Continuity of care 2006: what have we learned since 2000 and what are policy imperatives now?

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)

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Prepared by:

George K Freeman, Maria Woloshynowych, Richard Baker, Mary Boulton, Bruce Guthrie, Josip Car, Jeannie Haggerty, Carolyn Tarrant

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Project team

George Freeman	Emeritus Professor of General Practice (Principal Investigator)[1]
Maria Woloshynowych	Lecturer in clinical safety, Clinical Safety Research Unit[2]
Richard Baker	Head of department of health sciences[3]
Mary Boulton	Director of Research, School of Health and Social Care[4]
Bruce Guthrie	Professor, Department of Community Health Sciences[5]
Josip Car	Lecturer in Primary Care[1]
Jeannie Haggerty	Départements de Sciences de la santé communautaire et médecine familiale[6]

In consultation with
Ewan Ferlie   Head of School & Director, Centre for Public Services Organisations[7]

Revised version assisted by
Carolyn Tarrant   Senior Research Associate[3]

Participating institutions

1. Department of Primary Care & Social Medicine, Imperial College London
2. Department of Biosurgery & Surgical Technology Imperial College London
3. University of Leicester
4. Oxford Brookes University
5. University of Dundee
6. University of Sherbrooke, Canada
7. Royal Holloway, University of London.

Address for correspondence:
g.freeman@ic.ac.uk
c/o Kate Woodhouse, 3rd Floor, The Reynolds Building, St Dunstan's Road, London W6 8RP

Expert panel of advisers

International

Carol Adair   University of Calgary
Dmitri Christakis   University of Washington, Seattle
Per Hjortdahl   University of Oslo
John Saultz   Oregon Health and Science University, Portland
Henk Schers   University of Nijmegen
Barbara Starfield   Johns Hopkins University, Baltimore

National

Diane Ames   St Mary's Hospital, London
Angela Coulter   Picker Institute Europe, Oxford
Mike Crawford   Imperial College
Jill Mcleod Clark   University of Southampton
Martyn Partridge   Imperial College
Diana Rose   Institute of Psychiatry, London
Carolyn Tarrant   University of Leicester
Paul Wainwright   Kingston University
Kate Windridge   University of Leicester

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Executive Summary

Background

In 2000, the SDO commissioned a Scoping Exercise on Continuity of Care following their initial Listening Exercise among managers and consumers. The aim was to describe and limit the concept, and to summarise previous research and suggest priority areas. The scoping report recommended that research needed to focus on continuity from the patient's perspective and that a much clearer definition of continuity was required. It proposed a model multi-axial definition.

After considering the scoping report the SDO commissioned a major programme of research. This included six major empirical projects of three to six year duration[1] as well as several brief reviews. The six empirical projects covered the following topic areas: *diabetes* (type 2), *primary care*, *cancer*, cross-boundary issues (exemplified by *learning difficulty and stroke*), acute severe stroke (*main stroke)* and severe mental illness *(mental health)*. (The abbreviations in *italics* are the shortened project titles used throughout this report). By 2005 the SDO needed to evaluate this programme and it commissioned the present review to synthesise and interpret findings to date. This project ran for six months from June 2006.

The Canadian Health Services Research Foundation also commissioned a programme of research into continuity of care over a similar time period (1999-2005). This comprised over 70 projects, generally smaller but covering a wider range of topics. We welcomed the opportunity to link up with the evaluation of the Canadian programme.

Method

The multidisciplinary project team met monthly. One member (JH) was also the evaluator of the Canadian programme. Two members of the group (GKF & MW) collected most of the 'data' – this was from project reports, publications (where available) and from site visits to the research teams of the major projects.

While the original intention was a formal synthesis of project outputs with the aim of generating findings common to all projects, this proved impracticable for two reasons: first, three projects were incomplete, second, methods and contexts were so heterogeneous that formal data synthesis techniques could not be applied. Instead we conducted a series of case studies and synthesised the narrative findings using established methods. Subsequent interaction with the research teams encouraged us to focus particularly on issues of measurement of continuity arising in the projects.

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[1] Note that at the time of this report three of the six major SDO projects were not due to finish until later in 2007

Findings

A continuity research programme of unprecedented scope

This programme has been the largest and longest of its kind, with particular focus on the experiences of patients and their carers. Each project has seen substantial user involvement in its design and execution. Continuity of care is a phenomenon experienced over time – it is in essence longitudinal. It therefore particularly needs study over the longer time periods that this far-sighted programme has enabled. Unfortunately one paradox is that these longer term findings are not yet available for us to report and comment on!

Concept and definition

The projects have developed a range of new measurement scales for continuity as experienced by patients and carers. As a result continuity was conceptualised broadly, to include other aspects of quality of care such as access and availability of services. There has not been a particular convergence of definitions between projects. An important new finding has been the extension of the concept of informational continuity to include information transfer from professionals to patients. Some professional aspects of informational and management continuity were clearly less salient to patients. Thus both groups must be sampled to gather data as a basis for improving and monitoring services.

The cancer project developed the concept of continuity as an outcome rather than a process. This is useful because it improves our understanding of what patients are looking for but it does not directly help providers identify the process changes that are needed to improve care.

User and carer experience

The experience of continuity was often estimated as good in these projects. But each area revealed minorities with poorer experience. A common thread across many projects was the disadvantage of vulnerable groups who were less able to negotiate better continuity or other aspects of better care for themselves. In the case of cancer this appeared to be those who were either too ill (therefore unable) or else reluctant (due to cultural, class or language barriers) to be more directly involved as 'partners' in their care. In primary care it could take great persistence to achieve continuity with the patient's chosen doctor.

For people with learning disability struggling with the transition from school to adult life, problems of continuity across health, social care and educational boundaries were far more common. This appears to relate to a combination of shortage of resources (services) and low policy priority on the one hand, with years of 'organisational turbulence' on the other. The creation of new co-ordinating structures does not necessarily compensate for lack of resources and brings a heavy cost in transitional disruption.

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Effects of continuity

Few of these results were available at the time of this report, but the *diabetes* project reinforces evidence that both *relationship* and *management* continuity are associated with satisfaction for both patients and staff. On the other hand there was no association between either type of continuity and improved clinical indicators of diabetes (lower blood pressure or blood sugar levels). This could be because services respond to deteriorating diabetes by offering better continuity.

In the case of *cancer*, high experienced continuity was associated with lower physical and psychological health needs, better quality of life and less psychological distress at each subsequent follow-up point over the 12 month study.

Enhancing and frustrating continuity

The *diabetes* project found best continuity for primary care patients when care was led and co-ordinated by a named lead clinician in their practice. Continuity was assessed as less good without this lead person, and least good when care was led from secondary care.

Both in *primary care* and in *mental health*, users voiced a need for adaptability and flexibility in access to services. In the case of *cancer*, good planning at the initial stages seems vital. The project team are engaged in a second phase of their study planning to test an intervention designed to improve the effectiveness of initial multidisciplinary team planning meetings by helping them be more sensitive to individual patients' needs, and ability and willingness to be involved in various aspects of their care.

Insights from the parallel Canadian programme

This review covered 34 continuity studies. Five focussed on the concept of continuity from the patient perspective. As with the SDO projects, patients emphasised extra dimensions of care quality beyond strict continuity: access to services, and the interpersonal and perceived technical skills of providers. Patients were keen to be participants and saw their continuity role as complying with treatment and using appropriate self management – but also in advocating for access to recommended services. Flexibility of access was again emphasised to facilitate the achievement of desired relationship and management continuity.

Systems to facilitate information transfer were found to be necessary but not sufficient in improving care delivery. There was some evidence of specialist care savings being partially off-set by extra community expenditure. The most successful interventions were accompanied by improvements in quality of life and general functioning for patients with mental illness.

Conclusion

The term continuity of care has a number of meanings and therefore needs explaining or qualifying whenever it is used. It applies to individual patients (rather than groups) over time. We now distinguish three major types – management, informational and relationship. Management continuity involves the communication of both facts and judgements across team, institutional and professional boundaries, and between professionals and patients. Informational continuity concerns the timely availability of relevant information. Relationship continuity means a therapeutic relationship of the patient with one or more health professionals over time.

Access is closely linked with continuity and patients may have to trade off one for the other. This is particularly true for patients in primary care, where they have significant control over appointment making. In other settings, patients have less control over access. Perceived professional quality, both interpersonal and technical, is a vital influence on patients' choices about access and relationship continuity, so access needs to be assessed alongside continuity when reviewing a service.

The SDO programme, together with the parallel Canadian one, has added much to our understanding of the working of different types of continuity and confirmed that better continuity of both management and relationship are associated with better satisfaction for patients and staff, and with just a few improved outcomes.

More evidence is still needed on the causal links between continuity, particularly relationship continuity and better outcomes. This needs evidence from carefully designed trials.

These projects have greatly extended our understanding of continuity as experienced by patients and by their carers. There is strong support here 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. At the same time important groups of patients are more vulnerable and need extra professional help to achieve better continuity on the way to better care. In particular they need flexible access systems and help in negotiating these, together with adequate resources to deliver the advertised service.

While these projects had some success at identifying vulnerable groups it is likely that these were underrepresented. Future studies need more specific focus and original approaches.

All these projects except primary care focussed on single, if serious, problems. Increasingly patients have co-morbidities and future work needs to focus on the role of various types of continuity in providing better care for them.

Recommendations

Policy priorities for service development and delivery

a)   *Invest in policies in order to support continuity of care*

- Monitor the impact of policy initiatives on continuity. Ensure that every policy initiative considers its likely effects on the different types of continuity, both during implementation and later when (hopefully) running as intended.

- Be aware that user/carer/patient satisfaction is strongly associated with good continuity of care. This is positive for relationship continuity, i.e. good relationships will strongly enhance satisfaction; and potentially negative in respect of management and informational discontinuity, where evident lack of co-ordination leads to dismay and frustration.

- Optimise access to encourage continuity. Good access is inextricably linked with both management continuity and patient choice for relationship continuity.

- Target the most vulnerable. Continuity is already relatively good for many NHS patients. It is essential to concentrate resources and priority on vulnerable people who are either more ill or otherwise unable to negotiate their own continuity as they wish to.

b)   *Define and specify continuity*

- Specify the type or types of continuity whenever the term is used. The three main types are relationship, management and informational continuity. Also identify if it is disease- focused or person-focused care.

c)   *Beware of the hidden costs of organisational change*

- Minimise repeated organisational change ('organisational turbulence'), which acts strongly against management continuity and may even reduce relationship continuity through low morale. Policy makers need to be more aware of the opportunity costs of ill-considered short term change.

- Back priorities with adequate resources. Management Continuity is not a substitute for lack of resources, though relationship continuity may sometimes be some compensation. Where there are system barriers to the provision of seamless care, they may frustrate and demotivate staff and patients as well as directly impair continuity.

d)   *Create a continuity friendly service*

- Promote less paternalistic attitudes in care provision through example, education, and reward - to allow both patients and carers to realise their own potential in negotiating appropriate continuity.

Therefore future research should aim to:

1. Improve generalisable measures of various continuity types to enable sharing of findings.

2. Develop ways of costing the effects of enhancing/reducing the costs of various types of continuity and associated factors, such as access.

3. Devise and test complex interventions to enhance various types of continuity at both system and individual patient levels in longitudinal studies.

4. Focus on the contrasting needs of vulnerable groups, including patients with co-morbidity, and how to address these.

5. Maximise the opportunities for both national and international co-operation revealed by this programme.

List of abbreviations

CHRSF	Canadian Health Services Research Foundation
CMHT	Community Mental Health Team
ECC-DM	Experienced CoC Diabetes Mellitus (continuity measurement scale used in the SDO *diabetes* project)
ECHO	Experiences of Continuity and Health and social Outcomes in mental health (title for the SDO *mental health* project)
ED	Emergency Department
GHQ	General Health Questionnaire (a survey instrument)
LD	Learning Disability
NHS	National Health Service
PA	Personal Advisors
PCT	Primary Care Trust
PI	Principal Investigator
PPCI	Patient Perceived Continuity Instrument (continuity measurement scale used in the SDO *main stroke* project)
SDO	The NHS Service Delivery and Organisation (SDO) Research and Development Programme was established in 1999 to consolidate and develop the evidence base on the organisation, management and delivery of health services, and to promote the uptake and application of that evidence in policy and practice.
SnL	Snakes & Ladders (continuity checklist used in the SDO *main stroke* project)
SPDCE	Stated Preference Discrete Choice Experiment (research method used in the SDO *primary care* project)

Initials of project team members* appearing in the text

BG	Bruce Guthrie
EF	Ewan Ferlie*
GKF	George K Freeman
JC	Josip Car
JH	Jeannie Haggerty
MB	Mary Boulton
MW	Maria Woloshynowych
RB	Richard Baker

* Professor Ferlie was our consultant rather than a project group member

Section 1 Introduction

In 1999 the newly established SDO[2] conducted a 'listening exercise' amongst consumers and professionals to help prioritise its programmes of research (NCCSDO, 2000). Continuity of care appeared as a major concern and was chosen as its first priority and it commissioned a 'scoping exercise' in 2000 to help it both define and limit the programme. The scoping report summarised existing research and set out a conceptual review of continuity of health care (Freeman *et al*, 2001). One main conclusion was that studies of continuity as experienced by users/patients were needed. A second was that continuity was too seldom defined accurately enough to convey exactly what was being studied. Accordingly the report proposed a model definition specifying six aspects of continuity, with the intention that this could both inform, and be tested and developed, through further research. This model (see Box 1, p21) was referred to by the SDO in each of its subsequent calls for research in the programme and proved to be at least a starting point in all the SDO commissioned projects. *Appendix 1* gives the exact recommendations of the scoping report.

The SDO then commissioned a comprehensive programme of continuity of care projects, including six 'empirical' projects collecting new data and three review projects investigating existing evidence or professional views in specific fields (see http://www.sdo.lshtm.ac.uk/cpcontinuity.html). Further projects have been commissioned recently.

In Canada during the same period, continuity of care was identified as a research priority by the Canadian Health Services Research Foundation, their counterpart of the SDO. After two years of funding, the Foundation commissioned a synthesis similar to that of the SDO scoping exercise to bring clarity to the concept and measure of continuity. Based on a content analysis of the literature and with input from continuity experts (including GKF and JH), this synthesis identified two essential features and three types of continuity (Haggerty *et al*, 2003). Though more parsimonious, it relates well to the SDO scoping definition. Two essential features were that continuity is about of an individual (rather than a population group) and about care over time. Three types were defined. Relational continuity refers to therapeutic relationships that span healthcare episodes (*personal, longitudinal).* Informational continuity links past to current care (*continuity of information, cross boundary).* Management continuity is the delivery of coherent and complementary services to achieve health goals *(cross-boundary and team continuity, flexible).* Some SDO projects make reference to this typology as well as to the scoping definition.

The six SDO empirical projects have been exceptional in their duration – up to six years. In 2005 the SDO commissioned a review of progress with synthesis

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[2] The Service Delivery and Organisation Division of the Research and Development Programme in the English National Health Service – see abbreviations page 12.

and analysis of these nine projects. We report this review here. *Appendix 2* includes the project brief and the aims and objectives as listed when our proposal was accepted. We structure our report as follows:

1.   Findings from the SDO projects

- How we updated the continuity concept for this review
- How individual projects mapped on to this
- new insights
- how continuity interacts with related factors such as access, quality, availability/resources etc
- Users', carers' and professionals' experience, values and priorities
- Effects of various types of continuity
- How to enhance and prioritise aspects of continuity of care; the barriers to doing so
- Measurement of continuity of care.

2.   Findings from the parallel Canadian HSRF programme of continuity research.

3.   Discussion: The meaning of continuity; How the two parallel research programmes have contributed; Implications for health policy, service delivery and future research.

Our approach to this report

The series of projects which are the subjects of this review share a common focus on continuity of care, but vary widely in aims, contexts and scope. We have tried to summarise the essentials of these projects sufficiently to allow the reader to make sense of their findings and our synthesis and interpretation. We include a brief project summary at the start of our Findings section and *Appendix 4* is a structured one-page summary of each major empirical project.

Our original expectation of a formal synthesis of findings proved impractical owing to the heterogeneity of objectives and methods. We therefore undertook a narrative synthesis based on a series of project case studies. The narrative synthesis model involves examining the texts of these reports and elucidating text and findings which relate to a series of common themes which have been specified by reviewers.

Three studies were still in progress at the time of this review and this was a further impediment to any formal synthesis of findings. We have therefore focussed relatively more attention and analysis on definitions and methods of measurement of different types of continuity used and on how these reflect our evolving understanding of the concept and importance of continuity of care. This process was also encouraged by investigators of the projects still in progress when we convened a joint project workshop halfway through our review. Definition and measurement was a major problem identified in the initial scoping exercise and it remains a challenging issue though impressive progress has been made, with considerable implications for both service development and future research.

Section 2 Method

2.1 Reviewing the SDO projects

2.1.1 The main SDO projects and how we worked with them

The six empirical projects are described in detail in *Appendices 4 (process), 5 (administrative details) and 6 (cross-tabulation of findings)*. These projects are the main subjects of this report. For convenience we refer to them by their clinical focus: *diabetes[*]; primary care[*]; cancer; learning disability (LD) & stroke[*]; main stroke;* and *mental health.* Three ([*]) are complete at the time of writing (Dec 2006), with their reports publicly available on the SDO website, while the other three will report over the next 18 months. From these latter three projects still in progress we have seen the revised report of the main body of the *cancer* project and had also informally looked at an unfinished draft final report of the *mental health* study (by courtesy of their research team). We have seen no written findings other than periodic progress reports and an SDO workshop presentation for the *main stroke* project.

For each empirical project except *primary care* two of us (GKF & MW) undertook *site visits* and *key informant interviews* with one or more members of the research team. These were informal but structured with a checklist of themes/questions which we derived as a group early in this project (*Appendix 3*). They were an adaptation of the categories on JH's report form for the Canadian studies. We were particularly interested in the way that continuity was conceptualised, defined, and measured as well as in the methods, findings and contexts specific to each project. After each visit GKF completed a template employing the list and MW independently wrote up her field notes. We then compared notes to prepare an agreed draft of our visit report – again based on the template but with additional points and themes listed at the end. Each report was thus similarly structured. It was then sent to the host research team for them to check accuracy, answer queries, and add any relevant corrections, comments or suggestions. *Appendix 6* is a summary comparative table based on the template reports. The *mental health* project comprised several simultaneous strands, two of which were led from sites separate from the main site at St George's. We therefore made extra site visits to the *mental health* Organisational Strand (Prof Susan McLaren at South Bank University) and Developmental Strand (Dr Diana Rose at the Institute of Psychiatry). We examined all available reports and publications from each project.

For *primary care*, where the three lead investigators form part of the present project team, we invited two other project team members to critically review the final report and available publications. JH & BG had had no part in this project.

We have also briefly considered the *three review projects* commissioned early in the SDO's programme. A slightly modified checklist was used to summarise the findings in *Appendix 10*. While interesting in themselves and relevant at the time, especially to the relevant developing empirical projects, these projects appeared to us ultimately to add relatively little to the programme, and we did not consider them in detail.

In this report we have aimed to provide enough detail about the conduct and context of each *empirical* project to enable readers to understand what has been done and to interpret our findings. Inevitably this process loses much interesting material and we encourage readers to read the full reports and publications wherever these are available.

2.1.2 Analysis

We have drawn on recently described methods for combining qualitative and quantitative data in reviews (Mays *et al*, 2005; Pawson *et al*, 2005; Lavis *et al*, 2005). In relating SDO project findings to a coherent conceptual framework, we have distinguished between specific aspects of continuity, broader concepts such as coordination, and quality questions such as availability of resources.

We first summarised the projects individually as case studies and then put these together for comparison. We have referred the findings back to our updated conceptual framework. We used methods of synthesis based on thematic analysis to read our data and texts and organise our findings (Dixon-Woods *et al*, 2005; Ferlie *et al*, 2005).

We have aimed at development of concepts, themes and meaning as well as aggregation of evidence (Mays *et al* 2005), and our review has included themes and domains of process and effectiveness (Mays *et al* 2005). We have looked for contextual differences which might explain differences between the studies' findings relating to *client groups, professional groups* and *care setting*. While most of the routine work of the study was carried out by GKF and MW, a substantial contribution was made by all members of the project group, both collectively in regular round table meetings and individually. For example two members compared ways of measuring continuity (see below), and each project report was additionally reviewed by a 'non-visiting' member, using the same template (listed in *Appendix 5*). As our findings emerged we consulted with members of our *expert panel*. These members were invited to supplement the skills and experience of the project team by representing European and North American perspectives, user perspectives and secondary care medical and nursing perspectives.

Since the three largest and longest empirical projects were incomplete for this review, we have particularly emphasised *measurement issues* in this report. The SDO's programme has been notable for its emphasis on the patient perspective – including experiences of lay carers as well as of users. Remedying the lack of existing instruments to measure 'experienced' continuity has been a significant task for all the projects and we have been interested to compare them and look for generalisable lessons. Two of us (BG and JC) therefore studied the available measurement instruments from four of

the projects. They looked for common items and themes and also for differences and tried to link these with the aims and context of each study. Their method is set out below in section 3.2.2.

2.2 Findings of the Canadian HSRF programme

One of us (JH) has been undertaking a review of the 48 completed projects on continuity of care in the Canadian programme (Canadian Health Services Research, 2006). These projects were required to produce structured reports and JH has based her review/synthesis almost entirely on these reports (see section 3.7). We include in our report a summary of key findings pertinent to our review of the SDO projects. This summary does not present the Canadian studies to the same level of detail as the SDO projects, but the findings serve to place the SDO projects into a wider context as well as highlighting several important issues.

2.3 Other relevant issues arising

Certain issues arose during this work which we had not thought about beforehand, notably the relationship between each project and the programme as a whole, and possible lessons for future SDO programmes (see section 4.4.1). One reviewer of our draft report expressed concerns about the fact that the principal investigator of this review had also led the initial scoping study. We discuss this under 'strengths & weaknesses' below in section 4.

2.4 Implications for health policy, service delivery and future research

Section 4 brings together findings from the two parallel research programmes and discusses their implications. It concludes with specific recommendations for service delivery and for research.

Section 3 Findings and interpretation

3.1 The SDO programme: Overview of the six empirical projects

Five of the six projects started with a qualitative study of users an

d carers to develop their own user-orientated measure of continuity which they then applied in a variety of mixed method studies, usually over a time period from 10 months to three years. The *diabetes* project also developed a parallel complementary measure for aspects of continuity perceived by professional staff. More detail about each project is provided in *Appendices 4 & 6*, and interested readers can find full reports for three projects (and proposals for the other three) on the SDO website as indicated in *Appendix 5*.

The *Learning disability & stroke* project was a little different. In a series of contrasting case studies they purposively sampled three different service organisation configurations and used these two clinical conditions as examples. They too started off with wider ranging qualitative working to help define their so-called 'hinge points' – important points of care transition. They did not produce a continuity measure as such but generated their own topic guides.

Brief summary of the six projects

3.1.1 Diabetes project (Gulliford *et al*, 2002)

This studied patients in the community with type 2 diabetes receiving care from general practices and hospitals in SE London. Using mixed methods, the aim was to evaluate and measure patients', carers' and providers' experiences of continuity of care and to determine whether this was associated with clinical and patient outcomes. The team developed a new 19 item *measure of experienced continuity* for diabetes. They then used this measure, together with other assessments and measurement of height, weight, blood pressure and HbA1c. They repeated the interviews and measurements after 10 months. They undertook a parallel study of 25 health professionals and also did more detailed interviews with seven carers and with 12 South Asian origin patients. They report that higher experienced continuity (several aspects combined) was associated with higher global satisfaction but not with any clinical indices. Staff generally preferred to see the same patient at successive visits.

3.1.2 Primary care project (Baker *et al*, 2001)

This aimed to examine the importance to patients and carers of aspects of continuity in relation to other aspects of care. It was carried out in Leicestershire and in W London and the findings of the initial qualitative study informed the design of three further studies with contrasting methods:

a. Thirty–six-patients kept a diary of all their primary care contacts over 6 months and their medical records for 12 months were obtained from their general practice.

b. In a discrete choice experiment, 646 patients responded to structured questions related to three simple care scenarios designed to find out how they prioritised ('traded-off') their preferences for speed of access, type of professional consulted, whether they knew and trusted this person, and about the availability of clinical records.

c. In a cross-sectional survey, 1437 patients responded to questions further investigating experiences and beliefs in relation to their choices when making appointments, and whether patients were able to get the kind of care they thought important, in terms of continuity, access and the kind of professional consulted.

3.1.3 C*ancer* project (King *et al*, 2001)

This studied patients and their carers in three cancer networks in N and E London. Their overall aims were wide-ranging and included describing the 'physical, emotional, social and spiritual status of patients and nominated 'close persons'; assessing professional perceptions of how to enhance continuity; and identifying transition points in the care of cancer associated with low satisfaction.

