adulthood and adult services. Recognition that care pathways are linear, ideal types and that in reality, patient journeys are much more complex.

Models	Pre-SDO model	SDO scoping review model	SDO synthesis model
Assumptions re viewpoints	Professionals will have most insight into causes and factors that promote and hinder services that offer good CoC.	<p>Patients and close persons ultimately experience CoC and hence only they can assess it and their views are privileged. However patients and close persons may be best placed to comment on certain dimensions of CoC that are important to them and within their realm of experience, and not others that are defined by professionals.</p> <p>Close persons may also be seen as proxies for patients, rather than as people who experience CoC themselves.</p> <p>Professionals' perspectives may be sought and valued for what they reveal about correspondence with patients and close person's views, as well as insight into organisational areas patients and close persons have less knowledge of.</p>	Perspectives of all parties involved in co-construction of CoC are sought and valued.
Researchers' assumptions re jargon	Only professionals will recognise and understand jargon of CoC.	Tendency to reserve use of jargon for professionals and 'translate' this for patients and close persons. Researchers' avoid using CoC and use other terms instead.	Possibly more attention to language issues and effort made to explain jargon and observe where viewpoints are shared and where they diverge, in course of examining how CoC is co-constructed?

5 Experiences of and influences on continuity of care: the patients' views

In this chapter, we review evidence from the six empirical studies about patients' experiences of continuity of care and about what influenced these. As described in *Chapter 3*, some part of the objectives in six of the main studies was to explore health service users' experiences of continuity of care, and all of these studies used qualitative approaches in the early stages of the studies. The quantitative components for enquiry into service users' experience are mainly described in the chapter discussing measures of continuity. However, Baker's (2006) study in primary care settings included quantitative components that were not designed for development and testing of measures of continuity, and we include these findings in this chapter.

Burns, 2007 (severe mental illness) aimed specifically to examine how service users conceive of continuity of care, by exploring their understanding and evaluation of continuity, and comparing this to existing definitions. In focus groups and expert panels drawn from patients who had experienced severe mental illness, the researchers introduced ideas about continuity that patients then discussed. In a later stage of the research, semi-structured interviews with sub-groups of service users with psychotic and with non-psychotic conditions captured experiences and views of people for whom continuity of care had been particularly complex or problematic.

King, 2006 (cancer) in a phase 1 study, using qualitative interviews set out to explore patients' perceived continuity and satisfaction with care as they moved through phases of diagnosis, treatment, remission, relapse and palliative care. In a further small-scale prospective study, patients were interviewed to gain more detailed understanding of how perceptions of continuity of care changed with the treatment phase.

Hill, 2008 (stroke) aimed to explore how stroke patients understand and experience different types of continuity in their care, using qualitative interviews with patients from a local stroke database, and focus groups drawn from members of support groups and participants in a separate stroke study.

Gulliford, 2006 (diabetes) set out to understand patients' values and experiences of continuity in their care, through qualitative interviews with primary care patients, and went on to evaluate changes in patients' experiences of continuity of care over time in a cohort study. An additional series of interviews sought the values and experiences of continuity of care of diabetes patients from South Asian communities.

Baker, 2006 (primary care) did not refer directly to exploring service users' understanding or perceptions of the concept of continuity. Rather, overall objectives in that study included exploring patients' preferences and priorities about primary care services, using qualitative interviews in one location and an 'actor network' approach in a second location. The study went on to examine patients' use of primary care services in relation to their views, in two quantitative components – stated preference discrete choice experiments, and a cross-sectional postal questionnaire survey.

Hardy, 2006 (stroke and learning disability) aimed to explore service users' perceptions and experiences of care, through semi-structured interviews with young people making the transition from child to adult services, and older stroke patients at the transition 'hinge point' of discharge from hospital.

5.1 Qualitative approaches

As discussed in *Chapter 4*, only the severe mental illness study had within its objectives specific exploration of patients' conceptualisation of continuity of care *ab initio*, albeit after introduction of the concept and checking for understanding. The phase 1 cancer study set out to explore service users' perceptions of continuity, and the diabetes and stroke studies aimed to explore how service users understand and experience continuity of care. The primary care study, and the stroke and learning disability care studies lay emphasis on understanding service users' preferences, priorities, perceptions and use of care.

The topic guides for qualitative enquiry reflected these different approaches to examining service users' experiences, with varying scope and focus, and different approaches to data extraction and analysis. As already mentioned, only in the severe mental illness study did researchers specifically introduce the idea of 'continuity of care' to patients, in qualitative discussion groups. In all other studies, researchers initially avoided using the term in semi-structured interviews with patients. In the diabetes study, researchers report avoiding the use of 'jargon', and the cancer study favoured using a 'grassroots approach', based on patients' own perspectives on the care they had received. The topic guides used in these studies, however, reflect researchers' underlying assumptions about which issues and topics might be explored with patients in order to develop ideas about continuity of care, such as communication of information, timeliness and consistency of services, and changes in care over time. In the primary care study, a prompt guide for interviews in one study location was based partly on existing research about patients' preferences. In a second location, an 'actor network approach' was adopted in interviews with patients, in which there was less interest in the patient's opinion than in the researcher's translation of the patient's situated point of view.

In the stroke study, the researchers developed a topic guide from dimensions of continuity identified in the literature, and the stroke and learning disability study likewise used topic guides designed to reflect previously recognised major factors – structural, procedural, organisational and professional – that might influence continuity of care.

With this recognition that the findings reported from the studies were mediated to some extent by researchers' underlying or explicit assumptions of elements of continuity of care, we now go on to review the qualitative findings from service users about their preferences and choices for treatment and care, and the experiences contributing to their views.

5.2 Findings

5.2.1 Experiences of continuity of care

We found no evidence that patients used the term continuity of care spontaneously, when talking about their experiences of services. However,

we identified seven main categories within which to organise the qualitative material:

- relationships with professionals
- access to professionals and services
- understanding of condition and treatment
- co-ordination of care
- transitions in care settings and services
- personal agency
- the patient as a 'whole person'.

5.2.2 Relationships with professionals

In all studies, patients said they valued good relationships with professionals. Elements of a good relationship included being able to trust and confide in a professional (diabetes, cancer 1, primary care) with a belief that the professional would talk honestly, for example about likely levels of recovery after hospital admission for stroke and availability of services (stroke and learning disability). Professionals who spent sufficient time talking and explaining things were appreciated (diabetes, stroke).

Patients sometimes spoke about having good relationships of this kind with a named and usual professional who knew them and was concerned about them (diabetes). In approaching GP practices, some patients valued relationships with known and trusted practitioners with whom they had a history of positive and productive interactions (primary care) and seeing the same practitioner about an ongoing condition was important to some. Diabetes patients also valued seeing the same professionals who knew them, and said they were more likely to trust their usual provider. However, patients making transitions between hospital and primary care services expected professionals to have different roles in different contexts. Stroke patients valued clarity about who they would see following discharge, when, for how long and why (stroke and learning disability). They wanted to meet the staff who would be working with them when they went home, and for those staff to meet staff who had cared for them on the ward. Cancer patients did not often mention seeing the same person or care co-ordinator, but sometimes expressed the view that having some contact person was crucial to generating trust in the service (cancer 1).

Qualitative enquiry into patients' preferences and choices about consulting in GP practices and experience of recent use of primary care services paid close attention to the importance to patients of seeing the same professional (primary care). Findings were that people preferred to see the same person when consulting about ongoing problems, especially when the problem had emotional or psychological components. When the problem was perceived as less personal or likely to be quickly resolved, it was often more important to see somebody quickly, and different practitioners were acceptable. Experience within the wider family also influenced people's preferences for consulting with the same professional at the practice, especially where several members had longer term limiting conditions. The general 'history' of positive or negative interactions with a GP and practice influenced not only preferences in consulting, but also patients' trust and confidence, their understanding, and the extent to which they felt reassured (primary care). Some stroke patients explained poor relationships with professionals as being due to personality clashes, or staff being too busy or not listening (stroke). Mental health service users selected because they

had particularly complex or problematic experiences of continuity of care also had much to say about relationships with professionals (severe mental illness). Their experience was often that repeated staff changes led to feelings of helplessness and isolation. Having continually to retell their story to new staff was experienced as devaluing the story. Good relationships built with key workers were often only short term, which in turn led to expectations of transience in relationships, and the time required to build new relationships increased the emotional demands on themselves.

5.2.3 Access to professionals and services

Aspects of access to services were mentioned when patients talked about their preferences in care and treatment. For some, appropriate access involved quick response and support when needed (diabetes, cancer 1, stroke and learning disability, severe mental illness) and availability of a contact person or telephone number was helpful (cancer 1, severe mental illness). For mental health service users it was important that systems were in place to deal with crises that arose, providing immediate support day and night.

However, having access to services meant more than being able to generate quick and appropriate response when required. It also meant, for some patients, being able to rely on a proactive service that initiated contacts and provided regular monitoring and advice for long-term conditions (diabetes, primary care, severe mental illness). Mental health service users with both psychotic and non-psychotic conditions, who had complex or problematic experiences of continuity, were critical of services that were accessible and responsive only to crises, rather than providing preventative support. Some such people regretted that being well meant also feeling invisible to and abandoned by services.

Access to different kinds and levels of support was particularly important to people who experienced big changes in condition and needs, for example the swings between being 'well' (after treatment for severe mental illness, or in remission from cancer) and being acutely ill when symptoms recurred. Mental health service users stressed the importance of services that could adapt quickly to such changing needs, for example enabling people to start using appropriate day centres, or different kinds of support to help them move forwards. Reduction or withdrawal of different levels of service could be helpful when this boosted confidence and helped people maintain a feeling of normality (cancer 1, severe mental illness) but unhelpful when it left people feeling abandoned (severe mental illness).

5.2.4 Understanding of condition and treatment

From all studies came evidence that patients valued being able to understand aspects of their condition and treatment. This depended on more than provision of information. A trusting relationship promoted understanding (diabetes, cancer 1). Diabetes patients said that consultation with a known and usual professional after diagnosis helped them understand their condition and treatment regime. In the primary care setting, some patients with an ongoing condition valued seeing the same practitioner at consultations, to talk about their condition (primary care).

People's capacity to receive information varied (cancer 1) and professionals with good communication skills were valued (cancer 1, stroke). The way in which patients were given information was important, and stroke patients spoke positively about staff who were good at telling them things (stroke).

Knowing what was happening and why was reassuring, especially when people were admitted to or discharged from hospital, or moved between wards (stroke and learning disability). Patients in the same study said that informal communications could sometimes leave uncertainty. Understanding the purpose of some service elements such as home visits was important (stroke and learning disability).

Getting appropriate information from staff about their condition and treatment had been hard for some mental health service users (severe mental health). Those who had experienced problems in the continuity of care explained that being reliant on a 'key-worker' as a first port of call was problematic if this person did not have the information required, especially when responsibility for finding out was pushed back onto the patient. Patients in both the stroke and primary care studies were critical of being given conflicting or inconsistent information, and some stroke patients reported being given information and advice that turned out to be wrong. Some patients had negative experiences of receiving inconsistent advice and treatment (primary care, severe mental illness). Patients whose first language was not English described particular problems in understanding appointment systems, and information and advice from professionals (diabetes).

5.2.5 Co-ordination of care

From all studies came evidence that patients valued co-ordination among and between the professionals who cared for them. While the term 'co-ordination' was part of the language used by some diabetes patients, researchers in other studies observed that patients did not themselves use this term or similar phrases such as 'joined up' (cancer 1, stroke). Only some stroke patients who were asked specifically whether their care had been well joined up were able to give a view (stroke). However, patients in all studies showed they had some underlying concepts of possible interactions between services or different parts of the same service. Thus, it was important to some that the different professionals had the information about them that they needed (cancer 1, primary care). People disliked having to explain over and over again things about themselves which they knew were already detailed in medical notes (primary care) and were critical of 'lack of collective memory', for example in a hospital with which they had previous contacts (stroke and learning disability). Cancer patients identified particular problems in communication between professionals across the primary/secondary interface (cancer 1). It was also important that professionals were able to give correct basic information about aspects of their service for which they did not themselves have direct responsibility, such as waiting times (cancer 1, stroke).

Patients who discussed their discharge from hospital after treatment for stroke talked about the need for planning and communication between themselves, their carers, staff who provided aids and adaptations in their homes, and sometimes social service teams and voluntary organisations (stroke). It helped to address their anxieties about being able to manage if they felt a tangible sense of 'being handed over' with co-ordination and understanding among professionals. Mental health service users had different experiences of communication and co-ordination between hospital and community based teams, and some were critical of gaps in communication and information provision at this stage (severe mental illness).

5.2.6 Transitions between care settings

Transitions of patients between care settings and transitions between professionals were a focus of interest for the researchers in all the studies.

Patients themselves identified different kinds of transitions as part of their experience. Mental health service users talked from experience of transitions between teams of professionals in the context of their moving home or being discharged, but also because of team restructuring (severe mental illness). In this study, people who had complex or problematic experiences of continuity said that transitions could be stressful and drawn-out, with ineffective communication between teams of professionals. Change of psychiatrists was common. Transition at discharge was a key point of vulnerability, for example moving from a strict routine to coping alone and supportive transitions, personalised and situated in daily life, contributed to good continuity (severe mental illness). Although some mental health service users had experience of poor communication between different parts of the service, this was not true for everyone.

For stroke patients, transfers between wards and between hospitals were potential points for negative experiences for patients, with changes in environment, staff, and content and processes of care (stroke and learning disability). In this study, stroke patients' experience of being discharged from hospital was better when there was good communication, and patients and families had prior information and involvement in planning, opportunity to meet new staff and reassurance of being able to contact services again if there were concerns about progress.

Cancer patients often have to make many transitions between settings and services, and some reported problems due to difficulties in communications between their primary and secondary care (cancer 1). Patients in the diabetes study also talked about experiences at transition points. For them, significant transitions were transfer from hospital to routine GP care following diagnosis, referral to hospital following episodes of illness, a change in provider due to retirement or holidays, and changes in services provided on a regular basis, due to changes in patients' health status (diabetes). Diabetes patients who only received hospital based care described less favourable experience of seeing their usual providers, and less flexibility in service adaptation to changing needs.

5.2.7 Personal agency

In all the studies, we found evidence of how patients' own behaviour, based on personal and cultural beliefs and choices, and family influences, interacted with service provision and delivery, and sometimes influenced outcomes. Patients' experience of care and treatment was thus co-constructed with professionals, providers and carers; the idea that they were 'recipients' of care and treatment was only a partial reflection of their participation.

Thus, cultural issues influenced some patients' readiness and capacity to follow dietary advice designed for a western society (diabetes). Stroke patients in hospital valued being involved in planning, along with their carers, for their transfer or discharge (stroke and learning disability). Cancer patients spoke of their need to be active partners in their care, according to their coping style, and wanting to be involved in treatment decisions (cancer 1). Choice of treatment was also important to mental health service users as was development of a care plan with which they agreed (severe mental illness). Cancer patients described their need to

maintain a feeling of normality and sense of self (cancer 1). Their response to illness and continuation in care was influenced by both their personalities, and their perceived family roles and relationships. They wanted to build confidence that they would be able to manage when not in direct touch with services, and they sought reassurance that their families would cope. At the same time, they needed to be able to forget sometimes that they were a cancer patient.

In the stroke study patients also referred to the influence of their own personality on their experience of care, for example in development of positive relationships with individual staff (stroke).

In the primary care setting study, the longitudinal follow-up of patients showed how some patients who decided which GP in their practice they wanted to consult then exercised persistence, long-term strategies and immediate tactics to get to see their chosen GP. Others prioritised speed and convenience of access in getting an appointment and some patients made 'trade-offs' which determined waiting times. Older people, particularly women, generally preferred to see the same practitioner, and younger, fitter people often preferred swift access. Most people were consistent in their preferences, but some changed their views and behaviour during the study period. Patients differed in their ability to realise their preferences, and those less successful included people not in work, people in non-white ethnic groups, and people who were socially more isolated (primary care). In the severe mental illness scoping study (Freeman, 2002) being able to self-refer for admission allowed patients to judge for themselves when they needed residential care in a crisis.

Patients' response to negative experiences such as inconsistency in treatment and poor relationships with staff sometimes led to their withdrawing from the service, non-compliance with treatment, slowing in the recovery process (diabetes, severe mental illness) or delaying a consultation (primary care). Mental health service users sometimes chose to 'manage' a poor relationship with a key worker by just waiting for the next one to take over (severe mental illness), having learned how transient some such relationships were.

From some of these accounts of personal agency, we saw circumstances and situations when service users appreciated or actively chose what professionals might describe as **discontinuities** in service. Thus, cancer patients and mental health service users sometimes sought distance and separation from particular professionals and services and patients in minority ethnic groups chose advice from traditional non-professional sources (diabetes).

5.2.8 The patient as a 'whole person'

The focus of all the studies was care and treatment for health conditions, and qualitative interviews and discussions were moderated accordingly. We get glimpses in several studies, however, of patients wanting to be dealt with in a wider context that acknowledged their life situation rather than constructing them as people within pathways for care and treatment for a specific condition.

The primary care study showed patients feeling personal loyalties to practitioners, feelings built up through long histories of that GP's involvement with their family (primary care). There was evidence of stroke patients thinking about their lives ahead, and wanting to know what would happen if other conditions developed, with passage of time (stroke and

learning disability). Some cancer patients were also situating their experience within their wider lives – wanting to maintain a sense of connection with how their lives had been before diagnosis, and having broad concerns about longitudinal stability, what would happen in the future, their ability to cope and their roles and relationships with those close to them (cancer 1). In the diabetes study, patients from minority groups wanted understanding of and respect for cultural affinities (diabetes). Mental health service users valued supportive service responses that were personalised and situated within their everyday life, and they acknowledged the value of support from other people who had also experienced mental distress (severe mental illness).

Throughout the qualitative findings across the studies, we see also patients referring to the participation of family and close persons in their care and treatment. Some patients described sharing information with family members, who were sometimes key people in helping them understand their condition and the processes involved in care (diabetes, stroke) and making decisions about treatment (cancer 1). Family members had practical roles such as enabling people to make and keep appointments (diabetes) and family and carers were sometimes closely involved in decisions about and arrangements for hospital admission and discharge (stroke). Previous experiences of other family members were sometimes strong influences on decisions about choice of GP practitioners (primary care).

5.2.9 Summary of findings about users' experiences of continuity

The term 'continuity' was not one used spontaneously by service users. However, when introduced to service users in the severe mental illness study, people said they did understand the term, and were able to discuss their experience in relation to this concept. In all other studies, patients talked about their preferences and experiences of care and treatment using other language, but responding to questions and prompts that all reflected, to some extent, the researchers' underlying assumptions and beliefs about components of 'continuity'.

The issues that were important to users, in the qualitative enquiry, centred around their relationships with professionals and service providers; access to services, including both responsive and proactive elements; their understanding of their condition and treatment; the co-ordination of care; what happened to them in transitions in settings and services; their personal agency, and their existence as a 'whole person'. Throughout the qualitative enquiries, there are glimpses of the participation of family members and carers, and interesting examples of what we might call 'discontinuities' that were perceived positively.

Having reviewed the qualitative evidence for service users' preferences and choices for their treatment and care, and the experiences they described, we go on to look for the underlying influences on these experiences.

5.3 What influenced patients' experiences?

5.3.1 Qualitative material

We looked in the qualitative findings for the main influences on patients' experiences of their care and treatment, as they had described these

experiences themselves. We found seven general groups of sources of influence across the empirical studies:

- patients' characteristics and personal circumstances
- care trajectories
- structure and administration of services
- professionals' characteristics
- participation of close persons
- the wider context of 'the whole person'
- patients' satisfaction and judgements.

For purposes of this review, we discuss each source of influence in turn. It is important to remember, however, that although influences on experiences may come from different sources, they combine and interact in multiple ways for individual patients.

5.3.2 Patients' characteristics and circumstances

Across all the studies we see that patients have different preferences and choices related to differences in individual characteristics and circumstances. These influence both their perception of the care received and, through their personal response and behaviour, their overall experience.

Patients' capacities to receive information and different ways of understanding and levels of knowledge (diabetes, cancer 1, stroke), their personality and coping style (cancer 1, stroke), their motivation to maintain relationships with family (cancer 1, stroke and learning disability) and professionals (primary care), and their fears and concerns (cancer 1, primary care) may all influence their experience. Patients behave differently, related to personal characteristics and preferences, and their behaviour influences the direction and content of care (diabetes, cancer 1, primary care, stroke and learning disability, severe mental illness).

The diabetes study drew attention to some of the different preferences and experiences related to cultural group and spoken language, and the primary care study pointed to some differences in experience related to age, gender and the patient's perception of the 'sensitivity' of their condition.

As explained earlier, in some circumstances patients' preferences and choices lead to behaviour which we might construct as producing discontinuities in care and treatment, for example the trade-offs patients made in arranging appointments in GP practices, or when they wanted a second opinion (primary care). There was also evidence that patients did not always see gaps, delays and changes in personnel negatively. Some cancer patients valued being able to return to normal activities and forgetting the illness for a time during periods between treatment (cancer 1).

5.3.3 Care trajectories

Experiences of treatment and care depend, of course, on types of health conditions. What happens to people with different kinds of illness, in diagnosis, admission to hospital, nursing on acute wards, rehabilitation, discharge, and community nursing and care involves a wide range of different procedures, with different time parameters and a variety of services and professionals. Among patients with the same condition, people

have different trajectories of development of illness, treatment, recovery or deterioration.

With a focus in most of the studies on a specific health condition, there is evidence of different experiences of transitions across the primary care/hospital interface and different treatment regimes (diabetes, stroke, severe mental illness, cancer). Some of the transitions studied were those defined by reaching age-related milestones in growing-up (stroke and learning disability, the transition study) while the primary care study covered the range of trajectories involved in prevention, consultation, diagnosis, treatment, monitoring and advice at the level of general practice. The specific circumstances of individual patients' positions within these different trajectories and transitions in life and health, as we would expect, influenced their views and experiences.

There were many examples of this. Thus, patients variously spoke about experiences related to:

- their need for monitoring or checking (diabetes, primary care)
- response to changes in their particular condition and needs (diabetes, stroke, cancer 1, stroke and learning disability, severe mental illness)
- the way in which their illness was diagnosed and how they were told (cancer 1)
- opportunities to be involved in decision making (cancer 1)
- their circumstances as parents negotiating care for their children (primary care).

In the stroke study, patients' views on care received sometimes reflected whether they thought they were 'getting better'.

Mental health service users said that continuity in care was less likely when their condition was stable and they were not in a crisis situation. They emphasised how their social context – housing, employment and benefits situation – was a strong influence on their experience of continuity of care, negatively or positively. For them, continuity, satisfaction and social vulnerabilities were inter-related.

5.3.4 Structure and administration of services

Service setting (diabetes), geographical location, and proximity of services to home (primary care, stroke and learning disability) and co-location with other health related services (stroke and learning disability) influenced patients' experience of response to changing needs. The perceived quality of the environment in which services were offered (primary care) influenced some preferences.

The way services were structured and organised influenced availability and involvement of valued professionals such as 'contact person' (cancer 1) or 'key worker' (severe mental illness) or a known professional (primary care); the regularity of check-ups (primary care). The stroke and learning disability study brought into focus many aspects of service structure and organisation which influenced patients' experiences, including ways of team working; interdisciplinary structures, involvement of specialist nurses (for stroke care), incorporation of review meetings and support groups for patients and family, staff with roles aimed at co-ordination within and across disciplines, and waiting times. Some such aspects of structural organisation, and patients' waiting times, depended on the size of the facility (stroke and learning disability, primary care) and the resources

available, for example numbers and roles of professionals attached to a general practice (primary care) and staff turnover (severe mental illness, severe mental illness scoping study). Availability of interpreters affected people whose first language was not English: experience here of diabetes services users was that hospitals organised interpreting services more often than GPs, but these were not always available (diabetes). In only one site in the case studies of services for young people with learning disabilities were young people able to try out different options and/or make visits before leaving school.

Hospital administration arrangements, and the ways in which information was shared and made available was influential in various settings (cancer 1, primary care, severe mental illness), as were the ways appointment systems were structured and put into practice (primary care, diabetes) and telephone systems (primary care).

Administrative delays and mistakes could have negative influences on patients' experiences (stroke and learning disability). There was communication mismatching when the wrong people were invited to transition review meetings, and there was confusion in roles for taking matters forward (stroke and learning disability). This study also found that information that might be helpful, for example, from voluntary organisations was not always used, and there were communication gaps and communication confusion between parents and services and between different services.

Staff shortages also influenced patients' experiences (stroke and learning disability, severe mental illness).

5.3.5 Professionals' characteristics

Patients perceived the professionals they dealt with as having different characteristics (on top of their actual professional roles). Patients' experience was that clinical and medical professionals had different levels of concern and interest in their condition and care (diabetes), there were differences in personalities and personal styles (primary care) and motivation (cancer 1) and some had better memories of patients' cases (cancer 1). Some were prepared to take longer to listen and talk to the patient (diabetes, stroke), although time pressures on staff (stroke and learning disability, stroke) and staff shortages (stroke and learning disability, severe mental illness) were also acknowledged.

Professionals were perceived as having different skills and expertise, particularly in communicating, providing information and enabling patients to understand (cancer 1, primary care, stroke). Some appeared to be more motivated than others to meet patients' preferences (primary care). Some service users in the primary care study were influenced by the perceived reputation of the professional who dealt with them.

Service users also perceived differences in competencies and understanding among administrative staff and receptionists (primary care).

5.3.6 Participation of carers/close persons

Patients' family and close persons were sometimes influential in patients' preferences and choices, and decisions made about using services and treatment (cancer 1, primary care, stroke and learning disability, severe mental illness).

They also had active roles in enabling patients to use services, such as getting and sharing information with patients (stroke and learning disability, severe mental illness) and helping patients make and keep appointments (diabetes). When there were problems of communication for mental health service users, carers had to close information gaps. However, the ambiguous status of carers of people with severe mental illness itself created information gaps between user and carer and between services and carers (severe mental illness).

An important part of some cancer patients' experience was feeling reassured that their family would manage, and deal with the practical and emotional impacts of their illness and treatment (cancer 1).

5.3.7 The wider context of the whole person

As discussed earlier, most of these studies were not designed to look at the patient as 'a whole person'. Although findings are limited, there are strong suggestions that some influences of experience of treatment and care during illness come from the wider context of the patient's life.

Thus there was evidence of patients looking both backwards at family and life experiences (primary care) and forwards, towards developments in health and conditions as yet unknown (stroke and learning disability). For some cancer patients, their own family roles and responsibilities had important influences on how they felt about illness and treatment and decisions taken (cancer 1). Support for people with severe mental health conditions was thought sometimes best situated within the person's social context, encompassing the need for help and support with housing, employment and welfare benefits (severe mental illness).

5.3.8 Patients' satisfaction

People are different in their expectations of care and treatment, and they make different judgements about the quality of services received. Expectations can also change, for individual people, as they become more experienced as service users.

Cancer patients described the influence of the quality of their first appointment with secondary care services. Establishing 'trust' at an early stage in clinical contact was often crucial in setting the tone for their future consultations (cancer 1). Having 'confidence' in treatment was related to relationships with professionals and involvement in treatment decisions among diabetes patients. In the primary care study, judgements made by patients about the perceived 'quality' of the patient/professional interaction influenced their experience. They spoke of the importance of 'trust' and 'confidence' in their primary care professional. For some, the quality of the environment or the experience of the procedure was important, as was the perception of the service as free of charge.

5.4 Outcomes for patients

There was relatively little in the qualitative elements of the studies that could be interpreted as being about outcomes. We extracted data from only two studies – the primary care study and the severe mental illness study.

The two studies that had explored patients' outcomes did this in follow-up interviews, so views and experiences could be related to information patients had provided previously. Baker's study in the primary care setting

included a longitudinal, largely qualitative study of use of primary care services by a selected sub-group of patients who had been interviewed in an earlier stage of the research. The objective of the longitudinal work was to explore patients' use of primary care services in relation to their preferences and priorities expressed previously. The main phase of the severe mental illness study (Burns, 2007) involved qualitative interviews with selected service users with psychotic and non-psychotic conditions who had taken part in a structured survey, such that quantitative data about their experiences of care and transitional events and phases was already available.

Most of the findings here are concerned with personal relationships between service user and professionals. In the primary care study, patients who valued personal continuity with providers and achieved and sustained this within the time they wanted said they were satisfied. Patients who would have preferred personal continuity but experienced discontinuity had negative views about too much change, and doctors not knowing them properly. Similar outcomes for service users were reported from the severe mental illness study. Here, changes in relationships with staff could lead to feelings of dissatisfaction and reduction in trust, and sometimes feelings of helplessness and isolation. Being happy about a key-worker meant trusting relationships (severe mental illness).

For mental health service users, changes in personnel also meant negative outcomes associated with having to retell their story. This could lead to a sense that their experience was devalued and was particularly stressful for people whose history involved difficult past experiences (severe mental illness study). It also contributed to expectations of further transience. Experiencing team changes among staff, as well as being stressful for service users, led to communication gaps.

The primary care study showed that achieving personal continuity meant, for some people, waiting longer for appointments or making more effort in negotiations; some people were dissatisfied about this, but some were happy about the requirements on themselves. However, service users' pragmatic or strategic approaches, and acceptances or choice of discontinuity of this kind sometimes led to a rather chaotic use of services, and eventual dissatisfaction. Such discontinuities could also lead to inconsistency in treatment, for example feeling that unnecessary medication had been prescribed (primary care). For mental health services users also, inconsistency in provider could lead to some lack of consistency in treatment, which could also be felt as a lack of professional commitment, for example when a new professional was not supportive of the care set in place by a predecessor (severe mental illness).

From both studies there were some findings that personal continuity with professionals was not always experienced as helpful. A view from one carer in the primary care study was that the GP whom her husband always consulted did not see beyond the disease. For mental health service users, a change in relationships with professionals could be helpful if the previous relationship was poor (severe mental illness).

5.5 Quantitative findings

As explained in the introduction, most of the quantitative explorations of patients' views and experiences were conducted as integral parts of the development of assessment tools and measures of continuity (severe mental illness, diabetes' stroke, cancer) and are discussed in *Chapter 8*. The

primary care study, however, used two different quantitative approaches to pursue a different line of enquiry.

5.5.1 Conjoint analysis

A stated preference discrete choice experiment was conducted to model the different attributes of continuity of care to patients under different hypothetical consulting conditions. This tested whether different attributes were valued and the relative importance attached to each. Drawing on findings from the earlier qualitative work, the researchers chose four attributes that patients might consider when making decisions about consulting:

- seeing someone known and trusted (relational continuity)
- the consultant having information about the full medical history (informational continuity)
- type of health professional (GP or nurse)
- access (waiting days for consultation).

Patients considered vignettes of different consulting problems, in the context of their current health status and were asked to make a series of choices around the above attributes for each scenario, in a self-completed postal questionnaire administered to an age stratified random sample of people registered with nine GP practices, in two locations. Six-hundred and sixty-six questionnaires were available for analysis, of which 20 were from face to face interviews conducted by researchers with Asian language skills.

An econometric model was used for analysis, with regression modelling using interaction terms with personal and practice characteristics, to plot the effect of a health measure score on preferences.

The researchers found that patients were willing to make trade-offs between access and other aspects of primary care consultation. Patients were aware of a 'clash' between access and continuity of care and were potentially prepared to wait longer in order to receive increased continuity. The reason for consultation was important in determining the amount of delay patients were prepared to trade for increased continuity, wanting continuity for serious conditions or where there were high levels of uncertainty. Patients were prepared to trade-off longer delays in access for routine check-ups for chronic conditions. The models suggested a general preference for seeing a GP rather than a practice nurse. Patients placed high value on informational continuity, and patients in poorer health were likely to value continuity more, in circumstances of vignettes of new, uncertain and minor acute conditions.

Taking this line of enquiry further, the final component of the primary care study was a cross-sectional postal questionnaire survey of a random sample of patients in 13 GP practices in one study location, nine practices in the second location, and a walk-in centre in a large town in the first setting. There was a 46.5 per cent response rate, giving 1437 replies for analysis.

The questionnaire focused on the most recent consultation with the primary care provider, and closed response options covered background information about the patient, use of primary care services, self-reported rating of health status, and the importance attached to aspects of primary care:

- access
- choice of professional expertise (doctor or nurse)
- choice of particular person (relational continuity)

- length of consultation (time to listen)
- informational content (professional's knowledge of patient and their condition)
- gender (consultant of same sex)
- ethnic group (consultant of same group).

Descriptive statistics were generated using SPSS. From this analysis, variables were selected that appeared to explain differences between respondents in whether they received aspects of primary care they regarded as important. These potential explanatory variables were initially included in multinomial multi-level regression models, but this approach was replaced by single level multinomial regression using SAS.

Findings were that a large majority of people thought it was important to see somebody with time to listen and with information about their history. Two-thirds thought it important to see a particular person or somebody known and trusted. Three-quarters thought it important to be able to book in advance, to see the preferred kind of professional, and to see somebody who knew them personally. Seeing somebody of their own sex was more important to women, and seeing somebody of their own ethnic group was more important to people in non-white groups.

In terms of whether people got their choice, most people tended to experience those aspects of service provision they regarded as important. Practices with advance bookings for appointments made relational continuity easier to achieve, and smaller practices appeared to have an effect in facilitating relational and longitudinal continuity. More than 10 per cent of patients, despite considering it important to book in advance, see a particular person, or see someone they knew personally or somebody with information about their history did not experience these aspects. Patients in the second location (London) were less likely to have their preferences for aspects of continuity met than were those in the Leicestershire location, but it was difficult to find an explanation for this. London patients were also less likely to experience relational, informational or longitudinal continuity, even when they preferred these.

Some patients found it particularly hard to obtain care with preferred attributes; these included people not in paid work, those in non-white ethnic groups, and those who were socially isolated. The authors suggest that services may discriminate against such disadvantaged groups, for example in appointment systems and reception staff approaches.

The authors discuss the strengths and weaknesses of the methods used, and urge caution in generalising findings. For this review, however, the primary care study provides the only quantitative enquiry into patients' preferences and choices that was not designed as an integral part of development of a measure of continuity. Findings particularly inform understanding of the influence of patients' personal characteristics in their experience of continuity of care, the influence of service structure and administration, and the socio-economic contexts of different geographical locations.

5.6 Discussion

Findings reviewed here about patients' experiences of continuity of care come mainly from qualitative enquiries, which were conducted in all the SDO studies. The term 'continuity' was not one used spontaneously by

service users. People talked about their preferences and experiences of care and treatment using other language. When the idea of 'continuity' was introduced to service users in the severe mental illness study, people generally said they did understand this term, and were able to discuss experiences in relation to it. Nevertheless, it is important to stress that the researchers in the SDO studies who reported on the 'patient's experience' of continuity were generally interpreting patients' views on continuity based on some initial research assumptions of relevant topics to pursue, and sometimes translated into a professional and academic 'language' of continuity.

The issues that were important to service users centred around their relationships with professionals and service providers; their access to services; their understanding of their condition and treatment; the co-ordination of their care; what happened to them in transitions in settings and services; their personal agency; and their existence as a 'whole person'.

Having good relationships with professionals included aspects of trust, confidence, time available, and the professionals' communication skills. For some people it was also important that the professional was a known or chosen provider. This was not always the case and in some circumstances, people were ready to trade-off familiarity or choice with speed of access and service delivery, underlined by quantitative findings from the primary care study. Our review showed that access meant both responsive and proactive elements, the latter particularly important for preventative care. For service users, our review showed that understanding depended on more than information provision, and was promoted by a good relationship with a professional, trust and confidence, and time taken in explaining. Transitions of patients between care settings and between service teams were key points of vulnerability in experience of co-ordination of services, maintaining good relationships and understanding.

Our review found strong evidence of how patients' own behaviour, based on personal and cultural beliefs and choices, and family influences, interacted with service provision and delivery and sometimes influenced outcomes. There were also important glimpses of patients wanting to be dealt with in a wider context that acknowledged their life situation, with a history and aspirations for the future, rather than their construction as people within pathways for care and treatment for a specific condition.

Our review confirmed that discontinuities in care were sometimes perceived positively, and in some circumstances patients welcomed or actively pursued distance from services, change in personnel, or alternative strategies.

As to what influenced users' experiences, which are findings for policy makers which may point to entry and action points for service improvement, our review showed how much experiences were influenced by patients' individual characteristics and circumstances, the trajectories of their illness and the schedules of care and treatment. The quantitative work in the primary care setting confirmed qualitative findings from other studies that some groups of people found it particularly hard to obtain care with preferred attributes. Included here were people not in paid work, those in non-white ethnic groups and those who were socially isolated.

The way services were structured and administered were also key influences, including ways of team working; interdisciplinary structures; involvement of specialist nurses; incorporation of review meetings and support groups for patients and carers; roles of co-ordinators, and

appointment systems. Resource constraints were recognised by some patients, experienced as staff shortages and high turnover, and this was a particular issue for people with severe mental illness for whom relationships with staff and access to services in crises could be critical elements in trajectories of recovery.

6 Experiences of and influences on continuity of care: carers' views

As described in *Chapter 2*, some exploration of carers' views and experiences was part of the aims and objectives of all the empirical studies except the stroke study (although two interviews with carers were reported from this study). Carers are described and defined in different ways, however, for example as 'close persons' in the cancer study and as 'families' in the stroke and learning disability study. Qualitative research was conducted with carers in all the studies, including small scale enquiry in the stroke study, and in the primary care, stroke and learning disabilities, and diabetes studies carers' views and experiences are sought mainly in qualitative enquiry. Quantitative research with carers is reported in the severe mental illness and cancer studies, but as part of the development of measures of continuity. This material is reported in *Chapter 8*.

6.1 Approaches to researching carers' views and experiences

Recruitment of carers was approached in different ways. Carers' support groups were used to recruit carers to focus groups and expert panels in the severe mental illness study. In the stroke and learning disabilities study, carers and family members interviewed were those who were associated with the service users participating in the research. Cancer patients recruited for interviews were asked to nominate close persons who might be approached to take part. In other studies it was not always clear whether carers taking part in interviews had been purposively selected as such, for example in the primary care study in which some patients were also carers.

Some study components designed to focus specifically on carers' views and experiences were very small-scale, and views of carers and patients were not always disaggregated in analysis and reporting. In the diabetes study, seven interviews with carers were achieved, but in four of these the patients were also present, which is likely to have influenced the discussions. The case studies conducted in the stroke and learning disability project included interviews with carers and family members, but it is not clear how many, or whether any were separate from the interviews with patients.

Most of the findings about carers' views and experiences reviewed in this section thus come from the cancer study and the severe mental illness study. King conducted interviews with 18 'close persons' nominated by cancer patients and recruited 145 close persons to a prospective, repeat questionnaire survey. Burns defined carers as relatives or friends having at least weekly contact with the service user and recruited 11 to take part in initial focus groups, and 10 to join two expert panels. This study went on to achieve 14 interviews with carers of service users who had particularly complex or problematic experiences of continuity.

It is not easy, however, to separate findings about carers' perceptions of patients' experiences from carers' views of their own experiences. This was especially the case in the cancer study, in which there was emphasis in interviews with close persons on the patient's longitudinal care and support

needs and the impact of these on patients and carers. There was more emphasis in Burns' qualitative work with carers on their own preferences and experiences, and their own needs for support and care.

In this review, we have chosen to concentrate on the views of carers and family members about their own experiences in the care and treatment of the service user. At the same time, we recognise that the experiences of close persons are related to what happens to the person they care for in complex ways.

Putting together what qualitative findings there are about carers' own preferences and needs, across the empirical studies, the following themes are apparent:

- relationships with professionals
- understanding of the patient's condition and treatment
- recognition of the carer's contribution
- correct and timely information
- response to the carer's needs for support.

6.1.1 Relationships with professionals

Carers valued good relationships with the professionals involved in the care and treatment of the person cared for (cancer 1, severe mental illness, diabetes). Carers of mental health service users sought good, personal relationships with the patient's key worker. They recognised that staff turnover and working arrangements meant that it could be hard to maintain this, and some found transitions particularly stressful. What was important then was that some member of staff was always available, to take time to talk and listen to them, and provide support, understanding, advice and help. Some carers of diabetes patients commented negatively on the quality of their relationships with professionals, and thought that professionals' reluctance to involve them could lead to lack of appreciation of the needs of both patients and carers.

6.1.2 Understanding of the patient's condition and treatment

Understanding of the patient's condition and treatment was especially important to carers when they had key roles in helping with practical care, such as arranging appointments and helping with medication (cancer 1, stroke). Some carers of diabetes patients experienced poor communication with professionals (diabetes).

6.1.3 Recognition of their contribution

Carers valued recognition of their contribution to the patients' care, which was important in various ways. For practical reasons, it was important that professionals recognised that making and arranging appointments for the patient (cancer 1), maintaining home care regimes (stroke), and being alerted to aspects of the patient's condition (severe mental illness, diabetes) sometimes depended on the carer's participation. It was also important that professionals recognised that carers might be the first to see aspects of a patient's condition that required response, and accepted the carers' assessments and judgements here (severe mental illness, diabetes). Carers of mental health service users particularly wanted professional acknowledgement of and response to their assessments of the patient as

being in a crisis situation, and wanted sensitive response for themselves and the person they cared for.

6.1.4 Correct and timely information

Recognition of the carers' contribution also encouraged professionals to provide timely and correct information, for example about planned discharge from hospital (severe mental illness). In the stroke study, in the same way as patients, carers were sometimes dissatisfied with both the content of information and the way it was given.

Some carers of mental health service users found themselves cast into the role of having to 'close the information gaps' between services, and were critical of this requirement (severe mental illness).

6.1.5 Response to own needs for support

Recognition by professionals of carers' own needs for support, and responsive provision of help was important to carers in the diabetes, cancer and severe mental illness studies. In the diabetes study, carers mentioned their own mental health needs in their supporting role, and would have liked some help here. Some wanted, but had not found, access to social support (diabetes). Close persons in the cancer study described their own strong emotional responses to diagnoses and delays in the patient's treatment, and becoming aware of and having to deal with changes in family dynamics and relationships.

Carers of mental health service users said that when services responded to crises rather than providing preventative support to mental health service users, then they too could feel invisible, and feel that their support had been withdrawn (severe mental illness).

Some carers of mental health service users had found carer support groups helpful (severe mental illness).

6.2 Influences on carers' views and experiences

When we look for the influences on carers' views and experiences, the following factors contributed variously:

- nature and trajectory of patient's condition (diabetes, severe mental illness, cancer 1)
- carer's understanding of patient's illness and ways of managing it (diabetes)
- the patient's family structure and dynamics (diabetes, cancer 1)
- service structure (diabetes, severe mental illness)
- carer's access to and use of social and external support (diabetes)
- carer/professional relationships (diabetes, severe mental illness)
- the carer/patient relationship (diabetes, cancer 1, severe mental illness).

The previous section provided examples of the way in which these factors influenced carers' views and experiences, but we have more to say here about the influence of the carer/patient relationship.