They recruited from general practice for their initial qualitative study to describe the scope of experienced continuity for patients with cancer (breast, lung, colo-rectal). They went on to construct an extensive quantitative cohort survey where patients were recruited from secondary care and interviewed and followed up at five points over the next 12 months. Their analysis examined associations of their measure of *experienced continuity* at one time point, with various outcomes at a subsequent time point, making causal attribution more plausible. They conclude that patients experience continuity in a manner distinct from professionals' definitions of it, and that 'experienced continuity' as measured by their instrument does have a positive impact on satisfaction, care needs, quality of life and psychological status. They suggest that professionals are still not giving enough attention to patients' attitudes, families and their degree of involvement in the care process. They are developing an intervention designed to improve professional recognition of patient preferences to be tested in the next stage of their work.

3.1.4 Learning disability and stroke project (Hardy *et al*, 2001)

These projects differed from the others in focussing far more on the structure and management of services and the effects of changes in these. They studied contrasting care service configurations in three districts in northern England. They undertook extensive documentary analysis as well as interviews with patients, carers, professionals and managers. They were thus able to relate to the experiences of receiving, delivering and managing care resources and structures and to the effects of implementation of policy

developments over the preceding years. While there was a mixed picture of success and of problems for stroke patients, they found far more problems for young people with learning disability trying to make the transition from educational dependence to some kind of supported adulthood. It seemed that lack of priority for resources and services was very salient in a picture characterised by discontinuity and what they term 'organisational turbulence'. Shortages of resources, particularly clinical psychologists, were common across the three districts.

3.1.5 Main stoke project (House *et al*, 2001)

By contrast the *main stroke* project (in progress and as yet largely unreported) is potentially more comparable with the other empirical projects. This team has had to spend the most time developing a continuity measure suitable for assessing the experience of patients for 12 months after suffering a significant stroke. After interviewing a sample of patients and professionals they developed an instrument for sampling progress from both clinical records and interviews. They also tried out an existing questionnaire devised by Chao in North American primary care for assessing personal continuity (Chao *et al*, 1988) – but found this unhelpful as it did not correlate with any other of their measured aspects of stroke care. At the time of this review they have recruited and followed at least 123 patients but still have much analysis to do before being able to conceptualise aspects of continuity in relation to other aspects of care so as to be able to propose an intervention to make a measurable and relevant improvement in the care of people with acute stroke. They have much interesting data and are thinking about continuity in a novel manner informed by networks and aspects of complexity theory. We await their findings with great interest.

3.1.6 Mental health project (Burns *et al*, 2007)

Finally, this is another large project now nearing completion, having a draft final report with the researchers' interpretation and discussion only partially written. Here the initial qualitative work was with varied focus groups of users with separate groups of carers. The main continuity measure CONTINU-UM and a parallel carers' measure CONTINU-ES were carefully derived from these findings.

In the main part of the project (known as ECHO 1), these instruments, also with a range of quality of life and mental health measures to assess progress over the preceding year, were used three times, at annual intervals, with a cohort of patients with chronic psychotic mental illness. This gave three years' data. A sample of patients was studied qualitatively in depth (Qualitative strand).

There was a parallel organisational strand studying changes in care management in the relevant trusts over the same time period.

This was so encouraging that a separate but similar study was commissioned to study a group of non-psychotic patients over a shorter two–year period (ECHO 2). Possibly because they were more likely to experience transitions

between the two time-points, this group proved more difficult to recruit for the qualitative strand.

3.2 Definition and measurement of continuity

3.2.1 Definition

The SDO Continuity of Care scoping report provided an overview of continuity research, and highlighted a lack of conceptual clarity in definitions of continuity in previous work. Accordingly, the report proposed a patient-centred, multi-dimensional definition of continuity of care. The key concept of *experienced continuity* was proposed to be achieved through five separate elements or types of continuity. The exact wording was as follows:

Box 1 'Scoping definition' of elements of continuity of care

At a minimum a definition of continuity of care should include the following elements.

1 The experience of a co-ordinated and smooth progression of care from the patient's point of view *(experienced continuity)*.

To achieve this central element the service needs:

2 excellent information transfer following the patient *(continuity of information)*

3 effective communication between professionals and services *(cross-boundary and team continuity)*

4 to be flexible and adjust to the needs of the individual over time *(flexible continuity)*

5 care from as few professionals as possible consistent with other needs *(longitudinal continuity)*

6 to provide one or more named individual professionals with whom the patient can establish and maintain a therapeutic relationship *(relational or personal continuity)*."

The report pointed out that continuity is a phenomenon experienced by individual patients. Different patients may hold a variety of views about what continuity is, and its value, and an individual's views may evolve as their life progresses.

Carrying out the present review in 2006, we reviewed the SDO projects in the light of three later approaches to the definition of continuity.

The nature of experience

Krogstad *et al* (2002) differentiated 'frontstage' and 'backstage' continuity from a sociological perspective. They argued that these two different types of continuity may be experienced in different ways by patients. They equated 'frontstage' continuity with relational or interpersonal continuity, and suggested that patients can experience (and value) the presence of this type of continuity. In contrast, 'backstage' continuity goes on behind the scenes, being situated in the structures and routines of the organisational system, and

communication between members of staff. They suggested that this type of continuity may be experienced by patients (for example, through consistency of the information they are given by different members of staff), but is more commonly recognised by its absence.

Simplifying the five types

As we noted above (p13) the Canadian continuity review synthesis Haggerty *et al* (2003) defined two essential features that distinguish continuity from other aspects of health care, that continuity relates to *care of an individual patient*, and as such should not be described as an attribute of health care providers or organisations but rather in terms of individual patients' experience of the health providers or organisations. This reflects the scoping report's notion of experienced continuity[2]. Second, continuity relates to *care over time*, which distinguishes it from other aspects of service such as quality of communication.

Assuming these essential features, Haggerty at al (2003) then described three types of continuity: *informational* continuity (the use of information on past events and personal circumstances to make current care appropriate for each individual); *management* continuity (a consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs); and *relational* continuity ('an ongoing therapeutic relationship between a patient and one or more providers').

An independent approach

Saultz (2003) published an independent review at the same time (such that neither review could refer to the other). He focused specifically on 'interpersonal continuity' and also identified three types, two of which are the same as those identified by Haggerty *et al* (2003): *informational* continuity, longitudinal continuity (which occurs when a patient receives care from a consistent provider or team of providers), and interpersonal continuity (equivalent to *relationship* continuity).

Saultz argued that these three types of continuity can all contribute to the patient experience of continuity, and are hierarchical. *Informational* continuity, which requires simply the availability of information about the patient's medical and social history, provides the foundation for the experience of continuity. Longitudinal continuity builds on informational continuity, and some degree of longitudinal continuity is necessary to build a personal relationship, and thus the culmination is interpersonal (*relationship*) continuity. Longitudinal continuity can be seen as an aspect of *management* continuity, a mechanism supposed to improve consistency of care.

The key notions emerging from the literature thus far were

- Continuity relates to care of the individual patient over time, and is a phenomenon that is about care of an individual patient (user), rather than a population or social group. This may be seen either in the context of the patient and their immediate professional carers (frontstage) or in the wider organisation of care (backstage).

- Continuity is a multi-dimensional construct in which different types of continuity can interact with each other, and form the experience of continuity for the patient - a composite outcome.

- There is a distinction between the way continuity may be produced, and how it may be experienced by users (or providers).

We reviewed the SDO projects with these notions in mind. In addition, each SDO project also studied informal lay carers in addition to patients (users) and this expanded our perspective further. In this report we use the term patients to describe people directly receiving care and carers to indicate lay carers (as opposed to professional carers). Some of the projects use different terms such as users (patients) of mental health services and close persons (carers) of patients with cancer. These project-specific terms appear in direct quotations from project reports.

We also anticipate our concluding understanding of continuity types (described below in section 4) by writing these in italics in this report – *relationship, management* and *informational* continuity. The term 'relationship' seems to us to be slightly more helpful and descriptive than 'relational'.

3.2.2 Measurement

Many measures of continuity have been developed (see reviews such as Saultz, 2003, and Jee & Cabana. 2006), but most of these have measured visit patterns, duration of relationships, or frequency of seeing the same provider. Continuity is often included as a component in patient experience questionnaires in both primary and secondary care e.g. GPAQ (Ramsey *et al*, 2000), Picker Patient Experience Questionnaire (Jenkinson *et al*, 2002). However, there is a need for measures specifically of patient experience reflecting the newer multidimensional definitions of continuity. This review evaluates the measures of continuity developed in each of the SDO continuity projects – the dimensions included, the extent to which the measures are derived from patient and carer definitions of continuity, and the psychometric properties of the measures.

We present a detailed critique of the measures that were available from four of the projects at the time of our review in Appendix 7.

3.3 How each SDO project defined continuity

Highlighting the new understandings of continuity that emerged from each project.

We describe the initial definition of continuity used in each project, and how the findings informed a new or revised definition.

3.3.1 Starting points – conceptualising continuity

Four of the projects (diabetes, primary care, cancer, and mental health) started from the scoping report's 'multi-axial' definition of continuity (see Box 1). Interpretations of this differed somewhat. The diabetes, primary care and

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mental health projects appeared to assume that the types of continuity in the scoping report contributed to the patient's overall experience of continuity. These projects focused on exploring and measuring a range of different dimensions of continuity. In contrast, the cancer project explicitly claimed to be exploring and measuring 'experienced continuity', and set aside the other dimensions as care processes important to professionals but not to the patient experience. They stated:

> *We decided to develop ideas of continuity based the user view of what mattered. Thus, we did not approach patients and close persons with the aim of validating any particular model of continuity (Cancer project, p25)*

Some projects also referred to other definitions, particularly in their initial qualitative work exploring the meaning of continuity. The primary care project used the three-type definition proposed by Haggerty *et al* (2003), and the diabetes project drew on the distinction made by Starfield (1980) between 'longitudinality' ('the building and maintaining of a long-term patient-practitioner relationship'), and 'continuity' (concerned with 'aspects of secondary and tertiary care that involve the management of an episode of illness or chronic disease'). The mental health project report noted that continuity can encompass cross-boundary continuity at a single time point as well as 'longitudinal or temporal continuity and relationship continuity between service providers'

Two projects did not use the scoping report definition of continuity. The main stroke project considered the definition but subsequently found it not to be helpful. The LD and stroke project did not explicitly draw on prior definitions of continuity. This project had a different focus. While the five other projects explored patient experiences of continuity broadly across their care, the LD and stroke project focused specifically on understanding continuity and discontinuity across inter-professional and inter-organisational boundaries, and primarily explored management continuity (Haggerty *et al*, 2003).

In each project the initial conceptualisation of continuity evolved as a result of their findings and in the light of their previous research in their specific domain. For example the primary care project team had just completed a study into what made patients perceive primary care as personal (Tarrant *et al*, 2003). The main stroke project was linked to another large cohort study of early depressive symptoms and outcomes for stroke survivors and the cancer project researchers were already interested in the total experience of patients being treated by cancer networks.

3.3.2 How each project explored continuity

The projects had a range of aims and used several methodologies, although all involved a qualitative component. The diabetes, primary care, cancer, main stroke, and mental health projects included initial qualitative work to explore the meaning of continuity; the primary care project involved interviews with just patients and carers, while the remaining projects included interviews with professionals/health care providers as well as patients and carers. These five projects also included the development of questionnaires to measure continuity (although the questionnaires were specific to the aims of each

project). These show how continuity was operationalised in the context of each project. The LD and stroke project took a different approach in line with their aims, collecting detailed data across a range of care services, as well as carrying out interviews with patients, carers and professionals on their experiences of continuity across boundaries.

The initial qualitative studies

Across the projects, the term 'continuity' was seldom offered spontaneously by patients in describing or making sense of their experience of illness or care. Five of the projects (diabetes, primary care, cancer, and main stroke, and LD and stroke) did not use the term 'continuity' in their topic guides for interviews/focus groups (although the LD and stroke topic guide did use the term 'continuity' in the final question to patients). Rather, the topic guides reflected each research team's pre-existing understanding of continuity, and describing these helps show how continuity was conceptualised across the different studies. The cancer project report described the interviews as focusing on patients' experiences of 'linked up and consistent services', and health care professionals' opinions on the points at which continuity in service provision in cancer care might be improved, reflecting the broader aims of their study which included a focus on transition points and interfaces across care. The main stroke project gathered narratives of patient and health professional experience. The qualitative data collected in the LD & stroke study focused on patients' narratives of care across interfaces and transition points (discharge in the case of stroke patients, and the transition for young people leaving school and entering adulthood in the case of LD), as well as professionals' opinions of interdisciplinary/inter-organisational care.

This approach of exploring continuity based on the research team's prior understanding of the concept is shown in the diabetes project report (p 53):

Interviews covered respondents' experiences of the diabetes care provided by both hospitals and general practices, and probed particularly in relation to communication with staff and across settings; the flexibility of services; changes in care over time; the availability of information about diabetes; and their experiences of treatment. Examples of questions asked included: 'Are there any advantages/disadvantages with seeing a usual doctor or nurse?', 'Have you been able to get the services you needed?', 'How important is it for you to see a usual doctor or nurse?', 'How well is your care co-ordinated?' Respondents were also encouraged to discuss issues and directions of thought that went beyond this framework including the role of family in relation to continuity. To prevent patients from feeling uncomfortable, ignorant or confused jargon was avoided. The researcher also avoided using specific labels to describe the different dimensions of continuity and instead asked interviewees to use their own words and meanings to describe their experiences of continuity.

Only the mental health project explicitly used the term 'continuity' in their exploration of the meaning of the concept. In this project, focus group participants were asked to talk about their experience of illness and care, and the term 'continuity' was then introduced for discussion to generate survey

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domains and questions, and the team reflected that users engaged well with the term:

> *The first wave of focus groups began with participants 'telling the story' of their contact with mental health services. After this, the idea of continuity of care was introduced. Although most participants had not actually heard the term before, the groups were able to generate ideas around the term once it had been explained to them. (Mental health project, developmental phase, p 18).*

3.4 Findings and the meaning of continuity

The projects varied in the extent to which they focused on exploring the meaning of continuity; all have some relevant findings. This section provides an overview of the understanding of continuity provided by each project by describing the meanings of continuity emerging from qualitative findings (where relevant), summarising how continuity was operationalised in the measures developed in each study, and describing any quantitative findings that contribute to an understanding of the meaning of continuity.

3.4.1 Diabetes

This project included qualitative work aiming to derive a patient-based definition of continuity, and the development of patient and provider questionnaires.

Qualitative study – patients

From interviews with patients with type 2 diabetes, the team concluded that four distinct dimensions contribute to the experience of continuity of care: (*Diabetes* project, p 65-66)

- *experienced longitudinal continuity,* the experience of regular visits for testing clinical parameters and the provision of advice on self management. This is most satisfactory when the same professional is seen at each visit;

- *experienced relational continuity,* the experience of consulting with a trusted professional who knows the patient well;

- *experienced flexible continuity,* the experience of obtaining advice when it is needed urgently, or changing care arrangements according to new circumstances;

- *experienced team and cross-boundary continuity,* the experience of receiving consistent and well-coordinated care from different professionals or in different provider organisations.'

They emphasise that patients tend to focus on relational continuity as central to the experience of continuity.

The authors make a distinction between this conceptualisation of continuity and the scoping report definition. They seek to argue that the scoping report described *experienced continuity* as the patient's perception of continuity,

which is influenced by the delivery of the other sub-aspects of continuity by providers. In fact, their findings were that most of the sub-types were perceived as such by patients. The exception was *informational continuity* – they suggest that patients have little awareness of information transfer processes, although patients did describe experiences of *problems* of communication between professionals and across care boundaries. Patients were more likely to report issues of communication between themselves and their health professionals (here taken to be part of *relational continuity*).

Qualitative study – providers

Analysis of interviews with health professionals similarly identified the four dimensions described above, although there were some differences in professional and patient definitions of the four dimensions. Longitudinal continuity was defined by professionals in terms of organisational arrangements and regular processes for follow-up, rather than care from as few professionals as possible. *Relational continuity* included both building relationships and adopting a flexible approach to meeting patients' needs. Team and cross-boundary continuity included coordination of services both within and between organisational settings, as well as communication between professionals. Flexible continuity was evident across the other themes, and the authors argue that only patients are able to judge whether services are adequately adapted to their needs. The providers also described a fifth dimension, *informational continuity*, described as follows:

'*Informational continuity* involves appropriate recording and information transfer following the service user. Continuity of information is the continuity given to patients' care by information systems.' (*Diabetes* project, p 148).

This definition is narrower than that in the scoping report, focusing on professionals' access to information systems, and on the accuracy and completeness of medical records.

Questionnaire development

The patient questionnaire included the four sub-domains of continuity: experienced longitudinal continuity, experienced relational continuity, experienced flexible continuity, and experienced team and cross-boundary continuity. The provider questionnaire included the dimensions longitudinal, relational, team and cross-boundary, and informational continuity. Flexible continuity was omitted as the authors argued that it was inappropriate to ask providers to judge whether services were appropriate for patients' needs. (See Appendix 9 for details of the questions.)

Based on factor analysis of patient and professional questionnaire responses, the authors suggested that:

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. (*Diabetes* project, p 165).

Continuity of care 2006

This argument is supported by the findings from interviews.

Publication – overview of the meaning of continuity

The team's 2006 paper (Gulliford *et al*, 2006) gives an overview of their perspective on the meaning of continuity derived from their work on the *diabetes* study. They identify two 'ideals' for continuity, the ideal of a 'continuing caring relationship' with a health professional which underpins the patient experience, and the ideals for health professional which involve a 'seamless service', with integration, coordination, and sharing of information. They suggest that continuity needs to involve both ideals. Further, they argue that although patients' experiences of continuity may be valued, continuity in the delivery of care is often related to service organisation, and inter-organisational/inter-professional working, which may not be visible to patients, hence there are limitations to relying solely on patient experience as a measure of continuity.

Overall contribution

Overall, the diabetes project has produced a revised, multi-axial definition of continuity which differs to some extent from the Scoping report definition. The project highlights issues around differences between patients and provider definitions of continuity, and raises the concern that continuity should not be measured solely from the patient's perspective but should also include the provider's perspective. While the authors initially distinguish flexible continuity as a separate type, later they conclude that flexibility is an essential attribute of each of the other types of continuity. (*Diabetes* project, p 149).

3.4.2 Primary care

This project focused less on exploring the meaning of continuity than some of the other studies, given its aim of investigating patients' priorities for a range of aspects of care, including continuity. However, some findings relating to the meaning of continuity emerge across the study, and the team reflect on the contribution of their findings to their understanding of continuity.

Qualitative study

Interviews with patients and carers explored their experiences and priorities in primary care. Analysis of patient accounts identified two types of continuity. One was continuity reliant on seeing the same health professional: the 'same' GP (longitudinal continuity) and the 'personal' GP (*relationship continuity*). The other involved aspects of continuity not tied to a particular health professional: transfer of information within and between services and providers *(informational continuity)*; continuity of management through regularity of check-ups, teamwork, or having services under one umbrella/one geographical location (which maps on to team and cross boundary continuity, as well as *management continuity), and consistency of treatment or advice.

The team found that primary care patients primarily focused on *relationship continuity*.

Continuity of care 2006

Questionnaire development

Continuity was operationalised in terms of *relationship*, longitudinal, and *informational* continuity in the patient survey; *management continuity* was not included in the quantitative side of the study. The team clearly separated continuity and other aspects of care such as access and professional expertise, including additional questions about these aspects of care (see Appendix 9 for details).

Reflections on understanding of continuity

The team revisited the scoping report definition in their discussion, arguing that experienced continuity can be seen as an outcome, while the other dimensions of continuity can be seen as processes promoting this outcome. They suggested the need to explore how continuity can be produced through an interaction between systems, individual practitioners, and patients. They suggest that *relationship* continuity is jointly produced by the patient, the health professional and the organisation/ systems, while continuity of *management* and *information* are primarily the responsibility of the organisation and individual practitioners (although patients can have a role in the continuity of information).

Overall contribution

The *primary care* project supports a distinction between aspects of continuity related to ongoing patient-professional relationships, and those related to continuity and consistency across different health professionals: a distinction also emphasised by the *diabetes* study team. The findings suggest that in the primary care context, patients tend to conceptualise continuity in terms of ongoing patient-professional *relationships*, very much a frontstage concept (Krogstad, 2002).

3.4.3 Cancer

This project involved qualitative interviews and case studies of patients, carers and professionals, and the development of a questionnaire to measure continuity.

Qualitative study

As noted earlier, the cancer project explicitly focused on *experienced continuity,* conceptualising this as an outcome which should be understood from the patient's perspective. The continuity types described in the scoping report were seen as processes linked to the delivery of care and thus as not directly relevant to patients. The exploration of continuity was thus anchored to patient accounts of their experiences rather than being mapped on to prior definitions of continuity. The project team summarised their findings on the meaning of continuity as follows:

We found that experienced continuity was a complex concept determined by factors such as the quality of the first appointment with secondary services, communication with the family and professionals; information giving by professionals; patients' and close persons' ability to share treatment

decisions; the effectiveness of health administrative systems; patients' personalities and family dynamics. Patients' reactions to their illnesses and how they shared information within their families were critical to whether or not continuity could be achieved. (*Cancer* project p 3.)

Although the analysis avoided linking the qualitative findings to prior definitions of continuity, it seems to us that transfer of information between different professionals and availability of records (*informational continuity),* the establishment of a trusting relationship with a contact person (*relational continuity),* and coordination of care between different health professionals and between primary and secondary care *(team and cross-boundary continuity)* did feature in patient accounts. Also, the sharing of information with patients, and their involvement in treatment decisions was highlighted.

Interviews with health professionals identified the importance of trusting relationships (*relational continuity)* as well as other aspects such as availability of time.

Questionnaire development

The measure of continuity developed in the *cancer* project included questions relating to types of continuity recognised in the scoping report, however, it also included broader aspects of care identified in the initial interviews and case studies, including coping with illness, and social support (see appendix 8 for details). The team argue for the validity of their measure, based as it is on patient accounts of *experienced* continuity:

Although professionals may not regard [many of these] items as directly linked to their notions of the delivery of continuous care, there is no reason to expect they should; rather they were concepts that arose repeatedly from the qualitative data on experienced *continuity. … This moves away from the idea that continuity of care is a one-sided concept that is simply delivered by health professionals* (*Cancer* project p47.)

Overall contribution

Given the project's focus on *experienced* continuity as an outcome, the comparability of its findings to the other studies is limited. The findings of the qualitative study point to continuity as a complex concept and a number of factors were incorporated in the *cancer* questionnaire to represent a broad concept of experienced continuity of care. However, it is questionable whether these factors should be described as aspects of continuity, or recognised as factors which can impact on continuity, and this prompts further discussion of the methods used across the studies to elicit meanings from participants, and reflection on the implications of this on the findings across the projects on the definition and meaning of continuity (see section 4.1, below).

3.4.4 LD and stroke

As already described, this project focused on organisational issues and complexity across boundaries, and used case studies focusing on transition points in care as a means of exploring potential discontinuities. Hence this project did not explicitly explore the meaning of continuity of care, although it

has value in understanding the factors that lead to discontinuity, and potentially in informing reflection on whether this differs significantly from the concept of continuity.

Findings

Continuity was operationalised as synonymous with 'seamless care' and 'integrated care', matching the aspect of continuity described as 'seamless care' by Gulliford *et al* (2006).

The team concluded that organisational turbulence, overlapping boundaries, and lack of key staff impede continuity of care at transition points, although patient experience of continuity could be promoted by staff working across boundaries (team and cross boundary continuity). They described their understanding of what is needed for successful continuity across transition points:

> *Patients' experience of continuity of care was defined essentially … wherever there was a transition in care… that this was seen and felt as a smooth handover and seamless transfer… Handover literally means being taken by a member of staff in one unit and being given directly into the care of another member (or members) of staff in another unit. An apt metaphor would be the athletic one of handing over the baton in a relay race. The crucial elements here are passing the baton smoothly from hand to hand: it cannot be thrown, it cannot be left lying on the ground, and it certainly cannot be dropped.* (*LD & stroke* project p113).

The team agree with the scoping report in asserting: *'the study's main insight is that the term continuity of care is most meaningful when viewed from the perspective of the service user'* (*LD & stroke* project p iii), since the patient's experience is the constant over time, while services and professionals may change. They argue that continuity of care is about the organisation of care in general, and as such should extend across care rather than be focused on particular transition points or episodes in care. The team points to formal structures (e.g.) put in place by professionals, such as the 'machinery and tools of partnership working' (*LD & stroke* project p ii) and care pathways, but suggest there is limited evidence that these result in an improved patient experience of continuity, particularly in the case2 of people with learning disabilities. The team suggest that care pathways may be of limited value due to the diversity of patient's experiences and journeys, however, they also note that varation in care may be a reflection of professional's response to differing individual needs.

Overall contribution

The project highlights the factors associated with continuity and discontinuity across transition points, emphasises the centrality of the patient *experience* in understanding continuity, and highlights that organisational structures put in place by professionals with the aim of improving continuity may not actually improve the patient experience of continuity. In the example of young people with learning disability it also reminds us that continuity, in the sense of

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bridging gaps in care, is a meaningless concept if there is little of substance beyond the gap.