Carers recognised the close relationship between their own feelings and needs and their perceptions of what happened to the patient. They were

influenced by the patient's state of mind and emotional response to illness (diabetes). They wanted, for themselves, the person they cared for to be treated with skill (cancer 1) and sensitivity (severe mental illness); to receive good quality care (cancer 1); and not to have 'disjointed' care (stroke and learning disability). Carers of diabetes patients perceived problems of continuity in care at the interface between home, and primary and secondary health services (diabetes).

Parents of sick children have particular relationships and responsibilities – they wanted, for example, speedy access for consultation in the GP practice (primary care). Carers of mental health service users found it frustrating and stressful when they perceived staff shortages and frequent staff turnover. They had particular criticism for services which appeared to respond only to crisis situations, rather than providing preventative input and a range of services for patients when they were well (severe mental illness).

However, the needs of carers and patients were not always the same and sometimes they conflicted. Diabetes patients sometimes did not want their carers to talk to the professionals involved in their treatment and care. Confidentiality was a particular issue for carers of mental health service users (severe mental illness). In this study, carers valued being able to talk to professionals in confidence, and sometimes perceived 'lack of confidentiality' in the way staff judged how information should be shared with patients. They also sometimes felt their status was ambiguous, leading to gaps in communication.

6.3 Discussion

Findings reviewed in this chapter about carers' experiences of continuity of care come from qualitative enquiries. Recruitment of carers was approached in different ways; some study components focusing specifically on carers were very small-scale, and views of carers and patients were not always disaggregated in analysis and reporting.

Most of the findings reviewed in this chapter come from the cancer study and severe mental illness study. We chose to concentrate on the views of carers and family members about their own experiences in the care and treatment of the service user, although recognising that experiences of close persons are related to what happens to the person they care for.

Our review of qualitative findings about carers' own preferences and needs led us to identify the main themes as being their relationships with professionals; their understanding of the patient's condition and treatment; recognition of their own contribution; correct and timely information, and response to their own needs for support.

The contributory influences on carers' experiences were the nature and trajectory of the patient's condition; their understanding of the patient's illness and ways of managing it; the patient's family structure and dynamics; the structure of services; carers' access to and use of social and external support; their relationships with professionals, and their relationship with the patient. Parents of sick children have particular relationships and responsibilities, of course.

Our review showed that the needs of carers and patients were not always the same, and sometimes conflicted. They also felt sometimes that their status was ambiguous, leading to gaps in communication.

7 Professionals' views about and experiences of continuity of care

7.1 Introduction

As we saw in *Chapter 2*, all but one of the main studies included at the outset some formal intention of exploring professionals' experiences of and preferences in relation to continuity of care. Baker, 2006 (primary care) was the exception, although a small number of professionals (members of a service liaison group) were interviewed in a preliminary stage of the project.

Gulliford, 2006 (diabetes) aimed to evaluate health professionals' views and experiences of continuity in the delivery of care for diabetes patients via a qualitative sub-study followed by development and testing of a continuity of care questionnaire for professionals.

Hill, 2008 (stroke) aimed to seek professional views on aspects of service organisation relevant to determining continuity of care. However, in the light of findings from other components of the study, this aim was altered to exploring how professionals co-ordinated their activities to deliver stroke care, and the promoters and barriers to communication between professionals and between professionals and patients. Focus groups and semi-structured interviews were used to accomplish this.

Hardy, 2006 (stroke, learning disability) aimed to explore service providers' and managers' views of how service users and their families perceived and experienced care, via a case study design and in-depth, semi-structured interviews. The intention was to explore these views by triangulating them against 'normative descriptions of appropriate continuity of care', established from a literature review and consultation with 'experts' in the initial stages of the project (Hardy, 2006: 14).

King, 2006 (cancer), in a phase one study, aimed to examine professionals' perceptions of the structures and processes that enhance continuity of care, concentrating on the experiences of specific professionals who had been nominated by the patient as providing the most support during their illness. Individual, qualitative interviews were used here. The ultimate aim was to use this and information gathered from patients and their 'close persons' to develop a quantitative tool for assessing continuity of care in service settings. This tool was further developed in a phase two study (King, 2008), by which time it had developed into an instrument/intervention intended to 'capture continuity [not] as a process but rather as an outcome' (p.10). The results of this patient-completed assessment of continuity of care were then fed back to professionals in order to observe what changes, if any, the professionals made in response. Professionals' views in the phase two study were collected to assess the feasibility of using the tool as an intervention.

Burns, 2007 (severe mental illness) had aimed to assess congruence between service users' and carers' views of continuity of care and those of managers and professionals in the preliminary phase of the study, the main aim of which was to develop an instrument to measure continuity of care. While both qualitative and quantitative approaches were used in this phase of the study to explore professionals' experiences, the findings were not

then used to explore congruence. However, the study did analyse professionals' views about what delivery and organisational features of their services were effective in delivering continuity of care. In the main phase of the study, professionals' 'views' of continuity of care were captured only via their completion of the Camberwell Assessment of Need measure and the Scale to Assess Therapeutic Relationships measure.

Overall, then, there were two different aims in relation to involving professionals in the main studies. The first was about their views and experiences of continuity of care – in other words, exploring what they believed continuity of care to be. The second was about their views and experiences of what enhances or impedes continuity of care – either from their own direct experiences or from what they believed to be service users' or carers' experiences.

In reality, it was difficult to maintain any distance between these two aims in extracting and synthesising the material from the studies that reported professionals' views and experiences. Instead, we identified eight categories within which the material could be organised, some of which included both view and experiences of continuity and views about what enhances or impedes it. These categories were:

- continuity of professional care
- service users' personal agency
- formal information sharing
- informal information sharing
- geography and settings
- crossing boundaries
- working together
- policy and resources.

However, the amount of material ascribed to each category varied substantially. In some studies, this was due to the emphasis that the study itself gave to different forms of continuity, for example the changed emphasis in the main stroke study towards how professionals co-ordinated their activities to deliver stroke care and what promoted or impeded their communication. Beyond this, however, if we assume that the reports reflect the volume of material generated, the differing amounts available for each category suggest that professionals themselves gave different weights to different types of continuity. Qualitative methods predominated in the exploration of professionals' views and experiences and we present our synthesis of this material first.

7.2 Qualitative material

7.2.1 Continuity of professional care

The first issue within this category was that of the personal relationship between professional and service user. The initial contact between them was seen to be crucial in establishing trust and continuity (cancer 1) and in several studies a continuing relationship between individuals was seen as important in maintaining trust and ensuring continuity of care (diabetes, cancer 2, primary care, severe mental illness). This would enhance the professional's sense of responsibility for the service user (diabetes) and facilitate long-term management (diabetes). It would also allow the professional to advocate for the service user between formal contacts such

as hospital appointments (cancer 2) or provide support during periods of acute illness (diabetes). In the cancer study, this continuing relationship was characterised as a 'single point of contact', but it was felt that the service user rather than the professional should initiate contact outside the framework of scheduled appointments.

However, a personal relationship of this sort was an ideal model that was not always achievable. Staff numbers and rapid turnover of staff could make delivery of care by a single professional unfeasible (diabetes) and in primary care the policy emphasis on access and choice made this type of personal continuity the exception rather than the rule.

Indeed, primary care professionals did not necessarily see it as the general practitioner's role to provide continuity and in other studies, a sustained relationship was not felt to be essential to guarantee continuity of care as long as other factors were in place. In stroke care, for example, the most important issue was a good handover to other staff at points of transition along the care pathway (stroke study). In diabetes, accurate medical records documenting episodes of illness, follow-up care and management plans, could compensate for the lack of a continuing personal relationship between professional and service user, especially if these included information about accident and emergency and in-patient care.

In severe mental illness, making and maintaining contact with the service user could be difficult because of the complex nature of service users' needs. The implication seemed to be that a personal relationship was less important than simply keeping channels open between the service user and any professional so that changing needs could be picked up and dealt with. However, keeping any contact was also an issue in relation to diabetes care, where professionals talked about the importance of systems to avoid or reduce loss to follow-up. Neither accurate record keeping that crossed service boundaries nor systems to reduce loss of contact, both of which diabetes care professionals saw as ways of compensating for a lack of personal relationship, appear to have been mentioned by mental health professionals in the severe mental illness study.

The second issue in this category was the personal relationship between professionals and the family or carers of the service user. In the diabetes and the cancer study, families' or carers' understanding of the illness and treatment were felt to enhance continuity and, in the case of diabetes, to help with compliance. If service users did not keep their families or carers informed, then continuity could suffer (cancer 2). No other studies reported professionals' views related to this issue.

7.2.2 Service users' personal agency

Two studies reported professionals' views about service users' personal agency. The cancer study professionals gave a contradictory account of this. On the one hand, while they felt that it was important for service users to be involved in decision-making about their care, they should be involved only if they **wanted** to be. They also suggested that patients rarely wanted to know the likely prognosis of their condition. On the other hand, as we saw above, cancer care professionals thought that service users should initiate contact with their 'single point of contact' if they needed help or support between formal appointments. By contrast, the diabetes professionals were clear that service users should be involved in decisions about their treatment.

The different trajectories and likely outcome of cancer compared to diabetes no doubt account for some of this difference. However, it is also possible that some cancer professionals may be ambivalent about offering service users opportunities for continuing personal agency.

7.2.3 Formal information sharing

As outlined at the beginning of this chapter, the management of information between professionals was a focus of the research in the main stroke study. As a result, most of the material synthesised in this section is from that study. However, professionals in other studies did refer to formal information sharing, suggesting that it was a key part of their experience of continuity of care too.

The first issue was the role of information in enabling or impeding continuity of care in a general sense. Professionals in the main stroke study referred to the important role of documentation in co-ordinating care and, in this light, the stroke care pathway was seen as a positive thing in the acute setting. By contrast, they saw the Single Assessment Process less positively. However, flexible and reactive **patterns** of communication between professionals could be as important in meeting the needs of the service user. Similarly, professionals in the severe mental illness study believed that good communication with other agencies and with service users and carers facilitated continuity of care.

Conversely, getting information flows wrong could impede continuity both across and within service boundaries. Failure to follow information protocols resulted in delays transferring information (diabetes), and delays in sending or receiving discharge letters to general practitioners led to gaps in care (stroke and learning disability study). Within boundaries, non-integrated records, with each professional keeping their own records for individual service users (stroke and learning disability), or hospital records that hampered rather than enhanced communication (cancer 2) had a negative impact on continuity.

The quality of communication between agencies was also important. Voluntary sector agencies reported poor communication with some health care providers, which led to poorer relationships between them, which in turn impeded continuity of care (severe mental illness).

The second, but closely related, issue was to do with record keeping systems. Shared electronic systems for patient records enhanced care across boundaries, giving professionals quick access to information, comprehensive clinical data, and feedback from care given in accident and emergency departments or during acute hospital episodes (diabetes). Similarly, community stroke teams found that a dual system of patient-held and office-held records facilitated admission and scheduling processes, while good administrative support on hospital wards increased the likelihood of timely and accurate communication (stroke).

By contrast, when systems failed to keep pace with change in operational practice, continuity was affected negatively (stroke).

Only two studies seemed to throw light onto professionals' information sharing with service users and their families, friends and carers. As we saw above, cancer professionals believed that continuity of care suffered if patients did not keep their families informed about their condition and treatment. However, as this suggests, it is not clear that professionals felt that sharing information with families or carers was part of their role for everyone. They expressed the view that service users and their families had

varying requirements for information, depending on the individual and the stage of the disease.

7.2.4 Informal information sharing

The main stroke study, with its emphasis on professional communication, was able to highlight the importance of informal information sharing. This made it clear that while formal systems had their place, professional links and relationships could be just as important in terms of co-ordinating and delivering care. Thus, knowing whom to contact and getting information from them could save time and improve outcomes. Further, it seemed that professionals preferred communicating face-to-face or over the telephone, rather than electronically or through systems. They believed that this personal approach was more efficient and effective in ensuring continuity.

This is an interesting observation that runs somewhat counter to the idea that getting **systems** right will ensure that communication is optimal. However, the findings are from a single study, of a single condition, and in a particular part of the country, which limits the extent to which they can be generalised to other places and conditions.

7.2.5 Geography and settings

Co-location of professionals and teams has been a key theme in writing and research about integration and co-ordination of health and social care since the late 1970s. It is not surprising, then, that the geography and settings of services came up when researchers talked to professionals about their views and experiences of continuity of care. However, most of the qualitative evidence about this comes from three studies – the diabetes study and the two studies that covered stroke care. The severe mental illness study also tackled this issue through its quantitative survey of professionals and in less detail in the qualitative element.

In all four of these studies, there was a clear view that co-location or proximity of professionals helped communication between them and thereby enhanced continuity of care. Co-location over a long period was also felt to foster a good culture in multi-disciplinary stroke teams (stroke and learning disability study). Conversely, when managerial or geographical boundaries did not overlap, face-to-face communication and thereby supporting patients after discharge was more difficult (stroke study). Similarly, when stroke patients were discharged to a setting in a different authority or Trust contact with community-based colleagues was reduced (stroke and learning disability study).

However, not everyone agreed that co-location always improved continuity of care for service users. In the stroke and learning disability study, one site included co-located hospital and community teams for stroke patients. While clinical staff felt that this improved continuity, social workers saw it as good for the team but not necessarily for the service user. This was partly because they believed that being in the hospital setting restricted opportunities for outreach into the community. Further, the professionals in the diabetes study reported that co-ordination between staff could be as difficult when they were located in the **same** setting as when they were located in different places, particularly when that setting was an acute hospital.

Further, the professional accounts suggest that organisational arrangements can off-set some of the disadvantages of not being co-located. Effective multi-disciplinary team meetings could ameliorate the negative impact of

complex organisational arrangements on continuity in stroke care, as could dedicated specialist staff (stroke and learning disability study).

7.2.6 Crossing boundaries

Boundaries, of course, can be crossed, and professionals' views and experiences of continuity of care gave insight into how this was (or was not) achieved. Professionals talked about two different types of boundary to be crossed – actual boundaries related to geography and organisation, and virtual boundaries related to culture or knowledge about how to communicate beyond one's own service boundaries.

Professionals certainly believed that the **actual** boundaries caused by geographical or organisational separation could be crossed. Communication across health and social care boundaries to deal with combined therapy and care needs, and well-planned home visits before discharge from hospital after stroke, were believed to lessen the likelihood of failed discharge and readmissions due to problems managing at home (stroke study). Similarly, in-reach from community-based rehabilitation staff in order to see patients on hospital wards created the conditions for a good handover from hospital to the community (stroke and learning disability study). However, transfer issues in another site in the stroke and learning disability study were felt to need structural solutions. Here professionals supported the idea of a 'hospital to home' service supported by a specialist early supported discharge team that would facilitate a single transfer for service users, rather than the series of intermediate or interim transfers that they experienced without such a service. Professionals in this study felt that not having such a single transfer process sometimes led to longer hospital stays, as clinical staff retained patients until they were sure that they could manage the transfer to the next stage of care (stroke and learning disability study).

Issues that prevented working across actual boundaries were largely the converse of those that facilitated it: stroke specialist nurses whose role stopped at the hospital door and complex organisational structures that made both horizontal and vertical co-ordination more difficult (stroke and learning disability study).

Virtual boundaries were more puzzling, but nonetheless had an impact. Thus in the diabetes study primary care staff reported often being unable to speak to hospital staff, while hospital staff worried that treatment initiated in hospital would not continue when patients returned to the community. 'Boundary spanner' roles were important here. Specialist stroke nurses who could liaise with community-based colleagues (stroke and learning disability study) and good team leaders who acted as a bridge between staff members' daily work and senior management, and also between teams in the same organisation (severe mental illness) were believed to facilitate continuity of care.

7.2.7 Working together

Professionals in health and social care services do not work in isolation and we might expect working together – whether in the same service system or across systems – to be instrumental in enhancing continuity of care for service users. However, this issue was not evident in all the main studies; most material included in this category came from the two studies that looked at stroke care and the severe mental illness study.

Location and contact between professionals was one factor in enhancing opportunities for continuity. For example, regular contact through multi-disciplinary meetings was seen to increase the chances of a good handover when stroke patients were transferred to other parts of the service (stroke and learning disability study). Joint visits to service users by different professionals also led to better co-ordinated care because they were looking at the same issue together (stroke study). Similarly, working in teams in mental health services, particularly when that also involved co-location, was seen as a key facilitator of multi-disciplinary working and, therefore, of continuity (severe mental illness study).

However, location and contact were not guarantees, of themselves, for good quality working together. They also had to lead to trust and understanding if working together was to be effective. So, for example, one of the multi-disciplinary stroke care teams in the stroke and learning disability study was observed to work well because there was no 'preciousness' about organisational boundaries or about differential status between team members, and because discussion was open and without rancour, which enabled holistic discussion of service users and effective follow-up of progress. Similarly, the commitment and support of individual team members and quality of communication between them was seen as key to good team working in the severe mental illness study.

By contrast, when trust was lacking, continuity faltered. Stroke care professionals, for example, believed that poor understanding or skills and high turnover of staff in nursing homes led to poor information transfer when patients were being discharged (stroke study). Within teams, the lack of clear boundaries or overall philosophy increased the difficulties of delivering collaborative work, and thereby continuity, as did lack of guidelines, business plans and accountability for these (severe mental illness study).

This last point underlines the need for joint working to be managed; it does not happen by itself. The role of a team leader and wider management structures were thus seen as critical in securing a model of integrated working in the severe mental illness study. Strong leadership of teams and good supervision and management styles that emphasised support and guidance for team members were mentioned specifically.

The severe mental illness study also suggests that without strong leadership and supportive management, attempts to promote joint working can lead to 'border disputes' and the professional and cultural 'preciousness' referred to above. While professionals were generally positive about the notion of integrated working, there were more mixed reactions to integrated practice in reality. Anxieties about professional supervision and identity, taking on roles for which individuals did not feel trained or experienced, and service quality and safety were all raised. When combined with staff shortages, these anxieties could lead to defensive ring fencing of professional boundaries and insistence on role setting. This was particularly the case for community psychiatric nurses, social workers and occupational therapists.

7.2.8 Policy and resources

Professionals in all the main studies referred, if only briefly, to the impact of wider policy issues and resources on the likelihood of delivering continuity of care.

The first issue was that of staffing patterns and levels. Professionals in the diabetes study pointed out that restricted staff numbers and high turnover

could make the delivery of care by a single professional unfeasible, and cancer care professionals felt that limited time in the clinical consultation reduced continuity (cancer 1 study). Under-staffing was seen as a major constraint on continuity in both studies that covered stroke services, and follow-up after transfer in stroke services was limited if staff were spread thinly over services (stroke and learning disability study). However, the impact of staffing levels applied not only to clinical professionals but also to administrative support, whether personal or technological. Thus, good administrative support for doctors on hospital wards (stroke study) and shared electronic systems for patient records (diabetes study) could improve the flow of information between professionals. Similarly, a system of dually held records (patient-held and office-based) in stroke care made it easier to schedule care (stroke study).

The second issue was the profile of teams, raised as important in relation to stroke care. Small teams were unlikely to include a wide range of professionals, which led to gaps in continuity of care (stroke and learning disability study).

Finally, the primary care study highlighted that other policy agendas – access, flexible working, and choice – could conflict with a desire to promote continuity of care.

7.3 Quantitative material

As we saw at the beginning of the chapter only one study (severe mental illness) explored professionals' views and experiences of continuity of care using quantitative methods. This was achieved through a postal questionnaire survey of professional strategic and operational staff responsible for delivery of continuity of care in community mental health teams or associated acute units. Responses were obtained from 192 out of 276 identified staff in these settings.

With only one study reporting quantitative material, synthesis is obviously impossible. However, *Tables 3 to 5* do merge the findings from the professionals in the two Trusts. This was possible because there were few statistically significant differences between the responses given in the two trusts. Where there were differences these are reported in the tables.

The most striking thing to emerge from the tables is, perhaps, the relative lack of enthusiasm for specialist teams – such as home treatment (crisis resolution) or assertive community treatment (assertive outreach) teams. This issue was not apparently explored directly in the qualitative interviews with professionals so it is difficult to interpret the negative response. One could surmise that specialist teams have the potential to increase boundaries within mental health services and between mental health services and other agencies, which might account for the view that they do not facilitate continuity of care.

While there was little difference overall between the results for the two trusts studied, there were statistically significant differences between professional groups. Nurses were less likely to report integrated team working as effective in achieving continuity of care, compared to social workers or the group the study defines as PPOs (psychiatrists, psychologists and occupational therapists). By contrast, PPOs were more likely than the other two groups of professionals to see integrated working as a facilitator of continuity of care. These findings have an echo in the qualitative interviews with professionals in this study.

Table 3. Proportion of professionals finding different types of team work in their Trust effective in achieving continuity of care

Type of team work related to continuity of care	% finding this effective in achieving continuity of care	N (100%)
Team support	92	185
Integrated multi-disciplinary team working	88	186
Team skill mix	87	185
Personal involvement in team decision making	75	175
Maintenance of multi-disciplinary records ¹	74	181
Team decision-making structures	74	187
Development of specialist teams	59	177

1. Professionals in trust 1 were significantly more likely than were those in trust 2 to believe that multi-disciplinary records were effective in achieving continuity of care.

Table 4. Proportion of professionals finding different types of communication in their Trust effective in achieving continuity of care

Type of communication related to continuity of care	% finding this effective in achieving continuity of care	N (100%)
Between team members and leaders	86	188
Between team, users and carers	80	182
Between team and outside agencies	71	180
Between team and senior management ¹	46	169
Between staff and senior management	40	174

1. Professionals in trust 2 were more likely than were those in trust 1 to believe that communication between team and senior management was effective in achieving continuity of care.

Table 5. Proportion of professionals¹ finding different aspects of practice in their Trust effective and ineffective in facilitating or a barrier to continuity of care

Aspect of practice	% finding this effective in facilitating continuity of care	% finding this a barrier in facilitating continuity of care	N (100%)
Working in an integrated, multi-disciplinary team	89	7	183
Team support	87	8	184
Team skill mix	86	6	183
Team decision-making structures	76	14	185
Personal involvement in team decision making	75	12	173
Maintenance of multi-disciplinary records	72	15	180
Development of specialist teams	59	22	177

1. Proportions do not sum to 100% because of responses indicating that type of practice was neither effective nor ineffective

7.4 Discussion

The material reviewed here suggests that health and social care professionals tend to see continuity of professional care as a personal relationship between an individual professional and the service user. This was not the case in all studies, however, and stroke care stood out as a contrast. Conversely, while acknowledging that families' and carers' knowledge of and involvement in treatment could be important, professionals did not see a personal relationship between themselves and family/carers as crucial. Continuity of professional care thus stopped at the level of the service user, or at the service 'door'.

Enabling the service users' continuing personal agency was notable by its absence in most of the reported accounts of professionals' views and experiences.

As one might expect, information sharing was key in many professionals' reported accounts of continuity. Communication, of itself, was seen as key, and good quality record keeping was a part of that. However, informal information sharing was also important, facilitated by professional links and relationships. The geography or settings of services may have influenced this. Professionals clearly valued co-location and proximity, though it was less clear that they had a demonstrable impact on continuity for service users. Further, when co-location was not possible, systems could be put in place to transcend geography: co-location and proximity is thus not a *sine qua non* of continuity. This is further underlined by the view that processes

and structures could enable professionals to cross 'actual' boundaries, but that virtual boundaries were more difficult to deal with. Thus, working together effectively was not just about location and contact. Trust and understanding of other professionals and team members, which could be enhanced through contact, strong leadership and supportive management also had important parts to play.

Finally, professionals believed that wider policy and resource issues affected the chance of delivering continuity of care. Emphasis on other policy drivers might mean that enhancing continuity had lower priority when organising services. Regardless of policy, however, staffing levels and team composition could make the difference between services with and without gaps.

8 Quantitative approaches to measuring continuity of care

In this chapter, we describe the approaches that four of the projects took towards developing measures of continuity of care. All four projects (severe mental illness, diabetes, stroke, cancer) developed measures intended to be completed by service users, two projects (diabetes, stroke) developed measures intended to be completed by professionals, and one (severe mental illness) a measure intended to be used by carers.

We have described the methods that the projects used to develop these measures in some detail, as we believe that it is difficult to understand the relative strengths and limitations of these measures unless one understands how they were derived and developed. Further, as the projects were very different in the approaches they took, we have described and then discussed each separately, rather than attempt an overall synthesis related to measure development.

Each section also includes any findings from the individual projects that attempted to relate continuity of care, as measured by these new instruments, to other variables, whether patient/carers characteristics, aspects of service delivery and organisation, or 'outcomes'. Again, as the projects were different in what they attempted here, we have described them separately.

In the final section of the chapter, however, we do attempt an overall summary of the current 'state of play' in relation to measuring continuity of care and what it may or may not be associated with.

8.1 Severe mental health problems (*Burns et al, 2007*)

8.1.1 Experiences of continuity and development of the measure

The development phase of the severe mental illness project generated a measure of continuity of care based on the experiences of people with **psychotic conditions**. It also developed a measure based on the experiences of carers of people with psychotic conditions.

8.1.2 Measure of service users' experiences of continuity

Service users' views about continuity were first explored using qualitative approaches. This identified 17 domains – aspects of care - that contributed to service users' sense of having experienced continuity. Some of these clearly related to Freeman's (2002) model, as extended for mental health services. While the researchers felt that their user-identified domains mapped on to Freeman's extended model to a relatively modest extent, we felt that there was much more 'read over'. *Table 6* shows our assessment of this.

The final measure (CONTINU-UM) used these 17 domains, each split into four questions about how important the user thought the domain was; whether they had received this element of continuity in the past 12 months; how satisfied they were with this situation; and any other comments.

Table 6. User-generated domains of continuity of care from severe mental illness study mapped onto Freeman's (2001) model of continuity of care

User-generated domains	Possible dimension of continuity
Easy access to services when needed	Flexible/longitudinal
Getting all services felt to be needed	Flexible/longitudinal
Choice over types of treatment received	Flexible
Not having to wait for services	Flexible/longitudinal
Having access to support from services out of hours	Flexible/longitudinal
If discharged from hospital in past 12m, receipt of service support when leaving hospital	Flexible/cross boundary and team
Staff involved in care not changing frequently	Relational/longitudinal
Getting appropriate information from staff	Cross-boundary and team
Level of support from services changing to meet needs	Flexible
Services aiming to help user move forward	Experienced
Access to day centre to suit needs	Flexible
Having a care plan user agrees with	?
Having systems in place to deal with a crisis	Flexible
Staff involved in care communicate with one another	Cross-boundary/information
Support of other people who have experienced mental distress	?
Not having to tell life history to new staff	Longitudinal/relational
Avoiding contact with services when this was wanted	Flexible

The authors state that the measure 'represents what users feel are high-quality continuous services and what, therefore, would help prevent them falling through the gap' (p.35). The measure was subject to psychometric testing, during the main survey, from which the researchers conclude that it was psychometrically robust, though with 'areas of weakness' (p.36). Factor analysis showed that it had three underlying constructs - a 'general' factor (out-of-hours, information, flexibility, individual progress, day centres, care plans, crisis, staff communication, peer support, avoiding services), a factor for 'preconditions for continuity' (access, range, information, individual progress, hospital discharge) and a factor for 'transitions' (waiting, staff changes, life history, hospital discharge).

However, instead of continuing to develop and test this measure, it was partially abandoned at this stage while the project went on to operationalise the Freeman model of continuity of care. The 32 variables used to do this are included in *Appendix 2*.

Information about all 32 variables was collected in interviews with service users with psychotic conditions at three time points. Service users with non-psychotic conditions were also interviewed, but only at two time points. The report included simple descriptive data from the interviews but we have not reviewed these here.

After the descriptive analysis, some variables were dropped from subsequent analysis, because of small numbers with positive responses to questions, inconsistent recording of the variable during the interviews, or high inter-item correlations. Exploratory factor analysis using the remaining 22 variables from the first survey of people with psychotic conditions then identified seven continuity factors. These were:

- **Experience and relationship:** high score means high experienced continuity⁷, good therapeutic relationship, higher proportion of needs met, not having user-rated break in care.
- **Regularity:** high score means being seen more frequently by staff from fewer different non-medical disciplines.
- **Meeting needs:** high score means high level [number] of needs, high number of needs met, CPA copied to GP and user.
- **Consolidation:** high score means having contact with fewer different agencies, not seeing primary care professionals.
- **Managed transitions:** 1=no transition, 0=documented transition, -1= undocumented transition
- **Care co-ordination:** high score means having designated care co-ordinator, having no psychiatrist or more than two, having fewer needs met by informal carers.
- **Supported living:** high score means living in supported accommodation, attending day care, having more letters copied to user.

However, confirmatory factor analysis on data from the second and third time points in the study did not validate this seven-factor model. Neither did confirmatory factor analysis on data from the sample of people with non-psychotic conditions.

8.1.3 What is associated with continuity of care in severe mental illness?

Further analysis explored variables associated with each of the seven continuity factors for people with **psychotic conditions**. In this highly complex analysis, the variables tested were: time point, NHS Trust, team, gender, total number of lifetime admissions to hospital, type of accommodation, living situation, ethnic group, education, employment, presence of an informal carer, use of depot medication, use of alcohol or drugs, whether hospitalised in the previous year, age, duration of illness, functioning (GAF- global assessment of functioning), symptomatology

⁷ Experienced continuity defined as CONTINU-UM score, using only the questions for each domain asking about the degree to which each had been experienced (i.e. not the aggregate scores).

(BPRS – Brief Psychiatric Rating Scale), empowerment, and quality of life (MANSA – Manchester Short Assessment of Quality of Life and SIEQoL – Schedule for the Evaluation of Individual Quality of Life).

Only variables associated with a continuity factor at a 10 per cent statistical significance level were entered into the subsequent multi-factorial analysis, which controlled for inter-relationships between factors and explanatory variables. The following relationships were identified in the text; however, the text is sometimes at variance with the confidence intervals reported in the relevant tables. We have assumed here that the text is correct and that the confidence intervals reported in the tables have been subject to typographic error. If this is not the case then the relationships reported below are not wholly secure.

Experience and Relationship. This continuity factor was independently related to time-point and MANSA. (The table of results also suggests relationships with NHS Trust and living situation). This means that a better quality of life was associated with reporting a good therapeutic relationship, high experienced continuity, a high proportion of needs being met and not having had any breaks in care. The relationship with time point means that service users reported improvements in this factor over time.

Regularity was independently related to time-point, NHS Trust, team and having depot injections. This means that being a service user in Trust 1 and receiving depot injections were associated with having been seen more frequently by fewer different non-medical staff. A differential pattern was also evident between service users cared for by different teams. Again, services users reported improvements in this factor over time.

Meeting need was independently related to accommodation type, duration of illness, GAF, BPRS and MANSA. This means that living in supported accommodation, having been ill for longer, functioning at a lower level, having more symptoms, and reporting a poorer quality of life were associated with a high level of need, a high number of needs met and having the CPA copied to the GP and the service user.

Consolidation was independently related to NHS Trust, team, and receiving depot injections. This means that being a service user in Trust 2 or receiving depot injections were associated with having been in contact with more different agencies and having seen primary care professionals. Again, there was a differential pattern for service users cared for by different teams.

Managed transitions was independently related only to GAF (although the results in the table suggest that this was not the case, as the confidence interval for the reported odds ratio passes through 1). A five point higher (better) rating of function was associated with 10 per cent lower odds of experiencing transitions.

Care co-ordination was independently related only to informal care (although the confidence intervals reported in the table suggest that it was also related to not having depot injections). This means that having no identified informal carer was associated with having seen a designated care co-ordinator, having no psychiatrist or more than two, and having fewer needs met by informal carers.

Supported living was independently related to time-point, Trust, education, living situation and GAF. This means that being a service user in Trust 1, having left school by 16, living with others, and poorer functioning

were associated with living in supported accommodation, attending day care and having more letters copied to the service user.

The factors associated with each continuity factor for people with **non-psychotic** conditions were also explored. We have assumed that the same variables and analytical strategy were used as in the analysis of results from people with psychotic conditions. The following relationships were identified although, again, there are some discrepancies between the text and the confidence intervals reported in the tables.

Experience and relationship were independently related to Trust, team, having been discharged, age and MANSA score. There is no interpretation of the multi-factorial analysis in the text of the report. The table of results (pp.142-46) suggests that being a service user in Trust 1, having been discharged, being older, and having a better quality of life score were associated with a good therapeutic relationship, high experienced continuity, a high proportion of needs being met and not having had any breaks in care. There was also a difference between service users cared for by different teams.

Regularity was not independently associated with any of the variables explored, although the confidence intervals reported in the table do suggest that people were more likely to have higher scores on this factor at time 1.

Meeting need was reported to be independently related to number of lifetime admissions (1-5), drug use and GAF score (although the confidence intervals in the table suggest no relationship with drug use). No interpretation is offered in the text of the report other than worse functioning was associated with a higher score on this continuity factor. Overall, the results in the table suggest that poor functioning, drug use, and admission to hospital between one and five times were associated with a high level of need, a high number of needs being met and having the CPA copied to the GP and the service user.

Consolidation was independently related to accommodation type and alcohol use (although the confidence intervals in the table also suggest relationships with informal carer, depot injections and team). This means that living in supported accommodation and alcohol were associated with contact with different agencies and with primary care professionals.

Managed transitions appeared to be independently related to time although this was not mentioned in the text, neither was any interpretation offered.

Care co-ordination was independently related to GAF. This means that better functioning was associated with having a care coordinator, seeing no or many psychiatrists, and having fewer needs met by an informal carer.

Supported living was independently related to time-point only. This means that people were more likely to have letters sent or copied to them, to live in supported accommodation, and attend day centres or day hospitals at time 1 than at time 2.

8.1.4 Measure of continuity of care for carers of people with severe mental illness

A similar process as that for the service users' measure was used to develop a measure of continuity for people identified as carers of people with psychotic illnesses. Qualitative work with carers, via focus groups, identified elements of continuity important to carers. These formed the basis for a

measure (CONTINUES) that was developed using expert panels and a pilot study. Eleven domains were included in the final version:

1. staff take time to talk to carer
2. staff take action if carers tell them service user is in crisis
3. carer can get information and advice from staff
4. there is a member of staff carer can establish relationship with
5. carers have a right to confidentiality
6. hospital admission of service user is dealt with sensitively
7. carer is told in advance of date of service user's hospital discharge
8. staff involved in care of service user do not change frequently
9. access to carers' support group
10. access to support from services for self
11. access to support from services for service user.

As with the service user measure, carers were asked how important the factor was to them, whether they had experienced it in the previous 12 months and how satisfied they were with this. Psychometric testing of the measure showed its properties to be good. However, as with the service user measure, the test-retest reliability of individual items was low.

There is no account of factor analysis of CONTINUES in the main report or its appendices, perhaps because of the small numbers of carers involved in this stage of the project. The researchers themselves acknowledge the need for further testing of the measure on larger samples.

8.1.5 What is associated with continuity of care for carers of people with severe mental illness?

The study took a much less complicated approach to exploring the relationships between continuity of care and carer-related variables than it did with service users. Multi-level modelling was used to assess possible associations between continuity, as measured by CONTINUES, and psychological well-being (GHQ-12) and positive/negative appraisals of care giving. A range of other socio-demographic and caring related variables, plus the service users CONTINU-UM score and measures of their functioning and symptoms were also explored.

In adjusted models (controlling for other factors that might be related to experienced continuity) higher continuity scores were associated with being male, employed and regarding oneself as a carer for people caring for service users with psychotic conditions. No other relationships were statistically significant. For carers of people with non-psychotic conditions different relationships were found. Here, in the adjusted analysis, measured continuity was higher if the carer lived with the service user. No other statistically significant relationships were identified.

The study also explored the relationship between experienced continuity and outcomes over time. This was possible only for the carers of people with psychotic conditions because of the small numbers of carers of people with non-psychotic conditions who had data for both time points in this part of the study.

This analysis found no significant associations between continuity levels and changes in care giving experience or psychological distress in the previous 12 months. Neither were there any significant associations between experienced continuity and care giving experience or psychological distress in the following 12 months.

8.1.6 Discussion of the severe mental illness measures

The process of creating a measure of continuity of care for people with severe mental illness involved several stages, the first of which was using service users' own accounts of experiences to generate a 17-factor model of continuity. These service-user generated domains then formed the basis of a single measure of continuity (the CONTINU-UM). This measure simply asked service users how important each domain was to them, whether they had experienced this aspect of care over the past 12 months and how satisfied they were about this situation.

The researchers then left their own developing model of continuity, and went on to elucidate possible components of each element of Freeman's model of continuity of care. They explored how all these components related to each other, and reassembled them statistically into a new, multi-element, measure of continuity of care.

The validity of this approach depends, first, on whether one thinks the way in which the elements of Freeman's model were operationalised is adequate. So, for example, **cross-boundary continuity** is characterised in Freeman's (2001) model as 'effective communication between professionals and services and with users'. Burns, 2007 operationalised this with variables that recorded whether a service user had had a transition, had any contacts with primary care professionals and the number of agencies they had used in the previous year. These variables do not seem to us to operationalise Freeman's definition.

Freeman's (2002) extended model was based on work that had identified **contextual continuity** as important. The extended model reflected this in its developed definition of flexible continuity as that which is flexible and adjusts to changes in people's life over time in their own personal and social context (see *Chapter 1*). However, this element was operationalised in the severe mental illness study by variables that recorded attendance at day care and living in supported accommodation.

The second issue on which the validity of this approach depends is the coherence of the seven elements of the new measure of continuity. For example, the **Meeting needs** factor is made up of two variables about the meeting of need, but also one about copying the CPA to the service user and his or her GP. Similarly, a high score on the **Care co-ordination factor** means having a designated care co-ordinator, having **no** psychiatrist or **more than two**, and having fewer needs met by informal carers. It is difficult to understand what such a factor would mean in real life. That a service user has a care co-ordinator, therefore may not need a psychiatrist and can rely less on informal networks makes some intuitive sense. However, what sense is to be made of having a care co-ordinator **and** having more than two psychiatrists **and** relying less on one's informal networks? And why would one expect having a care co-ordinator and **one** psychiatrist to lead to less continuity of care?

The third issue is the degree of circularity involved in the **Experience and relationship** factor. This factor contains the aggregate CONTINU-UM score that sums service users' assessment of the extent to which they have

experienced each of the 17 user-generated domains of care. However, this factor also contains variables related to good therapeutic relationships, a higher proportion of needs being met, and not having a user-rated break in care. Yet CONTINU-UM already contains items that ask service users about whether the staff involved in their care have changed frequently, whether they have been able to get all the services they need and whether they received the support they needed when discharged from hospital.

The fourth issue is how to understand the relationships between the seven continuity factors and other variables argued to influence continuity of care, when they contain an inevitable degree of self-reference or when apparently similar variables are included in different factors. For example, **Experience and relationship** includes a variable for the proportion of needs met; **Meeting needs** includes the variables for total number of needs and number of needs met – i.e. the proportion of needs met, though in a 'raw' state. However, the survey of people with psychotic conditions showed that **Experience and relationship** was independently associated with a higher quality of life score, but **Meeting needs** was independently associated with a lower quality of life score. Again, it is difficult to make intuitive sense of this and, therefore, difficult to understand what one should do to improve continuity of care.

However, the authors of the report do make repeated references to the need to do further work with different samples of mental health service users (p.43) and further factor analyses (p.44) before firm conclusions can be drawn from their work. Our review leads us to underline this conclusion.

The development and subsequent use of the measure of continuity for carers was simpler than that adopted for service users. This was in part due to the relatively small numbers of carers recruited for this part of the project that limited both the psychometric testing that could be done (factor analysis) and the subsequent exploration of factors associated with continuity. However, as the researchers point out, this was the first ever attempt at developing a measure of continuity for carers.

8.2 Diabetes (Gulliford et al, 2006)

The diabetes study developed measures of continuity for use both by service users and by professionals. We describe the service user measure first.

8.2.1 Experiences of service users' continuity and development of the measure

As with the study of severe mental illness, the diabetes study used in-depth, qualitative methods to explore with service users their values and experiences of continuity in diabetes care. The Freeman (2001) model underlay the topics covered in the interviews, but the definitions in the model were not used directly. Thus, the researchers had the model as part of their mindset while interviewing, but the service users did not. The analysis then matched the qualitative material onto the Freeman model. This was apparently sometimes difficult to do 'because dimensions are interrelated and some experiences [of service users] illustrated several dimensions at once' (Gulliford, 2006: 46).

The researchers concluded that there were four distinct components to service users' 'experienced continuity' (ibid: 54). These were:

- **Experienced longitudinal continuity** - this involved a regular source of care and a decision by the service user to use it when care was needed.
- **Experienced relational continuity** – this involved establishing and maintaining a satisfactory relationship between the service user and the professional.
- **Experienced flexible continuity** – this involved health care professionals and services adjusting to change in the service users' life, over time.
- **Experienced team and cross-boundary continuity** – this involved effective communication between health-care professionals and co-ordination of services.

Each of these dimensions related directly to themes or experiences in service users' experiences of their health care (*Table 7*).

Table 7. Researchers' summary of themes and experiences derived from service users' accounts of each dimension of experienced continuity of care

Longitudinal	Relational	Flexible	Team and cross-boundary
Regular consultations	'Usual' doctor or nurse is identifiable	Can make and change appointments	Services are co-ordinated appropriately
Receives appointment letters	Usual doctor or nurse is felt to understand service user	Can speak to usual doctor/nurse when needed	All staff know medical history and treatment
Regular tests and checks	Doctor/nurse listens, has enough time to talk	Can get advice in an emergency	Staff communicate with one another
Regularly sees usual doctor/nurse	Can talk about anything, is a confiding relationship Doctor/nurse is concerned and interested There is mutual trust and confidence Doctor/nurse explains things		Staff give consistent advice

Derived from Table 8 (Gulliford et al, 2006)

As with the severe mental illness project, the researchers in the diabetes project confined cross-boundary continuity to issues of professional communication, rather than including communication between professionals and service users. 'Having things explained' could thus have been defined

as cross-boundary continuity, as it relates to communication with the service user.

Using these themes and experiences, the project then developed 19 questionnaire items to include in a continuity of care questionnaire. The qualitative material influenced the wording of the questions but similar items in other questionnaires⁸ were also influential. In the final version of the questionnaire (named the ECC-DM) 11 of the 19 items were 'similar' (p.57) to items in these other pre-existing questionnaires.

Each question had a six-response Likert-type scale, and in the final version of the questionnaire was repeated for primary care and for hospital settings.

The questionnaire was subject to psychometric testing in a cross-sectional survey of 209 people with type 2 diabetes in 19 general practices in inner-London. This survey also collected information about the type of care received, age, sex, ethnicity and language, socio-economic status, lifestyle variables, duration of diabetes, diabetes treatment, adherence, and general health. Clinical data (height, weight, blood pressure) and a blood sample for HbA1c estimation were collected when service users were interviewed and general practice records were used to collect information on the number of visits made to see a doctor or nurse in the preceding 12 months.

After excluding cases with missing data, analysis was based on 193 participants. Overall, mean ratings of continuity of care were lower for questions about hospital care than they were for general practice care.