3.4.5 Main stroke project

The final report from the stroke project was not available at the time of writing, and only a small amount of information about the findings of the project was available from a workshop organised by the SDO (Hill *et al*, 2006). The project involved interviews with patients and carers and the development of a questionnaire measuring Patient Perceived Continuity (PPCI).

Findings

Findings from the patient interviews suggested that patients recognised quality of care and satisfaction with care, but did not recognise or recount aspects of continuity in relationships, information transfer or management of their care. The team conclude that it may be difficult to separate continuity from quality and satisfaction when exploring patients' views. Interviews with health professionals indicated that staff recognised the importance of teamwork (cross boundary and team continuity), of committed and skilled professionals, and contact and communication (cross boundary and team continuity, *informational continuity*).

The PPCI questionnaire focuses on continuity operationalised in terms of delays, coordination, and support at transition points.

The team recognise the limits of care pathways as a means of promoting continuity, as did the *LD and stroke* study. The *main stroke* project team draw on the idea of networks of care as a better way of understanding patient experiences across their care. They argue that this may involve re-conceptualising continuity of care in terms of understanding:

> '*Who's involved (Professional v. Lay); Nature of the contact or linkage (Obligation, Trust, Chance); Mode of communication (Conversation, Telephone, Email); Content (Knowledge, Information)*' (Hill *et al*, 2006).

This suggests a focus on communication links across those involved in the networks (team and cross boundary continuity, and *informational continuity*), whilst recognising that communication between patients and professionals may be a key aspect of continuity (as recognised in some of the other SDO continuity projects)

Overall contribution (at the time of this report)

Although as yet only limited information is available from this project, initial findings have suggested problems with understanding the meaning of continuity from the patient's point of view (particularly in the case of frail older patients), and the potential value of using networks as a means of understanding and promoting continuity.

3.4.6 Mental health

This complex project's central thrust was the development and use of two continuity questionnaires: CONTINU-UM for patients and CONTINU-ES for professionals. The main quantitative studies of groups of psychotic and of non-psychotic patients with severe mental illness were supplemented by a parallel qualitative exploration of patient, carer, and service provider understanding of continuity. In addition, a further parallel organisational phase studied professionals' responses to change in the two large mental health trusts taking part.

CONTINU-UM questionnaire development and use

The questionnaire was developed with input from patients and experts, reflecting issues that were seen as important to patients. The final version was compared with the multi-axial Scoping report's proposed types of continuity of care. Two of the Scoping report types were not represented in the questionnaire: *experienced continuity* and *relational or personal continuity*. Notably, aspects of the questionnaire relating to *informational continuity* referred to the provision of information to the service user rather than the transfer of information between professionals (this issue was also identified by the *diabetes* project, however there this issue was subsumed under *relational* rather than *informational* continuity). Much of the CONTINU-UM questionnaire linked to 'flexible' continuity. The questions which map onto each domain are show in Appendix 9.

The main phase of the project operationalised and measured the dimensions of continuity proposed in the Scoping report, using the CONTINU-UM questionnaire along with other measures. Factor analysis was used to explore how domains related to each other. The following seven factors were identified:

F1 Experience & Relationship (experienced / relational continuity)
F2 Regularity (long-term / longitudinal continuity)

F3 Meeting Needs (flexible continuity)
F4 Consolidation (cross-boundary continuity)

F5 Managed Transitions
F6 Care Coordination (longitudinal continuity)
F7 Supported Living.

The factors were relatively independent, although Managed Transitions was positively associated with Regularity, Meeting Needs and Consolidation. The authors suggest these findings overall support the scoping report's argument that continuity of care is conceptually more than a single entity.

Qualitative exploration of patient, carer, and service provider understanding of continuity

The qualitative phase with patients and carers involved interviews with patients and carers who were identified as having experiences of problematic continuity, or discontinuity.

Continuity of care 2006

This work suggested that problematic experiences of continuity were associated with a number of factors. *Relational discontinuity* (repeated changes of staff, particularly key workers) was a common experience and overall had negative emotional impacts on patients. Discontinuity was often experienced at transition points such as discharge when the transition was *depersonalised*, and where carers were not kept informed. Patients described feeling *invisible and abandoned* when their condition was stable, with a perception that services only responded to crises. *Communication gaps* between different services were also an issue, and this was compounded by changes in staff. Communicative gaps between patients and their carers, and service providers and carers could contribute to discontinuity. Carers felt it was important for them to develop relationships with key workers, and raised issues around the difficulties of judging when to share confidential information. Patients and carers emphasised the vulnerability of patients with mental health problems, and the uncertainties of the condition, suggesting that *social support* in terms of 'supporting patients in negotiating the complex world of benefits, employment and housing needs' is 'a key element of providing continuity' (*Mental health* project, qualitative strand p 277). Continuity of key workers, and information, were seen as important in promoting continuity.

Based on content analysis of text comments from a survey of providers, the team state that definitions provided by service providers in the survey and interviews mapped onto the definitions in the scoping report. Service providers primarily described continuity in terms of cross boundary and team continuity, as well as relational continuity, and longitudinal continuity. In interviews providers also described seamless continuity, as well as using complex or compound descriptions of continuity:

Seamless service

> *"I suppose the easiest way to describe it is as a seamless service, everything integrated and working efficiently to provide a good standard of care to the client. That's efficiency of resources, efficiency of what you're doing. I think continuity of care is about giving the care on the care plan..." (CPN, Trust 1)*

Complex definitions including several types of continuity

> *"It's about having an overall package of care and treatment for each individual client, so different people may input into that package of care... obviously the relationship that the users have with whoever is providing their care is vital because if that doesn't work people will disengage from services... there needs to be user and carer involvement in setting up the package of care." (Senior Manager, Trust 2)*

(*Mental health* project, organisational strand, p 311)

Overall contribution

The mental health project provides support for a multi-type definition of continuity and their findings match several of the scoping report types. However, there were some differences. For this patient group, *informational*

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continuity was described in terms of information transfer to patients rather than between professionals, and the factors 'managed transitions' and 'supported living' emerged as important for continuity in the Factor analysis. These issues were also raised in interviews with patients and carers. Providers' accounts matched scoping study definitions, but also included 'seamless care' and showed their awareness of the potential complexity of the concept.

3.5 Findings from the SDO studies

3.5.1 Support for a multi-axial definition of continuity

Overall, these projects support the notion of continuity as a multi-axial or multi-type concept. Most of the types of continuity identified mapped onto the original scoping report definitions. The *mental health* projects proposed two additional dimensions: 'flexible continuity' and 'supported living'. The subtle differences in type definitions across the projects suggest the need to revisit the scoping study definition of continuity (see section 4.1 below).

3.5.2 Emphasis on patient and carer experience of continuity

These projects have each succeeded in expanding understanding of the patients' and carers' experience of different types of continuity. The *diabetes, primary care*, *cancer*, and *mental health* projects have all shown how patients and carers want care to be appropriate and flexible and this highlights the trade-off between access and *relationship continuity*. Patients with severe mental illness want the intensity of their care to vary appropriately with their mental state (finding from severe mental illness review project (Crawford *et al*, 2004)). But the present *mental health* project clearly shows the vital role of *relationship* continuity for some patients or, too often, the effect of *dis*continuity:

> *Users mostly provided accounts that emphasised repeated changes of staff and this appeared to be a major area of discontent with services for both users and carers.* (*Mental health* project, qualitative strand p265).

> *All users and carers spoke about how crucial the relationship with a key worker was and the energy that was invested in that relationship by all parties. Although most had experienced changes in key workers the process never became any easier and for some, the prospect of losing their key worker was devastating.* (*Mental health* project, qualitative strand p293).

Those in *primary care* are prepared to wait to see their chosen practitioner, particularly for more serious problems (Baker *et al*, 2001). And patients with *cancer* cope better between consultations when they report better 'experienced continuity'. Patients with *diabetes* often expressed a strong desire for *relationship* continuity, even when this sometimes seemed to conflict with better care outcomes for them (Naithani *et al*, 2006).

3.5.3 Lay carers' assessments

Relationship continuity, where assessed, was associated with improved patient satisfaction (Naithani *et al*, 2006). However, for carers, the picture was more mixed. In both the *diabetes* and *mental health* projects, carers reported poor communication with health professionals and indeed tended to feel left out – with their vital caring role unappreciated by the professional. In both the *cancer* and *mental health* projects (only qualitative findings available) carers tended to be more critical of care experienced than the patients themselves. For *mental health* carers this may be partly due to the specific demands of mental illness, including the difficulty of appropriately judging when to share confidential patient information, as the researchers note:

> *Many users and their families were not kept informed of expected duration of stay and it was common for carers to report being unaware of the discharge of the user …… Carers often felt excluded from the care that services provided. Many felt that they could complement the care that services were providing... Few had an established relationship with a member of the CMHT. …their frustration at this was doubled by the knowledge that having been kept on the fringes of the care the user received if the user were to relapse or have a difficult episode it would primarily be the responsibility of the carer to manage the situation. (Mental health project, qualitative strand p 294).*

> *The issue of confidentiality was raised by many carers, whilst they fully respected the user's rights to privacy; they felt it would be useful if there were a similar opportunity for them to contribute to the care programme of the user. …Carers spoke passionately about their frustration at not being heard by services especially when they were trying to get some intervention before a crisis period. By dismissing carers' accounts, much valuable information was being lost. (Mental health project, qualitative strand p 294).*

3.5.4 Professionals

It is noteworthy (if not surprising) that professional views did not always mirror those of patients or carers. In the *diabetes* project professionals' responses led the researchers to omit questions on flexibility and access as a separate category. Professionals were naturally more aware of elements of *management* continuity, whereas patients were more likely to emphasis the 'continuous caring relationship'. Even so, the professionals preferred to maximise *longitudinal* continuity (and hence the opportunity for *relationship* continuity as long as this did not conflict too much with other priorities.

The *LD & stroke* project graphically reports the experiences of professionals involved. Often the *stroke* team would be incomplete; there was a general shortage of clinical psychologists, and social worker shortages often made it difficult for the service to attach a named worker to the hospital stroke team. As the report says:

> *It is important to stress that this issue of understaffing was thought by managers and staff interviewed to be the main underlying source of difficulties with continuity of care in stroke services. It impacts along the patient journey – in hospital, at the point of hospital discharge. It was frequently raised by patients and families and has implications for the whole service, for example in terms of goal setting and progress towards meeting those goals. As one occupational therapist interviewee put it: "…if you haven't got the staff to do the treatment plan there is no point in having the goals [because it raises patient expectations]" (LD & stroke project report p 74).*

Social workers, on the other hand could find hospital staff too risk averse, and insufficiently aware of what support was available in the community after discharge:

> *…social services' assessments of risk should be given at least as much weight as those of health colleagues – the latter, it was argued, typically being more risk-averse. There were, it was argued, "very different perceptions of risk in the community and the social model of disability". In addition… there was insufficient understanding of the range of social service support available – including, in this particular case, 24 hour support for short periods to carry out an extended risk assessment. i.e. much fuller assessment than on the typical one hour home visit from hospital. (LD & stroke project report (Hardy et al, 2001) p 62).*

3.5.5 More nuanced definitions of informational continuity

In the existing literature and in the scoping Exercise, *informational continuity* has been described as being about communication between professionals in terms of "excellent information transfer following the patient". The *diabetes and primary care* projects' measures of *informational* continuity follow this definition, although the *diabetes* project found this was difficult for patients to judge, and the *primary care* project commented that patient perceptions of inter-professional communication may not accurately reflect the true state of affairs. A common finding across projects was that *informational continuity* in the sense of communication between professionals was not prominent in patient accounts, although it was incorporated into some of the patient measures developed.

However, information transfer from professionals to patients was central to patient accounts and to each of these patient measures except *primary care*. Both the *cancer and mental health* projects explicitly identify the importance of information transfer between professionals and patients/carers in their early qualitative work, and include questions about this in their measures. This wider concept of *informational* continuity is clearly additional to, rather than a replacement for inter-professional *informational* continuity. Given the increasing emphasis on self-care, patient involvement and patient choice, this concept may help in understanding how to promote continuity. For example, in the *primary care* project patients described how they could promote their own experience of continuity by taking responsibility for the transfer of information (either verbally, or by holding their own care records). This is

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likely to be particularly relevant across organisational and professional boundaries. However, a significant minority of patients, such as those who are socially disadvantaged, vulnerable, frail, or very old, may be unable to take responsibility for such information transfer.

3.6 Consequences of various aspects of continuity

3.6.1 Does improved continuity enhance outcomes?

None of these projects was designed to test the effect of an intervention to increase continuity and so associations (with types of continuity) rather than consequences of continuity are all that can be expected here. The *cancer* project had the strongest design for assessing any consequence through its analysis of links between experienced continuity measured at 'time 1' and other aspects of patient experience at subsequent time points. In addition, cancer is a diagnosis associated with rapid enough change in clinical status during the measurement period of the project for meaningful outcomes to be detected. In comparison, the clinical timescale for patients with type 2 diabetes is far more extended.

The *diabetes, cancer* and *mental health* projects all examined the associations between continuity (as variously defined by their different measures) and a range of outcomes at a later time-point. The *mental health* project report lists a number of associations of differing continuity scores with the clinical condition of the patients and comments:

> *Our analyses also suggest, however, that relationships between continuity of care factors and user characteristics, including clinical ones, are not uni-directional. On the contrary, our study provides evidence that key elements of continuity of care may be provided by professionals in response to specific service user needs as these change, as well as impacting on them, and that continuity of care may thus be a dynamic process. (Mental health project (Burns et al, 2007), main phase p 234.*

However, we did not have the interpretation of the final results of this analysis for the *mental health* project, so this is not further discussed here except to comment that interpretation is necessarily difficult and underscores the need for intervention trials to establish causality. The *primary care* project was shorter in duration and cross-sectional and so did not assess associations between continuity and outcomes. However, it did examine trade-offs between two dimensions of continuity and access in a discrete choice experiment (Turner *et al*, 2006).

In the *diabetes* project, there is strong evidence of higher user satisfaction (and also staff satisfaction) associated with better continuity (their measure includes elements of *management* continuity, *informational* continuity, some proxies for *relationship* continuity, access, and availability of services). But there was no association between better experienced continuity and better disease intermediate outcomes (HbA1C and blood pressure).

In the *cancer* project patients' perceptions of better continuity (as measured in this project) were associated with higher satisfaction, better quality of life, less psychological distress, and lower care needs assessed over 12 months during a potentially fear-inducing illness.

In summary, these projects provide little new evidence about the effects of more or less continuity, of any type, on 'hard' health outcomes. These projects were simply not set up to find these. Instead, existing evidence that users (patients), lay carers and professionals all welcome and encourage *relationship, management and informational* continuity is plentiful and these projects help us understand why this is so. Some may see this as a worthwhile outcome in itself and others may prefer to wait for harder outcomes. Inasmuch as changes in care organisation appear to incur penalties in types of discontinuity, these should perhaps be regarded as increased costs to be reckoned alongside any subsequent health gains of such changes.

3.6.2 Continuity and discontinuity: the access trade-off

The only project that specifically sought to study trade-off was *primary care*. Here it was evident that, when the problem is more serious and impactful, patients will trade off quick access in order to get appropriate *relationship* continuity and for *information* from records to be available. The diary study illustrated the efforts some patients had to make to achieve the continuity they wanted (Boulton *et al*, 2006), while the discrete choice experiment showed how many days patients might be willing to wait to see a professional who knew them for three different clinical scenarios (Turner *et al*, 2006).

3.6.3 Administrative change and lack of resources: the re-organisation trade-off

The *LD & stroke* project sheds light on the independent contributions and the parallel roles of care services/structures, and of the professionals working within them, to continuity of care. They were particularly interested in the effects on the ground of a whole series of official initiatives intended to promote 'joined up' care. But they found that where the structures and resources were lacking (*LD*) the professionals could do rather little and sometimes even reacted by becoming dysfunctional. Their final conclusion:

> *Our blunt conclusion to the learning disability case study was that 'the key feature of transition seems to be discontinuity rather than continuity'.*
> *(p 208 Hardy et al, 2006).*

In the case of *stroke* things were better and the researchers found examples of professionals working creatively to bridge gaps in continuity. In both these clinical areas resource shortages imposed discontinuities on patients' experience, the most prevalent being clinical psychology.

Efforts to reorganise and reconfigure services have a generally adverse effect on management continuity, at least initially in the change cycle, which is the timescale of these projects. The *LD & stroke* project highlighted the adverse effects of 'organisational turbulence' prevalent for many years in the NHS.

3.6.4 Enhancing and prioritising continuity of care; barriers to this

The *diabetes* project suggests that a named lead clinician can enhance continuity of diabetes care as perceived by patients in primary care. It would seem that this is even more needed when coordinating specialist and primary care for those receiving hospital outpatient care.

In the case of *cancer* events soon after initial diagnosis seemed crucial. If patient trust could be established early on, this would be associated with improved continuity (here seen as a beneficial outcome) over the following year.

Three of the projects emphasised the need to target vulnerable patient groups.

The *diabetes* project studied patients with language difficulties. In *primary care* also there were problems for working people who wanted to consult outside their normal working hours as well as for those who found it difficult to negotiate GP appointment systems. These might again include people with language difficulties or lacking in social skill and confidence. They advocate more flexible appointments systems and better receptionist training. For patients with *cancer,* those needing most help either had difficulty with their close person relationships or were less willing than others to take responsibility for their care. The *cancer* project advocates identifying such patients soon after diagnosis and the team are planning an intervention to feed into early multidisciplinary team meetings for care planning.

Some of the findings of the *LD & stroke* project had been anticipated in 2001 by the human resource management review project (*Appendix 9*) who concluded:

> *The most fundamental barrier identified to the successful implementation of policies in all six policy areas was the chronic and continuing shortage of staff (Humphrey et al, 2001).*

Much political and administrative effort has been spent on reconfiguring services, aiming, in particular, for shared administrative boundaries (co-terminosity and co-location). The *LD and stoke* project found that co-location was potentially helpful but by no means a sufficient driver of better co-ordination of care, especially if each set of professionals respond to different administrative criteria. At one site there were social workers, support workers and health care professionals, each with different line management, processes and systems:

> - *"different people doing different things but coming together for meetings"*
> *as one respondent described it. (p183 Hardy et al, 2006).*

This project also focused on the effects of both interprofessional and institutional boundaries. In spite of much encouragement there were still serious gaps between doctors and allied health professionals and between health and social care staff. In the case of *learning disability* there was also a considerable gap between social services and the education service.

In the organisational strand of the *mental health* project, resource shortages were again found to be a problem, but this was compounded by inadequate change management support. For example, social workers could find themselves co-located with healthcare staff (potentially helpful) but be find that their IT software was incompatible with that of their new colleagues, and so be severely handicapped at first.

3.6.5 Transition points and continuity

Several of the projects, notably *cancer, mental health, LD & stroke,* and *main stroke*, investigated continuity in the context of complex conditions where care extended across a number of inter-professional and inter-organisational boundaries. These studies identified that transition points in care can put continuity under strain, with examples of patients experiencing gaps and chaos in their care. The *main stroke* study points to the need for 'competent adaptable and resourceful professionals to bridge all kinds of unpredictable gaps in the care of these initially very dependent patients'. However, there are variations in the extent to which this seems to be achieved. For example, the *LD & stroke* study found that transition points were often successfully bridged in the case of patients with stroke, but less so in the case of individuals with learning difficulties.

For people with *learning disability* a key continuity initiative was the establishment of 'Connexions Personal Advisers' (PAs) within adult social services departments. The PA's job was to work directly with users and their parents and also to 'broker access to specialist support', hence filling this role of bridging gaps and smoothing transitions across boundaries. This appears to be a good idea and mirrors efforts in many health care programmes designed to improve management continuity by the appointment of a coordinator – typically a specialist nurse. However, PAs were often unable to carry out their role effectively because of the scarcity of services that could be 'connected' for patients. The difficulties of setting up a new role in an underfunded service also suggested problems of inadequate training and of role conflict, with individual PAs feeling the lack of both expertise and professional support to fulfil their role. As one PA said:

> *"I think there is a basic lack of understanding strategically about the needs of young people with special needs. There is nobody I know of up there who has a solid special needs background, interest or title. There is nowhere to feed into." (p 164 (Hardy et al, 2006).*

The study suggests that a lack of services compounds the problem and can make it impossible for gaps to be bridged.

3.7 Canadian perspective on 48 CHRSF studies

3.7.1 Background

From 1998 to 2004 continuity of care was one of the funding priority themes of the Canadian Health Services Research Foundation (CHSRF). During this

period the Foundation funded 72 research programmes. The present summary synthesis is based on 48 final reports that were available by May 2006. All final reports have a maximum of 25 pages and since their audience is expected to be decision-makers and managers, they differ in the extent of methods and results provided. Information from the reports was abstracted to a closely similar template of themes as used for the SDO projects (*Appendix 3*).

Of the 48 completed studies, 14 were judged not to address continuity as defined in the Canadian continuity of care 2000 Synthesis published in 2002 (Reid *et al*, 2002). The remaining 34 studies were analysed to draw out the essential lessons. Compared to the SDO programme, each Canadian project was smaller in scope (costs in the range £80k-£120k) and ran for a maximum of three years. However, given the larger number of studies the Canadian programme addressed a broader range of health conditions and services than the SDO one.

The objectives of the Canadian synthesis were to map the concepts of continuity against *informational*, *relational* and *management* continuity identified in the Reid-Haggerty synthesis (Reid *et al*, 2002); to summarize the findings and to identify key projects that advanced understanding of continuity and/or its impacts.

Overview of projects

Of the 34 Canadian studies that addressed continuity of care, all but five looked at more than one type of continuity. When we examined the type of continuity that was of principal interest, 69% looked at *management* continuity, 23% at *relational* continuity and 11% at *informational* continuity (defined according to the updated model of Haggerty *et al* (2003) which was published after input from the experience of the SDO Scoping study (Freeman *et al*, 2001).

In 19 of the 34 Canadian studies continuity of care was the *outcome* of interest. These looked at barriers and facilitators of continuity or interventions to improve some aspect of continuity. In seven of these 19, continuity was presumed to result from the implementation of policies or interventions such as care pathways, information or communication tools, and service integration. These studies focus on barriers and facilitators to implementation rather than continuity itself and they are relatively uninformative. The remaining 12 studies which focus on continuity provide some important insights into concepts or measures of continuity.

Patients and the definition of continuity

Five of the Canadian studies were focused specifically on the conception of continuity of care from the patient perspective. Like the SDO projects, the Canadian studies found that patients appeared to report on elements that relate to overall quality of care rather than elements specific to care transitions or consistency of care over time. Several extra dimensions that we consider to be distinct from continuity of care but which are, arguably, closely related were consistently referred to as dimensions of continuity: access to

services, interpersonal communication skills of the provider, and technical quality of clinical care.

These studies also lead to some further development around *informational* continuity. From the Haggerty-Reid conceptualisation it can be argued that this does not constitute a robust type of continuity, but is rather instrumental to *relational* or *management* continuity. Qualitative research on the patient perspective consistently highlights this component, but the innovation is that they speak about the inclusion of the patient and/or caregiver in the information flow. Patients and carers repeatedly express how critical it is for providers to give them information about their condition and education to enable them to self-manage their condition (Adair *et al*, 2004; Lee *et al*, 2006; Biem & Hadjistavropoulos, 2004; Contandriopoulos *et al*, 2003; Gagnon *et al*, 2001; Lemieux-Charles *et al*, 2002). This supports what was found in the SDO projects.

3.7.2 New continuity measures

Three validated tools were developed from qualitative inquiry into patient perceptions of care; they address specific health conditions (mental health (Adair *et al*, 2004), diabetes (Lee *et al*, 2006), cardiac (Biem & Hadjistavropoulos, 2004) and to a greater or lesser extent include these extra dimensions in the continuity construct. The inclusion of other care attributes in these measures may perhaps provide more meaningful representations of patients' experience of care but they lack specificity on types of continuity of care. Only the mental health measure (Adair *et al*, 2004) clearly and specifically identifies types of continuity as distinct from other attributes; as such it is a very promising instrument that may have relevance beyond mental health. The problems of lack of specificity have already been outlined in this report.

3.7.3 Mechanisms of achieving continuity: importance of patient participation

Patients and their carers perceive that they have a role to play in generating continuity of care, in partnership with providers. In particular, there is a clear sense that informal care-givers assume a role in achieving *management* continuity on behalf of the patient. Though this was not specifically addressed in the SDO projects, it is suggested in the *primary care* project where patients talk about different strategies they use to get continuity of care when they think it is important, and in the *cancer* project where some patients express a clear desire to manage their condition, not just cope with it. In the Canadian studies, many patients saw their continuity role as being clear in their communications to professionals - complying with treatment recommendations and engaging in self management; however, their role also includes advocacy for access to recommended services on the care continuum.