Factor analysis explored whether the composition of the measure was consistent with the dimensions of continuity derived from the qualitative data. A four-factor solution was chosen, and this broadly reflected the original dimensions. However, the item about the number of times people had seen their 'usual' doctor or nurse (a longitudinal continuity question) loaded strongly on the relational factor as well. Further, the question about how easy it was to see the 'usual' doctor or nurse if needed (a flexible continuity question) also loaded strongly on the relational continuity factor. Indeed table 15 in the report suggests that both these items fitted better in the relational factor.

A self-completion version of the questionnaire was also tested on a convenience sample of 60 people (56 of whom completed the questionnaire) who had already been interviewed in the follow-up survey (see next sub-section).

Reliability, test-retest reliability, and construct and criterion validity of the measure were tested and found to be acceptable. The researchers came to the overall conclusion that the measure had generally 'satisfactory' psychometric properties but that some issues required clarification in subsequent studies. They also suggested that it might be adapted into a generic form to allow measurement of continuity of care for other chronic illnesses.

8.2.2 What is associated with continuity of care in diabetes?

Like the severe mental illness study, the diabetes study explored the relationships between continuity of care and other factors in the same study

⁸ The GPAQ (National Primary Care Research and Development Centre, 2005) and the Picker Institute NHS Survey Questionnaires (Picker Institute, 2005).

that was used to test the psychometric properties of the measure. The 209 service users identified for the cross-sectional study (defined as baseline) generated 193 complete continuity scores, as outlined above. At a follow-up study (said to be 10 months later) 177 service users participated, of whom 156 generated complete continuity scores. In fact, as is clear later in the report, time between the baseline and follow-up surveys ranged between 24 and 76 weeks, with a mean of 43 weeks.

The main purpose of this stage of the project was to explore the association, if any, between continuity of care and health outcomes, including HbA1c (the primary outcome), blood pressure, weight and body mass index, and subjective health status. The same variables were collected at follow-up as at baseline (see previous section), although a global satisfaction with treatment question was added and the items about self-rated health were replaced with the SF-12. The same clinical measurements were taken in both surveys and the same data abstracted from general practice records (see previous section) with the addition of the **number** of professionals seen during the study period.

Multivariate analysis, controlling for a range of confounding factors, showed no relationship between HbA1c at follow-up and measured continuity of care, after adjusting for HbA1c at baseline. The same was true for other clinical or self-rated health outcomes. However, this relationship was assessed by examining the **mean** of the baseline and follow-up continuity scores. The presented analysis then examined the impact of a 10-point difference in these mean levels of continuity on clinical outcomes. In other words, the analysis of continuity of care was essentially cross-sectional.

Measured continuity of care did increase with the number of consultations in the previous 12 months, but decreased as the number of different individuals seen increased. The primary outcome (HbA1c) was not associated with either consultation variable. Global satisfaction with care was strongly associated with overall measured continuity and with three of the sub-scales (flexible, relational and team/cross boundary), after taking into account the care setting (hospital, primary care or shared). However, it is not clear whether this association was also tested controlling for other possible confounding variables.

8.2.3 Measure of continuity of care for professionals

The diabetes study adopted a similar approach in measuring professionals' views and experiences of continuity of care as used with service users. First, in-depth qualitative methods elucidated professionals' experiences and perceptions of what contributed to patients' experienced continuity of care for type 2 diabetes. This information then formed the basis of a measure of professional experiences of continuity in the delivery of care.

The topic guide for the qualitative interviews with 25 different types of professionals involved with delivering diabetes care was 'informed by Freeman's model' (Gulliford, 2006: 115) as was the subsequent analysis of the interview material. As a result, the model generated maps clearly onto the Freeman model. However, the researchers do say that participants brought up 'other' issues. Four dimensions were identified, related to 'characteristics of the organisation and delivery of care required to achieve experienced continuity of care for patients' (ibid: 121). These were:

- delivery of longitudinal care – organisational arrangements to facilitate follow-up care over time consistent with need

- relational continuity – continuity of relationship between staff and service users
- team and cross-boundary continuity – effective communication and co-ordination of services between professionals, within and between organisations
- informational continuity – appropriate recording and information transfer following the service user.

As with the service users' element, cross-boundary continuity related to communication with the service user was absent from the professionals' element.

There was no separate dimension for flexible continuity. The professionals interviewed largely regarded flexibility as inherent in existing patterns of patient care and, therefore, in the other four elements. The researchers also point out that perhaps only patients are in a position to judge whether services are adequately adapted to their needs.

Table 8 outlines the key factors in each continuity dimension and *Table 9* summarises the ways in which they were operationalised for the purposes of developing the continuity measure. As comparison of the tables shows, there was some lack of read over from the qualitative material to the questions included in the questionnaire. Further, five of the items included in the cross-boundary dimension would seem to fit better with Freeman's definition of informational continuity – excellent information transfer following the service user.

Table 8. Researchers' summary of themes and experiences derived from professionals' accounts of each dimension of continuity in the delivery of care

Relational	Longitudinal	Informational	Team and cross-boundary
Flexible approach	Regular visits	Access information	Shared treatment plan
Patient involvement	Send appointment letters	Information is understood	Shared guidelines
Explain things	See the same patients	Information is accessible	Consistent messages given
Enough time	Regular blood testing	Share records	Can speak with staff
Listen			Evaluation of overall care
Know medical history			

Derived from Table 35, (Gulliford et al, 2006)

Table 9. How the factors in each dimension were operationalised

Dimension	Questionnaire item	Factors from <i>Table 9</i>
Relational	Ease of personal consultation	?flexible approach

Dimension	Questionnaire item	Factors from <i>Table 9</i>
	Ease of urgent personal consultation	?flexible approach
	Knowledge of patients' medical history	Know medical history
	Time to address patients' concerns during consultation	Enough time
	Involve patients in decision making about treatment	Patient involvement
	?	Explain things
	?	Listen
Longitudinal	Number of practice visits per year under routine follow-up	Regular visits
	Frequency of appointment letters sent	Send appointment letters
	Frequency of HbA1c measurement under routine follow-up	Regular blood testing
	Proportion of diabetic patients who DNA	?regular visits
	?	See the same patients
Informational	Access to patient's notes during consultation	Access information
	Access to full patient records during consultation	Access information
	All necessary information accessible during consultation	Information is accessible
	Readability and comprehensibility of information available	Information is understood
	All staff share same clinical records	Share records
Team continuity	All staff provide consistent advice	Consistent messages
	All staff share agreed treatment plan	Shared treatment plan
	All staff share agreed guidelines	Shared guidelines
	Quality of co-ordination of diabetes care at the practice/hospital	? Evaluation of overall care
	Ease of speaking to colleagues about patient at the practice/hospital	Speak to staff
Cross-boundary continuity	Ease of obtaining information from hospital/practice	? Access information
	Hospital/practice letters/summaries available	? Access information
	Hospital/practice advice clearly stated	?Access information

Dimension	Questionnaire item	Factors from <i>Table 9</i>
	Current medication clearly stated	?Access information
	All necessary information is in letter/summary	?Access information
	Practice and hospital advice to patient are consistent	Consistent message
	Practice and hospital share agreed treatment plan	Shared treatment plan
	Practice and hospital share guidelines	Shared guidelines
	Quality of co-ordination of care between practice and hospital	?Evaluation of overall care

Derived from Table 36 and Appendix 1 (Gulliford et al, 2006)

For the questionnaire that was for use in primary care settings, the team continuity questions related to continuity within the general practice, while cross-boundary continuity questions referred to relationships between hospital-based care and the general practice. For the questionnaire for use in hospital settings, the focus of these sections was reversed.

The questionnaire used Likert-type scales for responses for most questions and was designed for self-completion, administered via a postal survey.

The questionnaire was tested psychometrically by sending it to professionals involved in diabetes care in general practices and hospital trusts. The majority of respondents were doctors.

Factor analysis largely supported the four/five dimensions of continuity suggested by the qualitative data and the questionnaire items that were ascribed to them. However, the items for cross-boundary, team and informational continuity appeared to give a better fit than those for longitudinal and relational continuity. Test-retest reliability was assessed by repeat administration of the questionnaire, the results of which suggested 'excellent' reliability (p.133). Overall, the researchers concluded that the measure had satisfactory psychometric properties.

There was no further use of the professional measure of continuity of care in the project, so it is not possible to explore what factors might be associated with it.

8.2.4 Discussion of the diabetes measures of continuity

There was a very direct link between this study's exploration of service users' views and experiences of continuity of care and the measure of continuity developed. This relatively simple measure (compared, for example, to the measure developed in the severe mental illness study) matched clearly and both intuitively and statistically onto Freeman's (2001) model of continuity of care. However, there is a suggestion that two items – the number of times service users had seen their 'usual' doctor or nurse and whether they were able to see their 'usual' doctor when they needed to – would have been better placed in the relational continuity sub-scale than, respectively, in the longitudinal and flexibility factors.

The importance of relational continuity for diabetes patients contrasts markedly with the findings for people with psychotic conditions where, as we argued earlier, issues of flexibility seemed much more important.

The authors discuss a number of perceived limitations in this element of their study, and argue why it may not be possible to demonstrate that continuity of diabetes care leads to better health outcomes. However, we would add that the analytical strategy adopted – examining what was essentially a cross-sectional measure of continuity (the mean value of continuity at baseline **and** follow-up) with clinical measures taken at follow-up – may also have limited the opportunity for displaying an association. It could be that **change** at an individual level in experienced continuity affects health outcomes, especially if people are moving from a low level of experienced continuity to a higher level. However, this possibility remains to be explored, either in an expressly designed longitudinal study or in a study of a tested intervention to improve experienced continuity in diabetes care.

In discussing the professional measure, the researchers point out that the poorer fit of the longitudinal and relational continuity items contrasted with findings from the service users' measure, where team and cross-boundary items had poorer fit. They suggest that this might indicate real differences between professionals' and service users' emphasis on what constitutes continuity of care. Thus, they argue:

'... patient responses primarily focus on the notion of the 'continuous caring relationship' and associated dimensions of relational and longitudinal continuity, whereas professionals give greater emphasis to the notion of a 'seamless service' with its associated dimensions of team continuity, cross-boundary continuity and informational continuity. Patients generally find it more difficult to evaluate these latter aspects of their care'.

(Gulliford 2006: 138)

An alternative possibility that occurs to us is that team, cross-boundary and informational continuity are necessary **precursors** to relational and longitudinal continuity.

8.3 Stroke (Hill et al, 2008)

8.3.1 Experiences of continuity and development of the measure

Qualitative exploration

As with the other studies reviewed so far in this chapter, the stroke study began its development of a quantitative measure of continuity of care by using qualitative methods. These aimed to explore how people who had had a stroke experienced their care and 'whether they would recognise and describe elements of continuity in its processes' (p.41). Twenty-four individual interviews (that often also included carers) and four focus groups with patients and carers were carried out. The interviews and discussions were semi-structured and guided by existing evidence and ideas about continuity of care, including Freeman's (2001 and 2002) and others' models. Similarly, the thematic framework for the analysis of the material was derived from existing work, although this was supplemented with

emergent themes and categories that arose during analysis and which fell outside the originally defined themes.

The themes used to categorise the qualitative material are outlined in *Table 10*, along with our judgement of their possible relationship to Freeman's (2001) model.

However, despite these links to the Freeman and other models of continuity, the researchers' overall conclusion from this element of their work was that it was impossible 'to derive specific patient-centred indicators of continuity' from service users' accounts (p.67). Neither could they 'readily map the accounts onto the elements of continuity that are part of the accepted model of continuity', with the exception of some elements of information transfer and communication (ibid).

Table 10. Themes from qualitative material in stroke study mapped onto Freeman's (2001) model of continuity of care

Themes from qualitative material	Possible dimension of continuity
Patterns of care:	
1. Experience of a co-ordinated and smooth progression of care	Experienced
2. Experience of flexibility of care and adjustment to needs of the individual	Flexible
3. Availability and accessibility of services	Flexible
4. Change in care over time	Flexible
Patterns of communication:	
1. Experience of information provision	Cross-boundary and team
2. Knowledge of information transfer	Informational
Patterns of relationships:	
1. Understanding of the roles of health care professionals	?
2. Nature of relationships	Relational or personal
3. Changing relationships over time	Longitudinal

Use of medical records

This project also assessed the feasibility of assessing experienced continuity of care for stroke patients by using clinical records. Using a method previously tried in studies of maternity care and primary care, the researchers counted the signatures of all care providers recorded in patients' hospital and community care notes during acute care, rehabilitation and after care. This approach was tested on the records of 10 of the patients who had been interviewed in the qualitative phase of the study. This work showed that the number of signatures was strongly related both to length of hospital stay and to the number of wards on which a patient had been treated. Despite this latter finding, however, the researchers concluded that a simple count of signatures showed 'no obvious

relationship with any identifiable dimension of continuity as nothing can be inferred about the nature or sequence of contacts using this approach' (Hill, 2008: 70). However, they did conclude that it was possible to map service users' care journeys and transitions using other potential indicators of continuity from their medical records.

Use of a pre-existing measure

Before moving on to developing a new measure of continuity, the stroke study also explored an existing measure of relational continuity identified during their literature review. This was the Chao Perceived Continuity Measure (Chao, 1988), designed originally for use in primary care settings. A feasibility study explored its applicability to stroke patients and its underlying constructs.

The researchers did not map the items in the Chao questionnaire to the Freeman model of continuity but we have attempted to do so in *Table 11*. This highlights some definitional and conceptual problems with the items in the questionnaire. However, the majority of the items seem to map onto relational and/or longitudinal aspects of continuity.

Table 11. Questionnaire items from Chao's perceived continuity measure mapped onto Freeman's (2001) model of continuity of care

Question	Possible dimension of continuity
If more than one family member needs medical care, we go to different doctors.	Not relevant
My doctor often mentions or refers to my past medical problems and treatments.	Relational
I receive my medical care at more than one location	Longitudinal
The doctor has a list of all the medicines which I am taking now.	Information/cross-boundary and team
I rarely see the same doctor when I go for medical care	Relational/longitudinal
My medical care improves when the doctor has seen me before.	Relational/longitudinal
I have medical problems that the doctor doesn't know about.	Information/cross-boundary and team
My doctor provides care for any type of problem which I may have.	Longitudinal
I feel that I have an on-going relationship with a doctor.	Relational
It is difficult to bring up unrelated medical problems with the doctor.	Relational/flexible
I am uncomfortable in discussing a personal problem with the doctor.	Relational/flexible

Question	Possible dimension of continuity
The doctor knows a lot about the rest of my family.	Cross-boundary?
I feel comfortable asking questions of the doctor	Relational
The doctor doesn't know about my family problems.	Relational/cross-boundary
The doctor does not explain things to me.	Cross-boundary
In an emergency, I want my regular doctor to see me	Relational
I would rather see another doctor right away, instead of waiting a day or two to see my regular doctor.	Flexible
My doctor provides appropriate referrals to other specialists.	Flexible/cross-boundary
My doctor would take care of me if I had to go to the hospital.	Meaning is ambiguous in UK context
My doctor would take care of me if I require emergency care.	Meaning is ambiguous in UK context
I trust a specialist recommended by my doctor.	Relational/cross-boundary
My doctor would know me by name if we met on the street.	Relational
I trust my doctor.	Relational

A sample of 310 patients taking part in another stroke study was used and received the questionnaire at various time points over a year. Responses to the questionnaire indicated that many respondents found the questions difficult to understand and/or respond to, and there was a relatively high level of non-completion of individual questions. Five questions had to be excluded from further analysis because they generated so few responses.

The researchers do not seem to have explored the underlying construct of the Chao measure through factor analysis, perhaps because of the high level of missing values, but did examine how scores related to individual service user characteristics. This showed no relationship with sex, age, dependence or mode of administration. Poorer scores were, however, associated with anxiety or depressive symptoms, as measured by the General Health Questionnaire (GHQ).

The overall conclusion of the researchers was that the Chao measure was not appropriate for measuring continuity of care in stroke.

Having decided that neither the qualitative work nor the exploration of other measures of continuity were helpful, the project then went on to develop two new instruments, one based on medical notes and one designed to assess patients' views and perceptions through a structured interview.

8.3.2 The Snakes and Ladders checklist

The first task was developing a checklist to evaluate care processes based on medical notes. This was given the title the Snake and Ladders (SnL) checklist. Twenty-nine rateable indicators of continuity – ranging from how patients were admitted to hospital to whether or not they had been put in contact with voluntary organisations after returning home – were assessed and scored. Higher scores indicated better care processes. The psychometric properties of the checklist were assessed and the items grouped, by a consensus process, into seven clusters ‘that corresponded to broader categories of care’ (Hill, 2008: 99). These are reproduced below (table 12).

Total scores on the SnL were tested against a number of other patient variables. There were no overall associations with sex, age, marital status, residential status, or living in an area with a community stroke team. Older patients had worse scores on the follow-up cluster and those admitted from residential care had worse scores on the admission cluster, though the researchers state that the small numbers involved make this difference difficult to interpret.

Table 12. 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
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Reproduced from Hill et al (2008)

Severity of the original stroke was the patient characteristic most strongly related to total SnL score and to scores on a number of clusters: multi-disciplinary team (MDT) care, discharge and community therapy. Continence was also related to total SnL score and to the discharge and community therapy clusters. By contrast, early discharge was negatively associated with total SnL and to the MDT care, discharge and community therapy clusters. The researchers conclude that these findings are consistent with the index measuring **intensity** of care.

The checklist and its scoring continued to develop as the project progressed, as both statistical and pragmatic factors were recognised and addressed. Thus, after the first stage of testing, some items were removed leaving only 12. These were tested statistically again, which showed that all contributed strongly to the overall measure and in the way expected. These 12 items thus became the final SnL measure:

Acute and rehabilitation hospital care:

- problem-based medical assessment
- stroke nursing assessment
- rehabilitation therapist assessment
- MDT review
- specialist stroke unit care
- rehabilitation goal setting
- discharge planning
- home visit complete (if required)
- discharge advice to GP.

Home and community care:

- aids and adaptations received
- any post-discharge therapy
- record of reassessment for targeted therapy at six months.

Scoring was simple – +1 for 'positive', -1 for 'negative' and 0 for stable/no change effect on patient's progress through care.

Further exploration of how patients' characteristics and stroke severity related to SnL scores again suggested that the measure was testing intensity of care input rather than any characteristic (such as continuity) of care processes. A lower score could not be assumed to mean lower continuity of care 'as good care does not necessarily mean more care' (Hill, 2008: 111). The researchers' overall judgement about the measure at this stage of its development was that, in effect, it was measuring 'the intensity of care proportional to the disability of the patient' (ibid: 141, original emphasis).

8.3.3 Patient Perceived Continuity Interview (PPCI)

The PPCI was developed as an interview, based on the themes and stages of care identified during the qualitative study. The interview was tested and further refined in stages before final testing.

There were 19 items in the PPCI schedule and after testing, these were grouped into five clusters. These were:

1. hospital care - perception of admission, awareness of MDT care, home visit if needed, perception of discharge process, experience of follow-up
2. GP care – GP housecalls, GP care, relationship with GP
3. community care – timely provision of aids and adaptations, community care services, relationship with community care teams, accessibility to (contact) community care teams
4. information transfer – information giving, information transfer
5. social function – patient/family rating of ability to cope, extent of social support, functionality of social support, extent of social capital, value of social capital.

As with the SnL measure, a simple scoring system of positive (+1), negative (-1) or stable/no change (0) effect on the patient's progress was used. Because the measure was interview-based, the rating scale was applied by interviewers who were trained specifically to do so.

A range of socio-demographic variables was tested for association with PPCI scores. This showed that women had poorer scores than men on the social functioning cluster, as did patients living alone. This last group also had poorer scores for GP care, information transfer and overall PPCI. Patients who had longer admissions had somewhat better overall PPCI scores and scores on the hospital and community care clusters. Stroke severity was also associated with better hospital and community care scores and with scores for information transfer and social function. Further analysis based on the impact of stroke (change scores) suggested that it was overall dependency rather than severity of the stroke *per se* that affected the score.

People who had a high GHQ score (that is, GHQ 'caseness') had poorer PPCI scores than those without mood disturbance. Finally, the researchers explored the relationships between the GHQ social dysfunction sub-scale and their own social function cluster. This showed that those with high GHQ social dysfunction had poor overall PPCI, social function, GP and community care cluster scores. The researchers suggest that 'those feeling less connected to others may require more support in order to facilitate their care and thereby enhance their perceptions of [that care]' (p.124).

The PPCI also included a short, self-report section. This included four items related to patients' perceptions of themselves (recovery, dependence on others, control, enjoyment of life) and six items related to perceptions of service (standard of care, confidence in people looking after them, service providers' knowledge about them or their condition, organisation and co-ordination of care, level of care provision as against need, satisfaction with care). All were scored on a 10-point linear rating scale.

Scores for the patient-rated items showed a 'moderate' association with overall PPCI. There were no relationships between age or gender and the self-reported ratings of services but both women and older patients reported lower ratings of self.

The overall assessment of the researchers about the PPCI was that, unlike the SnL, it was actually measuring 'patient perceived care' (p.141).

8.3.4 Further testing of the two measures of continuity of care in stroke

The SnL and the PPCI were subjected to confirmatory factor analysis, using Structural Equation Modelling, in order to uncover the latent constructs of 'patient perceived care' and 'disability'. The two continuity measures, plus four items from self-reported ratings of care (quality of care, co-ordination of care, co-ordination of information, and patient satisfaction) and four disability measures (Barthel score, Rivermead Mobility Index, Mini-Mental State Examination, and the General Health Questionnaire) were included in the testing.

Testing showed that both the SnL and the GHQ were associated with disability. The latent construct, patient perceived care, was associated with quality, co-ordination, information and the PPCI score. It was also negatively associated with the GHQ. The SnL measure was not significantly associated with the perceived care construct and the two latent constructs were not correlated with each other.

This part of the testing thus showed that 'the aspects of the health care process that [the] two new indices were measuring, and their relationship to health status and well-being, might be different and not fully understood' (p.150).

The next stage, in order to understand how continuity of care might affect outcomes, was to 'convert the latent variables into variables to replace the simple aggregated scores of [the] new instruments' (p.150). This was done mathematically, applying regression weights from the confirmatory factor analysis, rescaled to provide scores with a range from 0 to 100. Higher scores for the disability construct variable indicated poorer function while higher scores for the perceived care construct variable indicated better care. Both constructs showed an association with gender, with women having higher disability scores and lower perceived care scores. There were no or only small associations between disability and perceived care and age.

8.3.5 What is continuity of care associated with in stroke?

To explore the outcomes of continuity two variables were tested against the two construct variables. These were:

- Barthel Index 12 months after stroke⁹ turned into a binary variable indicating whether the patient was fully rehabilitated
- GHQ 12 months after stroke¹⁰ (square root transformation adjusted for skewed distribution of the original scores).

This analysis showed that the chances of successful rehabilitation increased as disability decreased and perceived care improved. However, the disability construct was three times more important in predicting rehabilitation at 12 months than was the perceived care construct, which is as might be expected.

By contrast, while both perceived care and disability were related to mood at 12 months, the perceived care construct was twice as important as the

⁹ The Barthel Index measure used in the disability construct variable was that assessed at 2 to 6 weeks after stroke.

¹⁰ The GHQ measure used in the disability construct was that assessed at 2 to 6 weeks after stroke.

disability construct in predicting high mood scores. However, as the researchers argue, it is difficult to understand what this latter finding means, as mood influences both the way in which people perceive and interpret life events and how they respond to questionnaires. The researchers acknowledge 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' (pp.161-2).

8.3.6 Discussion of the stroke measure of continuity

The work done in this project to develop and test measures of continuity of care in stroke was extensive and thorough. However, though measures were successfully developed, the subsequent usefulness of these in practice remains open to question. Both the SnL and the PPCI would be difficult to use in everyday practice and might be better seen as research instruments. Even here, however, given the doubt about the direction of the relationship between perceptions of care and mood, findings might be difficult to interpret, as the researchers themselves acknowledged.

As we saw above, Hill *et al* felt that the qualitative material, from which they derived the PPCI schedule, was not amenable to analysis using the Freeman (2001) model. However, we felt that there was some 'read over' between the final PPCI and the model and have indicated where this is so in column three of *Table 13*. Given this, the PPCI, in this form, could be seen as a measure of continuity of care as originally envisioned by Freeman and colleagues. This would be even more the case in relation to the extended (2002) model with its greater emphasis on the individual's personal and social context.

Table 13. Core items in the PPCI mapped onto Freeman's (2001) model of continuity of care

Type of continuity as defined by Hill <i>et al</i>	Core item rated by interviewer	Possible dimension of continuity
Managerial	Perception of admission	? experienced
	Perception of discharge home	Cross-boundary and team
	Timely provision of aids and adaptations to home	Cross-boundary and team
	Continuity GP care for stroke	Longitudinal/relational
	Experience of follow-up	Longitudinal
	Consistency of statutory home care services	Flexible
Informational	Perception of information giving	Informational
	Perception of information transfer [between professionals]	Informational/cross-boundary and team
Relational	Relationship with GP	Relational
	Relationship with statutory home care personnel [for those receiving home care]	Relational/longitudinal

Responsiveness of statutory home care services	Relational/longitudinal
Extent of social support	-
Functioning of social support	-
Extent of social capital [wider contacts]	-
Value of social capital	-

8.4 Cancer (King *et al*, 2006, 2008)

This study originally intended to take two approaches to measuring continuity of care: one based on patients' and close persons' views about what constituted experienced continuity of care and the other based on assessing the actual delivery of continuity in service settings. The second approach was to be used as an intervention in the second phase of the project, while the first was used in its own right to explore patients' and close persons' overall experience of continuity and its relationship to a number of socio-demographic and outcome variables. However, the phase 2 project ended up using a modified version of the experienced continuity measure developed in phase 1 as the intervention rather than the service-experience measure.

8.4.1 Views of continuity and development of the measure in phase 1

In their exploration of how perceptions of continuity of care might differ in different treatment phases for cancer, King *et al* developed a list of statements considered to be 'determinants of comprehensive, joined-up, long term care' (p.36) to include in their prospective study. The researchers developed the list by discussing the main themes identified from analysis of the qualitative material gathered in phase 1 of the study from patients, 'close persons' and professionals.

The researchers then shared the statements with the project's steering group and other clinicians and further modified them, where necessary. The statements do not appear to have been subject to any further testing before use in the study.

Table 14 shows the twenty statements used. The researchers suggest that some statements mapped onto 'the sorts of issues discussed in published models of continuity' (p.36) and these are marked with an asterisk in the table. However, the researchers do not suggest which statements map onto **which** elements of the models. Therefore, we have made our own judgement about which aspect of Freeman's 2001 model the statements relate to, if any, and list these in column two of the table.

The table suggests that issues of cross-boundary and team continuity (where this involves communication between professionals/services and the patient) and flexible continuity were important to cancer patients' sense of experienced continuity. However, some statements appeared to relate more obviously to issues of personal adaptation to illness, informal support, and standards of clinical care. We would also suggest that issues of support from 'non-medical' services and getting adequate advice about financial benefits could be seen as issues of cross-boundary and team continuity; a good quality service for people with potentially life-threatening conditions

should, surely, involve enabling contact with sources of support beyond the health service.

The interviews with close persons used the same set of statements, asking the close persons to give their views about the patient's experiences related to each statement.

A five-point, Likert-type scale was used for responses to each statement, with high scores in each case representing positive experiences.

Table 14. Statements about continuity of care in cancer mapped onto Freeman's (2001) model of continuity of care

Subject of statement about continuity of care	Possible dimension of continuity
*Received enough time and attention from cancer services	Flexible
*Seen cancer services often enough	Flexible
*Gets consistent information about illness from health care staff	Cross-boundary and team
*Need to chase up services to get things done	Flexible continuity
*Given information about treatment over following months	Cross-boundary and team
*Aware of side-effects from treatment	Cross-boundary and team
*Aware of likely overall health in following months	Cross-boundary and team
*Contact with cancer services between appointments	Flexible
Patient's ability to cope with minor complications	?
Patient's ability to cope between appointments	?
Acceptance of limitations health imposes	?
Support from non-medical services	Cross-boundary and team
Advice on financial benefits	Cross-boundary and team
Support from close persons	?
Friends and relatives help with coping	?
Emotional state of close persons	?
Level of dependence on friends or relatives	? longitudinal
*Receipt of misleading information from cancer services	Cross-boundary and team
*Full medical examination related to cancer	? flexible
*Worry that things have been overlooked	? information continuity

**Statements believed by researchers to relate to 'published' models of continuity*

The statements were included in a large battery of other questions and measures, used to interview patients and close persons every three months for up to a year.

Patients for this part of the phase 1 cancer study were recruited to represent three types of cancer – breast, lung or colorectal – and five different transitions of care – diagnosis, end of first treatment, remission, relapse, and specialist palliative care. The main rationale for the approach taken was to identify not only differences related to type of disease and transition but also changes in experienced continuity over time. There was an expectation that some patients, at least, would make the transition from one phase of care to another over the 12 months of follow-up. Further, using this design also made it possible to examine links between experiences at one time point with outcomes at the next.

8.4.2 Factor analysis of the continuity of care statements

Two of the 20 statements originally included in the questionnaire – the statements about support from non-medical services and about information about financial benefits – were excluded from analysis as many patients and close persons said that they did not apply to them.

Factor analysis of the remaining statements for patients revealed three factors: service quality, sense of control, and informal support. However, this solution proved to be unstable. As the 18 remaining items had high internal reliability, and removing single items did not improve on this, the researchers decided to retain them all and sum them to produce an overall continuity score. This overall score was then used to explore the relationships between continuity and other factors, including outcomes.

Factor analysis of the remaining statements for close persons produced a similar, but not identical, latent structure. Again, however, the researchers decided to retain all 18 statements and sum them to produce an overall continuity score.

The researchers also examined replies to other questions in their battery that they deemed relevant to existing models of continuity. These were questions about the medical team being up to date with the patient's situation and having access to the patient's most recent notes, scans, blood tests and X-rays at the most recent visit, and about the patient having a main contact person at the hospital over the previous three months.

8.4.3 What is associated with continuity of care for cancer patients?

There were no significant differences in the mean continuity scores between people with different types of cancer, at different phases of treatment, or by hospital, sex, age, ethnicity or marital status.

The only relationship tested¹¹ for close persons appears to have been that with treatment phase; while there was no statistically significant difference in close persons' mean continuity scores in different phases of the patient's treatment, there was a trend towards poorer scores in the palliative care phase.

Higher continuity scores at baseline for patients were associated with lower needs for physical support in daily living and for psychological support, with higher quality of life (Euroqol) and with lower psychological distress (GHS). These relationships remained when study design (tumour type, place of

¹¹ Or, at least, no others were reported.

treatment, treatment phase) and demographic variables (sex, ethnicity) were controlled for. Similarly, there was a strong relationship between measured continuity and satisfaction with services at baseline, which remained when confounding variables (design, sex, ethnicity, service need and quality of life) were taken into account.

Higher continuity scores at baseline for close persons were associated with their higher quality of life and lower psychological distress, after confounding factors (treatment phase, place of treatment, tumour type, sex and ethnicity) were accounted for. There was also a relationship between their assessment of continuity and their satisfaction with services scores at baseline but this was weaker than it was for patients. Adjustment for confounding factors made little difference to the strength of the relationship. Close persons with high continuity scores also tended to have higher spiritual scores, which indicated strong personal beliefs. Finally, the more closely people were involved in the patient's care, the lower was their assessment of continuity. However, after adjustment for confounding factors this relationship was no longer statistically significant.

The longitudinal design of the phase 1 cancer study allowed the researchers to explore the relationship between experienced continuity and 'outcomes' across the stages of the study.

First, they examined whether experienced continuity changed over time and found that it did not. Neither was there any relationship between continuity and a transition from one phase of treatment to another. Analysis also showed that the relationship between continuity and satisfaction with services remained constant over time, after confounding factors had been taken into account. Further analysis also showed that increases from low levels of measured continuity led to the greatest increases in satisfaction with services.

Secondly, the researchers explored whether the relationships between continuity and physical and psychological support needs, quality of life and psychological distress identified at baseline held throughout the follow-up period. This showed that, indeed, higher continuity scores were associated with lower support needs, higher quality of life and lower levels of psychological distress, regardless of when measured. Transitions between one phase of treatment and the next appeared not to affect these relationships.

Finally, the analysis tracked continuity scores at one stage to outcomes at the next. After controlling possibly confounding factors, this analysis showed that higher continuity at one point in time was related to lower needs for care or support at the next. There was no relationship with psychological distress or spiritual outcomes, but there was a (statistically non-significant) trend for higher continuity to be associated with higher, subsequent, quality of life.

8.4.4 Measuring continuity of care in cancer service settings – the intervention study

As outlined earlier, the second phase of the cancer study was designed as the feasibility stage of an intervention study to improve continuity of care in cancer services. The original intention had been to develop a measure for cancer service staff to complete. However, after initial observation in service settings and interviews with patients and staff this approach was changed and a patient-completed questionnaire was used as the intervention. This

started out as the 18-statement measure developed in phase 1, plus six questions on service continuity. These additional questions were:

1. I feel sufficiently involved in the decisions made by health care staff about my care.
2. I know I have a specific person at the hospital whom I can contact when I need to.
3. I know how to contact this person.
4. The last time I was in clinic I think the clinical staff had all my notes.
5. The last time I was in clinic I think the clinical staff has all my x-rays/scans.
6. I feel able to manage between appointments.

The questionnaire was cognitively tested with a small number of cancer patients (which suggested that it had face validity) and it was also assessed for test-retest reliability. After this, seven items were removed as their test-retest reliability was unsatisfactory.

Table 15 outlines the 17 statements used in the final version of the continuity assessment tool, along with our judgement of the elements of the Freeman 2001 model of continuity of care onto which the statements map.

Table 15. Statements about continuity of care in cancer services mapped onto Freeman's (2001) model of continuity of care

Subject of statement about continuity of care	Possible dimension of continuity
Received enough time and attention from cancer services	Flexible
Seen cancer services often enough	Flexible
Gets consistent information about illness from health care staff	Cross-boundary and team
Need to chase up services to get things done	Flexible continuity
Given information about treatment over following months	Cross-boundary and team
Support from close persons	?
Friends and relatives ability to cope with illness ¹	?
Emotional state of close persons	?
Level of dependence on friends or relatives	? longitudinal
Receipt of misleading information from cancer services	Cross-boundary and team
Full medical examination related to cancer	? flexible
Worry that things have been overlooked	? information
*Specific contact person at hospital	relational
*Knowledge of how to contact this person	relational

Subject of statement about continuity of care	Possible dimension of continuity
*Clinical staff access to all notes at last visit	Information/cross-boundary and team
*Ability to manage between appointments	?

** Items not included in the phase 1 study measure*

- 1. This is different from the statement in the phase 1 measure, which was about friends' and relatives' ability to help the patient to cope.*

The intervention element of this measure was an additional box against each statement that patients could tick if they wished to discuss the underlying issue with a relevant clinical nurse specialist. This intervention was then implemented in a feasibility study for a full, randomised controlled trial.

Further testing of the continuity assessment tool showed that it had a satisfactory level of internal consistency.

8.4.5 What was associated with continuity of care for cancer patients?

Six variables were associated with experienced continuity in this final element of the phase 2 study. Patients who had English as a second language had lower scores, as did those who had higher health system needs, higher care needs, higher psychological needs and higher physical needs.

8.4.6 Discussion of the continuity measure for cancer

In the absence of any further psychometric testing of the patients' and close persons' measures of experienced continuity, either in phase 1 or phase 2, it is difficult to conclude that the measures constitute robust instruments with which to assess continuity of care for cancer patients. The measures have some plausibility in relation to face validity, given that they were based on material from qualitative interviews with patients. The phase 2 measure was also tested satisfactorily for test-retest reliability and internal consistency. Beyond this, however, there was no formal assessment of the measures' robustness for use either as outcome indicators, or as tools for exploring the relationship between experienced continuity and outcomes.

8.5 Conclusions

This element of our review is the most descriptive and the one that has kept most close to the Freeman (2001 and 2002) models of continuity of care. This is because the development of all the measures of continuity was, in the end, influenced by these Freeman models, even if the researchers had initially intended to do something different. One of the most surprising things to emerge from our review of the measures is the extent to which researchers felt that their development work took them away from the Freeman models. By contrast, our feelings are that many of the measures clearly mapped onto the 2001 and 2002 models. We have shown this throughout the chapter.

Our first conclusion from this part of the review, then, is that there are commonalities in the measures, and that these have commonalities with the original and extended Freeman models of continuity of care. This is especially the case if one includes the wider definition of **contextual continuity**, as explored in Freeman *et al* (2002), because issues of service users', patients' and carers' personal and social context were identified in the development work on most of the measures.

Another conclusion is that different patient or service user groups do probably have different priorities in relation to aspects of continuity. For people with severe mental illness, flexibility and longitudinal continuity are the most important aspects, for those who have suffered a stroke flexibility is most prominent, and for those with cancer both flexibility and cross-boundary and team continuity are key issues. By contrast, for people with type 2 diabetes, relational continuity seemed most important. However, all types of continuity appeared in all service users' accounts, underlining the overall general applicability of Freeman's models.

Although only one measure was produced for use by professionals (diabetes study), the development work for this did suggest some difference between service users' and professionals' views of what continuity of care might be. Professionals did not include flexible continuity in their accounts, while service users did.

Overall, the simplest measure – that developed for diabetes – seems to offer the most potential for further development into a robust and evaluated tool that can be used to assess individuals' experiences of continuity in service settings. The researchers argue that this measure could be adapted for other patient groups and we believe that this might be a useful avenue for further research and development.

Although all the studies reviewed in this chapter tested the relationship between scores on their measures and 'outcomes' we do not believe that any of them actually provide robust evidence about outcomes from continuity. Rather, their analysis of these relationships was part of the testing of the measures and should be seen in this light. As a result, it is too soon to judge whether better continuity of care (however measured) leads to better health-related outcomes. There is also the larger question of whether one should **expect** continuity of care to lead to improvements in conventional measures of health or function. Another difficult issue, raised in *Chapter 4*, is whether experienced continuity of care is itself an outcome. None of the studies dealt with this issue directly, leaving another research question for the future.

Despite being too early to talk about the relationship between continuity and outcomes, there is a possibility in one study (cancer) and a hint in another (diabetes) that moving from a low level of experienced continuity to something better has more impact than does moving from a middling level of continuity to something better. Exploring whether such a law of diminishing returns does exist would be another question for future research.

9 Triangulation and conclusions

Our intention in this final chapter is to triangulate our synthesis and analysis of the findings of the programme of projects against the original scoping report (Freeman *et al*, 2001), the Reid *et al* (2002) report, and the interim programme review (Freeman *et al*, 2007). As we suggested in our proposal, we hoped that this final stage would allow us to come to some conclusions about the advances that have been made in conceptualising, measuring and understanding the precursors and outcomes of continuity of care, and for different groups.

We began the process of triangulation and comparison of findings from our review with those in the initial scoping review (Freeman *et al*, 2001), the Canadian review (Reid *et al*, 2002) and Freeman *et al*'s interim review (2007) in *Chapter 4*. There, we reported our qualitative synthesis of the conceptual underpinnings and definitions of continuity of care used in the primary and secondary projects completed in the SDO programme. We showed how the individual studies variously contributed to a 'perspectivist' model of continuity of care, but we developed a more interpretivist synthesis of the work which suggested an emergent 'partnership' model.

In this chapter we go further in the comparison, looking at our analysis of the substantive findings from the empirical work conducted in the SDO programme alongside the analyses from the earlier reviews.

9.1 *Experiences of and influences on continuity of care*

The scoping exercise proposed a multi-aspect definition of continuity of care with six dimensions. Thus, continuity was proposed as 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:

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

The interim review drew on empirical findings then available from the SDO programme projects and was informed by results in the parallel Canadian programme. Here, Freeman *et al* (2007) emphasised that continuity of care applied to individual patients (rather than groups) over time. They simplified the model by describing three major types of continuity:

- **management continuity**, involving the communication of both facts and judgments across team, institutional and professional boundaries, and between professionals and patients
- **informational continuity**, concerning timely availability of relevant information, and
- **relationship continuity**, meaning a therapeutic relationship with one or more health professionals over time.

9.1.1 The patient's experience

The findings about patients' experiences reported in Freeman *et al* (2007) are those then available, and as described by the researchers in the various projects. Freeman found that most of the types of continuity identified in his review mapped onto the original scoping study definitions. However, we discussed in *Chapter 4* how some of the research teams started their enquiries with assumptions about meaningful aspects of continuity of care, designing topic guides and exploring continuity based, to some extent, on the research team's prior understanding of the topic. Freeman acknowledges this himself in his review.

Our own analysis of the patient's experience treated outputs from the projects in their own right, without attempting to map them onto or match them with the scoping study definitions. Finding how patients themselves did not spontaneously use the term 'continuity of care' and that even concepts of 'joined up' care were sometimes hard to understand affirms what Freeman said in his review, that the patient experience of continuity does not necessarily mirror that of professionals. Our analysis showed, however, that patients in all the SDO studies readily talked about their preferences and choices for treatment and care.

We found that patients valued what they perceived as **good relationships with professionals**. This sometimes, but not always, included seeing the same person or care co-ordinator. Freeman suggested that having a continuous caring relationship grew in importance with the severity of the condition. However, our review of the quantitative approaches to measuring continuity of care (see *Chapter 8*) suggests a more complex picture than this. The two groups with the most severe **ongoing** conditions and ones where periods of remission were most likely (cancer and severe mental illness) seemed more interested in flexible continuity. Further, our exploration of the qualitative data showed that having a good relationship meant more to patients than familiarity with a known professional. Patients recognised that different professionals had different roles, in some care schedules, and they were thus likely to see a range and succession of different people. Having good relationships encompassed aspects of trust, the professional's style, their communication skills and the time they made available, and some looked for professionals with particular characteristics, rather than the familiar professional. Some patients were ready to trade-off quick access against seeing the same person.

From the patients' perspective, we found it was **understanding of their condition and treatment** they valued, and this was rather different from the concept of '**timely availability of information**' proposed in Freeman's interim review. 'Understanding' was wider than 'provision of information', incorporating patients' recognition that people had different capacity for receiving information, and that professionals' skills in communication, the time made available for discussion, and how far professionals were trusted were all influential.

We saw evidence in all studies that patients had underlying concepts of possible interactions between services or different parts of the same service, and valued co-ordination among and between the professionals who cared for them. They did not generally use the language of **management continuity**, but rather talked about aspects of communication, planning, and services' capacity to store and use existing information about them and their histories. It was sometimes important for co-ordination to spread across their carers and families, and other key actors such as voluntary organisations. This went beyond the inclusion of family and carers in the information loop, which Freeman *et al* (2007) included as an aspect of informational continuity in person, to encompass carers' involvement in planning for discharge, and in maintaining treatment.

Access to professionals and services was important to patients, and this meant more than being able to generate quick and appropriate responses when needed. For people with some long-term conditions, it also meant being able to rely on proactive monitoring and checking, and preventative support. Freeman's (2007) model discusses access as closely linked with continuity, which could be traded off against relational continuity in some circumstances. Our own analysis confirmed that patients accepted and achieved such trade-offs in some circumstances. However, our analysis also showed that some patients had a broader experience of access, as proactive and preventative, and we see this as contributing to continuity, rather than being linked with it.