This is an important finding because, in the literature, continuity has often been portrayed as being principally the responsibility of the provider. The inclusion of patients and carers in the information flow and care planning and

patient education are mechanisms for recognizing this partnership. Patients and carers repeatedly express how critical it is for providers to give them information about their condition and education to enable them to self-manage their condition (Turner *et al*, 2006; Boulton *et al*, 2006; Humphrey *et al*, 2001; Reid *et al*, 2002). They want to be included in the information loop.

Flexible access and continuity

Organisational flexibility around access to services facilitates an active patient/carer role in continuity. If services are difficult to obtain in response to changing needs over time, patients or carers will have to resort to various strategies in order to obtain needed care and avoid breaks in management continuity. In the home-care situation, patients may have to go into crisis (emergency room visit) in order to obtain the next level of home care service intensity (Adair *et al*, 2004; Brazil *et al*, 2002). If the provider has rigid rules surrounding access then continuity suffers. Likewise in *primary care*, if a physician's practice is organized rigidly around scheduled visits, intended to enhance relationship continuity for chronic problems, it may be difficult for patients to get good relationship continuity for acute problems (Haggerty *et al*, 2004).

Other mechanisms – some patients are more vulnerable

Not all patients or carers are equally willing or able to assume an active role in continuity. Some patients such as the frail elderly or those with severe and persisting mental illness require that the providers make the efforts to facilitate access to needed services, communicate with all the different providers, and give the patient confidence in a supportive caring relationship. Vulnerable groups also include those with cognitive impairments or with complex acute conditions, and those with limited social networks. Several studies (Naithani *et al*, 2006; Boulton *et al*, 2006; Humphrey *et al*, 2001; Adair *et al*, 2004; Lee *et al*, 2006; Haggerty *et al*, 2004) demonstrated that interventions to improve continuity had positive impacts on patient satisfaction, improved quality of care, and on patient functioning, and these were more likely to be seen in vulnerable patients such as those mentioned above, and those with acute complex health conditions.

The mechanisms to ensure continuity differ depending on the extent to which the patient is assuming an important role in the management of his/her condition. Ambulatory care patients conceive of self-responsibility as part of continuity of care (Naithani *et al*, 2006), and providers need to undertake actions to support that role through providing them with timely and accurate information to support their self-management (Boulton *et al*, 2006; Humphrey *et al*, 2001). On the other hand, if patients are not able to participate in their continuity of care, they need providers to assume responsibility for continuity, and some examples are discussed below.

3.7.4 Consequences of better continuity

Not all interventions to improve continuity lead to improvements in healthcare or functional health, and these examples are very informative. This seems to be particularly true of tools to improve information transfer and care planning.

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While providers always appreciated having better or standardized information about patients (Lemay *et al*, 2002; Afilalo *et al*, 2003; Goulet *et al*, 2006; Dudgeon *et al*, 2004), this did not necessarily translate to differences in care delivery. Information and communication tools or even shared care plans cannot compensate for problems with resource availability (Lemieux-Charles *et al*, 2002) or themselves overcome entrenched provider behaviour (Boulton *et al*, 2006; Gagnon *et al*, 2001; Lemieux-Charles, 2002). We surmise that information transfer – or *informational* continuity – is a necessary but not sufficient component of *management* continuity or quality of care.

Continuity alone is not enough

In particular, interventions to improve continuity in vulnerable populations require robust supports not just improvements at the margins. Two of the 'showcase' Canadian studies demonstrate the effectiveness of continuity supports for patients with severe and enduring mental illness, after discharge and generally in the community. Both entailed providing support to patients to enhance their transition to community care, including the maintenance of regular contact with providers (longitudinal and *management* continuity, and establishment of a good therapeutic *relationship* with community providers. The interventions in the Canadian studies addressed the barriers and facilitators of continuity that were identified in the SDO *mental health* project by patients, carers and care managers

In the cohort component of the Adair *et al* study (2004) 439 patients were followed for 18 months. Better continuity (measured with a validated instrument using both patient report and trained observer ratings) was associated with lower severity of symptoms, better community functioning, higher quality of life (both generic and disease-specific) and greater satisfaction with services. The findings from this cohort study were then used to design a community support intervention specifically focused on improving continuity (the Community Extension Team (CET)). The CET provides bridging support in the community after a crisis event or hospital discharge, until regular community supports are accessed. It was piloted in a pragmatic randomized trial. Compared with a usual care group, those who received support from the CET had lower severity of symptoms, higher observer rated overall functioning, better quality of life and self-reported health, and fewer admissions and in-patient days (Adair *et al*, 2005). However, emergency room presentations and crisis calls were higher in the intervention group. Work is continuing in a bigger sample to confirm the findings, and measure cost-effectiveness.

Forchuck *et al*'s (2002) intervention involved continued contact after discharge with the in-hospital provider with whom the patient had established the best relationship until a solid *relationship* had been established with a community provider and in addition the patient was given peer support from a previously discharged patient. After one year, continuity of care, measured by a sense of not being 'cut adrift', led to higher quality of life and levels of general functioning.

3.7.5 Tacit information

These two projects also demonstrate the importance to *management* and *relational* continuity of having providers that cross organizational boundaries. These 'organizational ambassadors' are able to understand the different organizational cultures and create effective bridges for care pathways and smooth transitions. Although no one questions the importance of having good information systems, it seems to be equally important for providers to have face-to-face communication in order to adapt care to the needs of the patient (*management* continuity?) and enhance quality of care. One of the advantages of having a consistent and limited set of providers is that the complexity of information transfer is reduced (Woodward *et al*, 2001) and *tacit information* is passed on. Tacit information about patient preferences and circumstances is embedded in the therapeutic relationship, and it may require trusting relationships between providers for this information to be passed on. By definition, tacit information is not found in a shared computerised record.

3.7.6 Costs

The projects that illustrate the benefits of continuity for quality of care and health suggest that robust continuity supports are costly but they can also result in cost savings to the system (Adair *et al*, 2004; Forchuk *et al*, 2002; Stewart *et al*, 2002).

In the Adair *et al* (2004) mental health project, continuity was associated with slightly higher community costs but lower hospital costs[3]. This finding is new evidence that health service systems with good continuity of care can save hospital costs (Mitton *et al*, 2005).

However, these three studies of expensive interventions demonstrated that while hospital costs were reduced as a result of better continuity, costs increased somewhat in the community services where the continuity intervention occurred. Such accrual of costs and benefits in different components of the system may be disruptive and hence a barrier to implementation.

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[3] Community costs averaging $1511.00 higher and hospital costs averaging $4790.00 lower (Canadian dollars). In either case this is for the highest continuity category compared to the lowest after adjusting for age, household income, suicidality (estimate of suicidal intent), and duration of illness.

Section 4 Discussion

The major contribution of both the SDO and Canadian programmes of continuity of care research comes from their emphasis on the patient's perspective. Making care more patient-led is a key aim of modern health service policy (Department of Health, 2005) and these projects help us understand the place of continuity in more patient centred care.

The SDO programme is exceptional in the field of research into continuity of care for its focus on patients' experience of continuity and for funding appropriately long term projects. But this last feature means that at the time of writing (2006) some of the most original work is incomplete and so, as yet, inconclusive. The SDO programme is also exceptional in the extent to which carers were included.

In contrast, the Canadian programme funded a larger number of smaller projects over a longer period. As a consequence they cover a wider range of topics than the SDO program. However, Canadian did not have an equivalent of the scoping review until 2001, so the initial set of projects were very heterogeneous in their conceptualisation of continuity. A number were later judged to fall outside the scoping review. As with the SDO, this clarified the parameters for researchers and generated original work on the measure of continuity. The results dovetail well with the SDO programme.

4.1 The evolving concept of continuity of care

4.1.1. Is it helpful to define experience as a type of continuity?

No previous body of continuity research has taken such pains to define specific continuity types. The clarity gained has been gratifying and it has greatly aided understanding of researchers' aims, methods and findings. Problems of definition and measurement noted during the scoping study in 2000 (Freeman *et al*, 2001) have decreased but not disappeared. As already noted, one consequence of the focus on patient and carer experience has been to equate overall experience of care with experienced continuity, and researchers have not always delineated what aspects or processes relate to defined aspects of continuity and which to other attributes such as access, interpersonal communication, and technical quality of care.

We applaud the efforts to assess patients' and carers' experience of health care and types of continuity, this is a welcome rebalancing of perspective. On the other hand we also voice a note of caution about the utility of 'experienced continuity' as an entity, particularly where it has been defined to include any aspect of care that patients considered important. There are likely to be a range of outcomes from *informational*, *management*, *cross-boundary* 'flexible', and *relational* continuity, but we are not now convinced that these can be meaningfully packaged together as 'experienced continuity', although naturally they form part of the overall experience of care. The observed

outcomes appear to vary according to condition and setting, perhaps related to the salient priorities of care. The outcomes will also be influenced by other features of care. Perhaps satisfaction, trust and so forth are the most consistent outcomes from various types of continuity in different contexts.

4.1.2 Access and continuity

As well as aspects of continuity in its strictest sense (as previously defined in the literature) the way in which experienced continuity has been used in these projects includes other aspects of care such as availability of services. It appears to us to have become a proxy for 'quality of care' in a more general sense. This is particularly true in the way that 'access' is repeatedly included in measures of continuity. It is of considerable importance that the intertwining of access and continuity previously found in primary care (and examined in detail in the *primary care* project) is replicated across care areas. The implication is that the two should always be studied together – *access to appropriate care*. However, we think it is not helpful to re-label 'access' as 'continuity' – rather it is important to distinguish them and highlight the trade-off that users have to make between them. Whilst access is necessary to enable continuity, difficulties or delays in access can cause some patients in some circumstances to trade-off continuity for early access. Systems of access are a key facilitator or barrier to continuity in all its forms. We have seen how the same tendency to widen the scope of the concept of continuity happened in Canada (see 3.7.1, above).

4.1.3 Distinguishing between longitudinal and relationship continuity

Systems of access particularly affect longitudinal and *relationship* continuity. A necessary minimum of longitudinal continuity (seeing the same person where appropriate) is needed for *relationship* continuity (a trusting, therapeutic relationship) to develop, but none of these projects supports the notion that patients should always see the same practitioner in any given care setting. However, longitudinal and hence *relationship* continuity may contribute to the achievement of *management, informational* and cross-boundary continuity. Additionally, longitudinal and *relationship dis*continuity can be intensely frustrating for patients when it is beyond their control – as reported by both patients and carers in the *mental health* project.

4.1.4 Tacit and recorded information

There is some cross-over between *informational* continuity and *relational* in that so-called *tacit* information is by definition not written in official records and so depends on a relationship with one or more trusted professionals ('oral history'). In addition, evidence from patients in both UK and Canadian projects indicates that we should distinguish between the *informational* continuity between professionals (within teams and across boundaries) and between patients and professionals. These projects have emphasised patients' and carers' desire for adequate and timely information from professionals.

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This enables patients to play their part properly in partnership with professionals.

4.1.5 Evolving definition: A relationship between continuity types

Considering the SDO and CHSRF programmes together leads to a potentially useful evolution of the concept of continuity of care. It appears that the 'multi-axial definition' model proposed in the scoping report (Freeman *et al*, 2001) may have been misleading because it gave no guidance about how the various types might relate to each other. And it also seems to have encouraged the idea that experienced continuity was a type of continuity in itself, rather than a plea to study various types of continuity as experienced by users.

Haggerty *et al* (2003) saw experienced continuity as being essential to the measure of continuity, rather than a type in itself. Saultz (2003) arranged continuity elements into a hierarchy and Gulliford *et al* (2006) simplified the typology to two: a 'continuous caring relationship' and 'a seamless service'. Common to all these efforts is a recognition that continuity of care is multi-dimensional, many of which related to the elements identified in the scoping definition of continuity. However, there seems to be no consistent hierarchy between dimensions or types of continuity other than to say that informational continuity is always at the service of and in support of either relational or management continuity. The hierarchy of relationship and management continuity appears to depend on the care context as well as what sort of person is experiencing the continuity.

Even within types of continuity, the experience (and consequently the measure) will depend on whether care is predominantly person-focused or disease-focused, as outlined in the following matrix (Box 2).

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Box 2 Proposed matrix of three continuity types – person or disease focus

	Person-focused care	Disease-focused care
Relationship continuity (*longitudinal, personal, continuous caring*)	• patient-provider relationship that spans various episodes and often different care settings or care given by a core group of providers (e.g. homecare) • identified main coordinator of health care (e.g. family physician)	• consistent with group of providers with clearly defined roles (e.g. mental health care team) • organizational culture responsive to personal needs of patients (e.g. cancer care). • identified main care manager for specific disease (e.g. diabetes nurse, mental health key worker)
Management Continuity (*cross-boundary, team care, flexible, seamless service*)	• identified main care manager for specific disease (e.g. diabetes nurse) • co-ordination of care directly affecting patients (e.g. members of individual primary care team or ward based team) • detection of significant changes in functional status (e.g. severe mental health care).	• common care plan between providers (shared goals and agreed-on means) • negotiation of ongoing access to needed services (e.g. long-term community mental health care) • inclusion of patient as partner in the management plan. (e.g. diabetes care)
Informational Continuity	• accumulated knowledge - often tacit - of values and personal circumstances of the patient (e.g. palliative care or psycho-social problems) • up-to-date record of care and test results available at point of service (primary health care) • patient and family included in information loop (e.g. follow-up cancer care)	• information transfer between different providers (hospital discharge to community care) • up-to-date record of past services and results available at point of service. (e.g. maternity care) • consistency of messages communicated to patient (e.g. self-management of diabetes)

In predominantly person-focused care such as primary care and palliative cancer care, it appears that relational continuity is most important and is the means by which informational and management continuity are achieved. The *primary care* projects demonstrate how patients value their personal physician and the accumulated knowledge if they suspect a problem is serious, whereas they are happy to rely on informational transfer and access to a team when the problem is perceived as minor. Patients are sensitive to and best able to evaluate *relationship* continuity. Relationship continuity can even mitigate gaps in informational and management continuity, which may partly explain the discrepancy between patient and carer viewpoint in the *cancer* project.

Predominantly disease-focused care is typical of specialty and chronic diseases management, where appropriate treatment is the key concern, often by various providers. In these, management continuity is crucial and informational and relational continuity are engaged as a means of

achieving management continuity (e.g. the *diabetes* and the *mental health* projects). The perspective of the providers or informal carers seems to be particularly sensitive to breaks in management and informational continuity.

Management continuity is closely linked and sometimes confused with quality of care. Quality of care refers to the content of care whereas management continuity concerns the processes by which appropriate care is given in a timely and coordinated manner over time.

Continuity links past care to current healthcare and provides a known pathway for future care. Breaks in continuity occur when information or knowledge about past care or about the patient cannot be brought to bear on current care, or when security about future care is jeopardised by inadequate resources or conflicting care plans or absence of a health professional who assumes principal responsibility for coordinating care. These projects have contributed significantly to the understanding of the experience of relationship, informational and management continuity from perspectives of patients, informal carers, and health professionals.

The SDO Scoping definitions (Freeman *et al*, 2001) have not been specifically challenged – rather they have been used as a departure point for each project and then sometimes left behind. The *diabetes* and the *primary care* empirical projects used the scoping model (with its 2003 updates by Saultz (2003) and by Haggerty *et al* (2003)) as the basis of both the conduct and interpretation of their work. (as did the *severe mental illness (Freeman et al, 2001b)* and the *human resource management (Humphrey et al, 2001)* review projects). The *mental health* project specifically tried to map each of their developed continuity elements against the scoping study ones. This project proposed two further specific types or elements, 'flexible continuity' and 'supported living'. We agree with the diabetes project in considering that flexible continuity cannot usefully be considered a distinct type of continuity. We see it more as an aspect of access to care, yet closely linked to continuity. Similarly supported living is an extension of care from hospital to community. Thus various types of continuity should normally be assessed alongside other care factors such as access, availability of resources (people and facilities) and organisational factors. Once again, we urge that researchers (and professionals) always be as specific as possible and say exactly of what type of continuity they are interested in when assessing patients' and professionals' experience.

4.1.4 Measurement of continuity

It follows that with more agreement on definition some progress has been made with measurement. But the progress of both the Canadian and British continuity research programmes has been marked by multiplication of project-specific instruments. Thus it remains very difficult for researchers to compare findings meaningfully across studies. And there is still no generally agreed measure for managers and professionals to use in assessing elements of the continuity of care that their services provide or

that their patients experience. Therefore it is a priority for both service and academic fields to develop and test more robust and user-friendly continuity measures.

Investigators of the *diabetes project* are already testing a modified version of their instrument (Gulliford, 2006) in a wider range of chronic medical problems.

While context specific elements must be needed for different care groups and settings, it is less clear how far specific diagnostic groups (*cancer, diabetes, mental health*) actually require their own continuity concepts. We think it is more helpful to specify the type of continuity carefully and then investigate context specific variation both in continuity types and levels and their association with other aspects of care delivery. For example, in the *mental health* project, the finding that some service users wish to have less continuity of contact when they choose is not a different type of continuity but rather, over time, a changing valuation of the importance to users of maintaining longitudinal continuity with a mental healthcare team when they feel they do not need this.

4.2 Patient and carer experience: priorities for types of continuity

4.2.1 Continuity and more general patient experiences

The *cancer project* suggests from patients' experience that continuity (as they define it) is less a package that professionals can offer and more an interaction between the care offered, the context and the patient's beliefs and attitudes about those close to them (King *et al*, 2001) (para 9.3.1 p 96). Thus it can be facilitated rather than provided. This strongly supports the concept of care being a product of partnership. They also show how their subjects who report greater continuity feel more in control and able to cope for themselves between professional contacts.

Patient experience of aspects of continuity of care does not necessarily mirror that of professionals. *Relationship* continuity (a continuous caring relationship) grows in importance as patients suffer from more complex problems – but realising it depends on commitment from both patient and professional. It was important in *type 2 diabetes* but it seemed particularly salient in *mental health* where severely ill patients may be very dependent and in *primary care*, where patients have more scope to control their access and trade off access with choice of practitioner. Here patients prioritised *relationship* continuity most highly for more serious conditions and were often willing to wait for this.

Other aspects of continuity are valued highly by patients. Many *cancer* project patients felt that improving NHS administrative procedures could go a long way towards improving continuity of their care; this is an aspect of *management continuity*. But the *cancer* project also raises more fundamental issues about the nature of care, in particular the degree of involvement of patients in their own care and the adverse effects of

paternal or even patronising behaviour by professionals (see next section). Well delivered care, perceived as having better continuity, appeared to enable patients and their close carers to cope better between consultations in this threatening and fear inducing condition.

Patients with *type 2 diabetes* valued both *relationship* and *management* continuity and the combined continuity measure used was strongly associated with satisfaction. Such continuity was better when led in the community, especially where one person was identified as leading diabetic care in the general practice. It was not, however, associated with better outcomes for blood sugar or blood pressure control over the period of this study.

4.2.2 Changed patient-professional relationships

The recently revised *cancer* project report (King *et al*, 2001) suggests that the experience of patients may be a very complex process and that 'experienced continuity' is not therefore a specific package to be offered by professionals. This is about the evolving relationships between patients and professionals, particularly doctors. Progress towards more of an adult relationship between equals (Tucket *et al*, 1985) has profound implications for care delivery, which Coulter, in particular, suggests has much further to go in Britain (Coulter, 2002; Coulter 2006). This reflects the difficulties faced by patients and carers, even in the 21st century, in negotiating and choosing the way their care is delivered. The scope for negotiating appointments in primary care, albeit flawed, is one important example. Likewise, *informational* continuity (professional to user) is necessary for shared decision making, and *management* continuity for the implementation of shared decisions in a complex health system. Both policymakers and professionals need to pay more attention to these aspects of continuity to achieve the goal of health care decisions shared with patients that is integral to the modern NHS Plan (the patient as partner as highlighted in the report of the Bristol Inquiry (Kennedy, 2001)).

Professionals need to be aware of user perceptions and they may be insufficiently aware of linked problems of access (Dixon Woods *et al*, 2005) but they have their own perspective. The *diabetes* project in particular shows how professionals are necessarily more aware of *management* continuity issues.

Another message for researchers is that it may be helpful to specify the *care context* of continuity studies in a more organised way. Continuity in a small system like a general/family practice is a different challenge from a large hospital and again from a whole system of healthcare or even health and social care. Each context may contain the elements of seamless care delivery and continuous caring relationships experienced by patients/consumers/clients over time. But different levels are not comparable and require different study approaches.

4.2.3 Lay carers

While the patient-professional relationship evolves towards greater equality and mutual respect, the SDO projects suggest that lay carers remain undervalued and even perhaps misunderstood. Carers played a crucial role for patients with diabetes, cancer and mental illness, all serious conditions (we await any parallel findings for carers of stroke patients). The cancer 'close persons' (carers) appeared to do best. This suggests that the role of carers is better recognised for patients with an illness likely to be fatal sooner rather than later. In the case of diabetes and mental illness it appeared that their role is not yet sufficiently appreciated by health professionals and this is an issue for further research in order to inform future training and continuing education.

4.2.4 Morbidity contrasts and co-morbidity

These programmes studied the experiences of contrasting diagnostic groups of patients and it is easy to see that patients suffering a fearful condition like *cancer* over a period of several years shared different priorities from those recovering from *stroke* (main project) or suffering *severe mental illness* or *diabetes* over much of a lifetime. But today's people are living longer and suffering more chronic conditions concurrently – co-morbidity. None of the projects reviewed addressed co-morbidity as a central issue.

Co-morbidity is a growing problem as more people live longer, particularly for the most vulnerable patients in deprived communities (Watt, 2002). It is complex to investigate and tends to be missed by disease specific research programmes; it can only be addressed by suitable combination of generalist and specialist care. This applies in both hospital and community settings. The generalist may not necessarily need to be medical but they do need to have expertise and organisational power. The *LD & stroke* project showed how an under-supported and under-trained generalist personal adviser was often effectively powerless to improve *management* continuity for adolescents with learning difficulty. Future studies should target disadvantaged groups, for example older people and their carers, both lay and professional.

4.2.5 The (linked) challenges of hard to reach populations and poor response rates

In general, levels of continuity of care in its several aspects were measured as good in many of these SDO projects. This seems encouraging, and, in the case of *cancer*, for example, may represent the beneficial effects of a well resourced well planned service with maximum national priority. But this may also be because it has proved more difficult than anticipated for researchers to access the more problematic areas of care and the least satisfied patient groups. In the *diabetes* and *primary care* projects response rates tended to be lower from patients in more deprived areas, and it was harder to recruit practices to participate. This means that we

cannot speak with confidence about how patients are experiencing aspects of continuity across all care areas.

4.3 Effects of continuity

Strictly the SDO projects could only seek associations with rather than consequences of changes in continuity. However, these were often persuasive and in line with other evidence. The *diabetes* project confirmed greater patient and staff satisfaction without any association with better clinical outcomes over the relatively short study period. The *cancer* project with a stronger design for showing time trends showed a wider range of associations with better well being and reduced care needs. The slightly confusing picture from *mental health* has been noted already, together with their suggestion of a dynamic two way relationship between user needs and provision of better longitudinal continuity. However, the *mental health* project is emphatic on the value of *relationship* continuity to both patients and carers. Further interpretation is awaited from the *main stroke* and *mental health* projects.

In Canada, both Adair *et al*'s (2004) and Forchuk *et al*'s (2002) studies showed encouraging improvements in health outcomes after one year. For the mental illness care in Adair *et al*'s study this meant reduced hospital costs but at the expense of greater community costs with little overall cost benefit (Adair *et al*, 2005). We look forward to the setting up of more intervention trials, particularly in the British context.

The effects of discontinuity are exposed in the *LD & stroke* project – but it is likely that this discontinuity is itself largely the result of inadequate resources, support and morale, rather than fragmentation in care processes.

4.3.1. Facilitators and barriers: vulnerable groups

Both the *human resource management* review project and *the LD & stroke* project highlighted the crucial role of adequate resources in encouraging management continuity, as well as the potential of repeated administrative re-organisation ('organisational turbulence') to inhibit it. But progress is vital, including changes designed to reduce interprofessional gaps in care. To achieve this properly change management support must always be factored in as shown in the organisational strand of the *mental health* project.

The *diabetes* project suggested the need for good clinical leadership of a disease specific care programme. The *cancer* project recommended giving more priority for *informational* continuity from professional to patient and the primary care project highlighted the trade-off patients have to make between access and *longitudinal or relational* continuity.

All projects reporting so far have shown that special attention is needed to enhance continuity for *vulnerable groups*. These include people with language difficulties (*diabetes* project), those who find it difficult to negotiate their choices (*primary care*) and those who are either more

severely ill or otherwise unable to take sufficient responsibility themselves for negotiating their care needs (*cancer*). This requires new priorities in staff training and ways of administering access to care. It also requires necessary resources for language translation where needed, and the best distribution of resources towards the most vulnerable.

4.4 Two programmes of research into continuity of care

4.4.1 The SDO continuity research programme: more than a series of projects?

Along with the CHSRF programme from 1999, the SDO's Continuity of care theme since 2000 is the largest ever funded concentration of research on the topic. In particular the SDO has funded some of the longest duration projects of this essentially longitudinal topic – up to six years.

The SDO has made considerable efforts to make project teams aware of each other's work and to profit from others' experience. Several early review projects were available to feed into ongoing review projects. In this review we were commissioned to synthesise the findings of the empirical projects in particular. Negotiations leading up to agreement of our contract emphasised the need for us to confirm our methodological expertise in synthesis of findings from heterogeneous projects (covering different clinical areas and contrasting care systems). Yet when we got to grips with the empirical projects at the start of our review it was immediately apparent that they differed so much in concept and method that any formal quantitative aggregation of findings would be impossible. In spite of starting with a scoping study which specified a model of continuity[4], each empirical study began with a qualitative study, usually focused on patients and carers. This was used to generate a new instrument, not usually sharing items from existing continuity measurement instruments.

This is partly because of a known paucity of suitable continuity measures, so new ones grounded in patient experience are very welcome. But this degree of heterogeneity does raise the question of whether it would be possible, in future programmes with similar challenges, for the SDO to take, or to otherwise arrange, a more active coordinating role? We venture to suggest that for a hypothetical re-run of this programme it would be worth having more comprehensive shared discussion of the concept of continuity in the light of initial grounded studies. Following this we could envisage each study sharing some common continuity measures as well as adopting their own instruments to suit their specific research questions. The general point is that convergence needs to be facilitated early in the life of research projects before their designs are too advanced. Such convergence would arguably encourage a programme to be more coherent.

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[4] The *diabetes* and *mental health* projects, in particular, took great trouble to try and map their measures on to the scoping study 'elements'.

4.4.2 Strengths and challenges of long-term studies.

We commend the SDO for its imagination and foresight in funding such long-term studies of this essentially longitudinal topic which so often suffers from short-termism both in policy and in research. Yet these long studies bring special challenges. One PI has fallen sick and another has made a major career move to another university. Some projects have had multiple changes of research staff – ironic when the lack of longer term posts is so often regretted. It is difficult to avoid these challenges but they need to be allowed for and anticipated at least in contingency terms. The SDO appears to have done this with equanimity. In fact setting up suitable longitudinal studies is itself time-consuming as these projects show, the actual maximum follow-up has not exceeded two years (covering three years' experience in the case of the *mental health* project).

4.4.3 Contribution of the Canadian programme

It has been immensely helpful to review the SDO programme in parallel with the Canadian one. The wider context and range of critical thinking has worked nicely in parallel with access to a wider body of evidence.

There has been no significant divergence of findings in the two programmes, suggesting that issues around continuity of care are largely shared across the developed world. But the parallels are important, notably our improved understanding of the patient's perspective. There are four main issues.

In *definition of the topic* the Canadian studies showed the same tendency as the British for patients to find continuity difficult to define and, perhaps because of this, the same tendency to expand the boundary of the concept to encompass very wide aspects of care quality, including access to and availability of services. In responding to this by not adopting this wide definition, we are not rejecting the patient's contribution but improving our awareness of the key factors associated with continuity that have to be assessed and perhaps improved along with it.

A key aspect of definition is better and wider understanding of *informational continuity*. The patient's perspective has clarified firstly that *professional to patient transfer* is potentially as important as that between professionals and across professional boundaries. Secondly the role of *tacit information* within relationship continuity has not been previously highlighted.

Increasing recognition of the *potentially active role for patients* is perhaps the most important parallel. The growing professional awareness of partnership with patients has someway to go and these reports suggest that Canadian patients may be ahead of British ones. But the same caveat applies in Canada and as in Britain: there is always a substantial minority of more vulnerable patients requiring more professional leadership in their care, for a variety of reasons to do with their social and disease context and their own personality. For patients with less autonomy, continuity

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initiatives that are not sufficiently robust and well-funded will not only be ineffectual, but serve to demoralize and frustrate providers.

Finally, several Canadian studies were able go beyond the findings that emerge from the SDO projects to demonstrate the *impact of better continuity of care*, not only on patient satisfaction, but also on patient health functioning and system costs. Again, we see that the maximum benefit accrues to the most vulnerable patients (with severe enduring mental health problems or complex disease management), but that successful continuity interventions result in cost-shifting rather than cost-saving.

4.5 Strengths and weaknesses of this review

Our team members have exceptional experience in research about continuity of care. The core team has been strengthened with an active advisory panel whose members cover a wide range of clinical and academic disciplines and, we would say crucially, international perspectives. We have been able to build excellent relationships with each of the SDO project teams and have had free access both to their thinking and to available documentation. Our process of establishing a conceptual framework, studying each project in site visits and in written material has been supplemented by two stages of feedback with project teams, firstly our initial field notes and later with the first draft of our report.

We also have a continuity of involvement with the SDO programme. The principal investigator (GKF) led the original SDO scoping study and subsequently worked on two SDO continuity projects. RB, MB and CT worked on the primary care project. GKF has collaborated with JH on continuity research since 1998, their joint work leading to a significant review paper in 2003 (Haggerty *et al*, 2003). This continuity has a downside with the risk of a partial and limited viewpoint, not sufficiently open to new approaches. We have been aware of this and have striven to minimise it. Notably, other members of our panel have not previously worked with the above named, and we have had repeated constructive criticism form colleagues in the USA, Norway and the Netherlands.

Our outcome findings are limited because:

- *The three largest studies were unfinished* (*cancer, main stroke* and *mental health*) and had not reported. Our funders (the SDO) are aware of this issue but perhaps had underestimated its impact and hoped for more in the way of preliminary/provisional findings. We did have a revised final report from the first and largest section of the *cancer* project. The second draft final report of the *mental health* project was available informally very shortly before our reporting date[5].

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[5] The submitted draft report of the mental health project appeared during our revision period and while we could not study it closely, page numbers of quotations refer to this latest version.

- *Absence of trials of interventions to improve continuity:* Although the *cancer* project in particular has shown that there are strong associations between their measure of 'experienced continuity' and subsequent patient outcomes, the SDO continuity programme has not included any projects in which interventions to change continuity were examined. The *cancer* project has used its findings to design an intervention to subject to examination in a trial (although the proposed intervention is more focused on getting professionals to discuss and take into account patient preferences for care, than on continuity processes per se). The *main stroke* project is also working towards a suitable future intervention.

- Our best information about interventions to improve continuity, and how these influence patient outcomes therefore comes from the review of the Canadian continuity of care programme.

- *Costs:* None of the SDO projects set out to assess cost-effectiveness. This remains an important issue for future research. The current large investment in the NHS programme Connecting for Health (2007) has obvious potential impacts on *management* and *informational* continuity which will need assessing.

4.6 Implications for policy makers, professionals and researchers

The overriding implication from these projects was that support structures need to be in place to enable the different types of continuity of care. The studies reviewed in this document indicate that this benefits both providers and users. Policy makers, professionals and researchers may be aware of the need to consider the effects of any changes in the provision of healthcare on both staff and patients/users and their experience of continuity.

Management continuity ('a seamless service') may seem most directly relevant to healthcare managers. No one makes a case for less management continuity, the questions are:

- how to deliver it?

- which interventions are more effective?

- are these cost-effective? and

- what are the unwanted or negative effects?

Relationship continuity is more visibly costly and with more salient trade-offs – for example poor access/longer waiting and restriction to a narrower range of expertise and services. Thus it is not such as self-evident good and may be easy to sacrifice in favour of more easily measured access targets. It is much appreciated by many, but not all, users and a significant minority of less empowered patients depend on it and are handicapped without it.

Informational continuity is being addressed across the developed world by electronic IT systems; in England this is called Connecting for Health (http://www.connectingforhealth.nhs.uk/itprogrammes). These seem

attractive, and indeed users in some of the continuity projects appeared to assume the availability of relevant information as a given. Yet no comprehensive IT development has yet 'delivered' and the challenge of interpreting ever increasing amounts of information of varying relevance is ever growing. These projects were not set up to investigate the effects of improved information systems; this remains a future research question.

Nevertheless, it is possible to speculate that the ambitious IT developments will improve information transfer for disease focused care but its impact on person focused care is less clear. Although better information may make the delivery of consistent care more likely, it may also promote fragmentation, particularly when implemented alongside other policy initiatives. For example, the disease-focused nature of the general practice quality and outcomes framework can, with the assistance of new IT systems, promote delegation of condition-specific care to different primary care individuals, creating a shift from person focused to disease focused patterns of care. Improved information transfer also helps to make possible the introduction of new provider organisations e.g. treatment centres, primary care facilities for commuters. These developments tend to promote disease focused care at the expense of person focused care, with implications for the aspects of care required to sustain the different elements of continuity (see table above). It is possible to argue, however, that other policies facilitated by better information flows might enhance person focused care. Plans to deliver care closer to home and transfer care from secondary to primary care might do so, depending on the extent of delegation and re-structuring to maximise the benefits of skill mix. It is important to note the uncertainty in the comments we have made about the potential impact of improved IT systems associated with new ways of organising services. It is critical, therefore, that as these innovations are introduced, careful studies are undertaken to evaluate the impact on the different elements of continuity. It would be inappropriate to make assumptions about the impact on continuity since the various innovations may interact in unpredictable ways, leading to unforeseen consequences for different elements of continuity.

Patient electronic access to their own medical record will be one feature of the new NHS IT system. This has obvious potential to improve information and management continuity. It also may improve relationship continuity, especially for people with co-morbid conditions, by enabling better informed decision making, planning of care, and improved communication between patient and professional. Further research into the implementation of patient record access is required. Practice based commissioning and patient choice offer potential counterweights to the trend towards disease focused care. By giving control over commissioning to the clinician with responsibility for person focused care, opportunities for tailoring disease focused care to the preferences of the individual and to providing disease focused care within the context of overall patient focused care, relationship continuity for those patients who want it might be maintained. Patient choice policies are currently concentrated on choice of provider of disease focused care. The extension of choice more widely into patient focused care as well would do much to put the patient (and carer) in control of decisions about relationship continuity. This may be the new, major challenge in policy development. But not all patients

may be so empowered. Both the SDO and Canadian projects show that there is an important minority of patients who either feel they cannot or else do not wish to actively manage their own care.

The problem of effective, consistent hand-overs – either in emergency care or in the long term care of people with *learning disabilities* for example – has yet to be satisfactorily resolved. The need for availability of relevant clinical information is again usually self-evident. Some studies (e.g. *primary care*) directly investigated patients' trade-offs between information and relationship continuity. Others such as *cancer* asked about the consequences of lack of information - aspects of care being overlooked. But the example of *tacit information* raised in the Canadian projects reminds us that we will never be able to rely entirely on formal record systems for the continuity of information which may be important for care.

Although in *primary care*, good *relationship* continuity may sometimes compensate for gaps and discontinuities in service provision, the *LD and stroke project* showed that resource shortcomings could not be solved by organisational measures to improve both *relationship* and *management* continuity for patients with serious conditions such as stroke or learning disability.

Continuity and outcomes

The *diabetes* project explained how the relationship between improved continuity and health outcomes is not linear. While satisfaction is improved for users, carers and staff, improved management or relationship continuity may be an appropriate response to deterioration in a long term illness and hence associated with poorer health. We still know too little about how the improvement of various types of continuity of care can improve health outcomes[6] and how best to achieve such changes. We also know too little about the cost effectiveness of such interventions. Research trials (or where possible natural experiments) are needed to evaluate the effects of types of continuity on health gains.

Scope for patients to exercise choice

In *primary care* while many younger patients are essentially healthy and far more able to control their lives, there is also a rapidly increasing proportion of older people and those with multiple problems and co-morbidities. Patients in *primary care* potentially have more choice of *relationship continuity* but this requires them to personally negotiate the option of waiting for someone they know and trust rather than urgently seeing an unfamiliar stranger, however competent. It is more difficult for them to exercise choice if access is poor or inflexible– see some of the examples in the *primary care* diary study (Boulton *et al*, 2006) which shows how much commitment may be called for from both patient and professional – not just 'choice'.

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[6] Even when death is the outcome, relational continuity of care from particular professionals may still be important in minimising stress experienced by the patient and carers.

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In *secondary care* patients can often only exercise their choice in negative ways – e.g. by defaulting from appointments – as well as by not complying with treatment regimens. Dixon Woods *et al* argue strongly that patients should not be morally judged for not attending, rather that professionals should critically examine access to their service (Humphrey *et al*, 2003). Current NHS initiatives such as 'choose and book' for secondary care referrals may change this. The *cancer* project shows that most patients are indeed autonomous and wish to have a major role in their care. the choice here is not so much who they see as of involvement in working out the best appropriate therapy and then making this happen. It is essential to know how to individualise care according to patients' specific needs (*King et al 2001* para 9.6 p102).

Unintended effects of other policies: Continuity and organisational culture

One consistent message from these projects is that, as fast as the NHS has initiated changes designed to make care more 'seamless' and hence continuous, it has frustrated this laudable aim by implementing so much organisational change as to cause disorientation and discontinuity. This is exacerbated by being unforeseen, so that no provision is made to preserve or enhance continuity. Therefore it is essential that aspects of continuity are highlighted and factored in during the planning phase of future reforms. In addition, Canadian work suggests that continuity interventions cannot compensate for lack of resources.

Our overall impression from these projects is that while policymakers are well aware of the need for co-ordination in an increasingly complex health system, the value of personal relationships is underestimated and undervalued in achieving this. The organisational culture of today's NHS does not value relationships and the need for trust and knowledge in making complex systems work. The *main stroke* project is best set up to demonstrate this. We await its findings with great interest.

The SDO and CHSRF projects have made impressive progress to the point where the next **main research priorities** are:

- Better measures of continuity types that are useable across a range of patients and clinical problems including co-morbidities.

- Better ways of identifying those patients who are most vulnerable and in need of help to maintain both management and relationship continuity.

- Well designed trials of complex interventions designed to improve delivery of all three main types of continuity (informational, management, and relationship) especially for identified vulnerable groups. These should be designed and powered to be able to show test the cost-effectiveness of successful continuity interventions.

- Study of the effect of organisational culture on management and relationship continuity of health care.

- Cross-referencing between the SDO and Canadian continuity programmes has been occurring at an administrative level and there has been some

academic linkage (Haggerty *et al*, 2003). The process of this review, including the involvement of a range of European and North American researchers has emphasised the potential for learning across international boundaries. Researchers now need to make a case for maintaining this momentum.

4.7 Recommendations

Policy priorities for service development and delivery

1. Invest in policies in order to support continuity of care

   - Monitor the impact of policy initiatives on continuity. Ensure that every policy initiative considers its likely effects on the different types of continuity, both during implementation and later when (hopefully) running as intended.

   - Be aware that user/carer/patient satisfaction is strongly associated with good continuity of care. This is positive for relationship continuity, i.e. good relationships will strongly enhance satisfaction; and potentially negative in respect of management and informational discontinuity, where evident lack of co-ordination leads to dismay and frustration.

   - Optimise access to encourage continuity. Good access is inextricably linked with both management continuity and patient choice for relationship continuity.

   - Target the most vulnerable. Continuity is already relatively good for many NHS patients. It is essential to concentrate resources and priority on vulnerable people who are either more ill or otherwise unable to negotiate their own continuity as they wish to.

2. Define and specify continuity

   - Specify the type or types of continuity whenever the term is used. The three main types are relationship, management and informational continuity. Also identify if it is disease- focused or person-focused care.

3. Beware of the hidden costs of organisational change

   - Minimise repeated organisational change ('organisational turbulence'), which acts strongly against management continuity and may even reduce relationship continuity through low morale. Policy makers need to be more aware of the opportunity costs of ill-considered short term change.

   - Back priorities with adequate resources. Management Continuity is not a substitute for lack of resources, though relationship continuity may sometimes be some compensation. Where there are system barriers to the provision of seamless care, they may frustrate and demotivate staff and patients as well as directly impair continuity.

4. Create a continuity friendly service

   - Promote less paternalistic attitudes in care provision through example, education, and reward - to allow both patients and carers to realise their own potential in negotiating appropriate continuity.

Therefore future research should aim to:

1. Improve generalisable measures of various continuity types to enable sharing of findings.

2. Develop ways of costing the effects of enhancing/reducing the costs of various types of continuity and associated factors, such as access.

3. Devise and test complex interventions to enhance various types of continuity at both system and individual patient levels in longitudinal studies.

4. Focus on the contrasting needs of vulnerable groups, including patients with co-morbidity, and how to address these.

5. Maximise the opportunities for both national and international co-operation revealed by this programme.

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Appendices

Appendix 1 Scoping report on continuity of care 2000

Discussion and recommendations

- The concept of continuity of care: implications for reviewing current knowledge
- Definition of elements of continuity of care
- Recommendations for research priorities

The concept of continuity of care: implications for reviewing current knowledge

Continuity of care is a broad and fluid concept which features in much of the literature on service delivery and organisation of care. It is clear that there is not a common understanding of what continuity of care represents. While we found a range of plausible definitions, even more frequently the term was used as an expression of striving for good quality care in an indeterminate way. It was not uncommon for the concept of continuity of care (or the lack of it) to be used to explain the results of a variety of measures of outcome, with little attention given to a specific definition or to any mechanism of application. The result was that searching for such a diffuse term identified a large number of articles for consideration, making the task of mapping the field without formally reviewing it an unusually challenging one. Even when attempts are made to define continuity of care it is usual for continuity of care to be part of a complex package of care.

This means that a rigorous and systematic review of the field of continuity of care, or even of discrete and defined parts of this field will need to go beyond conventional key-word-based searching techniques and to consider cross-referencing in detail. For example, had time allowed, the present authors would have obtained many papers not quickly available, read and digested these and then made repeated searches using modified criteria in an iterative fashion. We would expect to find relevant literature that was not listed as continuity of care research in any of our definitions.

Evaluations of complex models of care have disparate findings, making it hard to draw general conclusions. Although studies demonstrating the value of discrete interventions can be more usefully translated into practice this ignores the reality of delivering services, and teases out potentially important interactions in the way different components of a package of care relate to each other. In addition, 'standard care' is variable so that differences, if not stated, may account for the results of some evaluations.

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Definition of elements of continuity of care

We propose that at a minimum a definition of continuity of care should include the following elements.

1   The experience of a co-ordinated and smooth progression of care from the patient's point of view *(experienced continuity)*.

To achieve this central element the service needs:

2   excellent information transfer following the patient *(continuity of information)*

3   effective communication between professionals and services *(cross-boundary and team continuity)*

4   to be flexible and adjust to the needs of the individual over time *(flexible continuity)*

5   care from as few professionals as possible consistent with other needs *(longitudinal continuity)*

6   to provide one or more named individual professionals with whom the patient can establish and maintain a therapeutic relationship *(relational or personal continuity)*.

Recommendations for research priorities

In the light of this multi-element definition, research priorities should include the following.

1. *Studies of experienced continuity – to include process-based and longitudinal studies*

- Studies from the patient's perspective that investigate not only their experience of continuity and barriers to this, but also where discontinuous care might be perceived as especially problematic or, conversely, be highly valued by certain patients in particular circumstances.

- Research linking health care trajectories to patients' perceptions and values, which may require a combination of qualitative and quantitative methods.

- Investigations of patients' journeys through care to include their expectations and experiences of such care in a range of contexts (including the boundary between health and social care) – and especially in what ways these expectations and experiences are congruent with professional and managerial perspectives.

- Studies of adequate size to examine to what extent issues relating to continuity of care are more or less significant for patients from ethnic minority groups, and how interventions can be designed to overcome any major concerns found.

For some patient groups, including older patients and those with more severe problems, a longer-term, process-based perspective is needed to demonstrate

how experienced continuity might be enhanced. Thus some work with follow-up of at least three years should be encouraged.

2. ***The effect of elements of continuity of care on outcomes other than satisfaction***

- Studies that include the formal collection and analysis of costs and benefits from introducing particular service interventions aimed at improving continuity of care

- The examination of the extent to which different sources of information may be important in relation to the link between continuity of care and quality.

- The effect on patient outcomes (including process outcomes) of care being transferred from one setting to another, especially for patients who experience long-term health problems. This should include an examination of the benefits and costs of receiving care in a specialist setting or in less specialist settings nearer to home.

- The investigation of the extent to which high-quality processes of care in different settings may themselves constitute important outcomes of health care.

3. ***Innovative and multidisciplinary approaches***

We make the following more general suggestions about commissioning research in this area.

- Better understanding of how patients in a range of demographic and diagnostic groups prioritise alternatives and trade-offs between different types of health care. We suggest one aspect of the SDO's programme should call for imaginative qualitative or mixed approaches to this question.

- Studies which investigate when and how perceptions of continuity of care change or remain relatively constant, and to what extent these perceptions are contingent on life (or lifestyle) changes, rather than on specific health care experiences.

- Studies which investigate ways in which, in different settings, continuity of care is already being experienced, with a view to considering how such findings might be applicable to other settings.

- The unintended and conflicting effects resulting from the multidimensional and contingent nature of continuity of care. This could focus on the negotiation of different values and practices at all levels including relationships between patients and their carers, and professional, organisational and structural levels, as well as interactions between these levels.

4. ***Systematic reviews***

- A systematic review of patients' experiences of continuity of care.

  Such a review would go beyond what we were able to achieve in this rapid mapping exercise. It would take time and so should run in

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parallel with other work and be used to inform and contextualise findings rather than be used to define initial research questions.

- A systematic review of continuing care processes across professional, agency and legal boundaries for specific patient groups:

  – older patients

  – those experiencing illness from childhood into adulthood

  – those being discharged from hospital to intermediate or residential care settings

  – those with mental health problems.

We identified these areas in particular as needing wider search criteria. The last three were also identified as priority areas by voluntary organisations.

Appendix 2 - SDO 2005 brief

Directly quoted from the SDO call published in Sept 05

"In commissioning programmes of research about particular issues, the SDO Programme intends to produce more than a series of research reports on the individual projects undertaken. The intention is to bring the knowledge together, in order to make a significant contribution to theory, as well as practice, in respect of the specific issue. In order to do this for continuity of care, the SDO Programme now wishes to commission a piece of work to bring together the empirical and theoretical issues uncovered by the projects in the programme. This should include:

- a synthesis of the empirical findings from each project;

- advances made in conceptualising continuity of care;

- any differences in these concepts between care groups;

- advances made in measuring continuity of care;

- any differences in measuring continuity of care between care groups;

- any generalisable lessons about such issues as preferences (or lack of preferences) for continuity of care among service users and carers and methods for enhancing continuity of care (where appropriate).

"As noted above, some of the continuity of care projects have not yet been completed. The researchers on all the individual projects have agreed to co-operate with the group undertaking this piece of work.

Methods

"Applicants should provide a full description of the methods they propose to use to carry out the synthesis and conceptual analysis.

Outputs

"The principal output of this research project will be a detailed report. This should include:

- A short and coherent executive summary of no more than three pages;

- A main project report with supporting technical appendices suitable for academic peer review. This should include a commentary that indicates how these findings relate to current policy and practice in the NHS, with particular reference to England, and the key lessons to be learned, together with an agenda that establishes the key areas for further research and the appropriate methods that should be used in this research."

Appendix 3 Project visit checklist of themes and questions

Study title   **PI/RA**

Date started/duration   **Date of visit**

Sources and types of data:

Three types of data for each SDO CoC project

- available project protocols and reports
- project outputs including published papers and memoranda when available. *give details published papers - presentations*
- accounts of the research process through key informant interviews with principal investigators and main researchers (*names*)

Study Methods:

- Aim/purpose to:
- Stated objectives – to:
- Type of study: Qualitative, quantitative, mixed.
- Study design (survey, experiment (RCT), cohort, case-study (single or multiple) implementation evaluation
- Sampling frame, sampling strategy, response rate (for quantitative studies), size
- Study population (eligibility criteria)
- Data collection: cross-sectional, prospective, retrospective
- Principal outcome(s) of interest
- Is continuity dependent or independent variable?
- Intervention? (yes/no), specify
- Data collection modalities (in descending order of importance):

    closed answer questionnaire

    open answer questionnaire

    closed questionnaire

    medical record review

    administrative database

    key informant interview

    focus group

    participant observation.

- Cost analysis done? (yes/no)
- Portion of continuity pathway addressed (e.g. 1 to 3, see figure below)

Continuity of care 2006
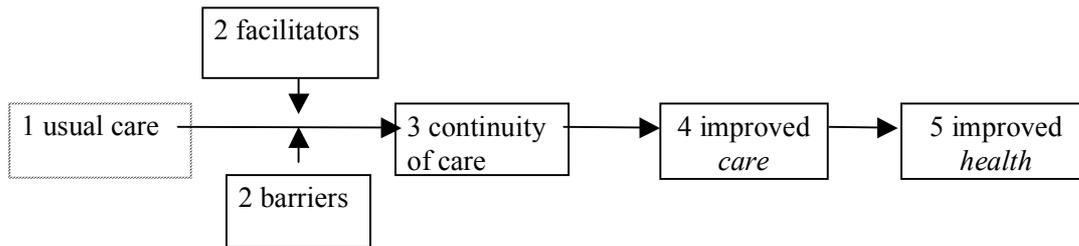
- research methods used – cross sectional/longitudinal/or experiment
- sampling strategy, sample size and response rate.