Our analysis provided evidence, from all the studies, of patients' **personal agency** in co-constructing their experience of care and treatment with professionals and carers. Freeman *et al*'s (2007) interim review identified this component, and our analysis emphasised its importance.

Freeman *et al* (2007) also pointed to the acceptability of discontinuity in some circumstances, specifically in the trade-off with access. Our analysis found several other examples of circumstances and situations where service users appreciated or actively chose what professionals might describe as **discontinuities** in services and care. Included here were wanting a second opinion, welcoming new staff with greater skills, and wanting to put some distance between themselves and the overall context of disease and ill health.

A new finding from our analysis was the way in which some patients wanted to be thought of and dealt with in a wider context that acknowledged their life situation rather than constructing them as people within pathways for care and treatment for a specific medical condition.

Our own analysis also emphasised the importance to patients of participation of carers and family.

A second strand in our own analysis of patients' experience was to try to establish the main influences on such experiences. It is these dimensions which provide entry points for policy action. We found the main general groups of sources of influence on patients' experience of care and treatment, as they described these themselves, to be:

- patients' characteristics and personal circumstances
- care trajectories
- structure and administration of services
- professionals' characteristics
- participation of close persons
- the wider context of 'the whole person'

▪patients' satisfaction and judgements.

A section of the interim review suggests that experience of dimensions of continuity depends on whether care is predominantly person-focused or disease-focused. Here, Freeman *et al* (2007) address questions about what kind of person is experiencing continuity, and what is the context of care in terms of the disease and the structure of the service (roughly mirroring our first four bullet points above). We did not go down this route ourselves, feeling that it reflected a professional clinical distinction that was less appropriate for our own social science approach.

Our analysis confirmed, however, how differences in patients' characteristics and their trajectories of health, illness and care, influence experiences of continuity. The transitions of patients between care settings and services were a focus of interest in all the SDO projects, and we found many examples of care-specific transitions in which patients had both positive and negative experiences of continuity. Transition at discharge was a key point of vulnerability for some groups of patients, such as people with severe mental illness, but for other groups transfer between wards or between hospitals were potential points for negative experiences, with changes in environment, staff, and content and processes of care.

Our analysis showed that illnesses characterised by alternation of periods of 'being well' with periods of acute illness or intensive care, for example severe mental illness and some forms of cancer, were associated with challenging issues in provision of continuity. While some patients might welcome distance from services when they were well, for others less frequent contacts and withdrawal of monitoring led to feelings of isolation and being abandoned.

Differences in scope and capacity for choice and participation in care mean that some people are particularly vulnerable and need additional professional help to achieve better continuity, as was identified by Freeman. One of his main recommendations from the interim review was for future research to focus on contrasting needs of vulnerable groups, and we would endorse this view.

9.1.2 The experience of carers

Although largely invisible in the initial scoping review and not identified in the initial multi-dimensional definition of continuity of care, some exploration of carers' views and experiences was part of the aims and objectives of all the SDO empirical studies except the stoke study. Freeman *et al's* (2007) interim review of the SDO projects began to bring the experience of carers into focus, and welcomed their inclusion in the evolving concept of continuity of care.

Freeman *et al* (2007) made some preliminary general observations about the contribution of carers to continuity of care. They said they played a crucial role for patients with diabetes, cancer and mental illness, all serious conditions, and commented on their potential inclusion in **informational continuity**. In relation to carers' own needs, the interim review observed that the mental illness project was emphatic about the value of **relationship continuity** to carers. Freeman *et al* (2007) suggest that health professionals differently appreciate the carer's role; beyond this, they awaited findings from other studies.

We found limitations in the completed studies related to carers' experiences. The basis of recruitment of carers differed widely; some study components

designed to look specifically at carers were very small-scale, and where qualitative work had been conducted with carers, it was not always possible to separate findings about carers' perceptions of patients' experiences from views of their own experiences as carers.

Given these limitations, in our analysis of findings from the qualitative enquiries, we chose to concentrate on the views of carers and family members about their own experiences in the care and treatment of the service user. At the same time, we recognise that the experiences of close persons affect the person cared for in complex ways. We found the strongest evidence about carers' own preferences and needs in the cancer study and severe mental illness study, with supporting evidence in some of the other studies.

Our review showed that carers valued good relationships with professionals. Understanding of the patient's condition and treatment was especially important to carers who had key roles in helping with practical care, such as giving medication and arranging appointments. Carers sought recognition of their contribution to patient care and their particular roles. Carers of people with severe mental illness particularly wanted professional recognition of and response to their assessments of the patient being in a crisis situation. Recognition of their role, they believed, encouraged professionals to provide timely and correct information, especially important for planning hospital discharges. Some carers also wanted acknowledgment of their own needs for support, and responsive provision of help including support for their own emotional responses to diagnoses, delays in service delivery, and the impact of the particular illness of the person cared for.

Our review brought into focus the particular contribution of parents of sick children, and their agency in making trade-offs between aspects of continuity in order to achieve what they felt best for their child. We also saw how the needs of patients and carers were not always the same, and sometimes conflicted.

9.1.3 The views of professionals

In summarising professionals' views available for the interim review, Freeman *et al* (2007) found it noteworthy, but not surprising, that professional views did not always mirror those of patients or carers. They found that professionals preferred to maximise **longitudinal continuity**, and hence the opportunity for **relationship continuity** as long as this did not conflict too much with their other priorities. Our own review found that most of the evidence about professionals' views again came from qualitative work.

We found that health and social care professionals (apart from those in stroke care) tended to see continuity of professional care as a personal relationship between an individual professional and the service users. Professionals did not see a personal relationship between themselves and family or carers as crucial, although they acknowledged that carers' knowledge of and involvement in treatment could be crucial.

Freeman *et al's* (2007) conclusions claim strong support for the concept of patients as partners in their own care and for professionals to devote more effort in working with patients rather than delivering a service to them, but do not describe professionals' views about this. In our own review we found little evidence of professionals expressing interest in enabling service users' continuing personal agency.

We might expect professionals to be particularly aware of issues to do with management and information sharing. Freeman comments on the 'natural' awareness of professionals of **management continuity**, and drew attention to problems reported to be due to staff shortages. Our review confirmed professionals' views that staffing levels and team composition could make the difference between services with and without gaps. This was true regardless of wider policy issues and drivers, although these were also believed to be important influences on the chance of delivering continuity of care. However, our analysis also highlighted the crucial issues of leadership and culture in service settings and how these, too, could impede professionals' ability to work in ways that enhanced continuity for service users. Working together effectively involved mutual trust and understanding, and could be enhanced by strong leadership and supportive management.

We found information sharing to be a key focus in many professionals' reported accounts of continuity. Good communication, good quality record keeping and formal systems for information transfer were all important, but there was also a place for informal information sharing. Freeman had also commented on the potential usefulness of '**tacit information**' about patients' preferences and circumstances to be passed between professionals – by definition, information not found in shared computerised records. We found that professionals valued co-location and proximity in services. It was less clear that these had a demonstrable impact on continuity for service users, and professionals believed that processes and structures could be put in place to cross geographical or service setting boundaries.

9.2 Outcomes of continuity of care

Our analysis of the SDO programme revealed little robust evidence about what the outcomes of continuity of care might be. The qualitative material related to service users did not seem to explore this in much detail, and there was nothing on outcomes for carers. By contrast, the projects that aimed to develop measures of continuity of care did explore what they called 'outcomes', but as we argue in *Chapter 8*, none of the studies was set up as an outcome study. Rather, as part of the testing of the new measures, researchers explored relationships between continuity and other factors. Even in studies with a longitudinal element, it was difficult to argue for cause and effect between change in measured continuity and possible 'outcomes'. Further, as we have argued elsewhere (Parker *et al*, 2009) assuming that continuity will or should have an impact on conventional outcomes such as functional status or health-related quality of life, runs the risk of ignoring much more important (from the service users' perspective) outcomes that **could** come from experiencing continuity. Freeman *et al*'s (2007) flagging of personal agency, underlined by our analysis, and our flagging of partnership and context, point to the need for more sophisticated understanding of what service users living with long-term conditions want from their interactions with health care services.

9.3 Limitations of this review

Freeman *et al* (2007) argue that the main limitations of the interim review were the unfinished status of some projects in the SDO continuity of care programme, the absence of trials of interventions to improve continuity, and the lack of studies that addressed cost effectiveness. Of course, we

carried out our review when all the projects were finished so have been able to present a finished account of the programme. However, the lack of interventions to improve continuity (with the exception of cancer study 2 which was a feasibility study intended to inform a trial) and the lack of information on costs remain.

However, these remaining limitations seem to us to be understandable in terms of the programme's intended contribution to building knowledge about continuity of care.

First, given the undeveloped understanding at the start of the programme about what continuity of care might be from a patient or service user perspective, it is difficult to know how intervention studies could have been planned at the outset. The second cancer study – the only 'intervention' study in the programme – could take place only once other work had elucidated cancer patients' views and experiences of continuity.

Secondly, without tested and agreed ways of assessing the experience of continuity, how could researchers assess the impact of interventions? Again, the second cancer study provides an example, because it could not proceed before it had a measure. Even there, there is some suggestion that the measure would require further testing and development. As the stroke study showed, adequate psychometric development of measures is a long and painstaking process.

Thirdly, without robust research to assess effectiveness, cost-effectiveness studies are impossible.

We would add a limitation, however. This is the missed opportunity for the programme's projects to explore (or, if explored, to report) in depth what patients or service users **wanted** as outcomes from experienced continuity of care. We suspect from other work on continuity of care (Parker *et al*, 2009) that, for people with long-term conditions that are not going to resolve, issues of health or functional outcomes may become less important as time passes and issues of empowerment, a sense of self, and 'ownership' of the health care process may become more important. The conceptual development of a model of continuity of care, to which the SDO programme has contributed in large part, is the start of understanding this.

9.4 Implications for policy and practice

The interim review (Freeman *et al* 2007) discussed a number of implications for policy and practice. These were largely related to the model of continuity and included references to the electronic patient record, the current emphasis in policy on patient-focussed care and choice, practice-based commissioning, the continuing problems with transfers of patients within and between different parts of the health and social care system, and the unanticipated consequences of frequent organisational change. We have not repeated these here.

However, policy development since the interim review may itself have opened up scope for further research. For example, will people involved in the integrated care pilots or those who received personal health budgets experience greater continuity of care?

We would also add here the substantial issue of the change of culture that is necessary, in health care systems, and among professionals and service users if experienced continuity of care is to become the norm.

Understanding that professionals need to see service users as partners if

they are to experience continuity of care has implications for professional training, for how professionals see themselves, and for how they see service users. It also has implications for how service users see **themselves** and **their** role in the health care system.

The notion that health is co-produced is not a new one; that continuity is co-constructed may be. Further, there are close links between these factors. For example, patients or service users who do not feel that the professionals working with them understand them and that, as a result, they (the service users) do not understand their condition or their health care, are unlikely to benefit from that care in the way they might. Ensuring that service users experience continuity in the ways that they would prefer is not, therefore, an optional extra but should be seen as a core component in delivering health care effectively and efficiently.

Seeing continuity as co-constructed also helps to understand that there is not, and never could be, a single way of delivering it. The components of the model originally developed by Freeman and colleagues in 2001 and subsequently seem to remain valid as a framework for **understanding** continuity. Further, there is evidence for the importance of each component from the findings of the projects in the SDO programme. However, it is also clear that different service users – differentiated by their health condition, whether their condition is deteriorating and at what speed, their age, their household or family circumstances, their ethnicity, and so on – will give different weights to the components, and that these will probably vary over time.

Thinking about co-construction of continuity enables us to see that it is the conversations that take place between professionals and the service user about what the service user needs, and can have, within the constraints of what is actually achievable, that will deliver a sense of experienced continuity. If professionals have an understanding of the components that play a part in experiencing continuity, then these conversations should be meaningful and ultimately fruitful.

9.5 Implications for research

We have referred throughout this report to questions that we feel warrant further research. Summarised these are:

- research to address carers' views and experiences of continuity of care, both for themselves and for those they support (chapter 6)
- research on if and how health care professionals see themselves and service users/patients and carers in partnership and what would facilitate this (chapter 7)
- research on if and how service users/patients and carers see themselves as being in partnership and what would facilitate this (chapter 5 and 6)
- research to explore how leadership and culture can encourage continuity of care, even if geographical or organisational structures militate against it (chapter 7)
- research to explore how systems in place to maintain contact with service users for some conditions (for example, diabetes) might help to facilitate continuity in others (for example, severe mental illness) (chapters 5 and 7)

- research to understand what causes virtual boundaries to effective communication in health care settings and what can be done to remove them (chapter 7)
- exploration of whether the measure of continuity of care for diabetes patients can be extended to other groups of people with long-term conditions (chapter 8)
- research to explore whether there is a 'law of diminishing returns' if experienced continuity is improved (chapter 8).

Implicit in all these areas of potential research is the need to pay particular attention to the experiences of people who are vulnerable and/or most likely to experience poorer continuity of care. This would include those who experience rapidly deteriorating conditions or those whose condition fluctuates considerably, where ensuring continuity of care will be a race against time and change.

In addition to these specific questions, there is the issue of whether the rich qualitative data generated by the individual projects should be brought together and re-analysed. This re-analysis could address some of the conceptual issues raised throughout our review, both about different views and experiences of continuity and about whether continuity is an outcome or a process. We are not sure that this is something that NIHR SDO would necessarily want to commission, but making the data available to other researchers, via the national data archive, could open up other sources of funding.

References: studies included in the review

Studies included in the review and their abbreviated references as used in the body of this report

The main studies

Baker 2006 – the primary care study

Baker R, Freeman G, Boulton M, Windridge K, Tarrant C, Low J *et al.* 2001. *Continuity of care: patients' and carers' views and choices in their use of primary care services*. London: National Co-ordinating Centre for Service Delivery and Organisation.

Burns 2007 – the severe mental illness study

Burns T, Catty J, Clement S, Harvey K, Rees Jones I, McLaren, S *et al.* 2007. *Experiences of continuity of care and health and social outcomes: the ECHO study*. London: National Co-ordinating Centre for Service Delivery and Organisation.

Gulliford 2006 – the diabetes study

Gulliford M, Naithani S, Morgan M. 2006. *Continuity of care in type 2 diabetes: patients', professionals' and carers' experiences and health outcomes*. London: National Co-ordinating Centre for Service Delivery and Organisation.

Hardy 2005 – the stroke and learning disability (LD) study

Hardy B, Hudson B, Keen J, Young R, Robinson M. 2005. *Partnership and complexity in continuity of care a study of vertical and horizontal integration across organisational and professional boundaries*. London: National Co-ordinating Centre for Service Delivery and Organisation.

Hill 2008 – the stroke study

Hill K M, House A O, Hewison J. 2008. *Continuity of care in stroke and its relation to outcomes*. London: National Co-ordinating Centre for Service Delivery and Organisation.

King 2006 –cancer study 1

King M, Jones L, Nazareth I. 2006. *Concern and continuity in the care of cancer patients and their carers: a multi-method approach to enlightened management*. London: National Co-ordinating Centre for Service Delivery and Organisation.

King 2008 –cancer study 2

King M, Jones L, Rogers M, McCarthy O, Williams R, Nazareth I *et al.* 2008. *Continuity of care in patients with cancer: development of an intervention*. London: National Co-ordinating Centre for Service Delivery and Organisation.

The scoping studies

Forbes 2001 - the transition study

Forbes A, While A, Ullman R, Lewis S, Mathes L, Griffiths, P. 2001. *A multi-method review to identify components of practice which may promote continuity in the transition from child to adult care for young people with chronic illness or disability*. London: National Co-ordinating Centre for Service Delivery and Organisation.

Freeman 2002 – the severe mental illness scoping study

Freeman G, Weaver T, Low J, de Jonge E, Crawford M. 2002. *Promoting continuity of care for people with severe mental illness whose needs span primary, secondary and social care: a multi-method investigation of relevant mechanisms and contexts*. London: National Coordinating Centre for Service Delivery and Organisation.

Humphrey 2002 - the human resources study

Humphrey C, Ehrich K, Kelly, B. 2002. *Policies affecting human resource management in the NHS and their implications for continuity of care*. London: National Co-ordinating Centre for Service Delivery and Organisation.

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Appendix 1

Table A.1 Stated aims and objectives of studies reviewed

Study	Health focus	Aims and objectives
MAIN EMPIRICAL STUDIES		
Baker, 2006	Primary care	<p>Aim</p> <ol style="list-style-type: none"> 1. To determine views of patients and carers about importance of various types of continuity compared with other aspects of care. <p>Objectives</p> <ol style="list-style-type: none"> 1. To describe views of patients and carers about meaning, value and importance of various types of CoC. 2. To identify context and circumstances in which various types of CoC are given greater or lesser weight in relation to other valued aspects of primary care (e.g. access) (p.16).
Hill, 2008	Stroke	<p>Purpose/aims:</p> <ol style="list-style-type: none"> 1. To study experience of stroke care from patient's perspective, and develop a description of patients' views and understanding of continuity in 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, reflecting where possible the patient view of CoC. 3. To apply quantitative assessments of CoC in a cohort of stroke patients, and to examine impact of CoC on functional and psycho-social outcomes for survivors. 4. To seek professional views on aspects of service organisation relevant in determining CoC.

Study	Health focus	Aims and objectives
Burns, 2007	Psychotic and non-psychotic severe mental illness	<p>Purposes/aims</p> <ol style="list-style-type: none"> 1. Examine how service users with severe mental illness and their carers conceive of continuity of care by exploring their understanding and evaluation of continuity (and comparing this to existing definitions) and to develop an instrument on basis of this to measure users' and carers' experiences of continuity. 2. Assess relationships between CoC and process variables for service users and their health and social outcomes. 3. Assess relationships between CoC for carers and psychological distress. 4. Describe organisational structures, cultures and processes that promote or inhibit CoC. 5. Assess congruence between users' and carers' views of CoC and managerial and professional views. (p.16).
Hardy, 2005	Stroke and learning disabilities	<p>Purposes/aims</p> <ol style="list-style-type: none"> 1. To explore the ways in which new Government policies on partnership working were affecting the CoC delivered on the ground. 2. To explore how CoC was affected by 'the complexity of inter- organisational arrangements and the complexity of inter-professional working. 3. To explore the relationship between inter-organisational and inter-professional complexity. 4. To explore the perceptions and experiences of care as viewed by service users and their families and carers, and as viewed by service providers and local managers (p.9).
King, 2006, 2008 Phase 1 study	Cancer	<p>Aims</p> <ol style="list-style-type: none"> 1. Describe the physical, emotional, social and spiritual status of patients and close persons as treatment evolves from diagnosis to palliation of cancer. 2. Examine professionals' perceptions of the structures and processes that enhance continuity of care. 3. Identify transitions in care that for patients and close persons are associated with a sense of abandonment by services and low satisfaction (p.9).

Study	Health focus	Aims and objectives
		<p>Objectives</p> <ol style="list-style-type: none"> 1. Develop a fine grained understanding of patients', close persons' and professionals' views of and ideas about continuity of care in cancer. 2. Translate key elements of continuity into a quantitative research tool. 3. Identify associations between continuity of care and satisfaction and to understand the effects of psychological status, expressed needs for care, spiritual belief, quality of life and coping strategies on these associations. 4. Model change in continuity and satisfaction over time and across transitions in cancer care. 5. Determine whether such transitions in care predict change in perceived continuity after adjustment for potential confounders (pp. 5, 9).
<p>King, 2006, 2008</p> <p>Phase 2 study</p>		<p>Aims</p> <p>Part 1</p> <ol style="list-style-type: none"> 1. To devise and develop a complex intervention. 2. To assess how, when and where two aspects of the intervention – assessment of patients views of CoC and action by staff to address any gaps – might be assessed and delivered (p.24). <p>Part 2</p> <ol style="list-style-type: none"> 1. To carry out an exploratory randomised controlled trial to test the feasibility of evaluating the intervention (plus usual care) compared to usual care alone (pp. 8, 22). <p>Objectives of feasibility trial</p> <ol style="list-style-type: none"> 1. Assess the feasibility of delivering the continuity intervention. 2. Monitor the consistency of its functional implementation. 3. Choose and measure outcomes. 4. Examine recruitment rates. 5. Assess the feasibility of cluster randomisation of teams. 6. Demonstrate acceptable follow-up rates. 7. Obtain further views from professionals and patients on the acceptability/practicality of delivering/receiving the intervention (p.22).

Study	Health focus	Aims and objectives
Gulliford, 2006	Diabetes	Purpose/aims 1. To evaluate and measure patients', carers' and providers' experiences of CoC in type 2 diabetes. 2. To determine whether CoC is associated with clinical and patient outcomes (p.40).
REVIEW AND SCOPING STUDIES		
Forbes, 2001	Transition from child to adult health services	Aims 1. To identify practices which address continuity during transition from child to adult care. 2. To assess merits of those practices thereby determining good practice.
Humphrey, 2002	Human resources management	Aims 1. To explore implications for CoC of generic policy initiatives affecting management and human resources (HR) in NHS. 2. In 4 exemplar areas of care, to look for good practice to address barriers to continuity.
Freeman, 2002	Severe mental illness	Aims 1. To find and understand mechanisms that enhance CoC for people with severe mental illness. 2. To comment on the contexts where these mechanisms operate.