What concepts of continuity were used?

- explicitly – clearly articulated; designed in or excluded for clear reasons?
- implicitly – not clearly articulated; probably more likely for concepts/dimensions which are not included?
- were these dimensions new, or did new dimensions emerge in the course of the study?
- whose perspectives were considered (researchers, policymakers, users, carers)?
- what assumptions and theories of continuity informed the development of these concepts?
- Was there confusion with closely related concepts (integration of services, quality of interpersonal care, communication skills implementation of information mechanisms, deployment of case manager)

How were these dimensions/concepts of continuity operationalised?

- how were they measured (if relevant)? -Instruments?
- were measures used already in existence or created afresh?
- how systematically were measures developed and tested?
- how was continuity conceptualised in qualitative analyses?
- NB : At analysis stage assess what dimensions of continuity addressed (nature of relationship, concentration of care in known provider, sense of clinical responsibility, information transfer, accumulated knowledge by provider, case management, coordination between providers, obtaining timely care, obtaining correct sequence of care)

What were the facilitators and barriers to continuity of care?

- what approaches to enhancing continuity of care were more/less effective?
- what did they cost?
- what theories of continuity underpinned these approaches?

What impact did continuity (or its absence) have on care?

- positive and negative, intended and unintended?
- on different stakeholders including patients, carers and service providers?

- on other valued processes and outcomes of care including access, choice of provider, anonymity?

How was continuity valued by different stakeholders?

- How were trade-offs with various aspects of care investigated, including trade-offs with other priorities and between aspects of continuity?
- What other processes of care or attributes were valued? e.g. access, choice of provider, anonymity, autonomy, technical competence, between types of continuity?

Additional points

(date of report)

Appendix 4 The six empirical projects: brief summaries

1. Diabetes project

Continuity of care in type 2 Diabetes: Patients', professionals' and carers' experiences and health outcomes

Martin Gulliford, Smriti Naithani and Myfanwy Morgan

This project investigated the experience of health care of patients with type 2 diabetes mellitus. The specific objectives of the project were to:

a) hold in-depth interviews with diabetic patients in order to understand their views and experiences with respect to continuity in diabetes care;

b) develop an experience-based measure of continuity of care in type 2 diabetes and test the reliability and validity of the measure in quantitative data;

c) evaluate changes in clinical and patient outcomes over time and to evaluate whether these are associated with continuity in the experience or delivery of care;

d) evaluate the views and experiences of carers and South Asian patients;

e) evaluate health professionals' experiences and values with respect to continuity of care and develop a questionnaire measure of continuity in the delivery of care.

Mixed methods were used to evaluate and measure patients', carers' and providers' experiences of continuity of care in type 2 diabetes and to determine whether continuity of care was associated with clinical and patient outcomes. The study was set in two inner London primary care trusts.

Experienced Continuity of Care: Development and evaluation of a new measure

They carried out semi-structured interviews with 25 patients with diabetes from 14 general practices. Interviews were transcribed and analysed thematically. They used the qualitative data to develop a 19-item measure of Experienced Continuity of Care in type 2 diabetes mellitus (ECC-DM). The measure includes four factors: longitudinal continuity, flexible continuity, relational continuity and team and cross boundary continuity. The measure was interview administered to 209 type 2 diabetic patients registered with 19 general practices. They found that the experienced continuity of care measure gives reliable, valid results.

Continuity of care 2006

Continuity of Care and Clinical and Patient Outcomes

They conducted "a cohort study of type 2 diabetic patients attending 19 general practices in two inner London Boroughs. Patients were interviewed at home; the study questionnaire included the experienced continuity of care measure, the short form 12 questionnaire, a measure of global satisfaction with care, and confounding variables. Measurements were made of height, weight, blood pressure and glycated haemoglobin. Patients were followed-up with repeat interviews and measurements after 10 months. "Higher experienced continuity of care was associated with higher global satisfaction ratings. Experienced continuity of care was positively associated with number of consultations in the last 12 months, but negatively associated with the number of different individual professionals seen. Experienced continuity of care was not associated with any clinical measures."

Carers and South Asian patients

They carried out further in-depth interviews with seven carers of diabetic patients and 12 South Asian patients. They report that difficulties in language, culture, disability or mental illness may contribute to difficulties in establishing and maintaining continuity of care.

Delivery of Care

Interview data with 25 health professionals recruited from primary care and hospital-based diabetes services were used to develop a 28 item measure of continuity in the delivery of care. This was tested in a postal survey of staff in two primary care trusts and three hospitals. Staff generally preferred to see the same patients at successive visits in order to develop a better understanding with the patient and deliver personally tailored care. The 28 item measure included the dimensions of longitudinal, relational, team, cross-boundary and informational continuity. The measure had good psychometric properties including excellent test-retest reliability. Continuity in the delivery of care was rated lower by hospital-based staff than by primary care professionals.

2. Primary care project

Continuity of Care: patients' and carers' views and choices in their use of primary care services

Richard Baker, George Freeman, Mary Boulton, Kate Windridge, Carolyn Tarrant, Janet Low, David Turner, Eileen Hutton and Stirling Bryan

The primary aim of this project was to determine the views of patients and carers about the importance of continuity compared to other aspects of care.

A multi-method approach was used to describe patients' views on continuity of care, their use of primary care, including preferences and factors that affect their choices. The study took place in two locations: West London and Leicestershire to reflect differences in service structures and other characteristics of localities that the authors anticipated would influence the available features of primary care.

The qualitative study on patients' views on continuity of care and choices

79 patients and carers were asked to describe their views on continuity in primary care and the choices they made with respect to different features of care.

The authors found that experienced continuity matters when: patients already have a good relationship with the professional; patients/carers are less likely to overcome problems in care themselves; and problems affect patients' ability to make sense of the progress of events over time, particularly with complex problems or with uncertainty. Patients were well aware of the trade-off between personal continuity and quick access in primary care. They often tended to take the term continuity to mean personal or relational continuity although they recognised other aspects when prompted and sometimes volunteered these. Patients and carers have clear views on when they need personal continuity - for more serious problems.

The longitudinal study of pattern of use of primary care

36 patients were followed up over an extended period of time to investigate their pattern of use of primary care, and the choices they made at different times and in different circumstances.

For 86% of consultations patients saw their chosen person at the time they wanted to, 7% had to wait longer than they wanted and 7% were unable to see whom they wanted. Two thirds of patients saw the same GP for at least two thirds of consultations, one third always saw the same GP, but five patients saw the same GP for less than half their consultations. When asked about preferences for personal continuity following patterns were identified: those who had succeeded in seeing a named provider; those who were not

successful in doing so; those who were successful in obtaining swift access to care; and those who had success in seeing a named provider for high priority occasions and success in obtaining swift access to care on other occasions.

A stated preference discrete choice experiment (SPDCE) or conjoint analysis

646 patients made judgements on case vignettes that demonstrated the relative importance of different attributes of primary care under different hypothetical consulting conditions.

Results revealed that individual and practice characteristics were linked to preferences, that previous experience was relevant, that relational and informational continuity overlapped (both were important), and that patients whose illness was more progressed, those who were older and poorer valued continuity more. The SPDCE also showed that patients gave high priority to the availability of records and were prepared to wait for such an appointment.

A cross sectional survey

1437 patients responded to this survey which investigated the patient and service characteristics that influence choices for primary care.

The authors found that patients want to consult someone with time to listen and who has information about their clinical history; that relational continuity is more important to people who have more health problems and that people are more likely to get relational continuity if they can adapt to appointment systems.

The overall conclusions are that: continuity of care, both informational and relational, became generally more important as patients get older, become more ill and feel more vulnerable. Some patients (e.g. those from non-white ethnic groups, the socially isolated, and those not in work) were not always successful in obtaining the type of care they prefer. It is possible that patients in these groups are less effective in negotiating for their care, although the structure and organisations of services may also present more barriers for them to overcome. Patients in London were less likely than those in Leicestershire to experience relational continuity, informational continuity or longitudinal continuity even when they preferred these attributes of care.

3. Cancer project

Concern and continuity in the care of cancer patients and their carers: a multi-method approach to enlightened management.

Michael King, Louise Jones, Irwin Nazareth

The objectives of this project were:

  a) to develop an understanding of patients', close persons' and professionals' views of continuity of care in cancer.

  b) to transform these key elements of continuity into a quantitative measurement tool.

  c) to identify associations between continuity of care and satisfaction and to understand the effects of other factors, such as psychological status, quality of life and coping strategies on these associations.

  d) to describe change in continuity and satisfaction over time and across transitions in cancer care (based on the following five stages: 1) initial diagnosis, 2) end of first treatment, 3) remission, 4) relapse and 5) referral to specialist palliative care).

  e) to test whether such transitions in care predict change in perceived continuity

Method

Patients with breast, lung or colo-rectal cancer were recruited from three London cancer networks at each of five transitions in care.

Part 1 – cross-sectional qualitative study

Patients recruited from general practice, their nominated close persons and health care professionals were interviewed.

The authors found that experienced continuity was a complex concept and was determined by factors such as the quality of the first appointment with secondary services, communication with the family and professionals. Other factors such as patients' and close persons' ability to share treatment decision, patients' personalities and family dynamics were also identified. Patients' reactions to their illnesses and how they shared information within their families were critical to whether or not continuity could be achieved. People with cancer needed to be active partners in their care according to their own personal coping styles. There was little mention of needing a named coordinator of care or needing to see the same health professional each time.

Part 2 – quantitative study

Data from part 1 were used to derive quantitative measures to explore continuity of care prospectively over twelve months in five cohorts of patients

recruited from secondary care (at each of the five transitions in care), and their close persons. The authors explored the effect of continuity scores on satisfaction, psychological status, needs for care and quality of life; and examined whether there was any transition between treatment phase on perceived continuity.

They found that patients' perceptions of experienced continuity of care were significantly associated with higher satisfaction with services, lower needs for care, better quality of life and less psychological distress. High experienced continuity also predicted lower physical and psychological health needs for care, better quality of life and less psychological distress over the 12 months of the study. Close persons' perceptions of high continuity of care for patients were also associated with higher satisfaction but the association was much weaker than for patients. Their perceptions of high continuity of care for patients were also associated with their own (better) quality of life, less psychological distress and stronger spiritual beliefs. Those close persons who were more involved in helping with the patients' needs and care tended to perceive continuity less favourably than those less involved.

The authors make several recommendations including that professionals in cancer services should make sure that patients have as much information as they require about their current treatments and what to expect in the future and that patients and close persons should be given the opportunity to assess their experiences of continuity and seek greater service support if it is lacking.

4. Learning disability and stroke project

Partnership and Complexity in Continuity of Care: a study of vertical and horizontal integration across organisational and professional boundaries

B Hardy, B Hudson, J Keen, R Young, M Robinson

This project examined continuity of care in two conditions: people with stroke and young people with a learning disability. The study was conducted in three locations: Darlington, South Tyneside and Lancashire, which were selected to represent a range of organizational complexity.

The aim of this study was to explore how government policies on partnership affect continuity on the ground. In particular to explore the ways in which CoC was affected by complexity of inter-organisational arrangements and of inter-professional working agreements and the relationship between these two.

The authors focused on transition points where they could look for discontinuities at significant inter-organisational and inter-professional boundaries. For people with stroke this boundary was the transition from hospital to home at the point of discharge; and for young people with learning disability - it was the transition for young people leaving school and entering adulthood.

They used a range of qualitative methods, including documentary analysis, non-participant observation and a substantial number of in-depth and face-to-face interviews with service professionals and managers and with patients/users and their carers.

They found that many of the contextual factors that hinder continuity of care are structural in nature. Key clinical roles such as clinical psychology in stroke services, which official guidance makes clear are important, were simply not present in two of the locations examined. In both conditions there were problems associated with shortages of allied health professionals. These are particular illustrations of long-standing problems associated with investments in service development in these two conditions. It was also suggested that this historic underfunding reflects national priorities.

They also found evidence that long-standing issues, such as the divide between health and social care, continue to impede continuity of service delivery for users. For the young people with learning disability the most prominent discontinuity was apparent at the interface between social care and education services.

In stroke services they found examples of continuity of care which reflected "organisations and service professionals working across boundaries". Regarding learning disability services they found partnership working but little evidence of this producing continuity of care for individual service users.

Their overall conclusion for young people with a learning disability was that the transition from school was characterised by discontinuity rather than

continuity of care. For example, services that had formerly been readily available and free were subsequently charged for and often unavailable. Furthermore, abrupt service deficits were a constant source of distress. There was conflicting evidence regarding stroke services where they found evidence of perceived discontinuities of care, such as in transfers between wards and between hospitals; and where several patients reported both well planned and well co-ordinated treatment, rehabilitation and care.

5. Main stroke project

Continuity of care in stroke, and its relation to outcomes

Allan House, Jenny Hewison, Alan Pearman

The aims of this project are:

a) to explore the meaning of continuity of care for stroke patients in order to develop a measure, with a view to looking at the effect on outcomes

b) to seek professionals' views on aspects of service organisation

c) to characterise local stroke services

Several different methods were used to determine patients', carers' and providers' experiences of continuity.

Qualitative interviews

Framework analysis was applied to qualitative interviews with 24 stroke patients.

These interviews elicited good narratives of experiences: patients recognise quality of care and their satisfaction with it, however, they did not didn't recognise or recount aspects of continuity in relationships, information transfer or management of their care.

Qualitative interviews with 14 professionals from a variety of disciplines and background also brought out good descriptions and understandings of teamwork, though staff had a less clear overview of services in general.

Case note reviews

Two methods were used: Signature counting (number of care-givers) as a measure of relational continuity and a checklist using a positive and negative scoring system: Snakes and Ladders. This framework was based on stages of care and elements identified from current concepts of continuity. A score of -1, 0, or +1 was allocated to each care indicators for 128 patients.

They found large numbers of signatures in notes indicating the length of admission and level of dependency but not continuity of carer. The 'snakes and ladders' framework analysis was in progress at the time of this report.

Chao questionnaire

Data from 178 patients was collected using the Chao questionnaire despite some difficulties with context.

The authors report that the pattern of responses suggests that the Chao doesn't measure service characteristics that respond to disease-based needs. Lower Chao scores (i.e. poorer relationships) were associated with higher symptom scores on the GHQ 28. This association with emotional state suggests that it measures perceptions of trust and satisfaction built around the relationship with the GP.

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Development of the Patient Perceived Continuity instrument (PPCI)

This instrument was based on the continuity literature and the above studies and remaining patients were being followed up at the time of this report.

Focus groups with staff

Four focus groups with frontline hospital and community staff showed that committed and skilled professionals are important for the continuity process in stroke and that contact and communication are the key factors.

Overview of findings to date

The authors report that current elements of continuity are interlinked with confounding concepts of quality and satisfaction. Measurement may be even more problematic in chronic disease settings. Patients may be elderly or frail, with multiple co-morbidity. If the definition is patient-centred, it may be artificial to limit measures of continuity to a single disorder. Furthermore, linear care pathways are not easily applied through all stages of stroke care; ideas about networks of care may prove more useful than the concept of a care pathway. They report that the concept of care networks is helpful for understanding the complexity of the interactions that take place during delivery of care.

Currently the authors of this project are seeking to develop an intervention to improve CoC in the first 12 months after a stroke.

6. Mental health project

ECHO - Experiences of Continuity and Health and social Outcomes in mental health

Tom Burns, Sarah Clement, Jocelyn Catty, Susan McLaren, Ian Rees-Jones, Til Wykes, Diana Rose and Peter Huxley

The aims of this project were:

a) to examine how seriously mentally ill patients and their carers conceive of continuity of care

b) to assess the impact of continuity of care for patients on process variables (such as therapeutic alliance) and health outcomes (overall functioning, time in hospital, quality of life, degree of unmet need) and for carers on psychological distress.

The project was divided into the following four strands:

Developmental Phase

Focus groups, expert panels, consultation and a pilot study were conducted to develop a user- centred and a carer- measure of continuity of care.

The users were recruited from day centres and user group drop-ins. The group facilitators were also users. The focus groups followed pilot interviews. The researchers then extracted six domains from each focus group discussion and then added the six elements from the scoping study. At the next meeting these were presented on cards and participants asked to rank the elements of CoC. There were separate carer focus groups, one of which was also led by a carer. Two instruments were developed CONTINU-UM for users and CONTINUES for carers, and were tested in the main phase of the project.

Main Phase

The main phase comprised a follow-up study of 180 service users with psychotic disorders (sample 1) over three years and 98 users with non-psychotic disorders (sample 2) over two years, along with their carers and professionals involved in their care;

The authors identified the following factors which accounted for 62.5% of the variation in all the data concerning continuity of care: *Experience & Relationship (experienced/relational continuity), Regularity (long-term / longitudinal continuity), Meeting Needs (flexible continuity,) Consolidation (cross-boundary continuity), Care coordination (longitudinal continuity) and Supported Living.* These factors were largely independent of each other, and behaved similarly in the two study cohorts. There was evidence of a dynamic interplay between user variables and the continuity factors rather than any uni-directional relationship.

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Qualitative strand

The Qualitative Strand involved in-depth interviews with 20 users from each of the Main Phase cohorts (samples 1 and 2) along with their carers. Detailed quantitative data on users' experience of care and on transitional events and phases in their care history were also available.

The analysis focused on the meanings associated with particular (dis)continuities and transitional episodes. The major themes that emerged were: relational (dis)continuity; depersonalised transitions; invisibility and crisis; communicative gaps and social vulnerability.

Organisational strand

The Organisational Strand comprised diagnostic analyses over three years of the two Mental Health Trusts which provided the setting for the study, focusing on factors promoting and those hindering continuity of care. They conducted a survey utilising questionnaires and semi-structured interviews. The survey encompassed an evaluation of the organisational effects of integration between health and social care on continuity of care for seriously mentally ill patients.

Based on preliminary findings only, they identified the following: a) f*acilitators to continuity of care included* measures taken to improve recruitment and retention (R&R) of staff (particularly in one of the MHTs), commitment to integrated working, and a positive view of emerging organisational cultures; and b) b*arriers consisted of:* R&R problems, the use of agency staff, factors influencing team integration, a lack of preparation for integration, the pace of change too fast, a lack of financial, and IT resources to facilitate such changes, and a lack of admin support.

Appendix 5 The six empirical SDO continuity of care projects: admin details

Short title[7], PI, site, dates, duration, status, available outputs on 6.12.2006

Short title[1]	Diabetes	Primary care	Cancer	LD & stroke (learning disability)	Main stroke	Mental health
Full title	Patient, carer and provider experiences of continuity and health outcomes in diabetes mellitus (type 2)	Patients' and carers' views and choices in their use of primary care services	Concern and continuity in care for patients with cancer and their carers: A multi-method approach to enlightened management Concern and continuity in the care of patients with cancer and their carer: developing the intervention*	Partnership and complexity in continuity of care: A study of vertical and horizontal integration across organisational and professional boundaries (relationships between organisations)	Continuity of care in stroke and its relation to outcomes	Patients' and carers' Experiences of Continuity of care in long-term conditions and the relationship of continuity of care to Outcomes (mental health) Continuity of care for people with non-psychotic mental health problems: An extension of ECHO study**
Principal Investi-gator(s) and site	Martin Gulliford, Department of Public Health Sciences, King's College London	Richard Baker, Department of Health Sciences, University of Leicester	Michael King, Psychiatry & Behavioural Sciences, University College London	Brian Hardy & Justin Keen, Nuffield Institute for Health, University of Leeds	Allan House, Academic Unit of Psychiatry & Behavioural Sciences, University of Leeds	Tom Burns & Jocelyn Catty** St George's, University of London
Status	complete	complete	ongoing	complete	ongoing	ongoing

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[7] our short title - used in this report only

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End dates	31.10.05	28.2.05	30.4.06 89/2005* 31.1.08	31.12.04	13c/2001 31.7.07	13d/2001 & 88/2005** both 28.2.07
Budget £k	183	301	399+191*	288	529	750+156**
Duration	39 months	39 months	44 months + 18 months*	36 months	63 months	62 months +22 months**
Output/ SDO no.	Website full report 14/2001	Website full report 13b/2001	Revised report of 13e/2001 seen	Website full report 13a/2001	SDO interim report 26.6.06 seen	Draft final report seen 03. 07
Publicat-ion	Yes	Yes	in preparation	in preparation	in preparation	in preparation
Reviewers	GKF/MW+JC	JH+BG	GKF/MW+MB	GKF/MW+RB	GKF/MW	GKF/MW+BG

Appendix 6 Empirical project findings: comparative table

Appendix 6 short title	Diabetes	Primary care	Cancer	LD & stroke	Main stroke	Mental health
Care system	type 2 diabetes - in primary and secondary care	primary care (generic)	cancer services in primary, secondary and tertiary care	multiple community and specialist services for Learning Disability (LD) & Stroke (S)	stroke services in primary/second-ary care with social care	specialist services for Severe Mental Illness, with social care
Main aims of project	Evaluate patients' values and experiences about continuity of care Develop measure of experienced continuity Do the same for professionals Evaluate clinical outcomes in relation to continuity Studies of carers and of S Asians	Examine the importance to patients and carers of aspects of continuity in relation to other aspects of care.	Describe the 'physical, emotional, social and spiritual status of patients and nominated 'close persons' Assess professional perceptions of how to enhance continuity Identify transition points in the care of cancer associated with low satisfaction.	Explore effects of government policies on partnership on continuity on the ground. How is CoC affected by complexity of: - inter-organisational arrangements? - inter-professional working agreements? and the relationship between these two	Explore the meaning of CoC for stroke patients to develop a measure to investigate effects of CoC on outcomes Seek professionals' views on aspects of service organisation Characterise local stroke services Feasibility of developing a care package for the first year after a stroke	Examine SMI patients and carers' concepts of CoC Assess impact of CoC on: - process variables (e.g. therapeutic alliance) and - health outcomes (functioning, time in hosp, QoL, unmet need) and for carers on: - psychological distress Describe: - patients' journeys over three years - organisational factors. Assess congruence of professional and patient views on CoC

Continuity of care 2006

Appendix 6 short title	Diabetes	Primary care	Cancer	LD & stroke	Main stroke	Mental health
Component studies (A – E, *main phases) *for details of methods, see Appendices 7,8	A qualitative study to develop their instrument B* cohort study	A qualitative B* Longitudinal Diary of consultations C* Discrete Choice Analysis ` D* Cross-sectional survey	A qualitative B prospective cohort C parallel qualitative cohort with five sets of data collected after transition points in care	A policy literature review B consensus development for 'hinge points' C Case studies LD + S	A qualitative B trial of case note review C test Chao quest. D develop PPCI E Focus groups: information transfer for professionals	A qualitative (user focus groups) B two main cohort studies C qual study D Organisational strand
Main data collection tools	Experienced CoC Diabetes Mellitus score ECC-DM	Three project specific data collection tools	'Perceived experienced continuity score'	Four project specific topic guides	Snakes & Ladders (SnL) Checklist Patient Perceived Continuity Interview) PPCI	CONTINU-UM CONTINUES
Sample (response rate)	B 177 from all eligible adult type 2 diabetics from 19 practices in S London	C (47%) D 1437 (47%) patients registered with 12 practices in Leicester and nine in W London	B 199 (64%) pts with breast, lung, colo-rectal cancer from three London Cancer Networks	C LD: 14 users & 36 professionals S: 18 users & 52 professionals	B 123 stroke patients recruited in hospital C (54%) D (78%) E	B1 180 psychotic B2 98 non-psychotic Attending two MHTs in S London
Duration of longitudinal study	B two data passes 10 months apart	B 12 months	B 12 months (five cohorts recruited at five stages of illness)	C two data passes: LD: 18months apart S: 9months	D prospective cohort up to 12 months	B1 36 months B2 24 months

Continuity of care 2006

Appendix 6 short title	Diabetes	Primary care	Cancer	LD & stroke	Main stroke	Mental health
Summary of key findings identified by researchers	Identified four CoC elements: longitudinal, relational, flexible and team & cross-boundary CoC score positively associated with type of care (GP better than hosp care & best with named GP lead) No element of Continuity of Care associated with better BP or glycemic control. Dimensions of CoC associated with traditional elements of satisfaction. Relational Continuity of Care may be an end in itself Professionals tend to be more aware of organisational aspects of CoC Language, culture, disability & mental illness may be linked to impaired CoC	Raised issue of advanced access hampering patients from achieving continuity Patients vary in their continuity of care priorities – seeing their chosen Dr may need much persuasive power Patients value relational and informational Continuity of Care more when the problem has greater impact Many are satisfied but working or socially isolated patients had most difficulty accessing the continuity of care they desire	Patients' reactions to illness and relations with their families critical Little mention of need to see same person Early trust important At baseline: positive association between perceived Continuity of Care and satisfaction with service; lower health needs; less stress. Broadly maintained over 12 months Transition points not assoc with change in Continuity of Care Need to be more aware of patients' & carers' personality types, coping behaviours and care needs Proposed intervention to enhance this last	The current time of severe organisational turbulence impeded Continuity Co-terminosity useful but not sufficient for joined up care Serious gaps in service – e.g. clinical psychology Health/Soc Care divide lives on The LD transition was characterised by discontinuity Stroke more +ve but very mixed Care pathways are a convenient fiction Diverse experiences need ingenious professionals to help bridge gaps	Analysis of main studies still in progress Concept of care networks appears more useful than linear care pathways They may be able to propose an intervention to improve care Their developing instrument is based on the concept of nodal points in the patient's care trajectory	Main phase (study B) analysis is asking three questions: Q1 nature and degree of continuity? Seven distinct factors identified: F1 Experience & Relationship F2 Regularity F3 Meeting Needs F4 Consolidation F5 Managed Transitions F6 Care Coordination F7 Supported Living. Users with psychotic and non-psychotic disorders had different factor levels but most factors behaved consistently between the groups. Q2 associations with continuity factors? F1 mental health + quality of life + F2 clinical need + F3 functioning & symptoms – F4 (inconsistent) F5 symptoms & illness duration F6 mental health + F7 poorer functioning + Q3 clinical/social outcomes?
© NCCSDO 2007						Evidence of dynamic interplay between users' illness and needs variables and continuity of care

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Appendix 6 short title	Diabetes	Primary care	Cancer	LD & stroke	Main stroke	Mental health
Reviewers' summary of findings for synthesis: a Concepts & Measures	Focussed on the choice about who and when for a consultation Questions on importance to patient of *relationship, longitudinal, informational* + access, expertise, time, gender	Topic guide based on scoping study. Questions map to these dimensions (loosely in the case of relationship) Include access under heading flexible continuity (users only) *Informational* for professionals only	Expanded concept based on a wide user derived view of continuity. Minority of items map to previously defined elements. Scale used as a whole in analysis, Conceived and used as a more total experience of care	Methods based on policy analysis and essentially concentrating on management continuity – especially team and cross-boundary with some informational Occasional references to users' experience of *relational* continuity	No measures seen (except discarded Chao questionnaire) Taking a very comprehensive and wide ranging view of stroke care and researchers report getting little help from Scoping study definition	Measures developed from specially recruited user focus groups with some carer and professional groups Have developed a comprehensive new measure for users and a separate one for carers. Have mostly mapped their continuity elements onto Scoping study definition
b. Experience, values, priorities; trade-offs	*Relational* continuity more important and salient to patients and *management* and *informational* continuity more for professionals	Patients seem prepared to wait up to 8 days for the right combination of knowing and trusting a doctor who has their records Colourful accounts of how patients achieve relational continuity	Strong message of a largely confident and relatively assertive sample of patients with their named close persons Interest for improvement focuses on the more vulnerable 20%	Great range of reported experience. Overwhelming effect of lack of ongoing provision for adolescents with LD. Variable stroke services but with some good examples and very appreciative patients	*Findings limited so far.* The project team reported being impressed with the need for competent adaptable and resourceful professionals to bridge all kinds of unpredictable gaps in the care of these initially very dependent patients	*Findings limited so far.* Project team reports that users value flexible access to known providers. A suggestion from the initial developmental phase that users valued being left alone when in remission was not much supported by the (differently recruited) main phase users.

Continuity of care 2006

Appendix 6 short title	Diabetes	Primary care	Cancer	LD & stroke	Main stroke	Mental health
c. Effects of aspects of continuity **(i) Positive effects**	Enhanced patient-centredness and acceptability of care	more appropriate care, esp for complex conditions.	Overall high score for 4/5 patients: better satisfaction and less use of services	S: some good examples LD: none found	*Findings awaited*	For the cohort with psychosis, higher continuity factors were positively associated with F3 reduced symptoms in the subsequent year F4 & F6 reduced odds of being hospitalised subsequently
(ii) Negative effects	None	Being trapped with a bad doctor Possible embarrassment with a familiar provider	None. Note that carers tended to be more critical than patients, esp. when they were more closely involved	(*Effects of discontinuity*) Demoralisation and failure to progress	*Findings awaited*	Suggestion that higher F2 & F3 scores associated with greater reported coercion

Continuity of care 2006

Appendix 6 short title	Diabetes	Primary care	Cancer	LD & stroke	Main stroke	Mental health
d. Prioritising Continuity of care **(i) Barriers**	Hospital based care is currently associated with lower experienced CoC and is a priority for improvement	Socially isolated unskilled patients Rigid access systems and the inflexible way these are applied by practice staff	A minority of subjects were either too ill to manage their own care or unwilling or lacking skills (?language/class issues)	Lack of resources – especially in LD led to unhelpful professional behaviours Powerless team leaders Teams are incomplete at weekends	Provisional impressions include*:* *Dysfunctional networks – cliques lack of competent generalists unfamiliarity with local systems*	Poor change management. Inadequate training, provision of up-to-date computing systems, and administrative support. Conflicts for professional identity role-blurring and cross-boundary work. Ineffective leadership Inadequate user accommodation Enhanced training & support needed to meet increasingly complex nature of users' mental health needs

Continuity of care 2006

Appendix 6 short title	Diabetes	Primary care	Cancer	LD & stroke	Main stroke	Mental health
(ii) Facilitators	Organising care through an identified lead professional.	Expert and persistent patients Flexible practices that prioritise CoC	Easier access to most informed care team members Good handling of early bad news	Adequate resources and well trained professionals positive attitudes good interpersonal skills flexible actions to bridge gaps Co-location only good if above in place	*Flexibility in a care network skills up carers* *A system that encourages good team work* *Trust and mutual obligation* *Professional skill*	Co-location of health and social care professionals Integrated teamwork; team skill-mix, communication between teams, users, carers, managers Decision-making structures; recording practices; shared decision-making through collaborative; democratic decision-making; Access to CPD; Manageable workloads, and administrative support; Workforce stability; low sickness, staff turnover & use of temporary staff;

Continuity of care 2006

Appendix 6 short title	Diabetes	Primary care	Cancer	LD & stroke	Main stroke	Mental health
Additional comments by reviewers	Negative findings of continuity score versus hard outcomes useful (note shortish follow-up period)	Value attached to different continuity dimensions varies in important but predictable ways	Novel view of continuity as a wider concept including the ability of patients to cope between contacts with professionals. Continuity seems quite good for these patients. Not a 'package' professionals can offer'; more an interaction between professional care and the patient's beliefs in the current context. *Relationship* CoC not salient. *Information* and *management* CoC taken as 'givens'	Relating *management* continuity to policy initiatives and professional behaviours	Potentially an original contribution to our understanding of CoC for stroke Trade-offs are complex/ multi-factorial *Now it's too early to say*	New mental health CoC measures. Substantial attempt to investigate the CoC experienced by psychotic and non-psychotic patients (and some carers) over a substantial timescale – up to three years. Organisational and qualitative strands have much to contribute

Continuity of care 2006

Appendix 6 short title	Diabetes	Primary care	Cancer	LD & stroke	Main stroke	Mental health
Significant unanswered questions	Association of provider continuity and patient safety &/or serious adverse events? Association with health outcomes How to enhance CoC for specific patient groups e.g. with language barriers	Longer, larger diary studies for people with major problems Follow up of newly registered patients Costs of low relationship CoC Interventions to enable/enhance Relationship CoC	Can care be better targeted for those who get less continuity at the initial Multi-Disciplinary Planning meeting? Their intervention is being developed as a separate, linked project (SDO 89/2005)	How to provide good continuity in a service which is not a national priority?	*Too early to say prior to completion of analysis*	*Too early to say prior to completion of analysis*

Appendix 7 Measuring continuity: review of four projects

The aim of this appendix (and the two that follow) is to "review and summarize *methods of measurement* with reference to care context." To do this, for each project we:

- Examined the description of the qualitative methods used, to understand how 'continuity' was initially conceptualised, how it was discussed in interviews and focus groups, and how qualitative findings were translated into quantitative questions (summarised in appendix 8)

- Examined the description of the quantitative methods used, to understand how survey instruments were developed and tested (summarised in appendix 8)

- For each survey instrument, the dimensions of continuity the instrument was intended to measure and the formal definitions of each of these dimensions (where the report formally defined dimensions – see appendix 9)

- For each survey instrument, the specific questions intended to measure each of these dimensions (where such a link was specifically made in the report – see appendix 9)

Having developed an understanding of each instrument, we then drew wider lessons by making comparisons between projects, seeking to understand the links between the initial conceptualisation, the methods used, and the final conceptualisation and operationalisation of 'continuity'.

Apart from the *LD & stroke* example, the SDO projects set up their own 'experienced continuity' measures. Each was based on an initial qualitative study focused on users and carers with some supplement or moderation by professionals. While projects operationalised 'continuity' in strikingly different ways, there are several generalisable lessons that can be drawn from examining them together.

1 Measures available for review

Copies of measures and final reports describing their development were available for four of the major projects in the programme[11,12,13,14] (Table A7.1). Reflecting the timing of the review, only a draft final report was available for the *mental health* project, with some sections only in early draft[8]. We did not seen the questionnaire or the interview schedules used in the organisational strand of the *mental health* project.

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[8] We have endeavoured to limit comment on this project to sections that appear near final, but caution that these may legitimately change in ways that may consequently alter some of our conclusions

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Table A7.1: Completed instruments developed for four projects

Study	Patient survey	Carer survey	Professional survey	Other
Diabetes	Yes		Yes	
Primary care	Yes		Yes*	
Cancer	Yes	Yes		
Mental illness	Yes	Yes		Yes (not covered here)

* - small scale – no details reported

All but one measure developed was a questionnaire, with patient survey development generally the most comprehensively described (and in at least some cases probably the most systematically developed). The *mental health* project Main Phase study additionally used a large number of existing quantitative measures to operationalise the dimensions of continuity identified in the scoping exercise. For example, *relational* continuity questions were included in the patient and carer survey developed, but additionally measured by the Scale to Assess Relationships in Community Mental Health Care. However, this more extended use of measures was in the section of the project draft final report least complete at the time of review and is therefore not further considered here.

Here we review measure development and form. Details of survey development are shown in *Appendix 8*, and the questions in each survey are listed in *Appendix 9* (mapped to the dimensions of continuity being measured, where these were clearly defined in the final report, and where an explicit link was made.)

In reviewing measures, we have striven to draw out generalisable lessons and the advantages and disadvantages of the different approaches taken, rather than to adjudicate which measures 'truly' measure continuity or are 'better' or 'worse'.

2 How were survey measures developed and used?

All four projects used a similar process of questionnaire development, although the emphasis given to different stages varied.

- Literature review, usually emphasising literature from the area of care being studied

- Qualitative analysis of data from individual or group interviews

- Creation of pilot survey and developmental testing

- Evaluation of questionnaire validity and reliability (to varying degrees)

- Use of questionnaire data either as an end in itself, and/or to examine associations with other processes and outcomes.

Table A7.2 shows which type of continuity each of the four projects identified. The *primary care* project conceptualised it in terms of Haggerty *et al*'s later

definition of continuity (Haggerty *et al*, 2003). The *diabetes* and *mental health* projects based their conceptualisation around the scoping report definitions, and assumed that what they were measuring was 'experienced continuity'. The *cancer* study explicitly claimed to be measuring 'experienced continuity' and rejected the other types as care processes important to professionals but not to patient experience.

However, although the words used to label types of continuity appear similar across studies, the underlying concepts are more divergent. This is discussed below where the detail of the questionnaires is examined.

Table A7.2: Continuity types in four projects compared with scoping report (Freeman *et al*, 2001 and with Haggerty *et al*, 2003)

Published continuity types		SDO Continuity projects				
SDO scoping report	Haggerty *et al*	*Primary Care*	*Diabetes patient*	*Diabetes professional*	*Mental Health patient*	*Cancer*
Experienced		Perhaps	Perhaps		Perhaps	Yes
Informational	Informational	Yes		Yes	Yes	Perhaps
Cross-boundary & team			Yes	Yes	Yes	
	Management	Yes			Perhaps	
Flexible		Perhaps	Yes		Yes	
Longitudinal			Yes	Yes	Yes	
Relational	Relational	Yes	Yes	Yes	Yes	Perhaps

3 Qualitative research

All four projects included an early, cross-sectional qualitative phase which, combined with a literature review, informed survey development. In none of these projects did 'continuity' appear to be a common term for patients to use in describing or making sense of their experience of illness or care. Three of the studies (*diabetes, primary care, cancer*) did not use the term 'continuity' in their presentation to patients or the construction of their topic guides, although some topic guides were clearly influenced by existing definitions of continuity. Rather, they focused on patient and carer experience of using particular services, and in the case of cancer, of experience of disease, as the following excerpts from the *diabetes* and *cancer* projects illustrate:

Interviews covered respondents' experiences of the diabetes care provided by both hospitals and general practices, and probed particularly in relation to communication with staff and across settings; the flexibility of services; changes in care over time; the availability of information about diabetes; and their experiences of treatment. Examples of questions asked included: 'Are there any advantages/disadvantages with seeing a usual doctor or nurse?',

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'Have you been able to get the services you needed?', 'How important is it for you to see a usual doctor or nurse?', 'How well is your care co-ordinated?'. Respondents were also encouraged to discuss issues and directions of thought that went beyond this framework including the role of family in relation to continuity. To prevent patients from feeling uncomfortable, ignorant or confused jargon was avoided. The researcher also avoided using specific labels to describe the different dimensions of continuity and instead asked interviewees to use their own words and meanings to describe their experiences of continuity. (Diabetes project report[12] pp 53-54).

Interviewers used a series of topic guides to ensure they kept to themes of interest for the study, namely how consistently information was communicated to the patient and close person; whether patients felt they received a timely and consistent service; the manner in which this helped them deal with the cancer within the context of their lives, both past and future and the physical and emotional impact of the illness and its treatment on patients and those close to them. Although in patient and close person interviews the word 'continuity' was avoided in order not to lead participants or impel us to define it for them, interviewers strived to keep the focus on linked up and consistent services. In close person interviews, further attention was paid to the impact of the patient's cancer on the close person him/herself, while health care professionals were asked to offer their opinions on the points at which continuity in service provision in cancer care might be improved. (Cancer project report para 3.2.2 p 27).

In the *mental health* project, focus group participants were asked to talk about their experience of illness and care, and the term 'continuity' was then "introduced" for discussion to generate survey domains and questions:

The first wave of focus groups began with participants 'telling the story' of their contact with mental health services. After this, the idea of continuity of care was introduced. Although most participants had not actually heard the term before, the groups were able to generate ideas around the term once it had been explained to them. (Mental health project developmental strand p 18)[9].

The constructs being used in measure development are therefore not simple descriptive themes that 'naturally' emerge from the data. So, rather than any one project being clearly more 'grounded' in patient data or more sensitive to patient perspectives, the differences in the measures created appear to flow from the different assumptions brought and embedded in topic guides (although we do not have copies of all of these) and/or analytical choices made by the various research teams in their conceptualisation of 'continuity'.

An alternative explanation is that variation arises from differences in the care settings being examined, although there are commonalities across care settings which we discuss in the main report (section 3.5).

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[9] draft final report from team received informally March 07

4 Validity and reliability of measures

Establishment of instrument properties is not our main purpose; each project team can make the case for the validity and reliability of their own survey. However, our understanding is that the *diabetes, cancer and mental health* projects were all intended to produce valid, reliable, standardised instruments useable in other studies. In different ways they therefore included systematic examination of the validity and reliability of the measures created, combining a range of standard quantitative techniques with more qualitative examinations of validity. Excerpts from the *diabetes* and *cancer* projects illustrate these points:

Item development involved a process of discussion and consensus among the three members of the study team. We also undertook cognitive testing to assess patients' views of the appropriateness, acceptability and ease of comprehension of successive draft versions of the questionnaire. This cognitive testing was implemented with small samples of diabetic patients who were attending the diabetic clinics of Guy's and St Thomas' Hospitals. (Diabetes project report p 70)

We obtained data for the measure in a cross-sectional survey of diabetic subjects and the data were used to analyse the properties of the measure. The following steps are presented: i) item responses and missing data; ii) scale and subscale scores, item-score and inter-item correlations and Cronbach's alpha; iii) factorial composition and construct validity; iv) criterion validity; v) results from self-completion and telephone interviews and assessment of test-retest reliability. (Diabetes project report p 75)

Twenty statements were developed from the qualitative data that patients, close persons and professionals considered determinants of comprehensive, joined-up, long term care. The core research team discussed in detail each main theme arising from the qualitative data and successively shaped them into statements that best represented each theme. This process was discursive and needed considerable time and thought. Once a skeleton set of statements were derived they were circulated to the project steering committee and clinician colleagues for further modification. We stress that we did not begin with a theoretical model but sought to turn patients', their close persons' and nominated professionals' views on experiences of continuity into a simple and understandable form. Our aim in the prospective, quantitative phase of the study was to take the main themes on experienced continuity that arose from the narratives and see how they predicted other important outcomes over one year. It was decided that the simplest method to present the ideas would be a Likert format in which patients selected one of five possible responses to each statement ranging from 'strongly agree' to 'strongly disagree'. (Cancer project report para 6.3.1 p 47)

Having developed their continuity scale CONTINU-UM the *mental health* project then subjected it to test-retest reliability and content and construct validity testing by factor analysis. The *primary care* questionnaire was solely intended for use in this study, and examination of validity was limited, less systematic, and not described in any detail.

5 What is being measured?

Process or outcome?

Continuity of care can be seen as a care process, a means to the end of better care. The *cancer* questionnaire differed from the other three projects by seeking to measure continuity as an outcome of care, rather than as a set of care processes. It is therefore discussed separately.

a) Patient measures for diabetes, primary care, and mental health

These three projects developed questionnaires that ask patients about their experience of care processes.

Definitions of continuity. All three found that patients valued many different aspects of care, but how this was handled varied.

In the *primary care* project, 'continuity' was defined in terms of Haggerty *et al*'s (2003) tripartite definition of continuity (*management*, *informational* and *relationship*)[4]. Other valued aspects of care like access, gender and ethnicity were labelled distinctly as separate. For example:

How important was it to consult someone you already know and trust)? – defined as measuring relationship continuity (Primary care project report, appendix 4 q 8(a)).

When did you want *to consult someone?* - defined as measuring 'access' (q 5(a).

In both *diabetes* and *mental health*, these other valued aspects of care were labelled as dimensions of continuity. For example, 'flexible continuity' questions in *diabetes* and some of the *mental health* questions primarily relate to access:

In general, how well is your diabetes care coordinated? - defined as measuring cross boundary and team continuity (Diabetes project report appendix p 199 q TCB1).

If you need advice urgently, how long would it take to get to speak to a doctor or nurse at the practice? – defined as measuring 'flexible continuity' (p 195 q FC4-gp).

This issue is further discussed below since the *cancer* questionnaires contribute to understanding the importance of this.

Patient preferences. A distinctive feature of the *primary care* and *mental health* questionnaires is that they explicitly include individual patient preferences, asking patients to rate how important particular aspects of care are to them, and then to rate their receipt of these aspects, and in the case of the *mental health* measure, their satisfaction with this aspect of care:

How important was it to choose a particular person (e.g. usual GP)?

Did you actually consult the person you wanted?
(Primary care project report, appendix 4 questions 7(a) & 7 (b)).

How important is it that staff involved in your care don't change frequently?

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Over the past 12 months, have the staff involved in your care changed frequently?

How satisfied were you with this?
(Mental health project CONTINU_UM questionnaire questions 7(a), 7(b) & 7(c))[10]

The *cancer* project also had a section asking about preferences for care, but this was distinct from the questions comprising the 'experienced continuity' measure, and although some questions were clearly related to continuity - longitudinal in the first example below, although it includes a trade-off with access, - most were not , as the second example shows:

For each statement, please circle the number which best describes your preferences NOW.   <u>GENERALLY, I PREFER...</u>[11]

To see the same doctor   <u>0 1 2 3 4 5 6 7 8 9 10</u>   **To see a different doctor even if less convenient   if it is more convenient**

To carry out my usual   <u>0 1 2 3 4 5 6 7 8 9 10</u>   **Not to carry out my usual duties and routines   duties and routines**

   (*Cancer* project report, appendix C pp 163-164).

In the *primary care* project, patients varied considerably in their preference for different kinds of continuity and speed of access. This was further explored in the stated preference discrete choice experiment (Turner *et al*, 2007), where patient preference was examined for different problems to be discussed in the consultation. Patient preferences also varied for some questions in the *mental health* project.

Measuring continuity over a series of care episodes is attractive when characterising a service but risks missing important pointers to better care. Continuity scales in which patients have to average their experience over a number of episodes or providers, may lose information because preferences and expectations change depending on the nature of the episode and the relationship with the provider. In other words, an experience of continuity or discontinuity may be specific to an episode of care. If, in addition, scales sum several dimensions of care (continuity and accessibility) they risk being uninformative about all but flagrant problems. However, this may apply in some settings more than others. In *primary care*, reasons for consultation are heterogeneous, and may encompass the trivial and routine one month, and something important and complex the next. In *diabetes*, the expectation of regular structured review for all patients means that much (but far from all) care is relatively predictable and pre-planned. In other conditions like cancer, pre-planned care according to protocol is also relatively common, but acute

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[10] CONTINU-UM questionnaire as kindly made available by authors November 2006.

[11] General heading introducing all questions in this section of the questionnaire ('Part Four: My Preferences').

complications are more frequent. The importance of changing preferences and expectations may therefore vary in different settings, although this was not explicitly examined in any project, except the *primary care* discrete choice experiment (Turner *et al*, 2007).

Informational continuity. As conceived in the existing literature and the scoping report, *informational* continuity refers to communication and information transfer between professionals. However, it is clear from the *diabetes* and *primary care* projects that this activity is not particularly visible to patients, and therefore cannot be well evaluated by a patient questionnaire. In contrast, the *mental health* (and *cancer*) projects also emphasise the importance of *informational* continuity in terms of communication and information transfer from professional to patient.

b) Patient measure for cancer

The *cancer* project is distinct from the others in aiming to measure 'experienced' continuity as an *outcome* of care, rather than a care *process*:

Although professionals may not regard [many of these] items as directly linked to their notions of the delivery of continuous care, there is no reason to expect they should; rather they were concepts that arose repeatedly from the qualitative data on experienced continuity. … This moves away from the idea that continuity of care is a one-sided concept that is simply delivered by health professionals (Cancer project report para 6.3.1 p 47).

From that perspective, the cancer measure most closely approaches capturing the idea of experienced continuity as "the experience of a co-ordinated and smooth progression of care from the patient's point of view" [2], and in examining associations of experienced continuity with a range of outcomes.

However, a consequence seems to be that qualitative themes have only been used to create experienced continuity questions that the researchers considered to be *outcomes* of care rather than *processes*, even if patients identify those processes as important. The clearest example is that in the qualitative results patients were described as valuing a main contact person they trusted, who could either be a GP or a secondary care clinician. On the face of the data presented, this could be mapped to the concepts of *longitudinal* and *relationship* continuity identified in the Scoping Report. However, there is no obvious question in their 'experienced continuity' instrument which captures this. Other valued aspects of care identified have been retained in the 'patient preferences' part of the questionnaire, which asks about preferences for styles of care (of which continuity is only a small part), and is the basis for the intervention study currently planned.

A potential weakness of this approach is that it remains uncertain how care processes relate to experienced continuity and therefore what kind of organisational intervention might improve either experienced continuity or other outcomes. In other words, although experienced continuity is associated with a range of better outcomes, whether it is on a causal pathway between organisation of care and these outcomes remains unclear. This makes it harder to conceive of organisational interventions to improve continuity and examine the effect on outcomes.

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c) Carer measures for cancer and mental health

Although the Scoping Report reflected the existing literature in conceiving continuity as being experienced predominately from the patient perspective, the *cancer* and *mental health* projects identify the lay carer perspective as important and informative, perhaps at least partly driven by the SDO commissioning brief. Given the increasing recognition of the role of lay carers in chronic illness, including them in the conceptualisation of continuity is to be welcomed. The two projects operationalised this in contrasting ways.

In the *cancer* project, the carer was asked to rate the patient's 'experienced continuity'. The carer ('close person') therefore functioned as an additional source of information about patient care:

Parts 2 to 6 and 9 to 10 of the close persons' questionnaire mirrored questions from the patient schedule but were adapted to enquire about the close person's perspective on the patient's care and experiences. However, parts 7 and 8 focussed on close persons' specific issues (Cancer project report para 6.3.2 p 50).