Table A.2 Focus and setting of studies reviewed

Study	Health focus	Settings for sample selection/service studied	Nature of setting
MAIN EMPIRICAL STUDIES			
Baker, 2006	Primary care	Setting 1 16 practices in 6 PCTs 6 of these practices for conjoint analysis	County with rural towns and large city. Mixed ethnically and in terms of deprivation and affluence.
		Setting 2 12 practices in area with changing PCT boundaries 3 of these practices for conjoint analysis	London borough, mixed ethnically and in terms of deprivation and affluence.
Hill, 2008	Stroke	Studies 1 and 2 – not based on service setting	
		Studies 3 and 4 – not based in a service setting	
		Study 5 – 2 acute trusts, 8 PCTs in one UK area	Not reported
Burns, 2007	Psychotic and non-psychotic severe mental illness	Focus groups and pilot study for questionnaire – drop in centres and user groups	South London
		Expert panels and consultation exercise – not clear	
		Main phase questionnaire study – 2 NHS mental health trusts (7 of their CMHTs)	Inner-city London Outer, suburban London
		Organisational strand – same 2 NHS mental health trusts (19 of their CMHTs and associated acute units) and their associated social services organisations, GP practices, and 2 voluntary sector organisations	As above

Study	Health focus	Settings for sample selection/service studied	Nature of setting
Hardy, 2005	Stroke and learning disabilities	<p>A unitary local authority with single PCT in 2002, but relating as 1 of 6 PCTs to a new, county-wide NHS Trust.</p> <p>A unitary local authority coterminous with a single PCT in 2002.</p> <p>A county with 11 districts and a city council, 4 acute trusts and 8 PCTs working wholly or partly within the county council borders. Most but not all PCTs coterminous with districts. One locality chosen to maximise complexity of boundaries and service delivery.</p>	<p>North East of England</p> <p>North East of England</p> <p>North-West of England.</p>
King, 2006, 2008 Phase 1 study	Cancer	Part 1 - 3 cancer networks	London
		Part 2 – secondary care cancer centres and units across 3 cancer networks	London
King, 2006, 2008 Phase 2 study		Part 1 – MDTs in 4 NHS Trusts, 2 ‘clinics’ and two hospices. Two sites, not specified, seemed to take part in later stage of this part of the study.	London
		Part 2 – 1 clinical network	London
Gulliford, 2006	Diabetes	Part 1 – 14 general practices	Two inner London boroughs
		Parts 2, 3 and 4 – 19/52 general practices	As above
		Part 5 – as for part 4 plus an additional hospital clinic	As above
		Part 6 – primary care and hospital-based diabetes services	??
		Part 7 – hospitals and general practices	??

Study	Health focus	Settings for sample selection/service studied	Nature of setting
REVIEW AND SCOPING STUDIES			
Forbes, 2001	Transition from child to adult health services	Children's services in 2 geographical areas	Not known
Humphrey, 2002	Human resources management	Expert seminars – not clear	Not clear
Freeman, 2002	Severe mental illness	Field studies - 4 sites of presumed good practice, selected from Beacon sites (3) or NSF (1).	Two outside and 2 within London
		Restricted Delphi exercise – not clear	Not clear

Table A.3 Study design, methods and sample size

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
MAIN EMPIRICAL STUDIES					
Baker, 2006	Primary care	Multi-method descriptive study	Part 1 Qualitative interviews with patients and carers using topic guide in one location and using 'actor network approach' in the other	What are patients' and carer's preferences and priorities about primary care services? What is their recent use of services?	56 and 23. Not clear how many were carers and whether purposively selected as such
			Part 2 Longitudinal study of use of primary care services by selected sub-group, largely qualitative.	What is patients' use of primary care services in relation to their views on CoC?	36 A sub group of 30 patients from part 1 plus 6 further recruits
			Part 3 Conjoint analysis using stated preference discrete choice experiments with people registered in practices via postal, self-completion questionnaire. Face-to-face administration in two PCTs by researchers with South Asian language skills.	What is relative importance of different attributes of primary care to patients, under different hypothetical consulting conditions?	666 from sample of 160 patients in each of 9 practices 20 face-to-face, rest postal

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
			Part 4 Cross-sectional postal questionnaire survey of patients in 13 setting 1 practices and 9 setting 2 practices, plus walk-in centre in large town in setting 1.	In what circumstances are types of CoC given weight, in relation to other aspects of primary care? How does this influence use of primary care services? What proportion of people in different groups hold particular views about importance of CoC?	1437 from age stratified sample of 3091
Hill, 2008	Stroke	Multi-method exploratory study with design and testing of instruments to measure continuity	Part 1 a. Exploratory interviews with stroke care professionals. b. Qualitative interviews with patients from local stroke database c. Focus groups with patients and carers, three from Stroke Association support group, one from patients from separate Stroke Association study	a. To gain understanding of organisation of local stroke services b. How do stroke patients understand and experience different types of continuity in their care? c. As above	a. 19 b. 22 patients, two carers from sample of 114 c. Recordings failed and data not included in formal analysis

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
			Part 2 Case note review for evidence of CoC. Method previously used in studies of CoC in maternity services and in primary care.	To identify type and timing of care, with a focus on continuity.	10 patients from those studied in Study 1, selected purposively for sex, age, severity and functional impairment.
			Part 3 Piloting of continuity questionnaire (Chao) identified from literature search. Face-to-face as part of routine assessment in separate Stroke Association study or by postal questionnaire for patients who had completed the separate study.	To determine feasibility of using well-established measure of continuity in new patient group. To examine associations with scores on the Chao Questionnaire, as a means of exploring the construct related to those scores	108/ 110 patients interviewed face-to-face 68/200 patients surveyed by post
			Part 4 a. Development, testing and use of continuity measure to be used to review case notes (Snakes and Ladders Checklist – SnL). b. Development, testing and use of structured interview	a. Use material from part 2 about key stages in care process to develop method for assessing the extent to which aspects of process had contributed to care of the patient. b. Use material from part 1 to develop structured	a. 126 set of case notes from 157 patients in Stroke Association study were available for review using SnL. b. 32 patients from separate Stroke Association study

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
			schedule to assess patients' views and perceptions of CoC (Patient Perceived Continuity Interview – PPCI).	interview schedule to assess patients' views and perceptions about CoC.	used to pilot version of PPCI 113/157 final version PPCI interviews carried out.
			Part 5 a. Focus groups with stroke professionals to explore inter-professional communication. b. Semi-structured, qualitative interviews with stroke professionals to explore inter-professional communication.	a. Explore aspects of inter-professional communication and communication with patients. b. As above.	a. Four groups, mainly hospital-based health professionals, 6-7 in each. b. 17 - mainly community-based health professionals and some other NHS staff.
Burns, 2007	Psychotic and non-psychotic severe mental illness	Multi-method exploratory study with design and testing of instruments to measure continuity	Phase 1 a. Focus groups with service users with psychotic conditions and with carers to explore perceptions of CoC. b. Expert panels with service users with psychotic conditions and carers.	a. Identify elements of CoC that are important to service users and carers thus generating items for instrument. b. Comment on items generated from focus groups and structure of items.	a. 26 service users in 4 groups that met twice. 11 carers recruited from carers groups and CMHTs. b. 12 service users, 8 from earlier group, 4 from other, unspecified groups of service users participated in two panels. For carers panel, 6 from focus group were in first panel, 4 from carers group or already involved in

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
					research in second panel.
			<p>c. Consultation exercise with experts in CoC, via questionnaire.</p> <p>d. Development, piloting and testing of test re-test reliability and acceptability of continuity measure for patients and for carer. Half piloting done face-to-face, half by post. Test-retesting done at this stage at interval of two weeks for service users and one week for carers.</p>	<p>c. As above.</p> <p>d. To produce 2 psychometrically sound and consumer-generated measures of continuity: CONTINU-UM and CONTINUES, measuring continuity of care from the user and carer perspectives respectively.</p>	<p>c. 'Small number' of service users and non-users.</p> <p>d. Pilot: 37 service user volunteers from 1 day centre and 2 user groups. 30 carers recruited via carers groups and their newsletters. Test re-test and acceptability testing: 55 'independent' service users and 18 carers.</p>
			<p>Main phase</p> <p>a. Structured interviews with service users with psychotic conditions and their identified carers. Used instruments developed in phase 1 plus a battery of other tests and collection of demographic and service use data. Interviews at baseline (T1) and annually for two years (T2 and T3).</p> <p>b. Structured interviews with service users with non-psychotic conditions and their identified carers.</p>	<p>a. and b. To test the psychometric properties of CONTINU-UM and CONTINUES.</p> <p>Using the instrument as a global proxy measure of experienced continuity (outcome), explore its relationship to different types of continuity of care.</p> <p>Explore relationship between range of variables and CoC, both at any given time and</p>	<p>a. 180 service users at T1, 165 at T2, and 141 at T3, out of 498 identified as eligible. 68 carers in total, of whom only 20 completed the questionnaire at all three time points.</p> <p>b. 98 service users at T1 and 85 at T2, out of 203 identified as eligible. 39 carers in total, of whom 17 completed</p>

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
			Used instruments developed in phase 1 plus a battery of other tests and collection of demographic and service use data. Interviews at baseline (T1) and one year later (T2).	across time. For carers, relate their experience of CoC to that of the service user.	questionnaire at both time points.
			c. Care co-ordinators for patients completed Camberwell Assessment of Need (CAN) measure and Scale to Assess Therapeutic Relationships (STAR). Face-to-face or by telephone.	c. Explore congruence of service users and professionals views about care.	c. Identified by service user at each time point so could differ between time points. Not clear how many were actually involved.
			Qualitative strand Qualitative interviews with service users with psychotic and non-psychotic conditions and their identified carers from main phase study.	Explore experiences and view of CoC where this has been particularly complex or problematic.	20 service users and 10 carers from people with psychotic conditions. 11 service users and 4 carers from people with non-psychotic conditions.
			Organisational strand a. Semi-structured interviews with strategic and operational health and social care professionals in CMHTs and acute wards, local GPs and voluntary organisation	a. and b. To evaluate organisational cultures, structures, processes and resources which could influence CoC for people with severe mental illness.	a. 113 staff in 8 CMHTs (4 per trust).

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
			representatives.		
			b. Postal questionnaire survey of professional strategic and operational staff responsible for delivery of CoC in CMHTs or associated acute units.	To identify organisational factors which could inhibit or facilitate the delivery of services or uptake of changing practices to promote CoC.	b. 192/276 identified staff.
Hardy, 2005	Stroke and learning disabilities	Case study of hospital discharge for stroke and transition to adulthood for learning disabilities	Literature reviews	Begin the process of identifying judgement criteria for continuity and discontinuity of care, distinguishing between what might be seen as appropriate and inappropriate continuities and discontinuities and establishing the location of key 'hinge points' in services, and hence key inter-professional and inter-organisational boundaries.	
			Consensus development process Meetings with groups of experts rather than formal consensus development work	To create 'initial, normative descriptions' of hospital discharge and transition to adulthood that could be investigated	Not reported

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
				in the main fieldwork.	
			Main fieldwork a. In-depth, semi-structured, face-to-face interviews with professionals, service users and family members. There were 2 rounds of interviews for professionals. Stroke service users and family members interviewed between 2 and 8 (average 5) times between admission to hospital and discharge. LD parents/carers interviewed twice.	a. To test out the 'normative descriptions' derived from the literature and consensus development process in each of the case study sites.	a. Stroke study: 52 managers and professionals from 3 sites in first round. 6 from only 2 sites in second. Not clear how identified or selected. 18 patients and family members – 5 from one site, 6 from second and 7 from third. Not clear if this is 18 patients and their family members or 18 patients or their family members. One patient died and one withdrew from study. LD study: 36 managers and professionals from across the 3 sites in first round. 14 people (not clear how many were the young people themselves or how many their parents/carers) in first round. In second round, 18 people interviewed in total but not clear how many were managers or professionals and how many parents. There is no reference to young people themselves in the second round.

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
			b. Observation of strategic planning and operational level service meetings and attendance at service planning groups. c. Obtained local management reports and other documentation. d. Examined patients'/service users' case notes.	b. Not stated c. Not stated d. To add detail to interview discussions.	b. No details given c. N/A d. No details given
King, 2006, 2008 Phase 1 study	Cancer	Pre-clinical phase of development of a complex intervention	Part 1 Qualitative interviews with patients, their 'close persons' and professionals.	To explore patients', close persons' and professionals' perceived continuity and satisfaction with care as patients move through different phases of cancer care. These were diagnosis, end of first treatment phase, remission, relapse and referral to palliative care. To use material to develop a questionnaire for part 2.	28 patients with breast (12), lung (7) and colorectal cancer (9) at 5 transitions/phases in cancer care. 18 close persons nominated by patients. 13 GPs and 10 secondary care professionals.
			Part 2 a. Repeated questionnaire survey of patients and close persons, every 3 months for up to a year.	a. To explore patients' and close persons' experiences of care and perceptions of CoC over time.	a. 199 patients with breast, lung and colorectal cancer. 145 close persons at T1. By T5, 111 patients and 69 close persons.

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
			b. Qualitative interviews with patients and close persons at three points over one year.	b. To understand in more detail how perception of CoC changed with treatment phase.	b. 8 patients at baseline, only 3 followed up once or more. 2 close persons at baseline only.
King, 2006, 2008 Phase 2 study		Development and exploratory RCT of a complex intervention	Part 1 a. Development and revision of an assessment tool, informed by observation at MDT meetings, interview with patients and staff, a meeting with clinical nurse specialists (CNS). b. Initial testing of the tool and review of action taken by CNS using it. c. Further revision and validation of the patient questionnaire developed in the earlier study – named Patient Experience of Care questionnaire (PEC).	a, b, and c. To use material from earlier study to inform the structure and content of an intervention to improve CoC. To develop the intervention further through an iterative process in consultation with patients and professionals	a. 8 MDT meetings in trusts and hospice observed. 38 patients interviewed. 12 clinical staff interviewed. c. 32 patients, 10 of whom had identified issues with CoC they wanted to discuss with CNS.

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
			<p>Part 2</p> <p>a. Random assignment to three arms: Arm 1 - usual care (control)</p> <p>Arm 2 - baseline assessment of CoC using PEC (component one of intervention) plus usual care</p> <p>Arm 3 - baseline assessment of CoC using PEC, plus component two of intervention (feedback to clinicians of PEC results).</p> <p>b. All arms - baseline assessment of socio-demographics, diagnosis and recruitment centre.</p> <p>c. Arms 2 and 3 - assessment of CoC, supportive care needs survey, and visual analogue satisfaction scales at baseline and six weeks.</p> <p>d. All arms - process data taken from hospital computer systems and notes on clinic activity, attendance and referrals.</p>	<p>To test the feasibility of evaluating the intervention (in addition to usual care) against usual care alone.</p>	<p>93 patients with breast, lung or colorectal cancer randomised: 29 to control arm; 32 to arm 2; 32 to arm 3.</p> <p>61 provided data, with attrition greatest in arms 2 and 3, mainly due to non-response.</p> <p>Process data were not properly recorded in computerised and manual records so were excluded from the analysis.</p>

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
			<p>e. Arm 1 – assessment of CoC at 6 weeks only as outcome measure.</p> <p>f. Arm 3 - clinicians recorded nature and time of their action and completed Clinical Feedback Form (CFF).</p>		
Gulliford, 2006	Diabetes	Multi-method exploratory study with design and testing of instruments to measure continuity	<p>Part 1</p> <p>In-depth, qualitative interviews with patients</p>	To understand patients' value and experiences of continuity in diabetes care.	25 type 2 diabetes, primary care patients
			<p>Part 2</p> <p>a. Development and cognitive testing of measure of CoC (the EEC-DM)</p> <p>b. Face-to-face piloting of measure of CoC</p> <p>c. Interview-based, cross-sectional survey using CoC measure to assess its psychometric properties</p>	Using findings from part 1, develop a reliable and valid measure of type 2 diabetes patients' experience of CoC.	<p>a. 'Small samples' of patients attending hospital diabetic clinics</p> <p>b. 40 primary care patients 209 from eligible population of 553. Data for 193 who had complete data for EEC-DM were included.</p> <p>c. 56/60 of a convenience sample participating in part 3.</p>

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
			d. Testing of final, self-completion version		
			Part 3 Retrospective and prospective cohort study via home visits at baseline and 10 months later. Data collected included clinical measurements, the EEC-DM and socio-demographic, service use, and medication data. Also abstracted information from case notes.	To evaluate changes in patients' experiences of CoC over time To examine whether changes are associated with clinical patient health outcomes.	209 from eligible population of 553 (the same group as used for testing of measure). 193 had complete data for EEC-DM at baseline and 156 at follow-up.
			Part 4 In-depth, qualitative interviews with carers.	To understand carers' values and experiences of CoC.	7 carers identified from part 3.
			Part 5 In-depth, qualitative interviews with patients from South Asian communities.	To understand the values and experiences of CoC of patients from South Asian communities.	12 patients identified from part 3 and from diabetic clinic.

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
			Part 6 Semi-structured interviews with professionals.	To explore professionals' views and experiences of continuity in the delivery of care for patients with type 2 diabetes.	25 professionals from primary and hospital-based diabetes services.
			Part 7 a. Development of a questionnaire for professionals. b. Postal survey to test psychometric properties of the questionnaire for professionals. c. Repeated postal survey to assess test-retest reliability.	Use findings from part 6 to develop a reliable and valid measure of professional experiences of continuity in the delivery of care.	a. Not stated b. 177/391 eligible professionals c. 63 professionals who had previously completed questionnaire
REVIEW AND SCOPING STUDIES					
Forbes, 2001	Transition from child to adult health services	Multi-method scoping study	Part 1 a. Systematic review b. Systematic review	a. To review effectiveness of transition and identify good practice. b. To review transition in 5 tracer conditions - diabetes mellitus, learning disability, cystic fibrosis, congenital heart disease and muscular dystrophy.	N/A

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
			Part 2 a. Telephone interviews with 21 key informants b. Postal survey of staff working with children and young people	To review established research and practice networks to identify practices, documents or reports focusing on continuity in transition.	a. 21 informants b. 111/244 sample of named health, social services or education staff working with children and young people with chronic illnesses and/or disabilities across two geographical areas
Humphrey, 2002	Human resources management	Multi-method scoping study	a. Identification and analysis of DH/NHS policy documents related to human resources, likely to have impact on CoC, not superseded, and with some likelihood of implementation. b. Expert seminars	a. To inform expert seminars under six thematic headings: reconfiguration of services; information and information technology (IT); flexible workforce; quality, safety and standards; better working lives; patient-centred care. b. To explore implications of implementing policies in relation to exemplars of maternity care, primary care, mental health care and cancer care.	a. N/A b. 23 people across four expert seminars – one seminar in each exemplar.

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
Freeman, 2002	Severe mental illness	Multi-method scoping study	Literature review	<p>How has CoC for people with severe mental illness been defined?</p> <p>How do service users and their carers perceive CoC?</p> <p>What are the obstacles and barriers to providing CoC to people with severe mental illness?</p> <p>How can these obstacles be overcome?</p> <p>What are the effects of providing improved CoC?</p>	N/A
			Case study Site visits, telephone calls, email, analysis of internal documentation, published work, focus groups, observation of team work in practice, and interviews off site.	<p>To study 4 areas considered to be providing exemplary services.</p> <p>To report the rationale of these innovative services as understood by those working there.</p> <p>To sample some day-to-day working to assess how much observed process reflected the aspirations of the service.</p>	<p>4 sites.</p> <p>Not stated how many people were interviewed or took part in focus groups etc.</p>

Study	Health focus	Design	Methods	Research question or objective	Achieved sample size
			Modified (two round) Delphi study with panel of provider stakeholders, service users and informal carers.	<p>To assess the extent to which the generic scoping study definition of CoC was found relevant to the care of people with severe mental illness and to modify this definition as appropriate.</p> <p>To identify factors perceived to promote or inhibit elements of CoC for people with severe mental illness.</p> <p>To identify mechanisms with potential to enhance CoC and to assess their perceived utility.</p>	20/40 key stakeholders in this field responded to first round and 10 of these to the second.

Appendix 2

Burns et al, 2007

Researchers operationalised the multi-axial definition of continuity of care for the main stage using 32 variables. The 22 variables that were entered into the factor analysis are in bold below. The text that describes the operationalised variables (pp.97-99) and the table that reports the continuity of care components are contradictory. For example, the text on p.97 refers to cross-boundary continuity having the following components: 'referrals to other services; admissions to hospital; discharges from hospital and number of agencies involved'. *Table M31*, by contrast, states that the components used to operationalise this type of continuity were 'Had a transition?; Referred to other agency; Contacts with primary care professionals; Number of agencies used in the previous year'. What follows is based on the table, rather than the text.

Experienced continuity was defined as CONTINU-UM score, using only the questions for each domain asking about the degree to which each had been experienced (that is, not the aggregate scores which, at an earlier stage of the report, had suggested could be used as an outcome measure).

Flexible continuity: CAN scores (total number of needs, *total met needs*, total unmet needs; *total level of needs*, *total level of needs met by informal carer*, *proportion of needs met*); increased contacts in three months before hospital admission; increased contacts in any three month period in a year when user assesses mental health to have deteriorated.

Cross-boundary continuity: *had a transition?; referred to other agency; contacts with primary care professionals; number of agencies used in previous year.*

Continuity of information: *documented transition; proportion of letters sent by CMHT which were copied to user; CPA copied to GP and user.*

Longitudinal continuity: *Designated care co-ordinators; designated psychiatrists; number of different non-medical team members seen out of the total number of contacts with non-medical team members; number of different medical team members seen out of the total number of contacts with medical team members.*

Relational or personal continuity: *STAR (Scale to Assess Therapeutic Relationships in Community Mental Health Care – service user version) total score for any professional, but related to care co-ordinator wherever possible.*

Long-term continuity: *Average gap between face-to-face contacts; gaps of two months or more; longest gap between contacts; gaps of (average gap*2 + 2 weeks); number of user-rated breaks in care; total number of face-to-face contacts; total number of 'phone calls; saw known CMHT member when hospitalised; any user-rated breaks in care.*

Contextual continuity: attendance at day care; supported accommodation.

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The management of the SDO programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Although NETSCC, SDO has conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.