In the *mental health* project, the carer was effectively treated as a recipient of professional services, and rated their own 'experienced continuity' using a set of questions (CONTINU-ES) derived from qualitative work with carers which overlapped with, but differed from questions for patients:

The motivation for developing CONTINUES was to address a gap in outcome measures on continuity of care from the carers' perspective identified in the Scoping Exercise[2] Carers were fully involved in, first, generating the items through focus group discussions, second, selecting items and developing the measure in Expert Panels and third, refining the measure further through piloting. Furthermore, the main researcher was a carer (Mental health project developmental strand; draft report p 54)[12].

d) Professional measure for diabetes

The *diabetes* project was the only one which systematically developed and tested a measure for professionals. The *primary care* project used a questionnaire to collect some data on practice priorities for continuity and access, but this was a relatively peripheral piece of work, and details were not presented. The *mental health* project also had an organisational strand, but this work was not intended to develop a new measure.

The most striking difference between the *diabetes* professional and patient measures was that *informational* continuity only appears in the professional measure, and 'flexible' continuity (where the questions asked primarily relate to access) only in the patient measure. This reminds us that patient and professional measures should be seen as distinct. Some aspects of professional work are not necessarily visible or open to judgment by patients. Equally, some aspects of patient experience are either not visible or valued by professionals, emphasising the importance of considering continuity from different stakeholder perspectives.

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[12] Draft final report from team received informally March 2007

Appendix 8 Measuring continuity: questionnaire development

Appendix 8	*Primary care*	*Diabetes*	*Cancer*	Mental Health developmental phase
How was underlying conceptualisation developed?	Literature review Qualitative study 56 participants in two PCTs, purposively selected for heterogeneity Not explicitly 'about' continuity (Leicestershire) Focused on the choice within the appointment of 'who' to see and 'when' to be seen (Le) Some questions about information (Le) London arm appears to be more explicit about continuity (diachronic and synchronic, or across patient's life versus across incident's life), and to have focused on 'gaps' which then never appear again! The survey and DCE seem based on Leicester topic guide and analysis, not the London one	Literature review Qualitative study (patients) 25 people with T2 diabetes in 14 practices in 2 London PCTs Interviews not explicitly 'about' continuity, but topic guide and data/analysis mapped to Scoping Exercise definitions Qualitative study (professionals) 25 primary care and secondary diabetes professionals Topic guide and analysis 'loosely based' on and 'informed by' Scoping exercise	Literature review Qualitative study 28 patients with various cancers, 18 close persons, 13 GPs, 10 secondary care professionals Considered and rejected existing definitions of continuity as a starting point, so interviews not explicitly 'about' continuity but topic guide and interview "strived to keep the focus on linked up and consistent services" [ie probably had an implicit definition] Explicitly rejected existing ideas of continuity, and "sought to turn patients' their close persons' and	Literature review Qualitative study focusing on instrument development. Two instruments. CONTINUUM (people with psychosis) 26 people with psychosis in 4 focus groups, each meeting twice No topic guide available in draft, but focus groups started with discussion of patient experience, and the concept of 'continuity' was then "introduced" for discussion. Groups identified continuity 'domains' which were combined with Scoping Exercise definitions, and all discussed in the original groups in the form of draft questions, with participants asked to rank them for importance CONTINUES (carers) 14 carers in 1 pilot and 2 substantive focus groups, the latter meeting twice No topic guide available in draft, but focus groups started with discussion of carer experience, and the concept of 'continuity' was then "introduced" for discussion.

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Appendix 8	*Primary care*	*Diabetes*	*Cancer*	Mental Health developmental phase
			nominated professionals' views on experiences of continuity into a simple and understandable form."	Potential questions generated and discussed in the original groups, with participants asked to rank them for importance
Question and survey development	Included questions about: Background/demography Use of primary care services Health status Importance to patients of various aspects of care derived from interview and literature rated on Likert scale (access, professional expertise, length of consultation, relational continuity, informational continuity, longitudinal continuity, gender, ethnic group) Patients then rated whether they had achieved that aspect of care	Included questions about: 4 clearly defined dimensions of continuity (longitudinal, relational, flexible, team and cross-boundary) based on qualitative data mapped to existing dimensions Development and cognitive testing phase using qualitative data and existing survey instruments for wording Piloted with 40 patients and psychometrics examined Psychometrics examined using substantive survey data	Included questions about: Needs for care Psychological and spiritual status Quality of life 'Experienced continuity' questions 'Preference for care' questions Started with qualitative themes, and "successively shaped them into statements that best represented each theme" for experienced continuity and preferences, rated by patients on a Likert scale.	CONTINUUM Identified domains presented to two Expert User groups (some overlap with original focus group membership) for comment/refinement, then sent for comment to individual user and professional experts. Final survey of 17 domains each with four questions 'How important do you think this element is?'; 'How often have you received this element over the past 12 months?'; 'How satisfied are you with this?' and 'Any other comments' (creates 3 scales of importance, experience, and satisfaction, with one free comment item) Not clear how all these questions link to either the scoping exercise dimensions, or those identified by focus groups (a few are linked to particular scoping dimensions, although 'experienced' and 'relational/personal' continuity are not represented, and implies that

Appendix 8	*Primary care*	*Diabetes*	*Cancer*	**Mental Health developmental phase**
		Professionals Four clearly defined dimensions (longitudinal, relational, informational, team and cross-boundary – note different from patients) No other details of testing and piloting Psychometrics on final study sample		the largest number link to 'flexible'). CONTINUES Draft questions from initial groups presented to two Expert User groups (some overlap with original focus group membership) for comment/refinement
Validity/reliability testing	None described except initial use of a long version with lower response rates, so switch to shorter version	Comprehensive framework for testing: Item responses and missing data Scale and subscale scores, item score and inter item correlations, and Cronbach's alpha Factorial composition and construct validity* Criterion validity Self completion and telephone completion Test-retest reliability	Clear framework for testing: Content and face validity of 9 of 20 continuity statements said to be similar to the literature [open to judgment]. Factor analysis of 20 continuity of care statements (unstable so treated as single scale) 14 preference for style of care scales, with Cronbach alpha of 0.69 for whole scale	Clear framework for testing of both CONTINUUM and CONTINUES Both tested for feasibility and acceptability with range of likely users, and by calculating readability scores Both had measured test-retest reliability Internal consistency measured by Cronbach's alpha for both Convergent validity tested by examining if predicted patterns of response occurred for both Factor analysis - only for CONTINUUM Precision and interpretability not quantitatively examined

Appendix 9 Survey questions mapped to continuity dimensions

Primary care project questions and dimensions – patients

Questions (short version of survey)	Linked dimension (as defined in report[12]) – not all 'continuity'
8a How important was it to consult someone you already know & trust? 8b Did you/patient actually already know & trust the person you consulted? 11b How important was it to consult someone who knows personally about you and your medical condition(s)? (or the patient and their conditions) 11b Did the person actually know personally about you/patient and your/patient's medical conditions?	"Relational continuity - choosing a particular person, consulting someone known and trusted"
10a How important was it to consult someone with information about your/ the patient's full medical history 10b Did the person you consulted actually have this full information?	"Informational continuity – consulting someone with information about the patient's medical history in notes or a computer"
7a How important was it to choose a particular person (e.g. usual GP)? 7b Did you actually consult the person you wanted?	"Longitudinal continuity – consulting someone who personally knows the patient and the medical condition"
4a How important was it to be able to make an appointment in advance? 4b Did you actually book an appointment in advance? 5a When did you want to consult someone? 5b And how soon did you actually consult?	"Access - being able to make an appointment in advance"
6a How important was it to be able to choose what type of professional to consult (e.g. a nurse not a doctor)? 6b If important, what type of professional did you prefer? 6c Did you actually get to consult the type of professional you wanted?	"Professional expertise - choosing a particular type of professional (for example, a nurse or a doctor)"
9a How important was it to consult someone who would take time to listen? 9b Did the person you consulted actually take time to listen?	"Length of consultation – consulting someone with time to listen"
12a How important was it to consult someone of your /the patient's own sex?	"Gender – consulting someone of the same sex"

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12b Did you actually consult someone of your/ the patient's own sex?	
13a How important was it to consult someone of your/the patient's own ethnic group or culture? 13b Did you consult someone of your / the patient's own culture/ethnicity?	"Ethnic group – consulting someone of the same ethnic group or culture"

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Diabetes **project questions and dimensions - patients**

Questions (essentially identical set for hospital)	Linked dimension (as defined in report[11])
1. In the last 12 months, how many times have you spoken with staff at the practice about your diabetes? 2. In the last 12 months, how many times has the practice sent you an appointment letter for your diabetes? 3. In the last 12 months, how many times have you had a blood test taken for your diabetes at the practice? 8. In the last 12 months, how many times have you seen your usual doctor or nurse at the practice?	"**Experienced longitudinal continuity** involves a regular source of care and a decision by the patient to use it when care is needed. This may involve patients visiting a specific setting for regular check ups, seeing a regular provider for their overall diabetes care or during an episode of illness."
10. How well does your usual doctor or nurse at the practice explain medical procedures and tests done for your diabetes? 11. My usual doctor or nurse at the practice involves me in decisions about my diabetes 12. My usual doctor or nurse at the practice listens to what I have to say 13. My usual doctor or nurse at the practice knows about my medical history 14. My usual doctor or nurse at the practice makes the best decisions about my diabetes treatment 15. My usual doctor or nurse at the practice is concerned about me	"**Experienced relational continuity** refers to the experience of establishing and maintaining a satisfactory relationship between patient-professional. This dimension was particularly important to all patients. Good relational continuity depended on patients' evaluation of how well their provider(s) knew their medical history, how confident they felt with their treatment and how involved they were in decisions about their treatment."
4. If you need advice urgently how long would it take to get to speak to a doctor or nurse at the practice? 5. How would you rate the length of time you would have to wait before you spoke to a doctor or nurse at the practice? 6. If you have a problem with your diabetes, how well does your practice respond to it? 9. If you need to speak to your usual doctor or nurse about your diabetes, how easy is it for you to speak to your usual doctor or nurse at the practice?	"**Experienced flexible continuity** refers to health care professionals and services adjusting to changes in a person's life over time. Patients from our interviews evaluated this dimensions in terms of how flexible professionals and services were in meeting their changing care requirements, for example, how quickly they could see their chosen health care professional or their regular provider, how quickly could they get advice from a professional in an emergency, and how they rated the waiting time."
31. In general, how well is your diabetes care coordinated?	"**Experienced team and cross-boundary**

32. They all give me the same information and advice 33. They all know my medical history 34. They all know about my diabetes treatment 35. They share an agreed plan of treatment for my diabetes	**continuity** involves effective communication between health care professionals and co-ordination of services. In this dimension patients tended to evaluate whether health care professionals involved in their care were aware of their diabetes status, treatment plan and their medical history and rated the overall service."

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Diabetes project questions dimensions - professionals

Questions (GP version, minor differences for hospital)	Linked dimension (as defined in report[11])
L1. For diabetic patients under routine follow-up, how many Practice visits do they generally make over 12 months L2. How many times a year does the Practice send appointment letters reminding them to attend? L3. How many times a year do patients under routine follow-up care have a HbA1c measurement at the Practice? L4. On average, what proportion of diabetic patients fail to attend their appointments?	"Delivery of **longitudinal continuity** primarily refers to organizational arrangements to facilitate follow up care over time consistent with need. Professionals described this dimension in terms of establishing regular processes (eg diabetes review consultations, regular monitoring for complications) and systems for reviewing and following up patients (eg recall systems or using repeat prescriptions as a method of identifying patient who need to be seen). Provision of care from as few professionals as possible was viewed as being of secondary importance in the establishment of longitudinal continuity but a precondition for establishing relational continuity."
R5. It is difficult for diabetic patients to see me personally for their consultation if they want to R6. If a diabetic patient wants to speak to me urgently about their diabetes, it is easy for them to speak to me R7. I generally know little about the medical history of the patients I see for routine follow-up at the Practice R8. I rarely have time to address all the concerns raised by patients during their consultation R9. I generally try to involve patients in decisions about their diabetes treatment	"**Relational continuity** refers to continuity of the relationships between professionals and patients, and also those who assist the patients through different aspects of the health care system (secretaries, receptionists and other practice and hospital staff). This involved building long-term patient-provider relationships and adopting a flexible approach in order to understand patients' behaviour, their medical history and family circumstances, and respond to their needs appropriately."
T15. All staff provide consistent advice to patients T16. All staff share an agreed treatment plan for each patient T17. All staff share agreed guidelines for the management of diabetes T18. Overall, diabetes care is poorly coordinated at the Practice T19. It is difficult to speak to colleagues about a patient at the Practice	"**Team continuity and cross-boundary continuity** refer to effective communication and co-ordination of services between professionals within and between organisational settings. Professionals discussed these aspects at length. They felt it was important to establish, use and share systems to bridge the primary and secondary interface and manage and integrate services provided to diabetic patients and their families. These might include information systems, new ways of sharing specialist skills with primary services and joint training sessions to encourage greater communication, improve awareness about the roles and responsibilities of its team members and keep individuals

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CB20. It is difficult to obtain information about a diabetic patient from the Hospital CB21. When I see a patient, Hospital letters/summaries are readily available CB22. The advice given by the Hospital is clearly stated CB23. The patient's current medication is clearly stated CB24. All the information I need is provided in the letter/summary CB25. The Practice and Hospital provide inconsistent advice to patients CB26. The Practice and Hospital share an agreed treatment plan for each patient CB27. The Practice and Hospital share agreed diabetes treatment guidelines CB28. Overall, diabetes care is poorly coordinated between Practice and Hospital	up to date with changes in care practices."
I10. I always have access to patients' diabetes notes during their consultation I11. I always have access to patients' full medical records during their consultation I12. All the information I need is easily accessible during the consultation I13. The information is generally difficult to read and understand I14. All staff share the same clinical records	"**Informational continuity** involves appropriate recording and information transfer following the service user. Continuity of information is the continuity given to patients' care by information systems. Unlike previous definitions this dimension specifically aims to evaluate whether professionals have access to information systems and whether medical records accurately document patient's health status, episodes of illness, follow up and management plans."
"**Flexible continuity**" was distinct in the patient survey, but argued to be distributed throughout the other dimensions in the professional survey, since flexibility was ubiquitous in professional accounts for all aspects of care. It was also argued to be something that only patients can really judge its success anyway.	

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Cancer questions and dimensions – patient (carer has same questions reworded)

Questions (see *footnote next page)	**Linked dimension** (as defined in project report)
1. I have received enough time and attention from the cancer services 2. I do not see the cancer services often enough 3. I am getting consistent information about my illness from health care staff 4. I frequently have to chase up cancer services to get things done 5. I have been well informed about what my treatment will involve over the next few months 6. I am aware of what side-effects to expect from my cancer treatments 7. I have been told what to expect in terms of my overall health over the next few months 8. I feel out of touch with the cancer services between appointments 9. I feel able to cope with minor complications that may arise 10. I am coping well between my appointments with the cancer services 11. I have difficulty accepting the limitations my health places on my life 12. I am well supported by non-medical services e.g. home help, social services etc 13. I have received sufficient advice on which financial benefits I can claim 14. I feel supported by the people closest to me 15. I feel my friends and relatives are able to help me cope with my illness 16. I am worried about the emotional state of the people closest to me 17. I feel I depend too much on my friends or relatives 18. I have received some misleading information from the cancer services 19. I am content that I have received a full medical examination	"**Experienced continuity**" which is never explicitly defined except in terms of being based on qualitative data about patient experience of care. The key distinction made is between "provided continuity" (service and professional focused) and "experienced continuity" (patient/user focused), with patient responses to these questions representing an *outcome* of care, not a *process.* "Our work suggests that experienced continuity is an outcome of service delivery that has a character distinct from the process models proposed by professionals." "The models of continuity debated in the literature are professional descriptions of "joined-up", consistent and integrated care. However, our brief was not to study these components in any detail; rather it was to explore and define continuity as *experienced* by users and their close persons. In so doing we have described an *outcome* and not a *process* of service provision"

with regard to my cancer 20. I am worried that some things may have been overlooked	

1. Were the medical team up to date with your situation?
2. Have you had a main contact person at the hospital over the last three months?
3. Did your medical team have access to your most recent:
   a. Notes
   b. Scans
   c. Blood tests
   d. X-rays?
	"Questions related to published models of service continuity"

* There are some missing themes mentioned in the qualitative analysis which don't appear to have a match here – "trust, confidence and making a connection" being the most obvious to me from the patient interviews; "advocacy", "trust and continuity" from the professional ones

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Mental Health project – questions and dimensions – patients (CONTINU UM)

Questions (see *footnote next page)	Linked dimension (as defined in early draft report Nov 2006)
1a. How important is it that you can easily access services when you need to? 2a. How important is it that you can g*et al*l the services you feel you need? 3a. How important is it that you have choice over the types of treatments you receive? 4a. How important is it that you don't have to wait for services? 5a. How important is it that you have access to support from services outside of office hours? 6a. How important is it that you receive the support you need from services when you leave hospital? 10a. How important is it that services aim to help you move forward? 11a. How important is it that you have access to day centres that suit your needs? 12a. How important is it that you have a care plan you agree with? 13a. How important is it that you have systems in place for dealing with a crisis? 15a. How important is the support of other people who have experienced mental distress? 16a. How important is it that you don't have to tell your life history to new staff? 17a. How important is it that you can avoid contact with services when you want to?	Not explicitly linked to particular dimensions (see #footnote next page)
8a. How It is important is it that you can get appropriate information from staff?	"*Continuity of Information*: excellent information transfers following the patient" (Note that the present review expands this concept to include information flowing from professional to patient).
14a. How important is it that staff involved in your care communicate with each other?	"*Cross-boundary and Team Continuity*: effective communication between different professionals and services"

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9a. How important is it that the level of support you get from services changes to match your needs?	"**Flexible Continuity**: flexible care which adjusts to the needs of the individual over time"
7a. How important is it that staff involved in your care don't change frequently?	"**Longitudinal Continuity**: care from as few professionals as possible consistent with other needs"
Not represented (didn't emerge in survey development)	"**Relational or Personal Continuity**: to provide one or more named individual professionals with who the patient can establish and maintain a therapeutic relationship"
Not represented (didn't emerge in survey development) – although CONTINUUM itself is said to be a measure of 'experienced continuity'	"Experienced Continuity: experiencing care as a co-ordinated and smooth progression"

* For each dimension, there are four questions as listed below, although for simplicity, only the first for each domain is shown in the table

1a. How important is it that you can easily access services when you need to?

1b. Over the past 12 months, have you been able to easily access services when you've needed to?

1c. How satisfied are you with this?

1d. Would you like to say any more about accessing services?

\# Where links are made in the draft report, it is as examples in a table, and it is possible/likely that all domains are linked in some way to a defined dimension

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Mental Health project – questions and dimensions – carers (CONTINU ES)

Questions	Linked dimension (as defined in early draft report Nov 2006)
1a. How important is it that staff spend time talking to you? 2a. How important is it that staff take action when you say the person you support is in crisis? 3a. How important is it that you can get advice and information from staff? 4a. How important is it that there is a member of staff you can establish a relationship with? 5a. How important is it that carers have a right to confidentiality? 6a. How important is it that hospital admission is dealt with sensitively? 7a. How important is it that you are told in advance the date the person you support is likely to be discharged from hospital? 8a. How important is it that staff involved in the care of the person you support don't change frequently? 9a. How important are carers' support groups? 10a. How important is it that you can get support from services? 11a. How important is it that users are able to get the support from services that you feel they need?	Not stated in draft report (section not complete)

Appendix 10 Three SDO review projects: comparative table

Appendix 10 short title	**Severe mental illness**	**Human resource management**	**Adolescent-adult transition**
Full title	Promoting continuity of care for people with severe mental illness whose needs span primary, secondary and social care	Policies affecting human resource management in the NHS and their implications for continuity of care	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
PI	George Freeman, Imperial College London	Charlotte Humphrey King's College London	Alison While & Angus Forbes King's College London
SDO no.	9/2001	10/2001	11/2001
Cost (£k)	60	60	59
Duration	9 months to 31.10.01	8 months to 31.10.01	8 months to 30.10.01
Output	full report online	full report online	full report online
Publication	Yes	Yes	Yes
Reviewer	MW	MW	GKF
Clinical area	Severe mental illness	General but focusing on maternity, primary, mental health and cancer care	Adolescent care for chronic conditions
Instrument	A coding sheet for the literature review; their own questionnaire for the Delphi study.	Own framework used on policy documents to structure a briefing paper for expert seminars	Their own questionnaire
Subjects	Staff and users at four mental health units	Experts in maternity, primary, mental health and cancer care	216 key informants (charities and professionals/managers listed in appendix 5)
Method	A Literature review; B field studies; and C a restricted Delphi exercise	Policy literature review, expert seminar discussions	Literature search plus questionnaire to key informants (appendix 4)

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Appendix 10 short title	Severe mental illness	Human resource management	Adolescent-adult transition
Duration	Four site visits, though it is not clear whether there were multiple visits to each site for observations and interviews	One seminar discussion for each of the four healthcare areas	Brief cross-sectional survey
Response rates	Field studies - not available: appears to be 100% (4/4 sites approached). No details of response rates of individuals approached. Delphi exercise round one 83% (20/24); round two 42% (10/24)	42% (25 of the 60 initially approached)	approx 51% (111/216)
Definition issues - dimensions	Taken from the Scoping study. (same PI) Definition clarified and expanded in round two of the Delphi exercise - see messages below	Taken from the Scoping study (one author – Kathryn Ehrich - also on scoping study)	Devised a completely new framework: Three domains – the service, the young person, the family Their new developmental element is description of a way of achieving management CoC. It is not a new dimension Clear links back to Scoping study in conclusions
Limitations Unforeseen problems	Unresolved definition issues regarding the ethics of informational continuity Poor response at the second stage of the Delphi exercise	Though all 60 approached expressed interest, not all were able to take part in the seminar due to timetabling; Two potential participants – a user representative and an employment relations advisor – had to cancel at the last minute.	Some time pressures led to incomplete f/u of secondary references Lack of suitable primary research and other evidence – wise discussion on pp 75-77. Scope of review limited to explicit practices rather than including context and mechanisms. They remark that this may tend to favour the explicit and the novel (p15). Their approach concentrated on overarching

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Appendix 10 short title	Severe mental illness	Human resource management	Adolescent-adult transition
			themes at the expense of local contexts. Rather rigid analytical system failed to distinguish between strength of the method and plausibility of the practice being reported. (If we understand them right - p79).
Outcomes	Issues in definition: - misunderstanding of the term was highlighted in the Delphi study. - see messages for expanded definition Importance of user involvement – though this can be challenging and is not necessarily a priority for patients (p31) Barriers to continuity (see below) Improving continuity – evidence focuses on the boundary between social and health care and the implied role of resources. Benefits of improved continuity (see below in positive effects)	Framework of policy issues and how this relates to continuity of care: Reconfiguration of services; information and information technology; flexible workforce; quality, safety and standards; better working lives; and patient-centred care	Four models. 1: direct transition; 2: sequential transmission; 3: developmental transition; 4: professional transition. Model 1 ignores personal growth and development; 2 addresses some aspects; 3 fully encompasses these aspects and 4 has more professional leadership and input. They say 4 is more appropriate to severe conditions/short life expectancy; and here the professional offers relational CoC. 2 & 3 offer flexible and their own developmental CoC. We think this means that CoC of this adolescent care gap has several dimensions. These include the need to recognise the adolescents own role, that of the family and to profitably combine these with various degrees of professional input.
Messages	Definition of CoC has been expanded to include continuity of social context – identified in the Delphi exercise and supported by the site visits (pp29-30)	Perceived impact of policy on continuity of care: impact on continuity in the system; and the impact on staff attitudes and values Reasons for the problems with policies and with implementation Recommendations: supporting	An in-depth review of an important gap in health and social care

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Appendix 10 short title	Severe mental illness	Human resource management	Adolescent–adult transition
		continuity in the system and reinforcing continuity of care as an objective	
Barriers/ Facilitators Positive/ negative effects	Barriers: Insufficient professional time, skill and perhaps motivation (p32) Negative patient perception and failure to identify with treatment regimens Cross boundary issues: wide variation in primary care skill and motivation. logistical problems liaising with multiple practices Boundary issues extend beyond fields of medical and social work. High staff turnover (p33) Facilitators: Underlying resource is implied (p33) Philosophy, compositions, morale and community setting of the CMHT Autonomous professions motivated to overcome traditional demarcation lines Positive "…more confident that better personal and relational CoC lead to improved patient and staff satisfaction and that improved informational continuity at least reduces frustration and delay" (p33)	increased: • continuity of information • consistency of practice • continuity of place for patient care • continuity of staff • collaboration between staff • flexibility of practice but • exacerbated effects of staff shortages • more fragmented care • reduced collaboration between staff • diminished continuity of staff • decreased continuity of knowledge • loss of leadership • more inequity between different patient groups	Facilitators Service structure Continuity workers/teams; information and education; use of 'existing continuous services' (e.g. primary care); inter/intra organisational liaison/agreements; planning; suitable frameworks Process components Preparation, active management, case management for transition; strong therapeutic relationships; advocacy; joint care management; flexible timing of transfer; specific communication systems; regular f/u or audit. User aspects – both adolescents and their carers (families) Specific service provision; self management skills development psychosocial development and focus on strengths and changed relationships with parents; patient and peer involvement; choice; information;

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Addendum

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